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**The Counselling, Self-care, Adherence Approach to Person-centred Care
and Shared Decision-making: moral psychology, executive autonomy and
ethics in multi-dimensional care decisions**

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Abstract

This article argues that standard models of person-centred care (PCC) and shared decision-making (SDM) rely on simplistic, often unrealistic assumptions of patient capacities which entail that PCC/SDM might have detrimental effects in many applications. We suggest a complementary PCC/SDM approach to ensure that patients are able to execute rational decisions taken jointly with care professionals when performing self-care. Illustrated by concrete examples from a study of adolescent diabetes care, we suggest a combination of moral and psychological considerations to support the claim that standard PCC/SDM threatens to systematically undermine its own goals. This threat is due to a tension between the ethical requirements of SDM in ideal circumstances and more long-term needs actualized by the context of self-care handled by patients with limited capacities for taking responsibility and adhere to their own rational decisions. To improve this situation, we suggest a *counseling, self-care, adherence approach* to PCC/SDM, where more attention is given to how treatment goals are internalized by patients, how patients perceive choice-situations, and what emotional feedback patients are given. This focus may involve less of a concentration on autonomous and rational clinical decision-making otherwise stressed in standard PCC/SDM advocacy.

Keywords: Person-centered Care, Shared Decision-making, Moral Psychology, Diabetes Care, Adolescents, Self-care, Adherence, Ethics, Bioethics, Autonomy, Decision Capacity

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This article questions key assumptions in the standard approach to person-centred care (PCC) and shared decision-making (SDM)⁵. We describe a complementary approach, thus aiming to expand rather than reject the general PCC/SDM notion. This new approach changes the communicative role of caregivers in a way that is more fitting to areas requiring substantial self-care by patients with vulnerable decision capacities.⁶ We do not offer immediate empirical support for this hypothesis, but rather present exploratory work that may lead up to further empirical studies. The argument is partly theoretical, partly drawing on widely accepted research results in the behavioural sciences, and we use representative, selected outtakes from an empirical study of diabetes care to *illustrate* the clinical significance of our points. We further use ethical theory to argue that the complementary approach to PCC/SDM implies hitherto unexplored virtue-ethical dimensions in need of analysis. Strategies to design future studies for ethical analysis, empirical testing and further development of our suggestion are sketched in the final discussion.

The standard image of PCC/SDM fits idealized situations where patients are independently robust and consistent decision-makers, fully capable of taking responsibility for the execution of made decisions or, alternatively, receivers of care-actions executed by authorized experts (Charles et al., 1997; Ekman et al., 2011; Luxford et al., 2010; Sandman & Munthe, 2010). Yet, PCC/SDM is widely advocated also for areas where care-actions are mostly taken by patients themselves, and where their decision capacities cannot be assumed to be robust, but the patient may rather be vulnerable regarding effective execution and responsibility-taking (Munthe et al., 2012). Application of standard PCC/SDM to such groups may undermine adherence, health and patient autonomy, as it ignores and may even counteract the extension of PCC/SDM into actual self-care in accordance with patients' own

⁵ Also other notions have been used to denote more or less the same thing, like consumer-, family- or relationship-centred care. See, e.g., Ekman et al., 2011; Luxford et al., 2010; Munthe et al., 2012.

⁶ This fits many chronic conditions and conditions in need of long-standing outpatient management, but by itself this is not a decisive factor.

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plans. Standard aspects of PCC/SDM therefore need to be toned down in such care situations and for such patient groups. This could support the long-term ability to autonomously and responsibly manage self-care in accordance with the patient's own autonomous decisions. We call this the *Counselling, Self-care, Adherence (CSA) Approach* to PCC/SDM, and suggest that this approach can complement the standard approach in, for example, situations that require significant amounts of self-care.

In section 2, we describe how standard PCC/SDM assumes human decision-making, motivation and action to operate in the care context and how this links to underlying values. In section 3, we describe how many care areas fault these assumptions, due to a more complex situation regarding human motivational psychology and the demands of the care. In section 4, this theoretical argument is illustrated by findings from a study on PCC/SDM in adolescent diabetes care (where the standard PCC/SDM approach is applied). In section 5 this is used as a stepping-stone for describing how PCC/SDM may be complemented in order to account for identified weaknesses, and we describe how this suggests a more complex ethical basis for PCC/SDM, implying new dilemmas to confront.

2. The Standard PCC/SDM Approach

PCC/SDM is advocated as an alternative to paternalistic care models in which medical experts analyze their patients using tests and other forms of physical examination, infer a diagnosis and then decide what to do on the basis of a rigid standard of suitable responses (Coulter, 2002; Ekman et al., 2011; Luxford et al., 2010). Such care models fit increasingly poor to the emancipated, educated and independent person in a time when personal self-determination and liberty are highly valued. Neither do they fit central values of medical ethics, such as autonomy (Beauchamp & Childress, 2013; Dworkin, 1988; Sandman & Munthe, 2009). There are thus both pragmatic and ethical reasons to make room for patients

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and their preferences, beliefs, interests, and desires in care decision-making (Coulter, 2002; Mead & Bower, 2000; Munthe et al., 2012; Sandman & Munthe, 2010).

The good outcome of the "shared rational deliberation" (Sandman & Munthe, 2010) approach to PCC/SDM relies on some key assumptions. A few inferential, momentary decisions are assumed to be core events in the care process – once they have been made, execution and continuity in forthcoming care are assumed to ensue. For this to be the case, however, more may be required of patients than meeting key assertions behind PCC/SDM: that they "have experiences and wants, that it is possible for them to communicate these to others, and that many of these experiences and wants may be relevant for clinical decisions" and "that it is possible for patients and caregivers to interact in ways promoting the inclusion of experiences and wants of patients in clinical decision-making" (Munthe et al., 2012, p. 233). In addition, patients often need to be *robust decision-makers*, equipped not only to participate in a shared rational deliberation leading up to a care plan, but also to take continuous responsibility for the execution of self-care according to this plan.⁷

3. How the Standard Assumptions Fail: Executive Autonomy, Habitual Decision-making and the *CSA Approach*

Much contemporary care is executed mostly by patients themselves or requires substantial participation of patients (e.g., in all forms of outpatient care). Furthermore, assuming patients to be robust decision-makers is often unwarranted and the assumption that they are is particularly problematic in areas where problems in facing the responsibility-burden of a shared rational decision may be anticipated (such as dementia, mental health and paediatric

⁷ Adherence problems may, of course, also occur when the assumptions of standard PCC/SDM are met, in which case they can be dealt with within this framework (Sandman et al., 2012).

care).⁸ However, even if such frailties are not present and the patient is capable of participating in a shared rational deliberation, there are many cases where this capacity cannot be *assumed* to be robust, i.e. continuously activated when actions of self-care are to be performed in a domestic context to ensure not only decisional but *executive* autonomy (Naik et al., 2009).

Nuanced models of human cognition and decision-making from contemporary psychology serve to amplify this point. A widely embraced notion of human action is that it involves (at least) two types of motivational processes (Sloman, 1996): considered, rational deliberation complemented by a more spontaneous and less controlled force influencing our daily lives, characterized by being "fast" (Kahneman, 2011), "heuristic" (Gigerenzer, 2001) or an adapted response to expected social reactions producing a "planned behaviour" (Ajzen, 1991). Most of our acting is of this sort: intuitive, yet often reasonably well-fitted reactions without much conscious attention or attentive deliberation; involving immediate association, habit, patterned simplifications, spontaneous adaptations based on past experience, and so on. There are, of course, also actions preceded by what Kahneman has called "slow thinking" (Kahneman, 2011): active deliberation requiring attention and focus, and engaging elaborate self-control in order to forestall impulses impeding desired results. This occurs when we face decisions of particular importance, or when our social surroundings require us to approach things as if this was the case, and when we are in favourable circumstances to engage in such exercises. The latter type of decision-making will in the following be referred to as *deliberative*, while the former one will be called *habitual*. Regardless of which particular bias might be present in a situation and to what extent that is a shortcoming, the (minimally) dual process model and its distinction between the well-ordered deliberative decisions described in

⁸ This has been held out as a general ethical problem for PCC/SDM advocacy addressing such areas (Munthe et al., 2012), and also been problematized in connection to specific cases (Birchley, 2013; Delaney & Galvin, 2013; Pelto-Piri et al., 2013; Seibel et al., 2014).

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standard PCC/SDM and the more fuzzy habitual decision-making activated in self-care will be applicable.

Standard "shared rational deliberation" PCC/SDM aims to facilitate well-functioning deliberative decision-making in a planning situation, while habitual decision-making affecting actual treatment is assumed to follow. However, habitual and deliberative decision-making may misalign in various ways, both irrationally and as rational responses to circumstances. Thus, no matter how autonomous and rational, deliberative decisions will not necessarily be manifested in actual behaviour. Extreme illustrations are addiction and certain psychiatric conditions, severely affecting individuals' abilities to self-control or elaborate cognition outside of protected circumstances. However, also in less extreme cases, habitual decisions are likely to depart from rationally made plans due to situational factors, personal features and social context. Thus, individuals cannot easily avoid misalignment of self-care with earlier shared deliberative decisions. This due to, for example, downsides of treatments frustrating important goals of patients (Larsman et al., 2012) or the inevitable use of decision heuristics, intuitions, and useful biases helping us all to navigate in a complex world (Kahneman, 2011; Railton, 2014).

Given suitable conditions, patients may share in rational deliberative decision-making, but the next challenge is to *actually realize* the care decided on. We propose *the CSA Approach* as a distinct complement in order to better promote executive autonomy than the standard focus on deliberative decisions when the care is dominated by self-care and there are reasons to fear that patients' capacities to take responsibility for self-care may be jeopardised due to misalignment of habitual decisions to deliberative ones. To effect this, the focus is less on achieving rational deliberative decisions than on interacting with patients to help them to (a) internalize care goals, (b) develop perception of choice situations relevant to these goals, and (c) emotionally empower patients through positive rather than negative feedback. These

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ingredients will be elucidated in context below. Their intended function is to secure the *actual execution* of deliberately decided self-care, helping patients to adhere to their own rational and autonomous decisions.

The CSA approach partly changes the role of the communication of caregivers compared to standard PCC/SDM. Besides factual education and reasoning support in deliberative settings, it forces caregivers to assume responsibility for how the health communication in deliberative SDM affects actual self-care execution, in turn influencing patient health and autonomy. As mentioned, standard PCC/SDM assumes decisional robustness, and then non-adherence is then primarily a reason to adapt deliberative decisions to actual patient behaviour (Sandman et al., 2012). In the care areas targeted by the CSA approach, however, robustness is not present and misalignment of habitual self-care decisions to a deliberately decided care plan suggests a need to strengthen patients' capacity of taking responsibility for self-care, thus adhering to their own rational deliberative decisions. Such support can promote habitualization of self-care decisions and actions by supporting capacity to develop sustainable self-control, stable emotional reaction patterns and general psychological "consonance" with respect to the overall life-situation in relation to the medical condition.

This complement to standard PCC/SDM implies attending to an amplified moral-psychological multi-dimensionality of decisions, resulting in new tensions between the values underlying PCC/SDM. Standard PCC/SDM highlights the value of autonomous and rational decision-making, to be activated and supported during consultative meetings where the patient's view of the situation is a basis for a *deliberative decision*. The CSA approach, in contrast, focuses on long-term personal development and the fostering of what, from an ethical perspective, stand out as *virtues* of the patient, influencing the continuous *habitual decisions* of self-care to enhance capacity for responsibility and, in effect, executive

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autonomy. Mastering virtues typically involves less elaborated, instrumental thinking, and our approach thus may require *less* concentration on the rational deliberation of standard PCC/SDM. This holds especially when adherence is poor and the conversational logic of a shared rational problem-solving à la standard PCC/SDM threatens to create a repeated pattern of fear of failure, increasing lack of self-confidence and resulting disempowerment.

In the next section, we illustrate these points with concrete examples from a study of adolescent diabetes care. We point to a variety of ways in which a CSA approach to PCC/SDM may be implemented. However, we also display how standard PCC/SDM may undermine desirable virtues and capacity for responsibility. In section 5, we then use this as a stepping-stone for arguing that, indeed, central aspects of standard PCC/SDM directly conflict with the ambition of the CSA approach to support the development of virtues that enable patients to take responsibility for self-care and enhance executive autonomy.

4. The Case of Adolescent Diabetes Care

In an ongoing project, we are studying PCC/SDM in the context of care for adolescents with diabetes type 1 in Sweden. Besides provision of technology and insulin, the bulk of this care consists of four yearly consultation meetings with paediatric diabetologists and nurses. In line with professional consensus, care professionals are committed to and apply standard PCC/SDM.

4.1 Adolescent Diabetes: Needs, Care Models, Outcomes and Challenges

Diabetes mellitus type 1 is a chronic disease, which generally appears in early age and with an increasingly global prevalence. The professional goals of treatment are 1) a high quality of life of patients and families; 2) normal physical and mental development; and 3) freedom from severe acute and long-term complications. None of these goals are easy to achieve and

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compromises between what is practically possible in the near future and what is desirable in the long run are frequent. Self-care is essential and demanding, as a rise or drop of the blood glucose level beyond certain limits may induce severe acute health risks, and prolonged less radical deviances induce severe threats to future health (Diabetes Control and Complications Trial Study Group, 1995).

Care professionals strive and, in our sample, mostly succeed in achieving shared rational deliberative decisions with patients, yet ensuring a combination of adherence, optimal health and executive autonomy is difficult. The communicative challenge is how, in the context of sub-optimal self-care execution, to pursue an optimistic approach for the future while simultaneously promote a healthy life-style, involving adjustments of habits and practices which often contradict patients' perceived wants in other areas of life. All paediatric diabetologists and diabetes nurses are trained to care for patients in adolescence and there is a professional consensus on the ideal of PCC/SDM. Still, the professionals find it difficult to ensure that the health communication meets the challenges faced by this specific group of patients (Wigert & Wikström, 2014). Adolescent patients in our study typically know their disease and the treatments well, and they desire good health and agree to care plans in accordance with that, but successful self-care is still difficult to achieve (Boman et al., 2014).

The teenage period is challenging as a time of separation from primary caregivers, questioning adult authority, and intensified importance of peers and social identity (Delamater, 2007). A complicating factor is difference in the evaluation of short- and long-term risks and benefits. Short-term risks are typically perceived as considerably higher than long-term ones, and short-term benefits are valued significantly more than long-term ones (Slovic, 2000; Zohar & Erev, 2007). Such evaluations inspire choices to refrain from adherence to self-care regimens if they interfere with short-term needs. Accepting such decisions made by adolescents may satisfy standard PCC/SDM, but is highly problematic

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from an ethical perspective, considering adolescents' developing maturity, future health and quality of life (Mol, 2008).

Diabetes treatment actualizes both habitual and deliberative decision-making. Patients and care professionals deliberate jointly in consultative meetings: problems are identified, goals are set, strategies outlined, intentions expressed, outcomes assessed, plans revised, and so on. In line with standard PCC/SDM, the main aim of professionals is to ascertain patients' understanding of the disease, the treatment and why different managements of self-care affect health as they do, so that informed decisions can be formed. For these decisions to have impact, however, habitual decision-making needs to align to them, lest even the best of patient understanding and rationality in meetings will have scant effect on self-care.

4.2 Materials and Methods

We made video-recordings of 12 meetings between adolescents with diabetes type 1 and diabetes care professionals (paediatric diabetologists and nurses) at a Swedish specialist paediatric diabetes clinic that embrace and apply PCC/SDM. Participants were recruited through standardized protocols at the clinic, involving verbal and written information, ample time to consider the offer, and written consent from patients and parents. The procedure was reviewed and cleared by the Regional Ethical Board.⁹ The recordings used four digital video cameras and two microphones, and the audio-visual raw material was transcribed, including body language. The same project also involved in-depth interviews with some patients (Boman et al., 2014) and staff (Wigert & Wikström, 2014), here used to corroborate results in the interpretation of the recorded meetings.

Analysis was qualitative, aiming at mapping both ethical challenges and promising aspects, and undertaken on the basis of models of SDM and their relation to ethical values

⁹ Regional ethics review board of Gothenburg, registration no. 532-10.

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presented by Sandman and colleagues (Sandman & Munthe, 2009, 2010; Sandman et al., 2012), as well as a previously developed theoretical map of ethical aspects of PCC/SDM (Munthe et al., 2012). The study was explorative, designed to generate rather than test hypotheses, and our use of it here is for the sole purpose of *illustration* of the argument developed in the previous section. The analysis presented below is thus not meant to be evidence of any type of causal or statistical claim, albeit the data is representative of the material studied.

4.3 Standard PCC/SDM in Paediatric Diabetes Care Meetings

In the recorded meetings, little attention was given to patients' habitual decision-making and actual adherence, whereas a lot of effort and time was invested in educating patients about biomedically optimal self-care. Care professionals focused strongly on the patients' metabolic control outcome (HbA1c), using this to formulate problems to be solved, while factors underlying non-adherence received little attention. When attempting to raise day-to-day themes of their own patients were often interrupted by professionals to restore a biomedical agenda. Patients tended to verbally agree to claims made by professionals, expressing clear desires to avoid serious health risks and mostly seemed to understand what is needed to achieve that. At the end of each meeting an agreement was formulated, albeit the patients here acted rather passively, mostly affirming suggestions. In other words, caregivers displayed a commitment to and application of a standard approach to PCC/SDM such as this translates to paediatric diabetes care. To an observer, there was little indication, however, that the professionals' pursuing of patients' knowledge of the biomedical ideal actually helped to promote the patients' capacities to take responsibility for the agreed self-care plan, something which is corroborated by the poor outcome of this approach. None of this is intended as a

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critique of the professionals, but is rather an expected outcome of standard PCC/SDM in a setting to which it is badly fitted.

Several examples from the conversations illustrate how a standard PCC/SDM focus on rational problem solving *inside* meetings may adversely affect opportunities to enhance responsible self-care *outside* meetings. Two layers of this phenomenon stood out in particular. Firstly, a pattern was discerned of reinforced shame created by high demands on self-care, combined with a pursuit of general ideals regarding food, sleep, exercise, drugs, et cetera. These demands and ideals attained a perfectionist nature, as failure to reach the desired goal attracted much attention – an expected outcome of the focus on rationality in light of biomedical objectives. There was, in contrast, little attention to contextual circumstances of such problems, but conversations kept inside a familiar biomedical territory, guided by the professional. Secondly, a conversational logic of threat, disappointment and incapacity provided the main emotional feedback to patients, since the attention was on failure rather than on (admittedly often small) improvements made.

There was, however, also a variety of ways in which robust habitual decision-making visibly *could* be, and sometimes also was, promoted in the meetings, in spite of an otherwise strict adherence to the standard PCC/SDM format. The following conversation excerpts illustrate the three dimensions mentioned in the previous section to be core attention targets in the CSA approach to PCC/SDM: internalization of goals, relevant perception of choice situations, and empowering emotional feedback.

Internalization of goals

Personal goals can be more or less internalized into a person's life. More internalized goals form the core part of what a person values and strive for, and have a higher potential impact on actual choices compared to less internalized ones – the latter motivating only in the form

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of instrumental reasons to achieve internalized goals. For example, someone who accepts the idea that she should work out to improve her health will be less inclined to actually work out than someone for whom it is a part of what her life is about (e.g. due to an interests in sports).

New goals can, moreover, be more or less harmonized with existing internalized goals. All of us have goals we cherish as part of our identity, and new goals actualized by external challenges must therefore be located in such a pre-existing structure. The extent to which the new goal is located in conflict-generating or harmonic positions can be expected to significantly impact their action-guiding potential. To affect behaviour in a desirable direction, more and quicker internalization to harmonize otherwise conflicting goals is thus crucial (Herlitz, 2012; Taylor, 1985). Our claim is that standard PCC/SDM fails to promote and tends to impede such a process in patients with weak adherence and decision capacities, while the CSA approach has the opposite function. How a professional may use CSA accordingly is illustrated by the following example of Danny¹⁰:

Professional: “If you have high values, and need to make corrections, do you measure then to see if the dosage was good?”

Danny: “No.”

Danny’s mother: “This is where we are weak. But Danny often does this before sports.”

Professional, very enthusiastically: “Yes!?”

Danny’s mother, to Danny: “That way you get an indication of whether it was correct.”

Professional: “Why do you want to measure these values in relation to sports?”

Danny: “Because I want to know if I will be up for the sports, whether I can do it.”

Professional: “So, practicing sports is important? I can recognize this. The instantaneous feedback that is offered by sports, how it can have positive effects. It could be that

¹⁰ All names are proxies introduced to increase readability.

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there is not enough motivational power to just check a value because it should be checked, it could be that it is important that there are more to motivation of a person. It is important to be curious of these values, to aim at having certain values, to think that it is good for the body to have certain values. Think of it like this: you are on the pitch, when you pass the ball, you check where the other players are positioned, and then you adjust your game in relation to that. Insulin is like when you hit the ball, and the blood sugar values are the positions of the other players. It is good if you can find a way to make it interesting for yourself to measure the values. It's much more important than doing it for a professional, or than doing it for your mother.”

The professional recognizes the way in which Danny spontaneously makes self-care choices out of his sport interest, and attempts to use this connection in order to internalize a diabetes-treatment goal. This is, of course, something that may take time and it is not finished in the segment above. Yet, this example illustrates a general stance that care professionals may take to patients and the problems surrounding internalization processes of external self-care goals.

The stance contains three steps. Firstly, the professional notices something that already motivates the patient, thereby identifying a goal already in place and internalized; playing soccer. Secondly, the professional perceives ways in which self-care goals may be included in what is involved in realizing the internalized goal, the latter thereby being possible to use for internalizing an initially external self-care goal. Thirdly, the professional tries to locate the self-care goal in relation to the already internalized goal, so that it becomes a part of it, thus affording the motivating powers behind the already existing goal to have the patient pursue self-care as a part of realizing already embraced aims. If successful, this strategy reduces the likelihood and severity of goal conflicts related to treatment, thereby facilitating improved

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executive autonomy, adherence and better health. This can clearly be a part of a PCC/SDM strategy, but this requires that the focus of conversation shift from the biomedical agenda to the understanding of the patient's personal life and priorities. In Danny's case, this happens spontaneously and is comparably easy to combine with a positive message around adjoining treatment details, as the sports activity already promotes adherence to the treatment regimen. Consider, in contrast, the case of Erik, who also has a strong personal interest, albeit less positively aligned to his self-care management:

Father: "Erik's values are a little high. He was going to a "Dreamhack" meeting you see."

Professional, turning toward Erik: "How long were you there for? How did you stay awake? Did you sleep anything?"

Erik: "I slept a bit. I drank Coke. Coke Zero."

Professional: "How do you check blood sugar values when you drink Coke and play computer games?"

Erik: "My brother helped me out, to check it every hour."

Erik's father: "He slept at his brother's place. In the morning there, Erik's values were very low, so we decided to consciously place him a bit higher, so that his brother wouldn't panic. He panicked in the morning, when Erik's values were so low so that it was impossible to communicate with him."

Professional: "Ok. So his values were that bad in the morning? And then he wanted of course for you to play well during the day. That is why you measured the values that often."

Erik, while nodding vividly: "Yes."

Professional: "And how were the values?"

Erik: "A bit high. 12."

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Professional: “Oh... I see. Did he want the values like that, your brother? Or did you want it like that?”

Erik: “We decided upon it together. I felt it was safer this way. If everyone fall asleep, it’s better if I don’t. So then it’s better if my values are high.”

This sequence reveals how the patient views self-care as conflicting with his personal interest. Erik wants to attend "Dreamhack", but knows that he should also manage self-care and approaches decisions as if they necessitate a balancing of competing goods. There is thus a complete disharmony between these goals and whereas the desire to play computer games is very much internalized, the goal of managing self-care well is at best only partially so. Thus, in the habitual decision-making, the latter goal is instrumentalized in relation to the more internalized ones, consequently being utilized mainly for maximizing gaming performance while trying to avoid fatal side effects.

Having received Erik's narrative, the professional accepts the implied premise of a goal conflict. This is well in line with the standard PCC/SDM idea of accepting patient narratives, but the professional is thereby led to miss the opportunity of instrumentalizing Erik's interest in computers and gaming for diabetes-treatment purposes, and the adverse habitual decision-making of Erik prevails. The professional could have tried to link Erik's interest to long-term health concerns and self-care adherence instead of accepting the narrative of a conflict and instead reasoned with Erik about what his interests involve, what skills and qualities they require, how these connect to his long-term dreams, eventually linking these to self-care decisions. Thereby, Erik could be made to see the self-care as an integrated part of his computer and gaming interest and adherence could become integral to the pursuit of a central life-plan, in a way similar to the case of Danny. Overlooking this opportunity threatens to strengthen Erik's alienated attitude towards self-care by implicitly reinforcing the opposition

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between goals. Standard PCC/SDM, however, seems to force professional attention away from this opportunity, rather accepting the apparent conflict and focus conversation on the negative outcome instead of exploring positive prospects. In the case of Danny, the standard approach does not seem to get in the way, but neither does it play any role in stimulating the constructive development of that conversation. The CSA approach to PCC/SDM, however, has as one of its main points to have professionals consciously seek openings for internalizing self-care goals into the pre-existing structure of internalized goals of patients.

Relevant perception of choice situations

Besides internalized goals, our decisions also depend on how we perceive the world. People pay attention to different aspects of choice situations and all decisions are shaped by what is involved in the initial realization that a choice needs to be made (Herman, 1993). Such shaping perception frames decision-making and affects how it is fitted to a person's goals. The pathways of such framing are complex and it is difficult to generalize how to manage them, besides pointing out that it is about more than mere appreciation of facts. The following example of Miranda illustrates how this aspect of habitual making may be a problem as well as how opportunities to influence it might arise, but where the standard PCC/SDM logic seems to get in the way.

Professional: “At lunch in school, you take insulin. Is the food in school any good?”

Miranda: “Sometimes.”

Professional: “Sometimes. And when it isn’t good? What do you do?”

Miranda: “I eat cornflakes.”

Professional: “What do you get more than cornflakes? They offer milk with it? What about jam?”

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Miranda: “Yes, there is jam.”

Professional: “What sort of jam?”

Miranda: “Strawberry.”

Professional: “Ok. If it’s cornflakes, milk and strawberry jam, then the blood glucose value will rise very high. Cornflakes are so easily digested. The milk is very sweet, as is strawberry jam. The problem is that first the blood glucose value rises a lot, and you need a lot of insulin. Then you run out of cornflakes, and the value drops. So, what could you do to make the cornflakes last a bit longer?”

Miranda: “We have lunch in school between 11 and 12. Sometimes after 2, or 3, I have a sandwich.”

Professional: “Ok. You know another thing you can do is to take a sandwich with the cornflakes. And don’t take more strawberry jam than this,” the Professional illustrates a small amount with the fingers. “You know why?”

Miranda: “So that the value doesn’t go up too high.”

Professional: “Yeah, because you know half of that amount is sugar.”

Miranda: “I take one spoon.”

Professional: “Yeah, just one spoon. Good.”

The professional clearly understands that Miranda in no way perceives of the cornflakes, the milk and the strawberry jam as anything of particular relevance to the self-care, but rather in terms of taste. She does express awareness of the jam being in need of rationing, but there is no manifested perception of the cornflakes as ‘easily digested carbohydrates that ought to be complimented with carbohydrates that take longer to digest’. She is apparently aware of the diabetes-treatment goals and they seem to have some impact on her behaviour. However, her response indicates that she does not perceive the situation through the lens of these goals and

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her habitual making is thereby impeded from being directed by them. The professional responds to this with straightforward advice, much in the spirit of standard PCC/SDM, to have a sandwich and by explaining the mechanisms of fast carbohydrates and how milk and cornflakes relate to that. However, there is no addressing of the apparent fact that Miranda does not perceptually connect her eating to her health at a basic level, although without such a link, she will not view eating as being an important part of the self-care. Perceptual gaps of this kind may be difficult to close, but they can be addressed. Professionals may spend time ascertaining in the conversation that lack of adherence does depend on gaps of this sort and, if they do, attend to them by making unperceived links explicit. There is, however, nothing in the standard PCC/SDM format to stimulate any such further action, while the CSA approach holds out the scanning for these kinds of impediments and attending to them by deepening the dialogue with the patient to close them, rather than repeating known details that will remain unconnected to patients' perception of habitual decisions.

Empowering emotional feedback

Emotional feedback plays a significant role for enabling both of the foregoing ways of promoting robustly executively autonomous habitual decision-making. If the pursuit and realization of a goal is unpleasant, or if failure to realize it is emotionally costly, chances are that an individual will alienate herself from it and avoid framing decisions in light of it. If, in contrast, pursuit of the goal is satisfying, achieving it rewarding and failure bearable, it is more likely to be internalized. Reactions of professionals visible to patients during deliberative sessions and how they tell patients about the proceeding of self-care have a direct impact on how patients feel (Boman et al., 2014). Standard PCC/SDM, however, contains no incentive for professionals to mind this aspect, but rather harbours a potential for giving negative feedback as soon as adherence is less than ideal. In our studied meetings, there is

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significant variation among patients regarding treatment adherence and outcomes in terms of health. Some do well, and some exhibit outcomes that are very problematic. However, such differences have little impact on professionals' general stance in our material, and our hypothesis is that this illustrates an unwelcome effect of the problem-orientation of standard PCC/SDM to have a perfectionist attitude prevail. No matter how well a patient performed, the response tended to focus on remaining flaws, concentrating on small details and emphasizing room for improvement. This threatens to create a destructive hopelessness, promoting patients to abandon treatment goals and view themselves as lacking capacity. Consider the following three examples:

Professional: "Your mean value is 7.2. That is very good! If it is the true value." [some time passes] "I see a pattern here in your daily values. Your value gets a bit low between 6 and 8 PM. What could you do to avoid that?"

Patient: "Think about it more..."

Professional: "Are the values good or bad?"

Patient: "They're 12-13 now, but they used to be worse."

Professional: "Do you think 12 is a good value?"

Patient: "No. 7-6 is better."

Professional: "Between 4 and 7 is ok."

Professional: "I can see here that you measure the values often most days. That is very good, and very important. But if we look at the glucose value. We have a list here. If we look at it between midnight and 6 in the morning, it is quite high."

Patient: "Yes."

Common to these cases is that the patients do reasonably well. The first patient reveals a good mean value. The second expresses good knowledge of the treatment and motivation to strive for a better value. The third exhibits a good routine for measuring blood sugar. Yet, in all cases, the professional – besides some positive comments in passing – focus on some aspect to improve and leads the conversation to centre on this "flaw". This stance of striving for perfection is in line with standard PCC/SDM but results in a constant search for shortcomings feeding back to stimulate a sense of insufficiency in patients, thereby impeding adherence, autonomy and health. Treatment goals are made to appear unreachable, whereas it would be more adequate to say that they always are at best *partially reachable*. The logic of standard PCC/SDM, however, steers towards the negative message rather than the positive and empowering one.

Professionals may instead focus on providing emotional feedback of satisfaction over partial success (however tiny) and stimulate feelings of evolving capacity in relation to self-care. This may involve less concentration on medical facts related to the treatment, but could facilitate the internalization process of externally imposed, yet rationally embraced, treatment goals, as well as the development of perception-generating mechanisms in line with self-care adherence. In effect, less concentration on the clinical objectives of professionals in conversations with patients aimed at improving self-care may lead to an improved achievement of this same objective. We close with a positive example in this direction from our study: the case of Anna:

Professional: "The values have been good. Your levels are remarkably better."

Anna: "I think so too. It's just that I have to take the correction insulin a bit more often."

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Professional: “Yes, when you take your doses, you’re on a good level. And when the values are low, remember that you don’t need to take that many extra carbohydrates, but just a little.”

Anna, fills in: “So I get back up a bit.”

Even though the values have not been perfect, the professional gives Anna generally positive feedback on how self-care proceeds. The atmosphere is amicable and it is Anna who eventually brings up a problem to discuss. Anna is trusted to take the initiative to identify further improvements, and the professional gives her no feedback that communicates disappointment. This unfolds, as the professional abstains from acting strictly within the standard PCC/SDM format, but what happens is, at the same time, in line with the *underlying ideal* of PCC/SDM to promote autonomy, adherence and health and a central point of CSA is to afford exactly such emotional empowerment within a PCC/SDM framework.

5. Final Discussion: Roads Forward and An Ethical Complication

Core assumptions of standard PCC/SDM fit poorly to many care areas, due to insensitivity to relevant complications linked to self-care, weak adherence and vulnerable capacities to take responsibility. Established ideas in moral psychology support this claim and we have illustrated it with examples from adolescent diabetes care. A complementary, "counselling, self-care, adherence" (CSA) approach to PCC/SDM was suggested. CSA points to three communicative strategies that care providers can use for strengthening patients' capacity for executive autonomy and responsible self-care aligned to their own deliberative decisions: internalization of goals, improved perception, and empowering emotional feedback. According to CSA, patient narratives should be employed to internalize treatment-goals into pre-existing goal-structures, stimulate perceptual stances reflecting the goals and emotional

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feedback affirming the patients capabilities to manage self-care. This would avoid unnecessary disharmony among patient goals, paradoxical perception of decisions and destructive emotional patterns. Further empirical research to test this general hypothesis¹¹ may employ various ways of concretely implementing the CSA approach, such as training of staff using illustrative examples (such as those in our study) support awareness of the potential tension between deliberative and habitual decision-making. Structured dialogue and motivational techniques could be employed in meetings to shape emotional feedback. Standardized "instruments" for qualitative thematic review of the patient narrative could be applied to assist the process of finding pathways to internalize treatments goals, and organizational adjustments could be made to systematically use the output of such actions in clinical conferences. Besides numerical measures to monitor treatment success, endpoints to look at may include ways of objectively assessing processes in consultation meetings, but also patient and staff self-reporting, and instruments for measuring various relevant capacities of patients, such as self-efficacy. Inspired by behavioral economics (DellaVigna, 2009), it may be beneficial to study more closely *which* specific biases, heuristics or types of "behaviour planning" that prevent alignment of deliberative and habitual decision-making, and which facilitates such alignment, to incorporate identified patterns into the toolbox available within the CSA approach to PCC/SDM.

It is important to recognise that our suggested complementary approach brings a risk of increased paternalism. Care providers need to be aware that the point is to impose their own care ideal and strive to manipulate patients to adhere to it, but that the point of reference continues to be the patient's own considered views on the care and its place in her life, such as it transpires in shared deliberative decisions. If so, adopting the CSA approach will not amount to a paternalistic stance, but to strive to empower the patient to execute *her own* will

¹¹ The form of testing may vary, where, of course, a bona fide RCT – possibly by comparable centres with comparable populations respectively apply the standard or CSA approach – would be the ideal.

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(Naik et al., 2009; Sandman et al., 2012; Thaler & Sunstein, 2008). Yet there *is* a tension within the underlying value of PCC/SDM being exposed by this move, as we have admitted that the CSA approach may require less focus on securing autonomous and rational deliberative decision-making compared to the standard approach.

This links to traditional frictions between decision- and virtue-oriented care ethics (Verkerk, 2001). Aristotle emphasized the virtuous person as someone who need not struggle to solve practical problems and contemporary virtue-ethics assigns importance to emotional and perceptual "capabilities" besides intellectual (Aristotle, trans. 1998; Nussbaum, 2000; Sen, 1999). The part of ethics dealing with decision-making has revealed how the rationality of solutions to practical problems is context-dependent, thus driving a wedge between what is rational to *decide* in a situation and what is rational to *do* on that basis. This more complex ethical picture has been ignored in the PCC/SDM discussion. A shared rational deliberation with patients may very well succeed, but simultaneously undermine adherence to the autonomous decision. Focusing only on the former means emphasizing themes likely to impede development of robust capacities to take responsibility for self-care, and existing such capacities may be undermined.

Thus, focus on achieving *autonomous and rational deliberative decisions* may have to be sacrificed if the aim is promotion of *the autonomy of the patient's entire life* together with desirable health outcomes. Education about objectively relevant facts may, in such cases, have to be toned down to foster a sense of security, control, and ability. Conversations need to address *emotionally* empowering themes, engaging the full potential of the patient experience to construe, together with professionals, positive images of the disease and its management as a part of one's life. Once a pattern of adherence to deliberative care decisions is established, capacity to take responsibility for self-care is continuously strengthened and minor self-care anomalies can be addressed more directly. The extent to which this friction is realized in

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clinical reality and how much of decisional autonomy may need to be sacrificed for the sake of executive autonomy may be investigated as part of the further studies suggested above.

Whatever the outcomes of these studies, however, the ethics of PCC/SDM needs to be reconceived as more complex than previously acknowledged, going beyond the fact that PCC/SDM harbors value conflicts (Munthe et al., 2012; Sandman & Munthe, 2010). In contrast to core assumptions of standard PCC/SDM, patients need not be robust decision-makers, who execute autonomous decisions. Therefore, PCC/SDM needs to include the distinctly virtue-ethical dimension of the CSA approach, where fostering capacities to take responsibility for self-care may require substantial deviation from the shared rational deliberation focus of standard PCC/SDM.

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