Confluence and Divergence of Emancipatory Healthcare Ideals and Psychiatric Contextual Challenges

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Abstract

Person-centered care (PCC) is generally understood to involve shaping healthcare processes, decisions, and plans according to the individual values, preferences, or goals of each patient. This is in contrast to more traditional approaches which provide care to patients based on standard clinical guidelines. In healthcare and bioethical literature, PCC is often praised as an ideal approach of healthcare provision because it is thought to empower patients and improve their adherence, satisfaction, and overall health outcomes. However, the notion has been defined in different ways, and it is unclear how and whether it can be implemented in all healthcare settings.

This dissertation aims to elucidate the concept of PCC and explore the implications of its intersection with psychiatry. The work contextualizes the concept within larger healthcare and social movements, and in that light, analyzes its values, decision-making process, and ambitions. The unique and complex challenges that psychiatric care settings engender are further used to examine how PCC commitments fare when faced with the limitations of mental illness and restrictive conditions of psychiatric facilities.

List of Papers

I.   El-Alti, L., Sandman, L., & Munthe, C. (2019). Person centered care and personalized medicine: Irreconcilable opposites or potential companions?. *Health Care Analysis, 27*, 45-59. doi:10.1007/s10728-017-0347-5

II.   Munthe, C., El-Alti, L., Hartvigsson, T., & Nijsingh, N. (2018). Disputing with patients in person centered care: Ethical aspects in standard care, pediatrics, psychiatry, and public health. *Journal of Argumentation in Context, 7*(2), 231-244. https://doi.org/10.1075/jaic.18022.mun

III.   El-Alti, L. (submitted for publication). Shared decision making in psychiatry: Dissolving the responsibility problem.

IV.   El-Alti, L., Sandman, L., & Munthe, C. (submitted for publication). Caregiver perspectives on patient capacities and institutional pathways to person centered forensic psychiatric care.

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To U.A.,

I've walked with you once upon a dream

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Contents

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List of Abbreviations

DMC	Decision-Making Capacity
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th ed.
HCP(s)	Healthcare Professional(s)
FP	Forensic Psychiatry
FPC	Forensic Psychiatric Care
PCC	Person-Centered Care
PCFPC	Person-Centered Forensic Psychiatric Care
PM	Personalized Medicine
PH	Public Health
PDBIC	Professionally Driven Best Interest Compromise
SDM	Shared Decision-Making
WHO	World Health Organization

Overview

This dissertation explores person-centered care (PCC) as an emancipation-oriented model of healthcare delivery and examines its intersection with psychiatric care contexts.

PCC has recently become a buzzword within healthcare and bioethical literature. PCC is often hailed as a benchmark for healthcare provision excellence owing to its alignment with bioethical ideals of championing patient autonomy and empowerment, as well as its recognized positive influence on patient adherence and satisfaction. PCC can be narrowly understood as a counter-response to medical paternalism in the form of catering for patient preferences. Yet, beyond this, PCC still struggles with establishing a unified understanding of itself. While much has been written in the literature about employing PCC in different contexts and its resulting discernible advantages when providing care to certain patient populations, what the concept of *person-centeredness* involves in theory, and how (or whether) this effectively translates in practice, lack rigorous exploration or unanimity.

Assuming the theoretical or instrumental superiority of PCC, in the absence of a sufficiently unambiguous understanding and exposition of its conceptual basis, values, practical commitments, and ambitions, threatens to turn PCC into a misnomer. At best, undisclosed and varying professional interpretations of PCC risk unequal care provision to different patients. At worst, using unexamined notions of PCC, patient participation, or patient centeredness may serve to conceal instances of medical paternalism, infringement of patient rights, or other ethical violations.

In order to avoid such misuse, this work strives to conceptualize a complex model of PCC which provides descriptive clarity to its constituents and accommodates for normative problematization of its aim, assumptions, tendencies, and limits. The latter particularly relates to examining the proposed PCC model within different, and perhaps more challenging, care contexts where patient and/or institutional characteristics deviate from common assumptions in the PCC literature.

The dissertation consists of an introductory chapter and four papers, which draw on overlapping ideas and debates from different theoretical, clinical, and empirical (sub)disciplines. These include medical practice, healthcare provision, empirical research studies, nursing philosophy, care ethics, psychotherapy, emancipatory social movements, disability theory, mental illness, psychiatry, philosophy of medicine, normative ethics, moral responsibility, and qualitative methods. The papers also employs different methods to address the overarching intersection of PCC and psychiatry.

The first paper in this dissertation presents a conceptual analysis of PCC in comparison to personalized medicine (PM). The second paper assesses PCC intersection with pediatrics, psychiatry, and public health (PH), through analyzing the idea of *disputing* or open argumentation between healthcare professionals (HCPs) and patients. The third paper constructs a *responsibility problem* through expanding on common concerns relating to responsibility of persons with mental illness within PCC, and addresses said problem by relying on ideas from psychiatric practice, empirical research, and moral responsibility. The fourth paper employs qualitative methodology to assess the possibility of PCC in forensic psychiatry (FP), through exploring HCP perspectives on patient agential capacities and FP institutional complexities.

In the next section, the four papers are introduced, first, in an overview then through individual summaries. The rest of the chapter is devoted to contextualizing PCC in emancipatory movements within healthcare and society at large, and to expanding on the value commitments, assumptions, goals, and processes of PCC. Psychiatric challenges and limitations to PCC are later explored in relation to the earlier analysis. Throughout the chapter, frequent links are made to ideas, findings, or arguments presented in the four papers. Following the concluding section are the list of references used in the chapter, the full versions of *papers I* through *IV*, and a short summary of the dissertation in Swedish.

Paper Summaries

The first paper in this dissertation provides a conceptual analysis of PCC as compared to yet another idea within the trend towards increased individualization of healthcare viz. PM. The two concepts on the surface seem to share numerous similarities, not least of which being anti-standardization healthcare perspectives that lack standardized definitions themselves. Based on a substantial[1] review of the literature for the purpose of elucidating the otherwise vague notions, the paper presents three-tiered models of PCC and PM, with the former emphasizing the idea of the *whole* person as its core assumption, shared decision-making (SDM) at the level of professional-patient interaction, and patient emancipation as its aim.

Like PM, PCC faces away from one-size-fits-all thinking prevalent in medical or other healthcare practices, thereby representing a *paradigm shift* from the *standardized* to the *personalized*, as well as a shift of responsibility from professionals to patients. Unlike PM, however, which aims for maximum control and optimization of biomedical outcomes, PCC pushes away from such biomedical reductionism, and instead embraces a *holistic* approach to healthcare provision. PCC thus shifts the traditional focus on biomedically defined outcomes to an emphasis on emancipation.

In contrast to a more conventional view of patients as passive recipients of care, PCC highlights patients' agency, authority, and personhood. It also recognizes the importance of providing an SDM environment for patients to exercise control over – and to take responsibility for – their health. This conception of PCC as an *ideal* for patient empowerment within healthcare thus distances itself from the traditional idea of preconceived treatment guidelines being the standard for treating *all* patients. Instead, PCC allows for individualizing a treatment plan to fit each individual person, so as to provide care which is respectful and adapted to the patient's personal circumstances and values. This is ensured not only by upholding certain values through active collaboration, but also

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[1] The purpose was not to conduct a systematic review, but to obtain a large sample of research articles upon which the conceptual analysis would rest.

through championing patient narrative[2] and continuity of care[3], such that the therapeutic HCP-patient relationship is based on knowledge of the other, mutual trust, and partnership.

Through its SDM process, PCC allows for the sharing and critique of information and values from both sides, including the appraisal of moral convictions, preferences, and arguments. *Paper II* targets such *disputing* activities which broadly and concretely determine how the treatment is designed which, in ideal situations, is expected to result in consensus between the two sides. The value thus motivating HCPs to engage in such deliberation practices within a PCC framework is respect for the *autonomous* person and recognizing her as an *agent* capable of reasoning, judgment, and making decisions for herself and her health.

In psychiatry, however, the freedom of persons with mental illness is at times significantly restricted in two ways, both of which conflict with employing SDM for an emancipatory purpose. First, psychiatric care commonly cites weakened capacities of agency and responsibility as reasons for reducing patient engagement in deliberations over care-related decisions and proceedings. Second, patient freedom can be, and often is, limited in a more literal sense, through incarceration[4]. In the latter case, a person's separation from society may be accepted for considerations extending beyond that person's own health needs, such as for ensuring the safety of others.

Each of *papers III* and *IV* expands on one of the above two aspects of freedom restriction for patients, as questions about agential capacities of persons with mental illness emerge as an inevitable concomitant of the intersection between an (allegedly) emancipatory PCC and restrictive psychiatric care. The third paper examines possibly weakened patient capacities, particularly the capacity to take responsibility, as one of three complex challenges constituting the *responsibility problem* of SDM. The second challenge relates to how HCPs can share responsibility with patients, whereas the third relates to blame practices resulting from sharing responsibility between HCPs and patients in SDM. *Paper III* continues with the argument that although it appears so, the participation of

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[2] Often understood to be the patient's own account of her situation (Sandman et al., 2016) including experience of the illness, psychosocial issues, view of the care, existential problems, etc. and assuming that this account is relevant to clinical decision-making (Munthe et al., 2012).

[3] Uninterrupted care provision to the patient by the same HCP, or other HCPs with whom the patient is familiar (Bernstein & Zander, 1981).

[4] Such coercive measures (including forced treatment) are usually also backed by laws (Sadler, 2004).

persons with mental illness in SDM is not contingent on any particular capacity or illness, but rather contingent on the understanding of PCC as an approach which fits the care to the patient, not vice versa. Accordingly, the responsibility problem could be dissolved if such an understanding of PCC is combined with a *functional* approach to mental illness and a *blameless* attitude to responsibility ascription.

The fourth and final paper explores the feasibility and value of PCC in arguably the narrowest and most constrained psychiatric care context viz. FP, which involves physically separating the person from society by means of involuntary confinement. In Sweden, persons who are mentally ill and deemed a danger to others in society due to a crime of which they have been found guilty, are sentenced to indefinite involuntary psychiatric care[5] by a court order[6], with release being contingent on care progress and social safety aspects. The FP context is thus challenging to PCC not only because of limitations to patient agential capacities, but also due to complex institutional factors. To explore this challenge, a qualitative study was designed and implemented with the aim to explore perceived room for PCC in terms of patient capacities and FP institutional complexity from the perspective of caregivers[7].

Eight semi-structured interviews were conducted in Swedish, transcribed verbatim, and translated to English. A deductive framework method of analysis was used, with four themes emerged from the analysis: "Fundamental Variability in Patient Capacity", "Patient Participation: Narration or Compliance?", "Antagonism Rooted in Power Struggles", and "System Structure Thwarts Patient Release". While the study results show FP to be at odds with a model of PCC geared toward patient emancipation, a constrained version of PCC with an advanced SDM variant is presented as an attempt to balance a certain degree of patient empowerment with current FP care strategies and restrictions.

The following subsections include individual summaries of the four papers, details about methods used in each, as well as current manuscript status, authorship, and contributions.

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[5] Instead of prison, owing to their mental ill-health.
[6] In Sweden, the court order is in the form of a criminal legal sentence. In other jurisdictions, a variation of formal arrangements can be found (Bennet, 2020).
[7] The term "caregivers" can sometimes refer to family members or other individuals who care for patients in a non-professional capacity. In *paper IV*, the term is used to exclusively refer to professionals who work at the FP facility and provide direct care to patients, but are not medical doctors.

Paper I: Person-Centered Care and Personalized Medicine

Authors	Leila El-Alti, Lars Sandman, Christian Munthe
First author's contribution	Literature review, conceptualization, figures, analysis, manuscript writing–original draft
Methods	Review of empirical and bioethical literature, descriptive conceptual and normative analysis
Status	Published

This paper presents a conceptual analysis of the two notions of PCC and PM which have recently trended in healthcare provision discussions for their ambitions of individualizing care to patients as well as their divergence from standardized guidelines and care practices. While both PCC and PM involve individualization of care and have started to take over each other's spaces through use of common terms, they also stem from different sources and hold rather different assumptions and values.

In order to analyze and clarify the meaning of the two ambiguous concepts, a literature review of 240 articles was conducted, of which 52 were chosen for inclusion in the paper. After grouping together common ideas and recurrent themes about PCC and PM from the selected literature, a three-tiered model for each notion was constructed. Each model consisted of three interconnected *base*, *action*, and *purpose* levels: the base level was defined as the core assumption on which the model rests, the action as the intervention level in which the interaction between the HCP and patient takes place, and the purpose level as the aim which the model aspires to achieve.

While the base assumption to both models included the idea of the unique individual, PM's base focuses on the *genetic* uniqueness of the individual whereas PCC's base highlights the individual's uniqueness as a *person*. On the action level, PM involves the use of genetic information to tailor-make interventions versus SDM and partnership in care for PCC. The latter's purpose, in congruence with its more holistic view of the person, does not include biomedical or health outcomes but rather focuses on patient emancipation. In stark contrast, PM's purpose is the optimization of medical outcomes. Please see Figure 1 and Figure 2 at the end of this summary.

One important idea lifted from the literature, common to both notions, is that of a *paradigm shift* in two ways. First, PM represents a shift from one-size-fits-all to individualized medical care and PCC from classifying the receivers of care as *patients* to referring to them as *persons*, the latter also being an indicator for a shift of power. The second shift is that of responsibility. In the case of PM, the responsibility shift takes place from the collective to the individual over the management of one's own health problems and control over health outcomes. For PCC, the shift of responsibility is linked to the transfer of decision-making power to the patient through the SDM process and partnership in care, as constituents of the model's action level. These described shifts are complex and make it unclear whether individualization of care is meant to completely replace traditional treatment guidelines.

A classic tension arises, on all the three aforementioned levels, between the more holistic and anti-reductionist PCC model which caters for a person's agency and focuses on the *subject*, and the more mechanistic and reductionist PM model which seeks more control over optimized biomedical outcomes and focuses on the patient as an *object*. Like the paradigmatic shifts, this *subjective-objective* tension is complex and underlines traps used by proponents of one model against the other but into which each model itself could unwittingly fall.

PM is theoretically a functional model without requiring input from an autonomous subject. Nevertheless, the existence of an optimal treatment for the individual does not necessitate (the possibility of) its delivery. PCC, on the other hand, pushes away from the reductionism of the biomedical model and in that sense, appears to be larger in scope than PM. However, since the person is necessarily embodied, if pushed to the extreme of complete contingency on the person's will, PCC can be just as reductionist as PM, just in the opposite direction. PM's optimal results cannot be guaranteed without agential considerations and PCC's empowerment purpose cannot be achieved if it divorces a person's agency from her body.

To the question of whether the two models can be companions in practice, the paper pointed out that merging ideas from both models, such as that of the *embodied mind*, could be one way of integrating both perspectives in care vis-à-vis the individual person. Practically, there could also be cases where PM is presented as one of the options inside a person-centered framework of care, yet not without the risk of PM complicating the SDM process or impeding its aim, for instance, concerning the handling of genetic information or genetic materials. Conversely, a PCC approach could be used instrumentally in order to achieve PM's optimal

biomedical outcomes. The tension between the two models' base assumptions, however, might lead them to be in perpetual, irresoluble conflict.
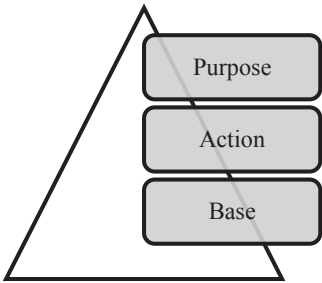
Figure 1

Three interconnected levels forming a model for each PCC and PM (El-Alti et al., 2019).
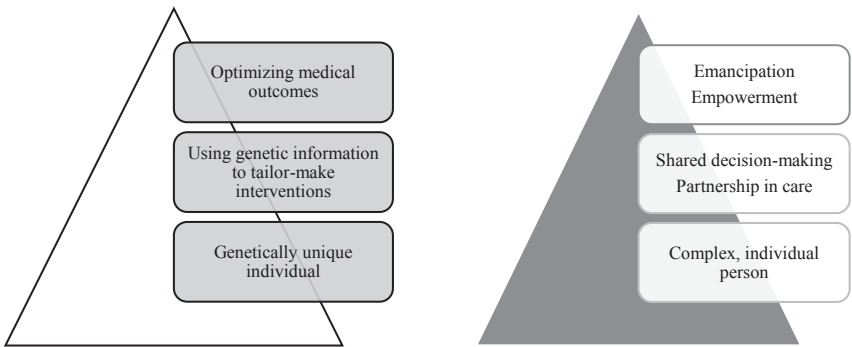
Figure 2

Comparing PM (left) and PCC (right) models with three interrelated levels: base, action, and purpose (El-Alti et al., 2019)

Paper II: Disputing with Patients in Person-Centered Care

Authors	Christian Munthe, Leila El-Alti, Thomas Hartvigsson, Niels Nijsingh
Second author's contribution	Manuscript writing–original draft (section: Forensic psychiatric care), writing–reviewing and editing
Methods	Conceptual analysis
Status	Published

This paper aims to analyze ethical aspects of open *disputes* which take place between HCPs and patients in clinical settings. This idea is an important part of the HCP-patient clinical interactions and has special relevance to advanced versions of PCC. The paper focuses on exploring this notion within less standard health settings, viz. pediatrics, FP, and PH.

While PCC is often explained in terms of patient narrative, HCP-patient collaboration, and continuity of care, *how* PCC processes are (or should be) practiced remains unclear. Some literature suggests that PCC ingredients feed into an SDM process grounded in ideals of patient autonomy and empowerment, and an acceptance that patient values, preferences, and ideas can be different from those of the HCP.

SDM often involves a joint deliberation between professional and patient, including mutual sharing of information as well as mutual critical appraisal of said information, values, and preferences. This may end in consensus and partnership, or in severe disagreement between the two parties. In both cases, the HCP might need to adjust biomedical goals of care in order to maintain the therapeutic relationship, or to challenge patient's assumptions when they are in conflict with fundamental biomedical or ethical considerations.

Examining such notions within the context of pediatrics can be viewed as both beneficial and harmful. PCC could be an opportunity to empower children and young adolescent patients through allowing them to develop their decision-making capacity (DMC). However, the vulnerability of the patient population in this context might as well counterproductively lead to their *dis*empowerment, reduced adherence, and harm especially when patients are not managing their care well. Minor disputes can still be constructive, especially as part of a good therapeutic

relationship with the HCP, but have to be aimed strategically toward long-term empowerment goals.

The above considerations are also relevant to psychiatric care contexts vis-à-vis patients' vulnerability and fragile DMC. Yet, in contrast to other care contexts, psychiatry sometimes allows its care provision to be contingent on considerations for persons other than patients themselves. The most severe example of this would be patient detention in compulsory care facilities. FP is a constrained care context where focus is placed on societal norms rather than on individuals' autonomy, and thus, patient participation in care decisions is often evaluated in terms of compliance to set rules and prescribed regimens. This has implications on both PCC empowerment goal and on disputing practices in SDM, leaving little to no room for PCC adjustments or advanced SDM dynamics.

PH shares common ground with FP in its concern for the societal over the individual, which creates tension between promotion of PH values and individual patient needs, autonomy, or wellbeing. SDM can thus be used to influence patient behaviors and decisions to accept PH aims, although it is not immediately clear to what extent this strategy is effective. Since the disputes taking place relative to PH considerations do not necessarily infringe on patient autonomy, they also do not necessarily negate the empowerment goal of PCC, especially if enacted in terms of the individual's responsibility as an agent in society.

The paper's conclusions were that HCP-patient disputes, as part of PCC, have different implications in different healthcare contexts. In pediatrics, the fragility of the patients' DMC translates into potential harm and disempowerment. Whereas in the case of PH, core PCC values are not necessarily endangered, as disputes in this context do not imply disrespect for patients or their autonomy. In contrast, FP seems to offer no room for PCC practices since the whole context is coercive and based on patients' compliance to the rules.

Paper III: Dissolving the Responsibility Problem in Psychiatry

Author	Leila El-Alti
Contribution	This paper has a sole author
Methods	Construction of "responsibility problem", interdisciplinary conceptual analysis
Status	Submitted for publication

The idea of sharing responsibility between HCPs and patients within psychiatric contexts creates a tripartite[8] problem, referred to as the *responsibility problem*. The paper aims to dissolve this problem and demonstrate that SDM as part of an emancipation-oriented PCC approach is, at least, theoretically feasible in psychiatry.

The *capacity question* represents the first part of the responsibility problem, and relates to the seemingly indispensable agential capacities required of patients for active SDM participation. This is due to implicit assumptions regarding the requisite capacity of responsibility for successful responsibility sharing within SDM. The *capacity question* thus seems like an intuitive concern when SDM is considered within psychiatric contexts owing to the tension between high SDM demands, on one hand, and potentially reduced patient capacities, on the other. Yet, this question involves the interpretation of SDM components as criteria to be fulfilled by patients to ensure participation. This would make participation in PCC dependent on specific patient characteristics, which opposes a core PCC feature viz. individualizing and adapting the care and its processes to fit the person. Therefore, from a PCC perspective, patient (in)capacities are irrelevant since the care and its processes, including SDM, are individualized to each person.

The second part of the problem concerns *how* HCPs share or ascribe responsibility to patients with mental illness, and is referred to as the *responsibility ascription question*. The latter is a byproduct of the empowerment goal of PCC, which makes it important to provide patients with opportunities to make their own decisions in care and take responsibility for their health. However, because of potentially fragile capacities of the patient population, HCPs run the risk of overburdening patients with decisions and responsibility at which they will probably fail. This practically translates into having opposing reasons to share responsibility with patients to empower them, and to withhold responsibility from them to prevent harm.

Addressing the *responsibility ascription question* is tricky because of the pervasive stereotypical image of persons with mental illness as well as the lack of consensus regarding accounts of responsibility in general. Therefore, a practical answer to the question has to take into account patients' variability of expression of mental illness as well as changes occurring in illness presentation over time. A *functional approach*, as opposed to a *status approach*, is beneficial here since it is concerned with

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8   Distinct, yet interrelated, parts with patient responsibility in SDM as a common denominator.

a person's functionality as relevant to time and context, rather than in general. Since decisions take place in a specific moment, the functional approach is suitable for responsibility ascription in SDM when relevant symptoms are different among patients or subject to change in one person over time.

The third and final aspect of the problem, the *blame dilemma*, is relevant to many healthcare contexts but is especially problematic in psychiatry. Shared responsibility in SDM invites an implicit worry about the blameworthiness of patients who fail to fulfill a care agreement. Yet, blame from HCPs opposes a therapeutic alliance with patients and risks creating hostility in the professional-patient dynamic, making such blame response both inappropriate and potentially harmful. Since responsibility and blame are often associated with one another, it becomes difficult to ascribe responsibility to patients without risking the harm resulting from blame. In order to address the blame dilemma, Hanna Pickard's notion of *responsibility without blame* is employed. Pickard's account acknowledges mental illness as a condition which limits, but not eliminates, a person's capacity for control. A *blameless responsibility* approach assigns responsibility to patients for their actions without the affective attitude of blame, and can be enhanced with a culture of compassion and respect.

There are limits to how far-reaching the answers provided to the responsibility problem are. Perhaps in the cases of persons with extreme intellectual disability or severely limited functionality, ambitious variants of SDM might not be possible. However, there is empirical evidence for the benefits of instrumentally employing SDM to improve care outcomes and patient involvement in care, as well as enhance patient DMC. Using SDM as a capacity-training tool empowers patients which in turn leads to further patient participation in SDM. Please see Figure 3.
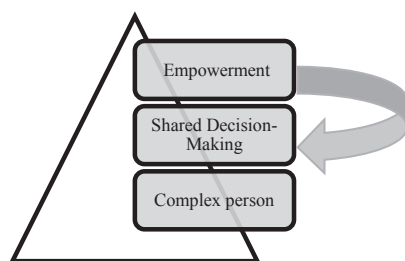
Figure 3

The three levels of PCC as adapted from El-Alti et al. (2019) showing a positive feedback loop from empowerment to SDM (El-Alti, 2021, unpublished manuscript).

Paper IV: Caregivers on Person-Centered Forensic Psychiatry

Authors	Leila El-Alti, Lars Sandman, Christian Munthe
First author's contribution	Conceptualization, methodology, formal analysis, data curation, visualization, manuscript writing–original draft
Methods	Semi-structured interviews, deductive framework analysis, open coding, thematic analysis, descriptive conceptual and normative analysis
Design	Exploratory qualitative study, (meta)descriptive ethics
Status	Submitted for publication

The aim of this paper is to explore caregiver perceptions of patient agential capacities and institutional pathways to PCC at a high-security forensic psychiatric (FP) care facility. The idea of person-centered forensic psychiatric care (PCFPC) has been gaining momentum despite the coercive nature of the FP context being potentially incompatible with an emancipation-oriented PCC model. As far as the authors know, no study has assessed how HCPs perceive the feasibility of (any variant of) PCC within FP in terms of patient capacities and institutional factors.

Patient agential capacities of relevance to PCC include the capacity to make decisions, ability to understand information relevant to care, ability to reason about the information, as well as capacity to take responsibility for the decisions made. Since weakened capacities are (one of) the main reason(s) behind patient admission to FP, these capacities can be reasonably questioned. From the FP institutional side, factors which may impact PCC implementation stem from potentially conflicting considerations to criminal law, healthcare, and public safety. The latter consideration is largely regarded as a non-negotiable goal of FP care and is the main motivation for the involuntary nature of this healthcare setting, which in turn appears to oppose PCC's emancipatory aim.

This study followed an exploratory qualitative design. After obtaining ethical approval from the Swedish Ethical Review Authority, eight semi-structured interviews were conducted with caregivers at an in-patient FP facility in Sweden. Data analysis proceeded with the framework method of analysis as described by Ritchie and Spencer (1994), but mixed deductive and inductive approaches to the data through the use of preselected framework categories and open coding, respectively. The deductive framework includes predefined categories of patient

capacities and care features relevant to PCC. Please see Table 1 at the end of this summary.

Under the first theme in our results, "Fundamental Variability in Patient Capacity", participants described substantial differences in motivation, intelligence, and personal histories among patients, as well as varying agential capacities such as moral reflection and responsible decision-making. Some patients were said to have advanced capacities whereas others lacked fundamental ones secondary to intellectual challenges.

Theme two, "Patient Participation: Narration or Compliance?", illustrated the lack of a unified definition of patient participation among the caregivers. Some assumed that listening to patients is sufficient for participation while others perceived that patients do not participate in care in any meaningful sense. In general, participants leaned toward understanding patient participation as equivalent to compliance to institutional rules and prescribed care regimens.

In the third theme, "Antagonism Rooted in Power Struggles", participants highlighted the hierarchal structure of the FP institution with doctors getting the lion's share of power over care decisions, nurses and care assistants having limited decision-making authority, and patients being at the bottom of the hierarchy with no formal power or control over how care proceeds. Participants linked patient powerlessness and the ever-present threat of coercion from HCPs to acts of patient defiance and antagonism, which in turn lead to major patient-professional conflicts. Another antagonism level was described to result from power discrepancy between the HCPs themselves. The value tensions between doctors and nurses could be observed in participants' objections to doctors' narrow biomedical focus on medicating patients.

"System Structure Thwarts Patient Release" was the fourth and final theme, and included descriptions of the coercive FP system with its multiple layers of complex interactions. When these descriptions are combined, they depict a structure which makes it near-impossible for patients to get (permanently) released. The combination of the system's rigidity, long institutionalization times, deficiencies in professional training, and lack of focus on improving patient capacities seem to create a vicious cycle of patient failure to leave the institution. The four themes and their respective subthemes are sketched in a tree diagram in Figure 4 at the end of this summary.

While the above results make it seem like the odds are against the implementation of PCC in FP, the authors suggested a way in which patient capacities can be fostered without sacrificing non-negotiable FP care goals. In

order to conceive of a PCFPC possibility, a less ambitious version of PCC (with a constricted patient emancipation ambition) must be accepted. This is possible by restricting high-level SDM dynamics as described by Sandman and Munthe (2010), and employing the SDM variant called Professionally Driven Best Interest Compromise (PDBIC). The latter offers a room for limited care adaptation, compromise, and basic therapeutic disagreements while simultaneously rendering full patient emancipation impossible.

When used as an instrumental tool, the PDBIC variant of SDM can help maintain and develop patient agential capacities by means of HCP acceptance of strategic compromises for the purpose of establishing a therapeutic alliance with patients. This would also mean that HCPs must accept that once patient capacities become sufficiently advanced, further conflict might arise as patients start questioning rules. Therefore, it becomes essential to provide space for patient-professional disagreements, trial and error, and potential failure in order to circumvent the counterproductive vicious cycle of the system as described in theme four. In addition, the non-negotiable and unnecessary care restrictions have to be made explicit in order to identify the potential *window of compromise*. This would require HCPs to be transparent with patients regarding care conditions and available room for influencing decisions.

Table 1

Patient Agential Capacities	Decision-Making	Ability to determine suitable action(s) based on reasoning about relevant information in relation to one's own views, wishes, goals, and/or values
	Moral Judgment	Ability to assess moral rightness or wrongness of own actions and/or of others'
	Control & Execution	Physical and/or mental ability to master emotions, impulses, and/or actions based on one's judgment(s) or decision(s)
	Responsibility	Ability to commit oneself to executing actions on which one decided and/or to which one agreed, and accepting consequences of such actions
PCC-Relevant Care Features	Patient Participation	Active involvement of patient in decision-making, including (deliberating about) objective-setting, planning care, and sharing responsibility for executing plan of care
	Care Flexibility	Adaptability of care processes to accommodate for patient's individuality, values, needs, desires, requests, and feedback
	Conflict & Tension	Discord of ethically-relevant nature between caregiver(s) and patient, among caregivers themselves, or inside (a) patient group(s)
	Rehabilitation Schemes	Goals that care aims to achieve as well as strategies employed to influence or correct patient's behavior(s) or action(s) toward these goals

Definitions of framework categories, under two broad headings of patients' agential capacities and care features of relevance to PCC (El-Alti et al., 2021, unpublished manuscript)
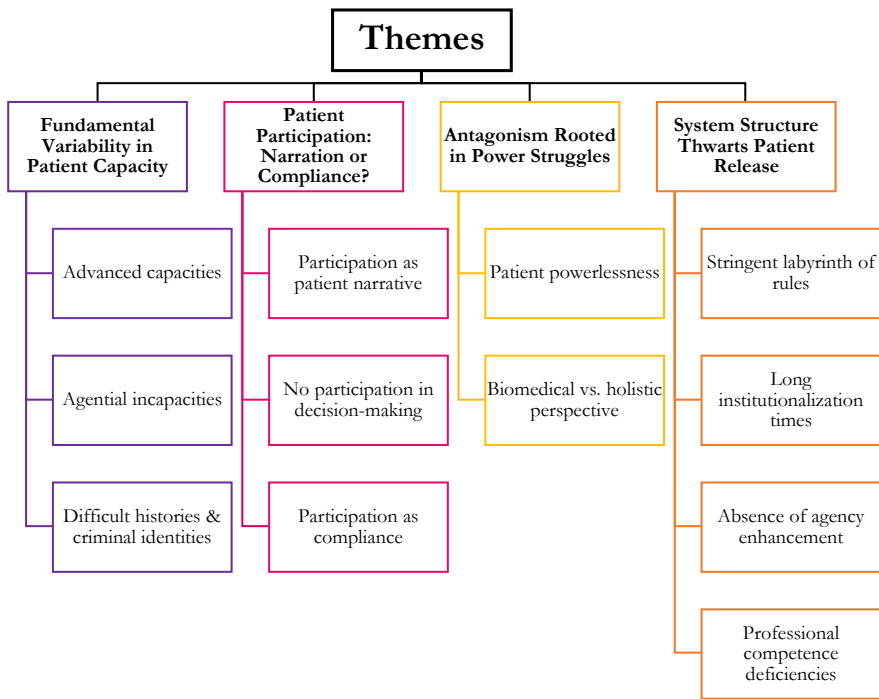
Figure 4

A tree diagram representing the four themes and their subthemes (El-Alti et al., 2021, unpublished manuscript).

Renouncing Biomedical Norms:
Patient Empowerment in Context

Traditionally, the responsibility of healthcare decision-making was left to doctors and, by extension, other HCPs[9], as it was taken for granted that they know what is best for the patient (Holmström & Röing, 2010). With this practice came the assumption that HCPs were the only party capable of making decisions for the patient (Slade, 2017), for instance, in order to help her change her behavior to achieve better health (Crawford Shearer & Reed, 2004). In the face of *biomedical dominance* (Hunter et al., 2012; Scales Rostosky & Brown Travis, 1996; Willis, 2006) and authority, patients assumed a passive, and often, submissive role (Wiens, 1993). Healthcare was and still is rife with paternalism[10] (Cody, 2003; Coulter, 1999), and patient demands or resistance are commonly construed as non-compliance (Britten, 2001).

Compliance to prescribed medical regimens has thus been traditionally expected of patients. This provided grounds for blaming patients for actions which are thought to fall short of medical expectations, that is, when patients do not act the way HCPs think they *should* act (Bissell et al., 2004; Britten, 2001). The idea that blame is justified as an appropriate measure to ensure patient compliance presumably stems from "the rise and solidification of scientific authority" (P. Brown & Zavestoski, 2004, p. 682). Yet, in spite of its longstanding place in clinical practice, lack of compliance remains a major challenge within healthcare (Bosworth et al., 2011; Kvarnström et al., 2017; van Dulmen et al., 2007) as well as a poorly understood phenomenon (Stockwell Morris & Schulz, 1992). This may

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[9] The term HCPs, as used throughout this work, is meant to be inclusive of all clinical professionals involved in direct patient care, such as through diagnosis, decision-making, treatment prescription, care-planning, or care execution. This includes doctors, midwives, registered nurses, nurse assistants, physiotherapist, midwives, psychologists, inhalation therapists, dieticians, anesthesiologists, or others.

[10] The term is derived from the reference to a patriarch's authority and alludes to power structures related to patriarchy (Cody, 2003).

partially be due to care plans being too rigidly designed on biomedical grounds, neglecting to take into account important aspects of the patient's life. This explains the shift of terminology from compliance to *adherence*, with the latter better understood as a plan of care adhering to the patient's *own* plan rather than the professional's (Rothert et al., 1997), making it a better fit with a PCC conception (Sandman et al., 2012).

Medicine as it is known today has seemingly secured its distinguished place within science and society by *not* giving consideration to values and other subjective aspects of patients' lives (Cassell, 1991). Medicine being based in *hard* sciences, which are presumably value-neutral and independent of personal authorities, is indeed part of the reason behind its constant remarkable developments and advancement (Cassell, 1991). Scientific *facts* derived from physiology, pathophysiology, anatomy, microbiology and other biomedical sciences – as well as data obtained from clinical tests, quantitative research studies, and measurable outcomes – are deemed *objective*[11] and of utmost importance for medical practice.

Perhaps with the exception of some subjective data provided by the patient to facilitate diagnostic processes such as the placement or onset of pain, *subjective* characteristics of the HCP or patient do not seem to guide the practice. It is perfectly plausible that assessment, diagnosis, tests, and treatment of an unconscious person in the emergency room, for example, can proceed without any input from her side. In that sense, it is theoretically possible for medical care or interventions to be carried out *objectively*, that is, without any subjective contribution from a patient. This is one of the main distinctions between the PCC

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[11]   The distinction between the subjective and objective can be interpreted in different ways. What is objective can be thinly understood as equivalent to an established truth which is not based on personal opinions or feelings. It can also be understood as that which is described relevant to an object. A thicker understanding of objectivity in a biomedical context would perhaps also involve *naturalist* descriptions of disease categories being grounded in non-evaluative theoretical concepts in biomedical sciences (Amundson, 2000). In this work, *objective* is meant to refer to input from the HCP side in healthcare processes which is often assumed to be based on measurable and verifiable facts from sciences, tests, or research, rather than on the HCP's or patient's opinions. This is contrast to the term *subjective* which is taken here to mean any input stemming from a subject (i.e. patient) or details about the patient's life which are assumed to be value-laden and non-verifiable. These include experiences, narrative, feelings, perceptions, opinions, social roles, education, preferences, values, memories, beliefs, emotions, socioeconomic information, cultural habits, behaviors, thoughts, and relationships.

and PM models presented in *paper I*, with PM being, in theory, functional in a one-sided direction without an autonomous person on the other end.

However, despite their obvious importance, such *objective* facts alone fall short of fulfilling the goals for which HCPs strive in terms of *adequately* treating patients (Cassell, 1991). A patient's *subjective* characteristics, knowledge about her own body, as well as her social, political, or economic factors do sometimes influence how treatment proceeds. For instance, one patient's financial situation can influence which medication a doctor prescribes depending on commercial pricing and another patient's religious beliefs can influence which medical procedures must not be implemented for the patient.

In addition, physicians and other HCPs themselves hold values of which they might be incognizant or dismissive[12], but which nevertheless affect the care and its outcomes, directly or otherwise. Statements about goals of care are themselves statements of value (Cassell, 1991) and HCPs often evaluate which signs and symptoms hold more importance than others, which conditions should be treated, and what counts as normal or pathological (Cassell, 1991). HCPs also accept a number of universal ethical standards[13] that circumvent and limit which achievable biomedical outcomes are, as a matter of fact, acceptable or desirable to pursue. Respecting a patient's right to refuse care, for example, is an accepted norm[14] even when a patient's subjective preferences or values go against what seems biomedically optimal from the HCP's viewpoint.

Hence, a rift is created between the *assumed* independence of medical practice from subjective preferences or normative values, and the reality in which this practice *is* dependent on evaluative assumptions. Prioritizing a person's biomedical needs, on one hand, and acknowledging the mutuality of healthcare practice and HCP/patient values, on the other, complicate clinical decision-making significantly. In the biomedical model, where biological and pathophysiological

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[12] This is not to say that values are consistently disregarded in healthcare or medical practice, but rather that they have wider influence on practice than is generally acknowledged.

[13] Examples include Beauchamp and Childress's (2019) four bioethical principles of beneficence, non-maleficence, autonomy, and justice; as well as the physician's pledge from the Declaration of Geneva (World Medical Association, 2018)

[14] Patient autonomous choices are not required to be rational (Walker, 2009). However, in practice, this might translate to different things. Sometimes, HCPs adopt a thin understanding of *respect for autonomy*, often reduced to the right to refuse recommended treatments. Notwithstanding, HCPs might still find ways to convince patients or nudge them in (what is thought to be) the *right* direction. This will be discussed in more detail in the next section of this chapter.

etiologies of disease are the main focus (Suls et al., 2019), biomedical considerations and biomedically defined outcomes are generally assumed to have greater value to patient's healthcare than other aspects of her life (Scales Rostosky & Brown Travis, 1996).

For this reason, HCPs often resist wasting time and effort on considerations they deem unimportant to biomedical outcomes, such as attending to the emotional needs of diabetic patients instead of focusing on controlling their HbA1c levels (Jones et al., 2015). It so happens that some patient decisions and values regarding diabetes and its management align with the professional recommendations, but in many other cases, this congruence does not take shape. HCPs, however, do not always concede that their expert knowledge on the patient's diabetes is not the equivalent to knowing what is *good* for the patient's life (Anderson & Funnell, 2010; Rothert & O'Connor, 2001). Values, in contrast to how they are often seen from a strictly scientific outlook, are not necessarily irrational, but can also be understood as the subject (or result) of reasoning (Cassell, 1991).

The tension between the biomedical model's narrow focus and the crucial, yet equivocal, role that non-biomedical considerations play within current medical practice, prompted critiques of traditional biomedical norms and assumptions. Several emerging models or concepts attempted to amend some of the perceived problematic aspects of the biomedical model, to introduce further considerations to medical practice, or to formulate new notions upon which the practice should be based. George Engel's (1977) critique of the reductionist focus of the biomedical model on neurophysiological or biochemical processes lead to his conception of the *biopsychosocial* model, which incorporates biological, psychological, and social factors as an essential part of a person's health, illness, and healthcare. To Engel, the belief that diseases are somatic and that doctors do not *have to* attend to a patient's psychosocial needs is seriously mistaken (Engel, 1977).

Similar to the biopsychosocial model, the *somato-psycho-socio-semiotic* health model includes additional aspects to concepts of health and illness viz. the immense variability of patients' experiences of the same illness (Sturmberg, 2009). In comparison, the *integration* model shifts the expectation of compliance to respecting and supporting a person's experience of integration with illness as a process (Hernandez, 1996). Other approaches with a larger scope on patient care than the biomedical model include *narrative medicine* which stresses patient narrative as an opportunity to understand the person therapeutically (Charon, 2004), and

the concept of *concordance* which recognizes a patient's autonomy and expertise as well as potential tension in the doctor-patient interaction (Britten, 2001).

Less ideologically framed forms of critique emerged more directly from professional clinical observation of the biomedical model's shortcomings in addressing certain aspects of patient care. For instance, the upsurge of *multimorbidity* of several mental and physical health conditions (Suls et al., 2019; World Health Organization [WHO], 2016) highlights another problem with the reductionism of the biomedical model.

Multimorbidity is defined as an interaction of (often chronic) conditions the total of which is worse than the sum of its individual illnesses (Vetrano et al., 2018). Caring for patients with multimorbidity requires medical, epidemiological, health psychology expertise (Suls et al., 2019), and a multidimensional approach incorporating the patient's functionality, preferences, and values (Vetrano et al., 2018). This is an approach the biomedical model cannot offer, as it lends itself badly to holistic perspectives. With the biomedical model's intense focus on technology and hyper-specialization (Vetrano et al., 2018), patient care is often fragmented (WHO, 2016) as it is difficult to adequately recognize, characterize, and tackle multimorbidity comprehensively (Suls et al., 2019).

Paper I describes in more detail PM as a technocratic model of healthcare. On the surface, PM seems to offer an individualization element missing from the traditional understanding of the biomedical model, yet in reality, PM consists of highly efficient, highly technical, and highly medicalized strategies striving to optimize narrowly (pre)conceived biomedical outcomes. PM is also often referred to as *precision medicine*, with its strategies firmly rooted in the idea of biomarkers (Glick, 2019), which yet again brings to light the potential shortcomings of biomedical reductionism[15] (Greene et al., 2012).

In stark contrast, PCC stands as an opposing outlook focusing on a bigger picture of the patient as a person. A PCC approach is more oriented to a humanistic and biopsychosocial (Taylor, 2009) milieu which aligns with patient values, desires, and preferences (Twungubumwe et al., 2020), and takes them seriously (Pierce & Hicks, 2001). In *paper I*, it is also argued that these are qualities

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[15] Other shortcomings of PM might relate to patient empowerment, for example, in terms of "limits of patients' control over their health, but also the limits of patient control over health care systems" (Juengst et al., 2012, p. 39).

that PM will need to adopt in order to avoid the aforementioned reductionist pitfalls[16].

Partly due to the expanded models of health and healthcare discussed above, and perhaps also due to sociocultural developments born out of educational and ideological reforms, medical authority is more easily challenged today than ever before[17] (Willis, 2006). Patients today have easier access to information (Britten, 2001), are more knowledgeable about biomedical facts (Wittmann-Price, 2006), and no longer see themselves in a submissive or passive light (Formosa, 2015).

The focus on autonomy, informed choice, and informed consent has further contributed to a shift in the HCP-patient relationship (Rothert & O'Connor, 2001). Theoretically, this shift to a non-hierarchical partnership motivates notions like SDM and shared responsibility (Adams & Drake, 2006; Coulter, 1999; Twungubumwe et al., 2020). Aiming for patient *empowerment* and democratization of clinical decision-making through SDM and shared understanding (Taylor, 2009) is something that many patients have now come to expect (Allsop et al., 2004; Formosa, 2015).

> Empowerment is defined as the interpersonal process of providing the resources, tools and environment to develop, build and increase the ability and effectiveness of others to set and reach goals for individual and social ends. (Hokanson Hawks, 1992, p. 610)

Empowerment can be regarded as an approach, goal, and characteristic consisting of – and contributing to – a person's self-esteem, self-efficacy, autonomy, freedom, and ability to control her life and effect change in the world (Barrett, 1998; Tengland, 2008). Similarly, Nygårdh et al. (2011) define empowerment as not only a process, but also an outcome or a developing

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[16] *Paper I* analysis includes a possibility where PCC itself could also be reductionist, albeit in the opposite direction of biomedical reductionism.

[17] These descriptions are meant as partial explanations behind challenges to medical authority and changing expectations of patients from healthcare and HCPs. These descriptions are not exhaustive of the reasons for such changes or of the kind of changes taking place, and are specified here due to their relevance to the discussion. Challenges to biomedical dominance could also be explained, for example, by certain economic reforms (Hunter et al., 2012), privatization of healthcare (Benoit et al., 2010), increased corporatization of doctors (Collyer & White, 2001), and ever-increasing medicolegal repercussions on HCPs such as litigation by dissatisfied patients (Willis, 2006). Changing patient expectations and health-seeking behaviors could also include preferences for alternative forms of medicine and healthcare (Hunter et al., 2012) instead of (or in addition to) the desire of being more involved in the decision-making processes of mainstream healthcare.

relationship between HCP and patient through the latter's active participation in health-related decisions and goal-setting. Barrett's (1998) theory of (patient) power, references the patient's awareness of – and confidence in – her own ability to prompt change through choice, intentional action, and active involvement in health and healthcare by means of a partnership with the HCP (Barrett, 1998; Crawford Shearer & Reed, 2004).

Although utilization of empowerment as a healthcare dimension and an overarching characteristic of PCC is common, the *movement* for patient empowerment was not founded within healthcare but arose from other social movements (Holmström & Röing, 2010). With roots in civil rights and women's rights movements (Rissel, 1994), patient empowerment movements developed as a reaction to oppression and inequality in society in general (Holmström & Röing, 2010), with disempowered groups often experiencing worse health than other social groups (Rissel, 1994).

When there is no opposition to power, questions about (threats of) coercion become immediately relevant (Wiens, 1993). In the context of healthcare, this relates to the beliefs that patients are oppressed by doctors, that many healthcare policies and accepted care standards are coercive (Williamson, 2008), and that attempts at emancipation aim to free both patients and doctors from the limitations brought by such power imbalance (Williamson, 2019). For persons living with mental illness, for instance, civil rights, rights to treatment, and rights to refuse treatment are part of the progress achieved through activism[18] (P. Brown et al., 2004).

Emanicpatory movements usually presuppose a number of components: a disempowered party (Pulvirenti et al., 2014), the holders of power as oppressors, an injustice in the subordinate position, and an interest of the disadvantaged group to put an end to the injustice (Mansbridge, 2001). It is generally assumed that a crucial difference between oppression in healthcare and other contexts is that in the former, doctors have their patients' best interest at heart (Williamson, 2019). Yet, while one aspect of this assumption may be acknowledged in terms of patient

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[18] Persons who are in recovery from mental illness have played an instrumental role in advocating for PCC and increased decision-making power for those with mental illnesses (Davidson, 2016). The recovery movement, on which *paper III* touches, is part of the disability movement (Barber, 2012) and parallels the emancipatory social and health movements in its demands for the recognition of patients' subjective experiences and autonomy within healthcare.

benefit (by her own standard) from the professional know-how, this also tends to include claims about which standards are acceptable for the patient to have.

The simplistic belief that HCPs know what is best for the patient sometimes enables them to circumvent attempts at emancipatory practices. This is part of what fuels common paternalistic healthcare practices which resist providing patients with a room to influence various care processes. Although hidden behind what may seem to be scientific or professional facts (of knowing best), oppressive healthcare practices appear to be no different from other oppressive contexts which infringe on freedom and self-determination. Thus, the problem lies beyond the HCP's knowledge or capacity to address patient goals, and relates more to which goals patients are assumed (they *ought*) to have.

Studies of alleged participatory or patient-centered healthcare practices aiming at empowerment, have demonstrated a crucial lack of emancipatory ambition from the HCP side. In a study conducted to assess self-care decision-making processes of chronically ill patients, participants revealed various ways through which HCP actions betrayed their declared aims of empowerment in favor of maintaining their professional dominance (Paterson, 2001). Participants also identified instances when HCPs met patients' attempts to be active participants in decision-making with skepticism and anger (Paterson, 2001).

For patients diagnosed with mental illness, the problem is even more pronounced, with patient exclusion commonly taking place on more than one healthcare level. A report by Calton et al. (2009) shows that North American and European research into subjective experiences of patients with mental illness has been scarce. Persons with psychotic illnesses often feel excluded from decision-making processes, for instance, regarding medication prescription or even consent to treatment (Gordon & Green, 2013). Hence, despite the declared centrality of patient-centered approaches in healthcare and ethical debates, in reality, patients still lack power and control (Botin et al., 2020), and HCPs continue to employ the biomedical model for care provision[19] (Paterson, 2001).

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[19] It is important to note that inadequate implementation of person-centered processes does not necessarily imply a resistance from the HCP side. Sometimes despite HCP intentions to empower patients, some lack the power to do so (Jansen & Hanssen, 2017). This relates to the tension between different players in the FPC hierarchy in *paper IV*, where nurses sometimes strongly oppose the narrow biomedical treatment of patients (and in some cases even find it ethically problematic).

Calls for sharing power with patients are sometimes viewed as radical and disruptive (Berwick, 2009) and might lead to HCP discomfort (Taylor, 2009). Williamson (2008) argues that the resistance of doctors to change policies and actions providing patients with more power over their health and health-related decisions is an example of an oppressive action. HCPs often use strategic tactics, such as secrecy and manipulating information[20] (Myskja & Steinsbekk, 2020), to maintain their authority status (Hindley & Thomson, 2005). When HCPs use secrecy, inadvertently or otherwise, they undermine patient autonomy by putting her at a disadvantage (Williamson, 2019). The lack of transparency and understanding participation in terms of a tool used to effect patient compliance, are two important data findings in *paper IV*.

When HCPs present treatment options as (potentially) right or wrong choices, instead of supporting patients in making informed choices, they disclose commitments to: a hierarchal power structure (Stapleton et al., 2002), to its accepted norms which deem one alternative decision superior to others (Wittmann-Price, 2004), as well as to an underestimation of patients' DMC (Coulter & Oldham, 2016; R. S. Morrison et al., 1996). For instance, Hindley & Thomson (2005) describe how midwives sometimes withhold information which they believe will lead women to make (what the midwives perceive to be) *wrong* choices, or sometimes intentionally bias information in favor of a certain option so that the women choose *right*.

Hence, when HCPs manipulate information to influence patient decisions instead of creating room for informed choice, they also bolster *informed compliance* (Stapleton et al., 2002). An empowerment *gap* thus occurs when HCPs uncritically assume that in order for patients to be empowered they should follow professional advice or judgment, thereby creating a chasm between the *intentions* to empower patients and empowering them in reality (Hernandez, 1996; Hindley & Thomson, 2005; Paterson, 2001; Zoffmann et al., 2016).

The lack of a sufficiently clear HCP understanding of the meaning and requirements of partnership, empowerment, or SDM (Stapleton et al., 2002), or failure to make sufficient changes to allow for such processes to take shape, is problematic and potentially dangerous for patients. Adopting the language of empowerment as mere rhetoric (Hernandez, 1996; Zoffmann et al., 2008) or "verbal analgesic" (Berwick, 2009, p. 557) "may lull health care professionals into

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[20] Patient decisions are many times influenced by *how* HCPs provide information which includes, for example, their choice of words (Berry et al., 2017; Heritage et al., 2007).

a false sense of security" (Paterson, 2001, p. 580) and disguise instances of power abuse (Berwick, 2009). Alluding to empowerment through paying lip service to patient participation while maintaining practices that keep professionals in a dominant position, hides paternalistic practices (Opie, 1998; Paterson, 2001) by making them more difficult to identify and target[21],[22].

An emancipatory decision-making process involves more than providing information or simply inviting patients to participate (Eldh et al., 2006), as it also "acknowledg[es] the affective experience of oppression" (Wittmann-Price, 2004, p. 378). This requires a flexible environment as well as the use of the patient's personal, experiential knowledge (Aujoulat et al., 2006; Wittmann-Price, 2004). If one were to understand paternalism as anathema to autonomy[23], compliance could then be considered the antithesis to empowerment (Anderson & Funnell, 2010). Accordingly, to ensure that patients make informed decisions, interventions which promote patient empowerment must actively be adopted (Anderson & Funnell, 2010) and necessarily be person-centered (Aujoulat et al., 2006) in the ambitious sense described in the analysis of *paper I*.

Empowerment seems to be inextricably linked to PCC (Aujoulat et al., 2006; Holmström & Röing, 2010; Pulvirenti et al., 2014; Zoffmann et al., 2016) and is a recurrent theme in its conceptualization, even when it is not explicitly identified as such. The PCC model put forth in *paper I* replaces biomedical reductionism with a holistic approach to healthcare provision, thus shifting the traditional focus on biomedical outcomes to an emphasis on emancipation. The PCC model is composed of three levels, each of which oriented toward empowering persons in healthcare: (1) patient's personhood and individuality in the base level; (2) SDM, partnership, and individualization of care design and execution in the action level; and (3) favoring emancipatory goals over narrower biomedical outcomes in the purpose level. Please refer to Figure 2 on page 22.

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[21] This relates to the potential risks of employing an empty concept of PCC, which was briefly mentioned in the chapter's overview, and is partly why PCC is sometimes understood simply as a response to the "excessive paternalism in clinical medicine and the lack of genuine concern for people's values and needs" (Pulvirenti et al., 2014, p. 303).

[22] Degrees of patient participation can also be influenced by HCP implicit bias, for example, in relation to certain patient characteristics (Street et al., 2005).

[23] There are relevant distinctions between weak and strong paternalism (Beauchamp & Childress, 2019), and discussions on whether (especially weak) paternalism can be justified are often framed in terms of autonomous DMC and its implications for a person's right to make decisions (Hartvigsson, 2020).

The benefits of employing PCC strategies in patient care have been invariably discussed in literature. Research in several areas of medicine shows that active client participation results in a variety of benefits, from increased satisfaction to decreased symptom burden (Adams & Drake, 2006). Olsson et al. (2009) found that individualized care was more cost-effective, as it decreases chances of wasting resources on tests or interventions which are otherwise prescribed generically to patients who neither need nor want them. PCC approaches have also been viewed as beneficial to persons with mental illness because they prevent fragmentation of care (Bernstein & Zander, 1981).

In order to shed light on the PCC notion, its meaning, and its potential ethical challenges, further scrutiny is needed. The next section will explore in more detail the roots of PCC as well as its central themes, values, tendencies, and SDM process.

What is Person-Centered Care?

If one were to define PCC by what it is not, then PCC is not doctor-, disease-, hospital-, or technology-centered (Stewart, 2001). *Person*-centered care is often used in the literature interchangeably with *patient*-centered care despite there being some references distinguishing between them. For instance, Håkansson Eklund et al. (2019) place PCC's focus on a *meaningful* life and that of *patient*-centered care on a *functional* one. More importantly, and as discussed in *paper I*, the recognition of the *person* replaces the (traditionally conceived) passive *patient* and partly motivates the shift of power attributed to PCC (Britten et al., 2017). This motivates the use of *person*-centered care, rather than *patient*-centered care, throughout this work to highlight this distinction.

The concept of PCC is ambiguous (Edvardsson et al., 2008; Entwistle & Watt, 2013; Robinson et al., 2008; Slater, 2006; Stewart, 2001). Because it has grown to be a driving force in healthcare development and care provision, it becomes crucial to provide it with a meaningful definition (Glick, 2019). The notion of centeredness of the patient in care is thought to have originated within caring perspectives in healthcare, with the idea of focusing on the individual rather than the illness tracing back to the founder of modern nursing, Florence Nightingale (Lauver et al., 2002; Mitchell, 2008).

> People say, oh ! she has a command over her patients. It is no command. It is the way she feeds him, or the way she pillows his head, so that he can swallow comfortably. Opening the window will enable one patient to take his food; washing his face and hands another; merely passing a wet towel over the back of the neck, a third; a fourth, who is a depressed suicide, requires a little cheering to give him spirit to eat. The nurse amuses him with giving some variety to his ideas. I remember that, when very ill, the way in which one nurse put the spoon into my mouth enabled me to swallow when I could not if I was fed by any one else. (Nightingale, 1860/2010, p. 168)

Other sources attribute the roots of PCC to psychologist Carl Rogers' work on client-centered therapy (Chapman, 2017; Hughes et al., 2008; Mezzich, 2012; Morgan & Yoder, 2012), which emphasized empathy and understanding of the person.

> One of the cardinal principles in client-centered therapy is that the individual must be helped to work out his own value system, with minimal imposition of the value system of the therapist. This very commitment is, of course, itself an expression of a value which is inevitably communicated to the client in the intimate course of working together. This value, which affirms the individual's right to choose his own values, is believed to be therapeutically helpful. The suggestion of an array of other values by the therapist is believed to be therapeutically harmful, possibly because, if they are presented by the therapist, they will inevitably carry the authority of the therapist and constitute a denial of the self of the client at the moment. (C. Rogers, 1951, p. 292)

The Rogerian influence on PCC relates to two ideas presented respectively in *papers I* and *III*. The first relates to the room that PCC provides for a person's values to be a part of understanding her as a complex person as well as to play a central role in adapting the plan of care to fit the person. The second relates to similarities between the emancipation-oriented PCC model from *paper I* and Hanna Pickard's account of *responsibility without blame* from *paper III*. In particular, this refers to Pickard's argument of empowering the person through holding her responsible while preventing the harms of affective blame. Similarly, in Rogers's client-centeredness, a therapist's[24] values are harmful when imposed on the patient because they do not come from the person herself but rather represent the authority of a more powerful party. This can amplify the client's sense of powerlessness which is opposite to what the therapy aims to achieve.

C. Rogers describes the results of his client-centered therapy in terms of congruence between a person's self and her *ideal* vis-à-vis the values she holds. This idea corresponds to uniting the person's embodied experience of illness, her values, and choices in one coherent whole[25] within the care partnership (see *paper I*). Rogers's aspiration for the patient to reach an acceptance of the self "as is" (1951, p. 141) without judgment, highlights the importance of avoiding certain evaluative elements in the interaction between HCPs and patients. This parallels the *paper III* discussion on avoidance of emotionally charged attitudes or language of blame as an essential part of caring for persons with mental illness.

However, values, value judgments, knowledge of values, and discussions about values remain crucial in PCC. Important value questions precede, and remain after, a healthcare partnership has been achieved. First, drawing attention to (discussions

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[24] Or a HCP's, more generally.

[25] *Coherent whole* does not necessarily mean that the parts are in harmony with each other, but rather that they are inseparable and interdependent inside a complex unit (i.e. the person).

about) values in healthcare shows the growing tendency for individualizing healthcare and reformulating the aim of treatment of a person's disease in terms of how this affects that *particular* person (Cassell, 1991). Second, assessing and identifying a patient's values are crucial for knowing the person by means of appreciating what is important *to her* (Cassell, 1991). In addition, considerations of patient values are part of what makes the PCC approach a *holistic* one. Arguments favoring a holistic approach see persons as complex and irreducible living systems whose parts cannot be understood without reference to the *whole* (Power, 2017).

The idea of holism is also found, for example, in the biopsychosocial model of health discussed in the previous section, which focuses on the whole person rather than exclusively on the pathophysiological basis of disease (Suls et al., 2019). The whole person incorporates both the *subjective* self and *intersubjective* social aspects linked to the self (Calton et al., 2009). *Wholeness* is a notion "inextricably linked to values" (Cassell, 1991, p. 173) since the whole affects the parts and the parts affect the whole as well as each other. This makes disease something which necessarily involves the whole person (Cassell, 2010).

> Sickness has an impact on the whole person whether minor illness or life threatening affliction. Sickness is not restricted to the physical derangements of disease, nor does it only include the psychological or social phenomenon that may accompany it. Sickness makes itself known by interference in functioning. Since sickness involves the whole person the impairments of functioning that characterize illness involve all aspects of the human condition—-physical, personal, psychological, social, and spiritual. (Cassell, 2010, p. 51)

The *subjective-objective* tension between PCC and PM, discussed in depth in *paper I*, demonstrates the conflicting values expressed by the two models when seen in isolation, and is comparable to the more general rise of opposing movements to traditionally accepted medical practices. PCC, as one of many other movements against established values and practices in healthcare, redefines certain relevant aspects of care as being equally worthy of consideration when they have (consistently) not been considered as such. This does not mean, however, that the PCC approach is equivalent to providing interventions based on patient requests[26], but rather that it involves provision of care that the patient deems important to her (Coulter & Oldham, 2016; Glick, 2019). This links the importance of

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[26] PCC and *consumer*-centered care are different. Adopting a PCC approach does not imply that HCPs should stand back and give patients what they want (Entwistle & Watt, 2013).

understanding a person's context to her subjectivity and intersubjectivity within PCC, and also relates to understanding the person in terms of the *functional* approach[27] as explained in *paper III*.

> For a dancer, a weakened ankle means the possibility of a fall on stage; for a person at a desk job, a weakened ankle is a minor convenience. (Lazarus, 1984, p. 51)

The PCC focus on the *subjective whole* constituting the person also does not necessarily dilute the *objective* stance toward patients, an assumption which was criticized in *paper I*. Similarly, giving patients more responsibility in decision-making need not (and should not) dilute the doctor's responsibility (Finnsbo, 2016), as discussed in *paper III*. PCC's opposition to the biomedical model is not merely a result of value differences and should not, therefore, be seen as blunt opposition to everything biomedically objective. More accurately, from a PCC perspective, the subject is an indispensable part of the application of medical sciences in healthcare. This does not exclude biomedically objective appraisal of patients and their needs, but makes it erroneous to limit the practice of medicine merely to that task.

The responsiveness to patient's subjective needs and preferences (Berwick, 2009; Mead & Bower, 2000; A. Rogers et al., 2005), and the recognition of her unique bodily knowledge as a valid form of expertise for clinical decision-making and treatment besides *objective* facts (van Eemeren et al., 2021), are essential for avoiding the shortcomings of biomedical reductionism. A patient's subjective contribution to the care process does not only include personal values and preferences but also first-person knowledge of her own body, which is knowledge no one else can provide.

> Nothing is more real than life, for one who lives it, and none can live one's life but in the first person, that is, as a subject. (Agazzi, 2001, p. 4)

Therefore, a sound version of an emancipatory PCC model does not claim that its two parties have the *same kind* of expertise but that their complementary expertise have a similar *value* for diagnosis, treatment, and outcome. In other words, PCC presumes that a subject's experience of disease is just as important as

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[27] In comparison, a *status* approach, also discussed in *paper III*, would regard the weak ankle from Lazarus's quote (above) as a necessary decrease in function without taking into consideration the person's circumstances. This is not only potentially disempowering to patients, but similar to the biomedical model, can also be a narrow outlook on patient care.

an objective understanding of the same disease. This implies the recognition of the patient as an *expert* (Coulter, 1999; Twungubumwe et al., 2020) such that her subjective experiences are regarded as "epistemic equivalents alongside objective or fact-laden theories of disease" (Calton et al., 2009, p. 166).

The recognition of patient expertise is crucial for creating new avenues of decision-making in healthcare. While this might reduce the certainty of patient outcomes in strict biomedical terms, it also helps reduce patients' own uncertainty (Dudas et al., 2012; Stewart et al., 2000) and powerlessness (Aujoulat et al., 2007) in the face of illness. Anderson and Funnell (2010) argue that requiring patient expertise for adequate disease management motivates the need for a collaborative relationship between the HCP and patient.

Values, Processes, and Aspirations

The recommendation that patients participate in their own healthcare and health-related decisions was announced by the WHO in 1977 (Bissell et al., 2004; Holmström & Röing, 2010). Active participation in decisions about one's own health and healthcare can also be understood as an obligation (rather than an option) (Myskja & Steinsbekk, 2020), a human right (Hipp, 2021), or a legal right in some contexts (Jansen & Hanssen, 2017). But while *participation* and SDM overlap, similar to the way *collaboration* and SDM do, these notions are not necessarily the same. SDM is often linked to two ideas viz. *shared responsibility* and *partnership* (Rothert & O'Connor, 2001).

Some works define the SDM process as the active and meaningful participation of patients in their own health treatment (Adams et al., 2007), or a process which itself necessitates the participation of at least one HCP and one patient to share information and collaborate (Rothert & O'Connor, 2001; Slade, 2017). SDM is sometimes defined in terms of a collaboration between two parties (Adams & Drake, 2006) aiming (and taking active steps) to reach a consensus, without necessarily believing that the chosen treatment is the best choice (Charles et al., 1997). Other analyses understand SDM as necessarily emancipatory, aiming for a positive state of being and for being free (Wittmann-Price, 2004). The partnership between midwife and woman, for example, can be seen as an indication of an equal power distribution between the two, such that the relationship is empowering to both (Myskja & Steinsbekk, 2020; Pairman, 2010).

SDM is sometimes used as means for *persuasion* in relation to patient participation or involvement in the care (Emanuel & Emanuel, 1992; E. G.

Engelhardt et al., 2016; Söderberg et al., 2020), and at other times, understood as mere sharing of information (Rothert & O'Connor, 2001) or a tool to achieve patient compliance (Söderberg et al., 2022). These ideas correspond to the second theme in the results of *paper IV*, "Patient Participation: Narration or Compliance?", where caregivers leaned toward understanding patient participation in terms of being present in meetings, being given the opportunity to express preferences, or following institutional rules.

This lack of unity in the definition or understanding of SDM explains an analysis of nine different SDM variants of which some are outright paternalistic, some put the main decision-making power with the patient, and others offer a more demanding notion of mutual critical deliberation (Sandman & Munthe, 2010). The more advanced and demanding forms of SDM, or what Sandman and Munthe (2010) refer to as *high-level dynamics*, can potentially end in consensus, discord, or strategic adjustments by HCPs to maintain a care relationship. As a result, ethical questions surrounding sharing of responsibility are immediately invited. The complexity, and perhaps confusion, resulting from the multitude of ways in which complex processes like SDM, participation, and collaboration can be understood and used, is a key finding in *paper IV*. This brings to light several challenges in the face of meaningful implementation of emancipation-oriented PCC in FP.

At the same time, the shift from paternalism to mutuality and from an authoritarian stance to collaborative efforts (Rothert & O'Connor, 2001), promote an understanding of the HCP-patient interaction as a meeting between (complementary) experts engaging in processes of discourse and dialogue (van Eemeren et al., 2021). The collaborative partnership grounding such argumentation processes in SDM is facilitated by a reciprocal (recognition of the) knowledge of the other. For HCPs, the observation of patient habits and narrative allows such knowledge to take form (Cassell, 1991), making patient narrative as well as continuity of care, as brought forth in *papers I* and *II*, principal elements in PCC practice.

The central idea in *paper II* is the act of *disputing* or argumentation within SDM. This is primarily a cognitive process which implicitly assumes the presence of a partner in dialogue (van Eemeren et al., 2021) capable of engaging in the manner required by the process. Such assumption underlines the recognition of advanced patient capacities which can accordingly be viewed as an act of respect.

> Argumentation is a verbal, social, and rational activity aimed at convincing a reasonable critic of the acceptability of a standpoint by putting forward a constellation of propositions justifying or refuting the proposition expressed in the standpoint. (van Eemeren et al., 2021, p. 4)

In contrast to paternalistic decision-making, it seems intuitive that such SDM process sits on the opposite side of the decision-making spectrum. The paternalistic model for decision-making, as relayed by Emanuel and Emanuel (1992), assumes a shared physician-patient understanding and agreement regarding the *best* goal of care. In this model, the doctor is considered to be a benevolent guardian who either selects relevant information for the patient to agree to or, more conservatively, determines and communicates the medical decision without the patient's input (Emanuel & Emanuel, 1992).

In *paper III*, however, SDM is not presented as the polar opposite of paternalistic decision-making, but rather as the middle ground between paternalistic and absolute autonomous patient decisions. The spectrum's extremes are described to consist of one side where HCPs make all decisions which patients execute accordingly, and another side where it is the reverse. Please see Figure 5.
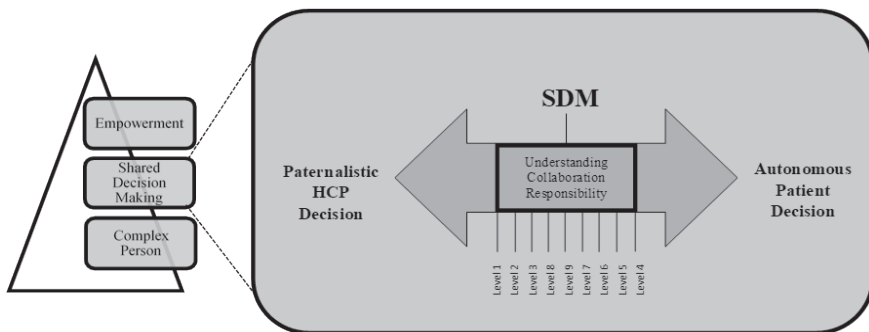
Figure 5

Essential elements of SDM illustrated as a continuum of different levels taking place between two extreme ends of paternalism and autonomy (El-Alti, 2021, unpublished manuscript). The PCC model (left) is adapted from El-Alti et al. (2019) and the nine SDM levels (right) are adapted from Sandman and Munthe (2009).
Level 1: Patient shares information about herself but HCP makes the decision
Level 2: Patient shares preferences but HCP makes the decision
Level 3: Rational deliberation but HCP makes the decision
Level 8: Rational deliberation followed by joint decision
Level 9: Rational deliberation, conflict, and compromise
Level 7: Rational deliberation but patient makes the decision
Level 6: HCP provides best decision but patient makes the decision
Level 5: HCP helps patient with preferences but patient makes the decision
Level 4: HCP shares relevant info but patient makes the decision

To address which combination of power, authority, and freedom for HCPs and patients is appropriate, one must turn to the basic normative stance behind the emancipation-oriented PCC model, i.e., that of the importance of respecting and promoting patient autonomy. Autonomous decision-making is a crucial part of almost all bioethical discussions (Verkerk, 2011), and are usually linked to certain functions or capacities in the individual including abilities to understand, reason, judge, and appraise available choices (Epright, 2010).

In addition to philosophy and ethics, ideas of autonomy have been consistently central in the sociology of medicine for decades (Britten, 2001). Autonomy is, first and foremost, conceptually understood as antithetical to paternalism and coercive influences (Oshana, 1998). Common intuitions about autonomy are succinctly described in the following quote.

> The autonomous person formulates certain goals, as relevant to the direction of her life, and is able to pursue these goals and make them effective in action. Moreover, she formulates these goals according to values, desires, and convictions that have developed in an uncoerced and conscious fashion. Such values can be described as the agent's own even while they reflect the influence of factors external to her. Additionally, an autonomous person is able to meet her goals without depending upon the judgments of others as to their validity and importance. Though the autonomous individual may require the assistance of others in meeting these goals, she decides which of them are most important. (Oshana, 1998, p. 82)

A thin understanding of autonomy often merely requires a healthy, self-governing person who does not suffer any 'psychological or physiological "affliction"' (Buss, 2005, p. 215). In more liberal and individualistic conceptualizations, autonomy is thought to be the basis for justifying ideas and practices like truth-telling, informed consent, and patient control (Cassidy & Oddi, 1986; Wiens, 1993) as well as more general norms of self-determination and governing one's life on one's own terms (Davy, 2019; Oshana, 1998) without interference from external influences which impede making meaningful choices (Beauchamp & Childress, 2019).

> The autonomous agent is understood to be the author of her own life. She defines herself, defines her own goals, acts on her own choices, and decides on her own values. The autonomous subject must govern herself, independent of her relationships with others, her cultural and social identity, and her place within social, economic, and political structures, otherwise we have no way of knowing that she is following her own authentic internal law, uninfluenced and uncoerced by others. (Davy, 2019, p. 104)

Governing oneself or self-rule in the Kantian understanding of autonomy, however, is defined in terms of legislating the law by oneself and applying the law to oneself through using reason, which holds the highest moral authority (Kant, 1785/2012). In comparison to other conceptions of autonomy which involve choices based on personally determined preferences, desires, and inclinations, Kant regards such choices as heteronomous, i.e., not truly autonomous (H.T. Engelhardt, 2001; Kant, 1785/2011).

> [...the human being] is subject *only to laws given by himself but still universal* and that he is bound only to act in conformity with his own will, which, however, in accordance with nature's end is a will giving universal law. For, if one thought of him only as subject to a law (whatever it may be), this law had to carry with it some interest by way of attraction or constraint, since it did not as a law arise from *his* will; in order to conform with the law, his will had instead to be constrained by *something else* to act in a certain way. [...] But then the imperative had to turn out always conditional and could not be fit for a moral command. I will therefore call this basic principle the principle of the **autonomy** of the will in contrast with every other, which I accordingly count as **heteronomy**. (Kant 1785/2011, p. 40-41)

Despite the presence of multiple conceptions and accounts of autonomy, the value of being autonomous is generally acknowledged for similar reasons. This relates, for example, to a person having power over her life, (the disvalue of) powerlessness as a loss of control (Aujoulat et al., 2007) and indignity as the loss of influence over what happens to the person (Berwick, 2009), and subsequent development of negative self-attitudes due to vulnerability (Kaplan, 1976). Linking to such ideas, an emancipation-oriented model of PCC may be described to employ strategies which are modifiable according to the person's narrative, for the purpose of empowering her to a position of active participant and autonomous decision-maker (Glick 2019).

Yet, the value of exerting power over one's life and its direction is different from the value of *experiencing* oneself as having power over one's life. The latter idea relates to subjective well-being and to the meaning this experience of power lends to a person's life. Understanding autonomy as a value, in the personal and individualistic sense, is not necessary for valuing the *experience* of having power. This experience can be viewed as a combination of the following ingredients: feeling that one's behaviors reflect personal values, feeling that said behaviors are effective, and having strong and meaningful bonds with others (Deci & Ryan, 2000; López Barreda et al., 2016). This experience of control or power over one's

life could be based on – or attained through – a *relational* understanding of autonomy, which is an idea stemming from the arena of care ethics[28].

Feminist scholars frequently oppose the individualistic understanding of autonomy and argue that women are "socialized primarily with a self-conception as *relational* instead of individual" (Potter, 2013, p. 76). Relational autonomy adds a social dimension to the concept of personal autonomy (Verkerk, 2011), and recognizes vulnerability and dependence on others as part of the human condition (Davy, 2019). Which understanding of autonomy PCC (should) adopt(s) remains to be determined, as the relational sense ties to its anti-reductionist tendencies while the individualistic/personal one is linked to its emancipatory ambition[29].

Understanding PCC in terms of emancipation[30] is implicitly based on the assumption of a typical patient: one with sufficient capacities for agency, collaboration, and responsibility. What is meant by a *typical person in healthcare* is in itself a form of standardization and is, of course, not unproblematic. Assumptions about who counts as a *default* patient, in terms of diagnosis or other individual characteristics, may lead to unjustified exclusion of certain patients and their relevant perspectives and interests.

This can also have implications for the justifiability or feasibility conditions of specific PCC practices in different healthcare contexts. Framing PCC in terms of highly collaborative SDM processes, emancipatory goals, and transfer of responsibility to the patient, gives the impression that PCC is a care provision scheme reserved exclusively for patients with certain psychosocial capacities. Therefore, exploring the intersection of the proposed PCC model with healthcare contexts where patient capacities are potentially constricted is crucial to test the viability and limits of PCC.

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[28] In nursing practice, for instance, autonomy is a fundamental concept based in the *caring* (as opposed to curing) and *holistic* approach to patients (Wiens, 1993).

[29] The relevance of this distinction is discussed in the concluding section.

[30] As is common in PCC literature.

Between Emancipation and Incapacity for Emancipation: Psychiatric Challenges to Person-Centered Care

> Meaningless disorder as madness is, it reveals, when we examine it, only ordered classifications, rigorous mechanisms in soul and body, language articulated according to a visible logic. All that madness can say of itself is merely reason, though it is itself the negation of reason. In short, *a rational hold over madness is always possible and necessary, to the very degree that madness is non-reason.* There is only one word which summarizes this experience, *Unreason.* (Foucault, 1965/1988, p. 107)

Psychiatric contexts can be understood in terms of psychiatric healthcare *settings* where specialized HCPs deliver care to persons with mental illness, more broadly as *any* healthcare setting where persons with mental illness can seek healthcare services for any health concerns, or as relating to recognized diagnostic *categorizations* of mental illness and their associated accepted practices. Psychiatric contexts are challenging to PCC in three major ways, to be discussed respectively in this section: (1) weight assigned to considerations and interests other than the patient's, (2) dissonance in psychiatry's theoretical and practical commitments in patient care, and (3) (potentially) weakened patient agential capacities.

First, despite in-patient psychiatric care contexts appearing similar in treatment purpose to any other healthcare ward, the institutionalization of persons with mental illness and the restrictive institutional rules within psychiatric facilities oftentimes involve considerations which have little to do with the patients themselves. Legal, social, and safety factors related to a patient's presence in society are many times deemed equally important, or at times even superior, to therapeutic or caring concerns, for instance, in case the patient is believed to pose a threat to other people. The PCC tendency toward defining the care as exclusively centered around the person herself are thus in tension with psychiatry's inclusion of other interests in its care considerations.

> Any legal regulation of compulsory psychiatric care is necessarily the result of a series of difficult adjustments made in order to satisfy colliding interests within both psychiatry and law, such as the patient's right to and need for care and his or her conflicting interests of autonomy, integrity and right to fair trial. Other dilemmas concern the patient's need for protection from his/herself as well as the demand on behalf of the caregiver to consider not only the patient's needs but also public safety. (Kindström Dahlin et al., 2009, p. 377)

Secondly, psychiatric classifications and treatments of mental illness appear dissonant with psychiatry's assumed scope and focus[31]. The traditional biomedical model of disease understands illness as an externally caused biological dysfunction, and is thus not useful for understanding mental illness (Eastman & Starling, 2006). In this respect, psychiatry seems to diverge from the biomedical model, as its classified disorders cannot be understood in terms of departures from normal biological functions (Eastman & Starling, 2006) but in relation to (ab)normal behavior, thoughts, personality, and through the lens of other people's interests or social mores. This is especially relevant when considered together with the concomitant absence of a clear understanding of mental illness etiologies (Clark et al., 2017).

Diagnostic categories in psychiatry, unlike their corresponding categories in other medical areas[32], are more overtly value-laden or have, at least, *some* evaluative content. For example, there are value judgments in diagnoses like paraphilia and moral categories in diagnoses like alcoholism, psychopathy, and malingering; while a change in a patient's *functioning* has both descriptive and evaluative dimensions (Fulford, 2004). This renders psychiatric assessment, diagnoses, prescribed treatment, or involuntary incarceration harder to explain in terms of patients' *medical* needs, without reference to other (normative) claims.

A more sympathetic interpretation of this divergence would perhaps describe psychiatry's perspective on the patient as wider than the biomedical model's outlook, since psychiatry also considers social and psychological aspects in patient care. This interpretation is bolstered by the assumed influence (and widespread evidence in support) of models and tools which incorporate psychological and

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[31] Sometimes invoking extreme criticism of psychiatric categorizations and practices, e.g. from Thomas Szasz (1974/2010).

[32] This is not to say that the general medical categorizations of diseases are necessarily descriptive or void of evaluative assumptions, but only that it is more difficult to understand psychiatric diagnoses in value-neutral terms.

social considerations to psychiatric patient care. Yet, despite assumptions about the influence of these holistic models or tools within psychiatry, things may look markedly different in practice.

For instance, the *biopsychosocial* model, discussed earlier in this chapter, is said to hold much influence on modern psychiatry (Benning, 2015). However, the model's *bio* aspect seems to hold more weight in research or practice than the model's other two dimensions (Benning, 2015; Suls & Rothman, 2004). Although there has been an increase in referencing the *biopsychosocial* model in literature, the biomedical model remains dominant[33] (Suls & Rothman, 2004).

The *recovery*[34] model, which recognizes that persons with mental illnesses are able to take part in society as functional individuals (Davidson, 2016), is also sometimes forwarded as an alternative for the medical model of psychiatry (Barber, 2012). Evidence of (partial) recovery from mental illness has been widely reported in empirical research studies[35]. Yet, how recovery values can be incorporated in evidence-based practice of psychiatry has yet to be addressed (Farkas et al., 2005), especially in light of pessimistic HCP attitudes regarding recovery (Gordon & Green, 2013) and a(n) (over-)reliance on pharmacological treatment of mental illness (A. P. Morrison et al., 2012).

The benefits of the instrumental use of SDM have been similarly well documented in literature[36], and many persons with severe mental illness seem to

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[33] In Medline, the ratio of citations of "biomedical" vs. "biopsychosocial" between 1974-2001 was 9:1 (Suls & Rothman, 2004).

[34] While HCPs usually define recovery in the clinical sense, in terms of remission or cure from illness (Slade et al., 2014), more than one kind of recovery is thought to exist. In addition to clinical recovery, illness management involves symptom control while personal recovery is understood as attaining one's maximum functionality (Barber, 2012) or the developmental process of finding meaning or purpose in life despite (and beyond) illness and its associated stigma (Spaniol et al., 2002).

[35] Almost thirty years ago, empirical evidence accumulated over two decades showed great heterogeneity within symptom presentation, outcomes, rehabilitation, functionality (Harding & Zahniser, 1994); with clinical recovery being more likely later in life (Barber, 2012; Harding & Zahniser, 1994). Retrospective assessment of clinical and social functioning of patients with schizophrenia showed that many were able to reach partial recovery, with one in four patients no longer needing to use their medications (Abdel-Baki et al., 2011; Harrow & Jobe, 2007).

[36] A systematic review of 115 studies from 1980 to 2007 related to decision-making preferences showed that majority of patients prefer SDM, with the preference increasing after the turn of the century (Chewning et al., 2012). Providing opportunities for collaboration within services has also been shown to improve outcomes (Stanhope et al., 2013). A Dutch study showed that SDM interventions increase independent behavior of patients with substance dependence (Joosten et al., 2011). Far better rehabilitation outcomes were also observed in patients actively and meaningfully involved in the design and decisions of services (Majumder et al., 1998).

have a preference for SDM (Adams et al., 2007; Hamann et al., 2005; Hamann et al., 2011). The instrumental use of SDM is an idea supported by *Paper III*, i.e., that it is theoretically possible for persons with mental illness to be fully engaged in the SDM process and that the latter can be used as a tool to enhance a person's capacity for solving problems (Aujoulat et al., 2006; O'Connor et al., 1999). It is, however, difficult to assess whether SDM is commonly practiced since medical paternalism still dominates HCP-patient interactions (Pelto-Piri et al., 2013).

Given that the role holistic models or tools play in psychiatric practice remains ambiguous, it is difficult to accept the interpretation that psychiatry only seems at odds with the biomedical model due to its more holistic understanding of patients. Moreover, psychiatry's tendency to treat mental illness through pharmacological means indicates a contradictory assumption of an underlying biopathology in mental disorders (Eastman & Starling, 2006) which, as mentioned earlier, cannot account for how mental illness is defined.

Psychiatry seems to be more aligned with biomedical dualism (Eastman & Starling, 2006), and this can be clearly seen in DSM-5 requirements to rule out physical conditions (which might be causing the psychiatric symptoms) in order to establish a psychiatric diagnosis of a disorder (American Psychiatric Association [APA], 2013).

> The philosophical basis of the biomedical model is Cartesian, and herein lies the root of the problem. Cartesian dualism leads to the idea of the mind as a substance separate from the body: but the mind is not a machine, as the body is. It operates in terms of reasons, so it cannot be diseased in the way that the body can. Mental illness is therefore self contradictory. Anti-dualists argue that the mind is purely physical ("the mind is the brain"). Both parties, however, make the fundamental mistake of treating the mind as 'a thing'. (Eastman & Starling, 2006, p. 95)

For PCC, these conflicts in psychiatric commitments translate into both convergence and divergence between PCC and psychiatric contexts. On one hand, the diversion of psychiatry from the typically objective biomedical position could be interpreted as being in favor of PCC, as it makes it even more important for the *subject* to be involved in the care process. Patient subjectivity seems central to psychiatric care, in contrast to other medical interventions which could theoretically take place without an autonomous agent on the receiving end, as previously discussed. On the other hand, the combination of psychiatry's dependence on biomedical means to treat mental illness are difficult to reconcile with the PCC objections to traditional biomedical reductionism.

Thirdly, constituting the most complex psychiatry-related challenge to PCC are issues relating to deficient or weakened[37] patient agential capacities[38]. For instance, the justification for coercive FPC variants of in-patient psychiatric institutions is often "built on the basic assumption that offenders suffering from (at least some sorts of) mental disorders are special in a number of respects (e.g. being less capable of acting responsibly, being unusually dangerous, being somewhat treatable with respect to their criminal tendencies, etc.)" (Munthe et al., 2010, p. 36). These assumptions are linked to broader medical and social perceptions of persons with disability, which are commonly seen by critical disability theorists as pervasive and problematic.

The medical model's normative definition of disability in terms of pathology has been critiqued by feminist theorists, whereas the social model which, despite itself being a response to narrower medical model, has also been critiqued for continuing to define impairment in relation to socially accepted norms (Carlson, 2016). Feminist theorists have also been critical of defining cognitive disability in terms of theories of intelligence (or IQ), as these bear similarities to social norms which historically labeled women or certain ethnic groups as intellectually or morally deficient or inferior (Carlson, 2016).

Other feminist theorists and bioethicists have themselves been critiqued by women with disabilities for perpetuating the understanding of (intellectual) disability vis-à-vis its negative portrayal as the ultimate tragedy (Carlson, 2016; Davy, 2019). Cognitive or mental disabilities, sometimes (assumed to be) associated to varying degrees with mental illness, are especially challenging to define without controversial evaluative or normative premises. Psychiatric disabilities and mental illness are sometimes included under the broader category of mental disability, such as in the work of Price (2015).

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[37] Understanding mental illness in terms of a deficit is reminiscent of the Foucauldian characterization of madness as a negative, an absence, and (his famous description of madness) as unreason, as seen in the quote from "Madness and Civilization" (1965/1988) at the beginning of this section.

[38] There is no agreement regarding what moral agency is and where persons with mental illness stand in terms of agency. Agency is many times understood in terms of autonomy, reason-responsiveness, judgment, responsibility, rationality, or a combination of some or all of them. A Humean conception of agency grants sentiments and character traits a large influence (1739/1978) while a Kantian understanding, for instance, only regards reason as the authority for moral judgment (1785/2012). Mental illness is often thought to be an agency-undermining condition and that patients with certain kinds of mental illness (such as autism and psychopathy) are by default excluded from being agents (Bülow, 2014; Damm, 2010).

The concept of *neurodiversity*, hence, emerged in direct opposition to defining intellectual or cognitive categories in terms of a *deficit*[39] or deviance from social norms (Carlson, 2016). Nevertheless, patients' potentially weakened agential capacities[40] are often cited as a reason for not involving patients with mental illness in SDM. When (even) the possibility of a threat to cognitive capacities is brought forth by psychiatric contexts, the *capacity question* in *paper III* inevitably arises.

Persons with mental illness are often seen exclusively in light of an assumed *in*capacity, lack of judgment, or diversion from the norm (Nicki, 2002). A clinical assessment of a person's rationality is often done in relation to some sort of understanding or model of mental illness which necessarily involves aspects of irrationality, uncontrollable emotions, cognitive deficits, confusion, or "illogical assessment of one's life prospects" (Nicki, 2002, p. 271).

In contrast to prisoners[41], the commitment of persons to FPC is authorized *specifically* because they have been recognized (at least at the time of the crime) as non-agents. This view persists inside the FPC system as evident in *paper IV* findings concerning the compliance-oriented approach to care. This is because requirements of compliance hint at an assumption of patients' *in*capacity to reason or meaningfully *engage* with moral (or other) rules, which would thereby justify employing a compliance-based approach to ensure that patients (at least) *follow* the rules. The immediate relevance of patient capacities to PCFPC also bring to light implicit assumptions about what *typical* patient capacities are expected or evaluative assumptions about how they should be.

Understanding persons (and pushing them to be seen) in terms of what they are (in)capable of, also highlights the preferability of a rational, well-reasoning, self-reliant agent to an emotional, irrational, incapable one (Verkerk, 2011). Therefore, questions relating to agency or agential capacities of persons with mental illness are crucial to both PCC and psychiatry[42].

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[39] For example, DSM-5 criteria consider *inattention* a central aspect of Attention Deficit and Hyperactivity Disorder (ADHD) (APA, 2013) while *hyperfocus*, often experienced by adults with ADHD, is not mentioned. There is also lack of clinical evidence and empirical support for *hyperfocus*, even though it is widely reported among persons with ADHD and might, in many cases, influence HCP treatment decisions (Hupfeld et al., 2018).

[40] Introduced in *paper II*, included in the *capacity question* in *paper III*, and used in the interview questions in *paper IV*

[41] Standard retributivist accounts of punishing criminals through imprisoning them can be interpreted as a way of assigning blame, which indicates the recognition of these prisoners as moral agents who are an appropriate object of blame (Bülow, 2014).

[42] And are accordingly being explored as a major aspect of the PCC-psychiatry intersection.

> The philosophical concept of agency is tied up with a traditional Western conception of the self as an autonomous, discrete, and atomistic individual. (Potter, 2013, p. 76)

The intersection of (what is perceived to be) substandard agential capacities due to mental illness with PCC as an emancipation ideal in healthcare, can be interpreted to underline this model's shortcomings in relation to (what seems like) *requisite* patient capacities. This might render the threat of *in*capacity greater to this PCC model than that of paternalism or biomedical reductionism, in the sense that what seems to impede *true* patient emancipation (through PCC) is the patient's own deficiencies rather than PCC's requirements of agency.

The notion that agential capacities come from within the individual herself, without interacting with the outside world has been widely contested by care ethicists and feminist theorists. Oshana (1998) criticizes *internalist* accounts which place the conditions for agential capacity in certain (psychological) elements within the agent herself, independently of the outside world, and "in virtue of which autonomy is safeguarded" (Oshana, 1998, p. 85). Burkitt also critiques the idea that agency is somehow possessed by the individual and revolves around reflexivity, i.e., choosing to act in a certain way when one is capable of acting otherwise. (Burkitt, 2016). Rather, individuals are described by Burkitt as *interactants* whose effect on the world come about through "relational connection and joint actions" (Burkitt, 2016, p. 323).

> […] as interactants no person is ever completely an agent or a patient in any one moment of interaction: instead we are always both agent and patient, acting upon others and being acted upon by others to varying degrees. (Burkitt, 2016, p. 334)

The *relational* understanding of autonomy, discussed earlier in the chapter, inform the notion of *relational agency* (Schlosser, 2019). Thinking in terms of relational *capabilities* acknowledges that the different ways a person is treated can allow or inhibit these capabilities (Entwistle & Watt, 2013).

> Thus in addition to whatever role social conditions play in bringing about a climate more conducive to self-government, an unconstraining social situation is partly constitutive of, or contributes "materially" to, self-government. (Oshana, 1998, p. 97)

Framing PCC (and other relevant) discussions in terms of personal, rather than relational, agential (in)capacities is problematic in two ways. First, it leads to

invoking a *status*-oriented view[43,44] of patients with mental illness, such that (in)capacity is a fixed quality in the person indicating either the presence or absence of a certain capacity. Second, it assumes that the capacities (solely or primarily) reside in the person herself rather than (also) being the result of external factors or an interplay between different factors.

It could be argued that a personal (non-relational) understanding of agency which place agential capacities within the agent herself also views said capacities as inviolable, in the sense that no external factors can strip an agent of her capacities (Wieland, 2017). However, there are countless accounts which illustrate the detrimental effects of mistreatment and oppression on victim's lives and capacities.

Many feminist theorists address the undermining influence of constraining external conditions, such as oppressive social conditions, on a person's capacity for autonomy (Stoljar, 2018). Oppressive socialization of women, for instance, is often argued to undermine women's autonomy (Meyers, 1987). Despite common beliefs that pain and suffering in oppressive conditions lead to group formation and collective action in the public sphere (Allsop et al., 2004), continuous monitoring of physical spaces of oppressed or segregated social groups[45] renders these groups less autonomous and thus unable to create free spaces[46] (Evans & Boyte, 1992) or develop oppositional consciousness[47] (Groch, 1998).

Drawing parallels to such oppressive external conditions are the FPC conditions[48] described by participants in *paper IV*, where patients are stripped of power and control, live with ever-present threats of violence and forced isolation,

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[43] Status approaches also complicate matters of criminal responsibility (Szmukler, 2014).

[44] In *paper III*, under the *responsibility ascription question*, this outlook on patients is rejected in favor of a *functional* approach which accommodates for variability in patient capacities. The functional approach is also arguably (especially) beneficial for patients in involuntary care settings (Szmukler, 2014).

[45] This includes limiting a group's free time, for example.

[46] Free spaces are "unmonitored indigenous settings that prompt an internal criticism of the group's condition" (Groch, 1998, p. iii).

[47] In emancipatory movements, oppositional consciousness is understood as an *awakening* which takes place when an oppressed group becomes aware of – and actively questions – dominant norms and values (Williamson, 2008).

[48] These conditions establish a power structure which is assumed to have a deterring effect on patient misbehavior (Roberts, 2005).

and are closely supervised to ensure compliance[49]. If they were to take place in a different healthcare setting, such measures would otherwise be indicative of patient abuse. Yet, in relation to assumed patient *in*capacities, these conditions are oftentimes justified within FPC as necessary for the patient's own good as well as the good of others. This becomes even more relevant when considerations of vulnerability are taken into account as well. In comparison with other patients in healthcare, persons with mental illness are commonly regarded as more vulnerable to physical and psychological mistreatment, and as less protected against such abuse.

> There are historical paradigms of unethical behavior towards patients with mental illness committed by relatives, professionals, governments, and society as a whole. (Christodoulou et al., 2016, p. 41)

This leads to an impasse, as currently practiced oppressive psychiatric measures in relation to assumptions about patient capacities seem unjustifiable, even when modifications to different variables within these assumptions are made.

If one were to accept that current FPC conditions are reasonably justified then one would also have to assume that (most or all) patients in FP lack agential capacities in a fundamental way which is not subject to change in any situation, such that they are not (and can never be) considered moral agents. However, a static lack of capacities in persons with mental illness cannot be assumed because it is contested by empirical evidence relating to: (1) heterogeneity of mental illnesses (Harding & Zahniser, 1994), (2) symptom variability in different patients with the same diagnosis (Gordon & Green, 2013), (3) symptom variability across time in the same patients (M. A. Brown & Velligan, 2016), (4) partial or full recovery from mental illness (Barber, 2012), and (5) enhanced capacities following capacity training by tools such as SDM (Morrison et al., 2012).

Accordingly, it is reasonable to question the compliance-oriented approach in FPC, particularly in light of evidence showing an association between compliance and patient dependency on HCPs or the healthcare system (Coulter & Oldham, 2016). This idea was highlighted by participants, under theme four in *paper IV*, as one of the reasons for patients' long institutionalization times in FPC.

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[49] This gives the message that these patients cannot be trusted and are not capable of becoming responsible (Bülow, 2014). In *paper IV*, this was said (by participants) to result in HCP-patient disagreements as well as patient dissent and refusal to follow the rules.

If, however, one were to accept that FPC coercive measures are justified due to diminished patient capacities at a *specific point in time*, then one would have to also accept that: (1) patient capacities are only temporarily weak and are thus subject to change given the right treatment, and (2) when these capacities are sufficiently developed then coercive measures must also be lifted. However, as the results of *paper IV* show, this is not the case, since patients often remain under involuntary FPC for multiple reasons which have little to do with the development of their capacities. This invites a further need for, first, justifying the lack of SDM (or another capacity-training tool) use to effect capacity development and subsequently limit FPC's coercive measures. Otherwise, it has to be explicitly clarified how short-term coercion, isolation, restraints, incarceration, and other forceful measures have long-term benefits for patients and for their capacity development.

Another way to resolve this impasse is to argue that while FPC's conditions are coercive and stringent, they do not affect patient capacities in any significant way. This means that either external coercive conditions have no influence on capacities or that they are less harmful to those whose capacities are diminished (Wieland, 2017). The first option would preclude the possibility that capacities can be lost or weakened because of mistreatment, oppression, or freedom restriction and thus contradicts the aforementioned accounts of harms caused by oppressive external conditions. Moreover, this could be understood as an attempt to understate just how problematic coercive measures can be (Wieland, 2017) and to redirect the issues of patient (in)capacities back to the patients themselves rather than examine the current system setup.

In the second case, if FPC's current coercive measures are indeed acknowledged as harmful to patient capacities or a hinderance to their development, then the only way left to justify these measures is to assume that they are somehow less harmful to persons with diminished capacities (Wieland, 2017). This is both counterintuitive and discriminatory, because it implies that only persons who (are deemed to) have *full capacities* can *truly* be harmed by oppression or mistreatment.

This impasse clearly has implications for the feasibility of PCFPC. First, the coercive measures in psychiatric care such as forced treatment, restraints, and incarceration are obviously in conflict with the emancipation-oriented PCC focus on autonomy and empowerment. Second, a subtheme in *paper IV* included descriptions of the FP system as restrictive and rigid. This inflexibility goes against another core feature of the PCC model viz. adapting the plan of care to the

individual person. When FP care, by default, opposes bending the rules to accommodate for patient wishes or values in addition to restricting patient freedom, it renders the consideration of PCC within its context almost impossible.

One way to circumvent this is to accept less ambitious versions of SDM, which is one of the main discussion points of *paper IV*. However, instrumental reasons may motivate the use of PCC ingredients (such as listening to the patient narrative) for patients with very weak capacities. Beyond that, conceiving of emancipation-oriented implementation of high-level SDM dynamics in the most security-sensitive FPC areas is difficult. This is largely due to the shift of power to patients resulting from such SDM dynamics, but also to the way the system is structured. Implementing less ambitious versions of SDM would then place constraints on patient empowerment in view of institutional security aspects. This, in turn, requires advanced HCP training for this purpose, which might also likely bring changes to some of the more rigid institutional constraints.

Hence, at the end of the day, it seems that currently accepted psychiatric practices and institutional factors, rather than weakened patient capacities, constitute the major hurdle for implementing emancipation-oriented PCC in psychiatry. When this is considered in relation to the dissonance between accepted involuntary psychiatric conditions and assumptions about patient agential capacities, it also has far-reaching implications for the ethics of psychiatric practices in general.

Concluding Remarks: Boundaries, Limitations, and Intersections

As part of reflecting on this work and its limitations, it is important to clarify that due to the predominantly interdisciplinary nature of the discussion, the task of restricting its scope has not been by any means simple. There are obviously more ways than one which could bring about conceptual clarity for PCC. For the purpose of keeping the discussions grounded within a bioethical framework, this dissertation focused primarily on morally-relevant claims, goals, and commitments of PCC rather than delving deeper, for instance, into ontological or epistemic claims about disease which could also be of relevance to PCC.

The two descriptions of a person *feeling sick* and *being sick* are many times used interchangeably, and at face value, it might seem practically irrelevant to distinguish them. However, the deeper ontological assumptions lurking behind the descriptions about the existence of *disease* in relation to the *subject* experiencing it, can inform evaluative positions toward disease and motivate favoring a certain approach to disease treatment. For example, accepting that disease entities or species do not exist independently of the subject experiencing them (Viesca, 2001) can be linked to a commonly recognized goal of medical practice, namely that of alleviating people's suffering and unpleasant experiences of illness[50, 51]. This would make shaping healthcare provision more intuitively aligned with PCC commitments, in terms of treating illness necessarily in relation to a subject.

Epistemic considerations relating to whether HCP clinical intuitions are sufficient for claims of knowledge about disease (Ashcroft, 2005), were also not lifted in this work despite having some significance to PCC. However, certain epistemically-relevant aspects were indeed discussed in the *subjective-objective* tension

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[50] Rather than motivating medical practice, for instance, in terms of a generic undesirability or devaluation of the disease itself.

[51] This might also explain patients' healthcare-seeking behaviors such as seeking interventions to alleviate an intense pain, treat the cause behind unpleasant symptoms, or relieve an anxiety about a suspected illness, all in order to make the (potential) experience of illness as short, mild, and temporary as possible.

in *paper I* and, more briefly, in PCC's evaluative stance assigning the same value to a subject's knowledge of her body as to a professional's medical knowledge. The latter relates to recognizing the subject as an *expert* about her own body, life, values, and experience, and in that light, regards the person's expertise as essential for the decision-making process, as discussed earlier.

Attempts to gain a deeper understanding of PCC in this work also involved employing different methods and inevitably lead to revealing PCC's intimate, and often complex, connections to several relevant notions and analyses, which do not themselves fall strictly under healthcare or bioethical discussions. While drawing connections from separate disciplines without contributing to any of them could still be viewed as a contribution in its own right, it is worth mentioning that as a result of this interdisciplinary focus, other ideas of relevance were not explored in depth.

The dissertation does not dwell, for instance, on which understanding of responsibility is being employed, *how* patients can be held responsible in the practical sense, and whether this changes in cases of diminished agential capacities. A useful distinction regarding practices of holding patients responsible is made between forward-looking and backward-looking responsibility (Hansson, 2018), where the former includes assigning self-care tasks to patients and the latter can be seen when HCPs shame patients for a past action, for example (Hartvigsson et al., 2018; Hartvigsson, 2020).

In practice, such judgements express responsibility attribution of a blaming type, especially when made the content of conversation in patient consultations. Yet, blame is not an ideal way to maintain a professional-patient relationship, and for people unequipped for full agency and responsibility, it can have detrimental effects (Herlitz et al., 2016; Hartvigsson et al., 2018; Pickard, 2015). Meeting patients' poor adherence to care plans with blame risks "creat[ing] a repeated pattern of fear of failure, increasing lack of self-confidence and resulting disempowerment" (Herlitz et al., 2016, p. 966).

This is discussed as one of the motivations for divorcing responsibility and blame practices (Pickard & Ward, 2013) in *paper III*. In *paper IV*, this idea resurfaces in caregivers' descriptions, as a practical challenge to PCC. Thus, it might be more appropriate to think of backward-looking responsibility attribution in terms of providing an opportunity for patients to engage in self-reflection regarding their actions or capacities for action. This would be a good case in point for communicating in terms of responsibility without relying on affective blame, as Pickard proposes.

It is often not entirely clear, however, how ascription of responsibility to patients can take shape without assuming that they are the object of blame and praise. Shoemaker (2011) distinguishes between three kinds of responsibility viz. *attributability*, *accountability*, and *answerability*, with the latter implying a reasonable demand of justification from an agent when she is being morally criticized. This would make *answerability* the strongest (or strictest) kind among the three, requiring that an agent is only *answerable* to things which reflect her evaluative judgment (Smith, 2012).

Shoemaker also argues that there are cases in which things can be *attributable* to someone without the latter being *answerable* for those things (2011). Hence, it is perhaps helpful to consider *attributability without answerability* as one way for ascribing responsibility to persons with mental illness, for example, without making them an object for blame. Nevertheless, there is no agreement about whether these distinctions in responsibility kinds hold (Hartvigsson, 2020) or whether *answerability* is, in fact, the only true kind of responsibility (Smith, 2012)[52].

Another (perhaps more obviously central) aspect on which the dissertation does not touch, is the personhood aspect viz. who the person in *person*-centered care is. This choice was a conscious one, and was made for two reasons. First, the issue of agential capacities were deemed of more immediate relevance to SDM vis-à-vis patient participation, PCC's shift of responsibility, and empowerment goal. Exploring the intersection of PCC with psychiatric contexts made questions about capacities all the more important to prioritize in the discussion, as they are often assumed to be diminished in mental illness. Second, because psychiatric contexts were the focus of this analysis, invoking questions about personhood and criteria for personhood in PCC might have also inevitably lead to counterintuitive questions about the personhood *status* of patients with mental illness.

To clarify, it is assumed throughout this work that patients diagnosed with mental illness *should* be regarded as persons and that their personhood is maintained in mental illness even if they lack (some) agential capacities. It is common in PCC literature to regard cognitive capacities as irrelevant to personhood in PCC and assume that personhood persists despite impairment in mental faculties (Fazio, 2013; Mast, 2013; Stein-Parbury et al., 2012). In this work,

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[52] For further discussions on moral responsibility, please see Talbert (2019).

this is reflected in the distinction made between a person and her mental illness such that the two do not become synonymous[53] (King & May, 2018).

Finally, the dissertation did not (aim to) critically appraise common bioethical notions such as autonomy and paternalism, but only employed them as they are generally understood by different sources. There was no assumption, for example, that respect for autonomy is absolutely (morally) superior for patients, HCPs, or healthcare provision in general. And while criticism of paternalism is not particularly scarce or unusual within bioethics, the author also did not assume that paternalism is absolutely wrong or unjustifiable in all situations. Portraying the pushback to paternalism and the biomedical model, and the endorsement of autonomy and patient empowerment, was not meant to reflect favoring either approach. Rather, it was employed to illustrate tensions, tendencies, and commitments *from the PCC standpoint*.

To recapitulate, this work aimed to: (1) expand on the concept, values, commitments, assumptions, roots, processes, and ambitions of PCC; (2) explore the different ways PCC is understood in the literature in order to inform the emancipation-oriented model of *paper I*; as well as (3) examine how PCC fares in the face of limitations of mental illness, psychiatric practices, and involuntary care institutions. To what degree this work has been able to achieve these aims will depend on at least two considerations: (a) how successfully this research has afforded insight and clarity to PCC, conceptually and contextually, and (b) how adequately it has illustrated the feasibility and limitations of the proposed emancipation-oriented model of PCC in challenging healthcare contexts.

However, further considerations could be given in relation to more ambitious aims, which were not overtly stated but nevertheless intended, particularly in connection to the interdisciplinary setting of this chapter. The tacit aspiration was that by expanding on PCC's multidirectional connectedness to multiple complex notions, debates, and movements, this research would: (i) first, highlight that PCC is more than a reactionary slogan in healthcare but is better understood in light of larger movements which aim to subvert established power dynamics, (ii) more broadly, reveal how the simple act of patient care delivery relates to much larger contexts than healthcare and is laden with implicit assumptions, layers of description and normativity, philosophical commitments, and ethical implications, and (iii) most importantly, facilitate through this analysis the problematization of

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[53] E.g. using "person with mental illness" rather than "mentally ill person". However, in some cases, this distinction is opposed by patients themselves (Kenny et al., 2016).

values and other assumptions reflected in healthcare provision choices and accepted practices.

It is worth clarifying at this point that despite the lack of a unified PCC definition being one of the motivations for undertaking this research project, the clarity and thoroughness of the emancipation-oriented PCC model alone might be insufficient for realizing consensus regarding PCC. The model merely represents one PCC conception among many others, and can be accepted and contested on various grounds. Thus, it cannot be ascertained that this PCC model is *the* correct or most accurate conception. More importantly, there are additional factors which might influence the conceptual understanding as well as practical implementation of the emancipation-oriented model of PCC. This means that regardless how exhaustive any conceptualization of PCC is, it might still translate to more than one PCC version in practice.

Placing an accent on a certain PCC value or ambition will guide how PCC is understood as well as whether it is feasible in a certain context. For instance, a commitment to an individualistic sense of autonomy and empowerment would need to inevitably emphasize individual capacities in order to champion them. This might paradoxically lead to less emphasis on individualization of care to fit different persons, and more focus on emancipatory efforts[54] toward patients who themselves are deemed fit for said efforts. *Paper I* partially addressed this through discussing how a shift in power to patients can risk exposing them to experiences of disempowerment, thus leading PCC to fall prey to its own kind of reductionism.

Alternatively, emphasizing a *relational* understanding of autonomy or capacities places more weight on PCC's flexible, anti-reductionist, and holistic tendencies which prioritize adapting care processes to fit different persons *regardless* of their capacities. The latter version more closely resembles the PCC description in *paper III*, which allowed the *capacity question* to be dissolved[55]. This would arguably be a PCC version better suited for patients with non-typical capacities. This is because when relational aspects to agential capacities are highlighted, PCC processes would necessarily be more accommodating of patient variability as the interaction of agential capacities with external conditions is readily recognized. More importantly, this version also allows for the instrumental use of its processes, as

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[54] Including high-level SDM dynamics, as described by Sandman and Munthe (2010).
[55] This PCC version would also be aligned with the *capabilities* approach, as described by Entwistle and Watt (2013).

described in *paper III*, in order to instrumentally empower patients and positively influence the development of certain abilities.

How PCC or any healthcare provision approach thus takes shape in practice ultimately not only *exposes* underlying value commitments, assumptions, and contextual limitations to patient care reality, but also *demonstrates* the impossibility of a comprehensive understanding of PCC without such exposition. Therefore, the definition, ethical analysis, and evaluation of PCC – as a model by itself or in comparison with other patient care provision models – must also integrate critique of broader contextual conditions, including (un)accepted healthcare practices and their associated assumptions.

References

Abdel-Baki, A., Lesage, A., Nicole, L., Cossette, M., Salvat, E., & Lalonde, P. (2011). Schizophrenia, an illness with bad outcome: Myth or reality?. *The Canadian Journal of Psychiatry, 56*(2), 92-101. doi:10.1177/070674371105600204

Adams, J., & Drake, R. (2006). Shared decision-making and evidence-based practice. *Community Mental Health Journal, 42*(1), 87-105. doi:10.1007/s10597-005-9005-8

Adams, J. R., Drake, R. E., & Wolford, G. L. (2007). Shared decision-making preferences of people with severe mental illness. *Psychiatric Services, 58*(9), 1219-1221. https://ps.psychiatryonline.org/doi/epub/10.1176/ps.2007.58.9.1219

Agazzi, E. (2001). Illness as lived experience and as the object of medicine. In A. Tymieniecka & E. Agazzi (Eds.), *Life interpretation and the sense of illness within the human condition* (pp. 3-15). Springer, Dordrecht. doi:10.1007/978-94-010-0780-1_1

Allsop, J., Jones, K., & Baggott, R. (2004). Health consumer groups in the UK: A new social movement?. *Sociology of Health & Illness, 26*(6), 737-756. doi:10.1111/j.0141-9889.2004.00416.x

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://ebookcentral.proquest.com/lib/gu/reader.action?docID=1811753

Amundson, R. (2000). Against normal function. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences, 31*(1), 33-53. doi:10.1016/S1369-8486(99)00033-3

Anderson, R. M., & Funnell, M. M. (2010). Patient empowerment: Myths and misconceptions. *Patient education and counseling, 79*(3), 277-282. doi:10.1016/j.pec.2009.07.025

Ashcroft, R. E. (2005). Current epistemological problems in evidence-based medicine. *Journal of Medical Ethics, 30*, 131-135. doi:10.1136/jme.2003.007039

Aujoulat, I., d'Hoore, W., & Deccache, A. (2006). Patient empowerment in theory and practice: Polysemy or cacophony?. *Patient education and counseling, 66*(1), 13-20. doi:10.1016/j.pec.2006.09.008

Aujoulat, I., Luminet, O., & Deccache, A. (2007). The perspective of patients on their experience of powerlessness. *Qualitative health research, 17*(6), 772-785. doi:10.1177/1049732307302665

Barber, M. E. (2012). Recovery as the new medical model for psychiatry. *Psychiatric Services, 63*(3), 277-279. doi:10.1176/appi.ps.201100248

Barrett, E. A. M. (1998). A Rogerian practice methodology for health patterning. *Nursing Science Quarterly, 11*(4), 136-138. doi:10.1177/089431849801100402

Bennet, T. (2020). *Straffansvar vid atypiska sinnestillstånd*. [Doctoral dissertation, Lund University]. Norstedts Juridik AB.

Benning, T. B. (2015). Limitations of the biopsychosocial model in psychiatry. *Advances in Medical Education and practice, 6*, 347-352. doi:10.2147/AMEP.S82937

Bernstein, S. B., & Zander, K. (1981). Continuity of care: A patient-centered model. *General Hospital Psychiatry, 3*(1), 59-63. doi:10.1016/0163-8343(81)90024-4

Berry, K., Butt, M., & Kirby, J. S. (2017). Influence of information framing on patient decisions to treat actinic keratosis. *JAMA Dermatology, 153*(5), 421-426. doi:10.1001/jamadermatol.2016.5245

Berwick, D. M. (2009). What 'patient-centered' should mean: Confessions of an extremist. *Health Affairs, 28*(Suppl1), w555-w565. https://doi.org/10.1377/hlthaff.28.4.w555

Beauchamp, T., & Childress, J. (2019). *Principles of biomedical ethics* (8th ed.). New York: Oxford University Press.

Benoit, C., Zadoroznyj, M., Hallgrimsdottir, H., Treloar, A., & Taylor, K. (2010). Medical dominance and neoliberalisation in maternal care provision: The evidence from Canada and Australia. *Social Science & Medicine, 71*(3), 475-481. doi:10.1016/j.socscimed.2010.04.005

Bissell, P., May, C. R., & Noyce, P. R. (2004). From compliance to concordance: Barriers to accomplishing a re-framed model of health care interactions. *Social Science & Medicine, 58*(4), 851-862. doi:10.1016/S0277-9536(03)00259-4

Bosworth, H. B., Granger, B. B., Mendys, P., Brindis, R., Burkholder, R., Czajkowski, S. M., Daniel, J. G., Ekman, I., Ho, M., Johnson, M., Kimmel, S. E., Liu, L. Z., Musaus, J., Shrank, W. H., Whalley Buono, E., Weiss, K & Granger, C. B. (2011). Medication adherence: A call for action. *American Heart Journal, 162*(3), 412-424. doi:10.1016/j.ahj.2011.06.007

Botin, L., Bertelsen, P. S., Kayser, L., Turner, P., Villumsen, S., & Nøhr, C. (2020). People centeredness, chronic conditions and diversity sensitive eHealth: Exploring emancipation of the 'health care system' and the 'patient' in health informatics. *Life, 10*(12), 329. doi:10.3390/life10120329

Britten, N. (2001). Prescribing and the defence of clinical autonomy. *Sociology of Health & Illness, 23*(4), 478-496. doi:10.1111/1467-9566.00261

Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2017). Elaboration of the Gothenburg model of person-centred care. *Health Expectations, 20*(3), 407-418. doi:10.1111/hex.12468

Brown, M. A., & Velligan, D. I. (2016). Issues and developments related to assessing function in serious mental illness. *Dialogues in Clinical Neuroscience, 18*(2), 135–144. doi:10.31887/DCNS.2016.18.2/dvelligan

Brown, P., & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness, 26*(6), 679–694. doi:10.1111/j.0141-9889.2004.00413.x

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness, 26*(1), 50-80. doi:10.1111/j.1467-9566.2004.00378.x

Burkitt, I. (2016). Relational agency: Relational sociology, agency and interaction. *European Journal of Social Theory, 19*(3), 322-339. doi:10.1177/1368431015591426

Buss, S. (2005). Valuing autonomy and respecting persons: Manipulation, seduction, and the basis of moral constraints. *Ethics, 115*(2), 195-235. https://doi.org/10.1086/426304

Bülow, W. (2014). Treating inmates as moral agents: A defense of the right to privacy in prison. *Criminal Justice Ethics, 33*(1), 1-20. doi:10.1080/0731129X.2014.902654

Calton, T., Cheetham, A., D'Silva, K., & Glazebrook, C. (2009). International schizophrenia research and the concept of patient-centredness: An analysis over two decades. *International Journal of Social Psychiatry, 55*(2), 157-169. doi:10.1177/0020764008093449

Carlson, L. (2016). Feminist approaches to cognitive disability. *Philosophy Compass, 11*(10), 541-553. doi:10.1111/phc3.12350

Cassell, E. J. (1991). *The nature of suffering and the goals of medicine* (2nd ed.). New York: Oxford University Press.

Cassell, E. J. (2010). The person in medicine. *International Journal of Integrated Care, 10*(5), 50-52. doi:10.5334/ijic.489

Cassidy, V. R., & Oddi, L. F. (1986). Legal and ethical aspects of informed consent: A nursing research perspective. *Journal of Professional Nursing, 2*(6), 343-349. doi:10.1016/S8755-7223(86)80009-6

Chapman, H. (2017). Nursing theories 1: Person-centred care. *Nursing Times* [online]*, 113*(10), 59. http://hdl.handle.net/10034/620759

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine, 44*(5), 681-692. doi:10.1016/S0277-9536(96)00221-3

Charon, R. (2004). Narrative and medicine. *The New England Journal of Medicine, 350*(9), 862-864. http://hdl.handle.net/10822/992630

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: A systematic review. *Patient Education and Counseling, 86*(1), 9-18. doi:10.1016/j.pec.2011.02.004

Christodoulou, G. N., Van Staden, C. W., Jousset, D., Schwartz, M., & Mishara, A. (2016). Ethics in person-centered psychiatry. In J. E. Mezzich, M. Botbol, G. N. Christodoulou, C. R. Cloninger, & I. M. Salloum (Eds.), *Person centered psychiatry.* Springer International Publishing. https://link.springer.com/book/10.1007/978-3-319-39724-5

Clark, L. A., Cuthbert, B., Lewis-Fernández, R., Narrow, W. E., & Reed, G. M. (2017). Three approaches to understanding and classifying mental disorder: ICD-11, DSM-5, and the National Institute of Mental Health's Research Domain Criteria (RDoC). *Psychological Science in the Public Interest, 18*(2), 72-145. doi:10.1177/1529100617727266

Cody, W. K. (2003). Paternalism in nursing and healthcare: Central issues and their relation to theory. *Nursing Science Quarterly*, *16*(4), 288-296. doi:10.1177/0894318403257170

Collyer, F., & White, K. (2001). *Corporate control of health care in Australia* (Discussion Paper No. 42). The Australia Institute.

Coulter, A. (1999). Paternalism or partnership?: Patients have grown up—and there's no going back. *BMJ, 319*, 719-720. doi:10.1136/bmj.319.7212.719

Coulter, A., & Oldham, J. (2016). Person-centred care: What is it and how do we get there?. *Future Hospital Journal, 3*(2), 114-116. doi:10.7861/futurehosp.3-2-114

Crawford Shearer, N. B., & Reed, P. G. (2004). Empowerment: Reformulation of a non-Rogerian concept. *Nursing Science Quarterly, 17*(3), 253-259. doi:10.1177/0894318404266325

Damm, L. (2010). Emotions and moral agency. *Philosophical Explorations*, *13*(3), 275-292. doi:10.1080/13869795.2010.501898

Davidson, L. (2016). The recovery movement: Implications for mental health care and enabling people to participate fully in life. *Health Affairs, 35*(6), 1091-1097. doi:10.1377/hlthaff.2016.0153

Davy, L. (2019). Between an ethic of care and an ethic of autonomy: Negotiating relational autonomy, disability, and dependency. *Angelaki Journal of the Theoretical Humanities, 24*(3), 101-114. doi:10.1080/0969725X.2019.1620461

Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review, 33*(7), 846-861. doi:10.1016/j.cpr.2012.09.007

Deci, E. L., & Ryan, R. M. (2000). The" what" and" why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological inquiry, 11*(4), 227-268. https://www.jstor.org/stable/1449618

Dudas, K., Olsson, L. E., Wolf, A., Swedberg, K., Taft, C., Schaufelberger, M., & Ekman, I. (2012). Uncertainty in illness among patients with chronic heart failure is less in person-centred care than in usual care. *European Journal of Cardiovascular Nursing, 12*(6), 521-528. doi:10.1177/1474515112472270

Eastman, N., & Starling, B. (2006). Mental disorder ethics: Theory and empirical investigation. *Journal of Medical Ethics, 32*(2), 94-99. doi:10.1136/jme.2005.013276

Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2008). Swedish language Person-centred Climate Questionnaire–patient version: Construction and psychometric evaluation. *Journal of Advanced Nursing, 63*(3), 302-309. doi:10.1111/j.1365-2648.2008.04709.x

El-Alti, L., Sandman, L., & Munthe, C. (2019). Person centered care and personalized medicine: Irreconcilable opposites or potential companions?. *Health Care Analysis, 27*, 45-59. doi:10.1007/s10728-017-0347-5

Eldh, A. C., Ekman, I., & Ehnfors, M. (2006). Conditions for patient participation and non-participation in health care. *Nursing Ethics, 13*(5), 503-514. doi:10.1191/0969733006nej898oa

Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA, 267*(16), 2221-2226. doi:10.1001/jama.1992.03480160079038

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129-136. doi:10.1126/science.847460

Engelhardt, E. G., Pieterse, A. H., van der Hout, A., de Haes, H. J., Kroep, J. R., van Ufford-Mannesse, P. Q., Portielje, J. E. A., Smets, E. M. A., & Stiggelbout, A. M. (2016). Use of implicit persuasion in decision making about adjuvant cancer treatment: A potential barrier to shared decision making. *European Journal of Cancer, 66*, 55-66. doi:10.1016/j.ejca.2016.07.011

Engelhardt, H. T. (2001). The many faces of autonomy. *Health Care Analysis, 9*(3), 283-297. doi:10.1023/A:1012949730926

Entwistle, V. A., & Watt, I. S. (2013). Treating patients as persons: A capabilities approach to support delivery of person-centered care. *The American Journal of Bioethics, 13*(8), 29-39. doi:10.1080/15265161.2013.802060

Epright, M. C. (2010). Coercing future freedom: Consent and capacities for autonomous choice. *Journal of Law, Medicine & Ethics, 38*(4), 799-806. doi:10.1111/j.1748-720X.2010.00533.x

Evans, S. M., & Boyte, H. C. (1992). *Free spaces: The sources of democratic change in America*. University of Chicago Press.

Farkas, M., Gagne, C., Anthony, W., & Chamberlin, J. (2005). Implementing recovery oriented evidence based programs: Identifying the critical dimensions. *Community Mental Health Journal, 41*(2), 141-158. doi:10.1007/s10597-005-2649-6

Fazio, S. (2013). The individual is the core—and key—to person-centered care [Editorial]. *Journal of the American Society on Aging, 37*(3), 16-22. https://www.jstor.org/stable/10.2307/26591676

Finnsbo, J. (2016). Shared decision making and moral responsibility for treatment and health. [Master's thesis, University of Gothenburg].

Formosa, C. (2015). Understanding power and communication relationships in health settings. *British Journal of Healthcare Management, 21*(9), 420-424. doi:10.12968/bjhc.2015.21.9.420

Foucault, M. (1988). *Madness and civilization.* New York: Vintage. (Original work published in 1965).

Fulford, K. W. M. (2004). Ten principles of values-based medicine. In J. Radden (Ed.),*The philosophy of psychiatry: A companion* (pp. 205-234). New York: Oxford University Press, Inc.

Glick, M. (2019). Precision-, patient-, and person-centered care, oh my. *The Journal of the American Dental Association, 150*(3), 161-162. doi:10.1016/j.adaj.2019.01.008

Gordon, C., & Green, M. (2013). Shared decision making in the treatment of psychosis: Should we include whether and when, as well as which antipsychotic?. *Psychiatric times, 30*(4), 33. https://link.gale.com/apps/doc/A325892647/AONE?u=anon~e4c959cb&sid=googleScholar&xid=79767519

Greene, J. A., Jones, D. S., & Podolsky, S. H. (2012). Therapeutic evolution and the challenge of rational medicine. *New England Journal of Medicine, 367*(12), 1077-1082. doi:10.1056/NEJMp1113570

Grisso, T., & Appelbaum, P. S. (1995). Comparison of standards for assessing patients' capacities to make treatment decisions. *American Journal of Psychiatry, 152*(7), 1033-1037. doi:10.1176/ajp.152.7.1033

Groch, S. A. (1998). *Pathways to protest: The making of oppositional consciousness by people with disabilities.* [Doctoral dissertation, Northwestern University].

Hamann, J., Cohen, R., Leucht, S., Busch, R., & Kissling, W. (2005). Do patients with schizophrenia wish to be involved in decisions about their medical treatment?. *American Journal of Psychiatry, 162*(12), 2382-2384. doi:10.1176/appi.ajp.162.12.2382

Hamann, J., Mendel, R., Meier, A., Asani, F., Pausch, E., Leucht, S., & Kissling, W. (2011). "How to speak to your psychiatrist": Shared decision-making training for inpatients with schizophrenia. P*sychiatric Services, 62*(10), 1218-1221. doi:10.1176/ps.62.10.pss6210_1218

Hansson, S. O. (2018). The ethics of making patients responsible. *Cambridge Quarterly of Healthcare Ethics, 27*(1), 87-92. doi:10.1017/S0963180117000421

Harding, C. M., & Zahniser, J. H. (1994). Empirical correction of seven myths about schizophrenia with implications for treatment. *Acta Psychiatrica Scandinavica, 90*(s384), 140-146. doi:10.1111/j.1600-0447.1994.tb05903.x

Harrow, M., & Jobe, T. H. (2007). Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: A 15-year multifollow-up study. *The Journal of Nervous and Mental disease, 195*(5), 406-414. doi:10.1097/01.nmd.0000253783.32338.6e

Hartvigsson, T., Munthe, C., Forsander, G. (2018). Error trawling and fringe decision competence: Ethical hazards in monitoring and address patient decision capacity in clinical practice. *Clinical Ethics, 13*(3), 126-136. doi:10.1177/1477750917749955

Hartvigsson, T. (2020). Explorations of the relationship between the right to make decisions and moral responsibility in healthcare. [Doctoral dissertation, University of Gothenburg]. Acta Philosophica Gothoburgensia, 37.

Heritage, J., Robinson, J. D., Elliott, M. N., Beckett, M., & Wilkes, M. (2007). Reducing patients' unmet concerns in primary care: The difference one word can make. *Journal of General Internal Medicine, 22*(10), 1429-1433.
https://link.springer.com/article/10.1007/s11606-007-0279-0

Herlitz, A., Munthe, C., Törner, M., & Forsander, G. (2016). The counseling, self-care, adherence approach to person-centered care and shared decision making: Moral psychology, executive autonomy, and ethics in multi-dimensional care decisions. *Health communication, 31*(8), 964-973. doi:10.1080/10410236.2015.1025332

Hernandez, C. A. (1996). Integration: The experience of living with insulin dependent (Type 1) diabetes. *Canadian Journal of Nursing Research, 28*(4), 37-56. PMID:9128475

Hindley, C., & Thomson, A. M. (2005). The rhetoric of informed choice: Perspectives from midwives on intrapartum fetal heart rate monitoring. *Health Expectations, 8*(4), 306-314. doi:10.1111/j.1369-7625.2005.00355.x

Hipp, K. (2021). Patient participation in pro re nata medication in forensic psychiatric inpatient care. [Doctoral dissertation, University of Turku]. Annales Universitatis Turkuensis.

Hokanson Hawks, J. (1992). Empowerment in nursing education: Concept analysis and application to philosophy, learning and instruction. *Journal of Advanced Nursing, 17*, 609-618. doi:10.1111/j.1365-2648.1992.tb02840.x

Holmström, I., & Röing, M. (2010). The relation between patient-centeredness and patient empowerment: A discussion on concepts. *Patient Education and Counseling, 79*(2), 167-172. doi:10.1016/j.pec.2009.08.008

Hughes, J. C., Bamford, C., & May, C. (2008). Types of centredness in health care: Themes and concepts. *Medicine, Health Care and Philosophy, 11*(4), 455-463. doi:10.1007/s11019-008-9131-5

Hume, D. (1978). *A treatise of human nature.* Oxford: Clarendon (Original work published in 1739).

Hunter, J., Corcoran, K., Phelps, K., & Leeder, S. (2012). The integrative medicine team—is biomedical dominance inevitable?. *The Journal of Alternative and Complementary Medicine, 18*(12), 1127-1132. doi:10.1089/acm.2011.0393

Hupfeld, K., Abagis, T., & Shah, P. (2018). Living "in the zone": Hyperfocus in adult ADHD. *ADHD Attention Deficit and Hyperactivity Disorders, 11*(2), 191-208. doi:10.1007/s12402-018-0272-y

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Meranius, M. S. (2019). "Same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling, 102*(1), 3-11. doi:10.1016/j.pec.2018.08.029

Jansen, T. L., & Hanssen, I. (2017). Patient participation: Causing moral stress in psychiatric nursing?. *Scandinavian Journal of Caring Sciences, 31*(2), 388-394. doi:10.1111/scs.12358

Jones, A., Vallis, M., & Pouwer, F. (2015). If it does not significantly change HbA1c levels why should we waste time on it? A plea for the prioritization of psychological well-being in people with diabetes. *Diabetic Medicine, 32*(2), 155-163. doi:10.1111/dme.12620

Joosten, E. A. G., De Jong, C. A. J., de Weert-van Oene, G. H., Sensky, T., & van der Staak, C. P. F. (2011). Shared decision-making: Increases autonomy in substance-dependent patients. *Substance Use & Misuse, 46*(8), 1037-1038. doi:10.3109/10826084.2011.552931

Juengst, E. T. Flatt, M. A., & Settersten Jr., R. A. (2012). Personalized genomic medicine and the rhetoric of empowerment. *Hastings Center Report*, *42*(5), 34-40. doi:10.1002/hast.65

Kaplan, H. B. (1976). Antecedents of negative self attitudes: Membership group devaluation and defenselessness. *Social Psychiatry, 11*(1), 15-25. doi:10.1007/BF00578796

Kant, I. (2012). *Groundwork of the metaphysics of morals.* (Cambridge Texts in the History of Philosophy). Cambridge University Press. (Original work published in 1785).

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462. doi:10.1177/1362361315588200

Kindström Dahlin, M., Hellner Gumpert, C., Torstensson-Levander, M., Svensson, L., & Radovic, S. (2009). Mentally disordered criminal offenders: Legal and criminological perspectives. *International Journal of Law and Psychiatry, 32*(6), 377-382. doi:10.1016/j.ijlp.2009.09.007

King, M. & May, J. (2018). Moral responsibility and mental illness: A call for nuance. *Neuroethics, 11*(1), 11-22. doi:10.1007/s12152-017-9345-4.

Kvarnström, K., Airaksinen, M., & Liira, H. (2017). Barriers and facilitators to medication adherence: A qualitative study with general practitioners. *BMJ Open, 8*(1), e015332. doi:10.1136/bmjopen-2016-015332

Lauver, D. R., Ward, S. E., Heidrich, S. M., Keller, M. L., Bowers, B. J., Flatley Brennan, P., Kirchhoff, K. T., & Wells, T. J. (2002). Patient-centered interventions. *Research in Nursing & Health, 25*(4), 246-255. doi:10.1002/nur.10044

Lazarus, R. S. (1984). *Stress, appraisal, and coping.* New York: Springer Publisher Company, Inc.

López Barreda, R., Trachsel, M., & Biller-Andorno, N. (2016). Towards a broader understanding of agency in biomedical ethics. *Medicine, Health Care and Philosophy*, *19*(3), 475-483. doi:10.1007/s11019-016-9706-5

Majumder, R., Walls, R., & Fullmer, S. (1998). Rehabilitation client involvement in employment decisions. *Rehabilitation Counseling Bulletin, 42*(2), 162-173. https://eric.ed.gov/?id=EJ585358

Mansbridge, J. (2001). Complicating oppositional consciousness. In J. Mansbridge & A. Morris (Eds.), *Oppositional consciousness: The subjective roots of social protest* (pp. 238-264). Chicago: University of Chicago Press.

Mast, B. T. (2013). Bringing person centered care to people with early stage Alzheimer's. *Journal of the American Society on Aging, 37*(3), 63-65. https://www.jstor.org/stable/10.2307/26591683

Mead, N., & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature. *Social Science & Medicine, 51*(7), 1087-1110. doi:10.1016/S0277-9536(00)00098-8

Meyers, D. T. (1987). Personal autonomy and the paradox of feminine socialization. *The Journal of Philosophy, 84*(11), 619-628. https://www.jstor.org/stable/2026764

Mezzich, J. (2012). The construction of person-centered medicine and the launching of an International College. *International Journal of Person Centered Medicine, 2*(1), 6-10. https://doi.org/10.5750/ijpcm.v2i1.197

Mitchell, P. H. (2008). Patient-centered care—a new focus on a time-honored concept. *Nursing Outlook, 56*(5), 197-198. doi:10.1016/j.outlook.2008.08.001

Morgan, S., & Yoder, L. H. (2012). A concept analysis of person-centered care. *Journal of Holistic Nursing, 30*(1), 6-15. doi:10.1177/0898010111412189

Morrison, R. S., Meier, D. E., & Cassel, C. K. (1996). When too much is too little. *New England Journal of Medicine, 335*(23), 1755-1759. doi:10.1056/NEJM199612053352308

Morrison, A. P., Hutton, P., Shiers, D., & Turkington, D. (2012). Antipsychotics: Is it time to introduce patient choice?. *British Journal of Psychiatry, 201*(2), 83-84. doi:10.1192/bjp.bp.112.112110

Munthe, C., Radovic, S., & Anckarsäter, H. (2010). Ethical issues in forensic psychiatric research on mentally disordered offenders. *Bioethics, 24*(1), 35-44. doi:10.1111/j.1467-8519.2009.01773.x

Munthe, C., Sandman, L., & Cutas, D. (2012). Person centred care and shared decision making: implications for ethics, public health and research. *Health Care Analysis, 20*(3), 231-249. doi:10.1007/s10728-011-0183-y

Myskja, B. K., & Steinsbekk, K. S. (2020). Personalized medicine, digital technology and trust: A Kantian account. *Medicine, Health Care and Philosophy, 23*(4), 577-587. doi:10.1007/s11019-020-09974-z

Nicki, A. (2002). Feminist philosophy of disability, care ethics and mental illness. *Nursing Philosophy, 3*(3), 270-272. doi:10.1046/j.1466-769X.2002.00115.x

Nightingale, F. (2010). *Notes on nursing: What it is, and what it is not.* (Cambridge Library Collection - History of Medicine). Cambridge: Cambridge University Press. (Original work published in 1860). doi:10.1017/CBO9780511751349

Nygårdh, A., Malm, D., Wikby, K., & Ahlström, G. (2011). The experience of empowerment in the patient–staff encounter: The patient's perspective. *Journal of Clinical Nursing, 21*(5-6), 897-904. doi:10.1111/j.1365-2702.2011.03901.x 897

O'Connor, A. M., Rostom, A., Fiset, V., Tetroe, J., Entwistle, V., Llewellyn-Thomas, H., Holmes-Rovner, M., Barry, M., & Jones, J. (1999). Decision aids for patients facing health treatment or screening decisions: Systematic review. *BMJ, 319*(7212), 731-734. doi:10.1136/bmj.319.7212.731

Olsson, L. E., Hansson, E., Ekman, I., & Karlsson, J. (2009). A cost-effectiveness study of a patient-centred integrated care pathway. *Journal of Advanced Nursing, 65*(8), 1626-1635. doi:10.1111/j.1365-2648.2009.05017.x

Opie, A. (1998). "Nobody's asked me for my view": Users' empowerment by multidisciplinary health teams. *Qualitative Health Research, 8*(2), 188-206. https://doi.org/10.1177/104973239800800204

Oshana, M. A. L. (1998). Personal autonomy and society. *Journal of Social Philosophy, 29*(1), 81-102. doi:10.1111/j.1467-9833.1998.tb00098.x

Pairman, S. (2010). Midwifery partnership: A professionalising strategy for midwives. In M. Kirkham (Ed.), *The midwife-mother relationship* (2nd ed., pp. 208-231). Basingstoke: Palgrave Macmillan.

Paterson, B. (2001). Myth of empowerment in chronic illness. *Journal of Advanced Nursing, 34*(5), 574-581. https://doi.org/10.1046/j.1365-2648.2001.01786.x

Pelto-Piri, V., Engström, K. & Engström, I. (2013). Paternalism, autonomy and reciprocity: Ethical perspectives in encounters with patients in psychiatric in-patient care. *BMC Medical Ethics, 14*(49). https://doi.org/10.1186/1472-6939-14-49

Pickard, H., & Ward, L. (2013). Responsibility without blame: Philosophical reflections on clinical practice. *Oxford handbook of philosophy of psychiatry*, 1134-1154. doi:10.1093/oxfordhb/9780199579563.013.0066

Pickard, H. (2015). Psychopathology and the ability to do otherwise. *Philosophy and Phenomenological Research, 90*(1), 135-163. doi:10.1111/phpr.12025

Pierce, P. F. & Hicks, F. D. (2001). Patient decision-making behavior: An emerging paradigm for nursing science. *Nursing Research, 50*(5), 267-274. doi:10.1097/00006199-200109000-00003

Potter, N. N. (2013). Embodied agency and habitual selves. *Philosophy, Psychiatry, & Psychology*, *20*(1), 75-80. https://muse.jhu.edu/article/511272

Power, J. J. (2017). Reductionism and nursing clinical reality. *Biomedical Journal of Scientific & Technical Research, 1*(3), 720-721. doi:10.26717/BJSTR.2017.01.000285

Price, M. (2015). The bodymind problem and the possibilities of pain. *Hypatia, 30*(1), 268-284. doi:10.1111/hypa.12127

Pulvirenti, M., McMillan, J., & Lawn, S. (2014). Empowerment, patient centred care and self-management. *Health Expectations, 17*(3), 303-310. doi:10.1111/j.1369-7625.2011.00757.x

Rissel, C. (1994). Empowerment: The holy grail of health promotion?. *Health Promotion International, 9*(1), 39-47. doi:10.1093/heapro/9.1.39

Roberts, M. (2005). The production of the psychiatric subject: Power, knowledge and Michel Foucault. *Nursing Philosophy, 6*(1), 33-42. doi:10.1111/j.1466-769X.2004.00196.x

Robinson, J., Callister, L., Berry, J., & Dearing, K. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners, 20*(12), 600-607. doi:10.1111/j.1745-7599.2008.00360.x

Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of patient-centeredness: Implementing a self-management trial for chronic illness. *Qualitative Health Research, 15*(2), 224-239. doi:10.1177/1049732304272048

Rogers, C. (1951). *Client-centered therapy: Its current practice, implications, and theory.* Boston: Houghton Mifflin.

Rothert, M. L., Holmes-Rovner, M., Rovner, D., Kroll, J., Breer, L., Talarczyk, G., Schmitt, N., Padonu, G., & Wills, C. (1997). An educational intervention as decision support for menopausal women. *Research in Nursing & Health, 20*(5), 377-387. https://doi.org/10.1002/(SICI)1098-240X(199710)20:5<377::AID-NUR2>3.0.CO;2-L

Rothert, M. L., & O'Connor, A. M. (2001). Health decisions and decision support for women. *Annual Review of Nursing Research, 19*(1), 307-324. doi:10.1891/0739-6686.19.1.307

Sadler, J. Z. (2004). Diagnosis/Antidiagnosis. In J. Radden (Ed.), *The philosophy of psychiatry: A companion* (pp. 163-179). New York: Oxford University Press, Inc.

Sandman, L., & Munthe, C. (2009). Shared decision-making and patient autonomy. *Theoretical Medicine and Bioethics, 30*(4), 289-310. doi:10.1007/s11017-009-9114-4

Sandman, L., & Munthe, C. (2010). Shared decision making, paternalism and patient choice. *Health Care Analysis, 18*(1), 60-84. doi:10.1007/s10728-008-0108-6

Sandman, L., Granger, B. B., Ekman, I., & Munthe, C. (2012). Adherence, shared decision-making and patient autonomy. *Medicine, Health Care and Philosophy, 15*(2), 115-127. doi:10.1007/s11019-011-9336-x

Sandman, L., Gustavsson, E., & Munthe, C. (2016). Individual responsibility as ground for priority setting in shared decision-making. *Journal of Medical Ethics, 42*(10), 653-658. doi:10.1136/medethics-2015-103285

Scales Rostosky, S., & Brown Travis, C. (1996). Menopause research and the dominance of the biomedical model 1984–1994. *Psychology of Women Quarterly*, *20*(2), 285-312. doi:10.1111/j.1471-6402.1996.tb00471.x

Shoemaker, D. (2011). Attributability, answerability, and accountability: Toward a wider theory of moral responsibility. *Ethics*, *121*(3), 602–632. doi:10.1086/659003

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S., & Whitley, R. (2014). Uses and abuses of recovery: Implementing recovery-oriented practices in mental health systems. *World Psychiatry, 13*(1), 12-20. doi:10.1002/wps.20084

Slade, M. (2017). Implementing shared decision making in routine mental health care. *World Psychiatry, 16*(2), 146-153. doi:10.1002/wps.20412

Slater, L. (2006). Person-centredness: A concept analysis. *Contemporary Nurse, 23*(1), 135-144. doi:10.5172/conu.2006.23.1.135

Schlosser, M. (2019). Agency. In E. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Winter 2019 ed.). Stanford University. https://plato.stanford.edu/archives/win2019/entries/agency

Smith, A. M. (2012). Attributability, answerability, and accountability: In defense of a unified account. *Ethics*, *122*(3), 575-589. http://www.jstor.org/stable/10.1086/664752

Spaniol, L., Wewiorski, N. J., Gagne, C., & Anthony, W. A. (2002). The process of recovery from schizophrenia. *International Review of Psychiatry, 14*(4), 327-336. doi:10.1080/0954026021000016978

Stanhope, V., Barrenger, S. L., Salzer, M. S., & Marcus, S. C. (2013). Examining the relationship between choice, therapeutic alliance and outcomes in mental health services. *Journal of Personalized Medicine, 3*(3), 191-202. doi:10.3390/jpm3030191

Stapleton, H., Kirkham, M., & Thomas, G. (2002). Qualitative study of evidence based leaflets in maternity care. *BMJ, 324*(7338), 639. doi:10.1136/bmj.324.7338.639

Stein-Parbury, J., Chenoweth, J., Jeon, Y.H., Brodaty, H., Haas, M., & Norman, R. (2012). Implementing person-centered care in residential dementia care. *Clinical Gerontologist, 35*(5), 404-424. doi:10.1080/07317115.2012.702654

Stewart, M., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *The Journal of Family Practice, 49*(9), 796-804. https://www.researchgate.net/publication/12292586

Stewart, M. (2001). Towards a global definition of patient centred care: The patient should be the judge of patient centred care. *BMJ: British Medical Journal, 322*(7284), 444-445. doi:10.1136/bmj.322.7284.444

Stockwell Morris, L., & Schulz, R. M. (1992). Patient compliance—an overview. *Journal of Clinical Pharmacy and Therapeutics, 17*(5), 283-295. doi:10.1111/j.1365-2710.1992.tb01306.x

Stoljar, N. (2018). Feminist perspectives on autonomy. In E. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Winter 2018 ed.). Stanford University. https://plato.stanford.edu/archives/win2018/entries/feminism-autonomy

Street, R. L., Gordon, H. S., Ward, M. M., Krupat, E., & Kravitz, R. L. (2005). Patient participation in medical consultations: Why some patients are more involved than others. *Medical Care, 43*, 960–969. doi:10.1097/01.mlr.0000178172.40344.70

Sturmberg, J. P. (2009). The personal nature of health. *Journal of Evaluation in Clinical Practice, 15*(4), 766-769. doi:10.1111/j.1365-2753.2009.01225.x

Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model. *Health Psychology, 23*(2), 119-125. doi:10.1037/0278-6133.23.2.119

Suls, J., Green, P. A., & Boyd, C. M. (2019). Multimorbidity: Implications and directions for health psychology and behavioral medicine. *Health Psychology, 38*(9), 772-782. doi:10.1037/hea0000762

Szasz, T. M. (2010). *The myth of mental illness: Foundations of a theory of personal conduct.* (Original work published in 1974).

Szmukler, G. (2014). When psychiatric diagnosis becomes an overworked tool. *Journal of Medical Ethics, 40*(8), 517-520. doi:10.1136/medethics-2013-101761

Söderberg, A., Wallinius, M., & Hörberg, U. (2020). An interview study of professional carers' experiences of supporting patient participation in a maximum security forensic psychiatric setting. *Issues in Mental Health Nursing, 41*(3), 201-210. doi:10.1080/01612840.2019.1658833

Söderberg, A., Wallinius, M., Munthe, C., Rask, M., & Hörberg, U. (2022). Patients' experiences of participation in high-security, forensic psychiatric care. *Issues in Mental Health Nursing*, 1-10. doi:10.1080/01612840.2022.2033894

Talbert, M. (2019). Moral responsibility. In E. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Winter 2019 ed.). Stanford University. https://plato.stanford.edu/archives/win2019/entries/moral-responsibility

Taylor, K. (2009). Paternalism, participation and partnership—the evolution of patient centeredness in the consultation. *Patient Education and Counseling, 74*(2), 150-155. doi:10.1016/j.pec.2008.08.017

Tengland, P. A. (2008). Empowerment: A conceptual discussion. *Health Care Analysis, 16*(2), 77-96. doi:10.1007/s10728-007-0067-3

Twungubumwe, T., Tantchou Dipankui, M., Traoré, L., Ouédraogo, J., Barro, S., Castel, J., Savard, I., Mbakop Nguebou, M., Ramdé, J., Côté, A., Lapierre, J., Ndjaboue, R., & Dogba, M. J. (2020). Health professionals and patients' perspectives on person-centred maternal and child healthcare in Burkina Faso. *PLOS ONE, 15*(4), e0230340. doi:10.1371/journal.pone.0230340

van Dulmen, S., Sluijs, E., Van Dijk, L., de Ridder, D., Heerdink, R., & Bensing, J. (2007). Patient adherence to medical treatment: A review of reviews. *BMC Health Services Research, 7*(1), 1-13. doi:10.1186/1472-6963-7-55

van Eemeren, F. H., Garssen, B., & Labrie, N. (2001) *Argumentation between doctors and patients: Understanding clinical argumentative discourse*. John Benjamins Publishing Company.

Verkerk, M. (2011). Care as process and the quest for autonomy. *Asian Bioethics Review, 3*(2), 150-154. https://www.muse.jhu.edu/article/440470

Vetrano, D. L., Calderón-Larrañaga, A., Marengoni, A., Onder, G., Bauer, J. M., Cesari, M., Ferrucci, L., & Fratiglioni, L. (2018). An international perspective on chronic multimorbidity: Approaching the elephant in the room. *The Journals of Gerontology: Series A, 73*(10), 1350-1356. doi:10.1093/gerona/glx178

Viesca, C. (2001). The construction of illness: A context problem. In A. Tymieniecka & E. Agazzi (Eds.), *Life interpretation and the sense of illness within the human condition* (pp. 17-32). Springer, Dordrecht. doi:10.1007/978-94-010-0780-1_2

Walker, R. L. (2009). Respect for rational autonomy. *Kennedy Institute of Ethics Journal, 19*(4), 339-366. doi:10.1353/ken.0.0301

Wieland, N. (2017). Agent and object. *Social Theory and Practice, 43*(3), 503-517. doi:10.5840/soctheorpract20178111

Wiens, A. G. (1993). Patient autonomy in care: A theoretical framework for nursing. *Journal of Professional Nursing, 9*(2), 95-103. doi:10.1016/8755-7223(93)90025-8

Williamson, C. (2008). The patient movement as an emancipation movement. *Health Expectations, 11*(2), 102-112. doi:10.1111/j.1369-7625.2007.00475.x

Williamson, C. (2019). The emancipation of patients: A theory whose time has come. *British Journal of General Practice, 69*(680), 150-151. doi:10.3399/bjgp19X701741

Willis, E. (2006). Introduction: Taking stock of medical dominance. *Health Sociology Review, 15*(5), 421-431. doi:10.5172/hesr.2006.15.5.421

Wittmann-Price, R. A. (2004). Emancipation in decision-making in women's health care. *Journal of Advanced Nursing, 47*(4), 437-445. doi:10.1111/j.1365-2648.2004.03121.x

Wittmann-Price, R. A. (2006). Exploring the subconcepts of the Wittmann-Price theory of emancipated decision-making in women's health care. *Journal of Nursing Scholarship, 38*(4), 377-382. doi:10.1111/j.1547-5069.2006.00130.x

World Health Organization. (2016, December 13). Technical series on safer primary care: Multimorbidity. https://apps.who.int/iris/bitstream/handle/10665/252275/9789241511650-eng.pdf

World Medical Association. (2018, July 9). WMA declaration of Geneva. https://www.wma.net/policies-post/wma-declaration-of-geneva/

Zoffmann, V., Harder, I., & Kirkevold, M. (2008). A person-centered communication and reflection model: Sharing decision-making in chronic care. *Qualitative Health Research, 18*(5), 670-685. doi:10.1177/1049732307311008

Zoffmann, V., Hörnsten, Å., Storbækken, S., Graue, M., Rasmussen, B., Wahl, A., & Kirkevold, M. (2016). Translating person-centered care into practice: A comparative analysis of motivational interviewing, illness-integration support, and guided self-determination. *Patient Education and Counseling, 99*(3), 400-407. doi:10.1016/j.pec.2015.10.015

Svensk Sammanfattning

Denna avhandling utforskar etiska och filosofiska aspekter av skärningspunkten mellan personcentrerad vård och psykiatri. Personcentrerad vård kan förstås som ett förhållningssätt där patienten placeras i centrum för vårdens processer och ses som en aktiv deltagare i vården. I litteraturen brukar detta betraktas som det bästa sättet att leverera vård av två skäl. För det första verkar personcentrerad vård främja värden såsom patientens autonomi och egenmakt. För det andra hävdas det ofta att personcentrerad vård hjälper till att förbättra patienttillfredsställelsen och efterlevnaden av vårdplanen.

Personcentrerad vård är dock ett otydligt begrepp och har ingen enhetlig definition i litteraturen. Enligt vissa källor ska det förstås som det att helt enkelt ta hänsyn till patientens preferenser, medan andra hävdar att det involverar komplexa filosofiska idéer. Därför kan det vara problematiskt, eller till och med farligt, att anamma personcentrerad vård utan att förstå vad det innebär teoretiskt och praktiskt. Detta beror på att olika tolkningar kan leda till ojämlik vård mellan olika patienter, eller dölja medicinsk paternalism. Det är fortfarande inte tydligt om personcentrerad vård, eller relaterade processer, såsom delat beslutsfattande, kan implementeras i olika vårdmiljöer. Till exempel skulle psykiatrin kunna vara en svår vårdmiljö för detta eftersom man ofta utgår från att patienter inom psykiatrin inte kan vara fullvärdiga deltagare i delat beslutsfattande.

Därför syftar denna avhandling till att presentera en modell för personcentrerad vård, förklara dess värderingar och processer och utforska hur denna modell står sig i psykiatriska miljöer. Avhandlingen består av ett inledande kapitel följt av fyra artiklar, och utgår från idéer och metoder från olika studieområden. Dessa inkluderar till exempel etik, medicin och omvårdnadsvetenskap, filosofi, forskningsstudier, psykoterapi, sociala rörelser, handikappvetenskap, psykisk ohälsa, psykiatri, moraliskt ansvar och kvalitativa metoder.

I det inledande kapitlet knyts personcentrerad vård till sitt ursprung i sociala rörelser utanför vården för att tydliggöra dess värderingar och syfte. Den första artikeln analyserar personcentrerad vård genom en jämförelse med personaliserad medicin. Den andra artikeln utforskar idén att invända mot eller uttrycka oenighet med patienter som en del av delat beslutsfattande inom pediatrik, psykiatri och folkhälsa. Den tredje artikeln analyserar olika problem som rör personer med psykisk ohälsa och deras ansvarstagande i vården. Den fjärde artikeln innehåller intervjuer med personal inom rättspsykiatrin för att undersöka möjligheten till personcentrerad vård i den miljön.

En av slutsatserna är att personcentrerad vård med ambitiösa mål om att stärka patienters självbestämmande kan komma runt utmaningar med psykiatriska patienters bristande beslutsförmågor om den anpassas på rätt sätt. Samtidigt finns stora institutionella utmaningar för denna typ av personcentrerad vård, särskilt inom den slutna tvångsvården, som i rättspsykiatri.

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Person-centered care (PCC) is generally understood to involve shaping healthcare processes, decisions, and plans according to the individual values, preferences, or goals of each patient. This is in contrast to more traditional approaches which provide care to patients based on standard clinical guidelines. In healthcare and bioethical literature, PCC is often praised as an ideal approach of healthcare provision because it is thought to empower patients and improve their adherence, satisfaction, and overall health outcomes. However, the notion has been defined in different ways, and it is unclear how and whether it can be implemented in all healthcare settings.

This dissertation aims to elucidate the concept of PCC and explore the implications of its intersection with psychiatry. The work contextualizes the concept within larger healthcare and social movements, and in that light, analyzes its values, decision-making process, and ambitions. The unique and complex challenges that psychiatric care settings engender are further used to examine how PCC commitments fare when faced with the limitations of mental illness and restrictive conditions of psychiatric facilities.

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