

Person Centred Care and Shared Decision Making: Implications for Ethics, Public Health and Research

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Abstract: This paper presents a systematic account of ethical issues actualised in different areas, as well as at different levels and stages of health care, by introducing organisational and other procedures that embody a shift towards person centred care and shared decision-making (PCC/SDM). The analysis builds on general ethical theory and earlier work on aspects of PCC/SDM relevant from an ethics perspective. This account leads up to a number of theoretical as well as empirical and practice oriented issues that, in view of broad advancements towards PCC/SDM, need to be considered by health care ethics researchers. Given a PCC/SDM-based reorientation of health care practice, such ethics research is essential from a quality assurance perspective.

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1. Introduction

For about two decades, a practice that has become known as *patient- or person centred care* (PCC) and the associated notion of *shared decision making* (SDM) have been making headway in Western health care research, organisation, policy and business. This emphasis has been visible as a general initiative (Emanuel & Emanuel, 1992, Charles, Gafni and Whelan, 1997, *British Medical Journal*, 1999 and 2000, Mead & Bower, 2000, Lewin et al, 2001, Luxford, Piper et al, 2010, Van Royen et al, 2010), but is especially salient regarding chronic or durable conditions (Dubois et al, 2008), care of the elderly and demented (Brooker, 2007, Edvardsson et al, 2008, Kitwood and Collins, 1997, McLean, 2006), as well as other areas involving long-term, home-based and/or quality of life oriented care. To some extent, this trend has evolved into an alleged 'culture' or 'movement', embodying a special ideology or mission (McLean, 2006 and Koren, 2010)¹. Recently, further terminology has been employed for the basic themes found in PCC and SDM, e.g., the notions of *partnership* and *personalisation* (*British Medical Journal*, 1999, Sandman & Munthe, 2010). In addition, variations, such as *consumer-*, *family-* or *relationship-centred* care, have been introduced, stressing aspects in certain contexts of PCC (Goodrich, 2009, Luxford et al, 2010). Similarly, a number of different terms for the vague decision model of SDM have been suggested (Sandman and Munthe, 2010). At the same time, approaches and practices such as genetic counselling (Clarke, 1994, Juth, 2005, McCarthy Veach et al, 2003), involving the core ideas of PCC/SDM, have been developed in other areas of health care at least since the early 1970's, albeit not under the explicit heading of PCC or SDM. Notably, then, terminology in this field is diverse, appreciably variable in its application and may potentially connect to many different ideas of the basic values and ethical restrictions of health care practices. From

an ethics point of view, this creates notable uncertainty as to the desirability and ethical implications of PCC/SDM.

This paper presents ethics and policy issues that, in light of the just sketched development, need to be attended to with some urgency. The ethical landscape of PCC/SDM is analysed, whereby a large number of particular questions of interest to bioethicists and health care ethicists are pinpointed. The complexity of these questions, we argue, goes far beyond the rather simplistic value stances typically held out when PCC/SDM is presented and discussed. On the basis of this, we suggest a research framework for bioethics and health care ethics necessitating close collaboration with clinical practitioners as well as the behavioural and social sciences.

2. Conceptual and Philosophical Preamble

In spite of the terminological confusion indicated at the outset, certain generic components are recurring when PCC and SDM are described (regardless of which of the above-mentioned terms are used). We will henceforth refer to these components in terms of patient narrative, collaboration, and continuity.

The notion of *patient narrative* refers to the idea of basing care and associated decision making on a rich base of information about the patient, her general situation, experiences, views on the care, et cetera – besides the sort of biomedical "signs" acquired through biochemical tests and physical examination. This particular term seems to have won popularity since it alludes to a tradition of oral narration, thus suggesting the complexity and multidimensionality of the information, the time needed for the narrator to deliver her story as well as for the listener to comprehend it, and the salient social and interactive nature of this process. Ideas regarding the role of narratives in health care ethical thought, practice and

decision making (see e.g. Hudson Jones, 1999) may also have played a role. The interactivity and sociality aspects reappear in the second key component – that of assessment, decision making and planning of the care to be, in some sense, a *collaboration* between caregiver and patient. It is, of course, here that the notion of SDM becomes central. Finally, *continuity* is stressed in different ways when PCC/SDM is presented, indicating the idea that whatever PCC/SDM boils down to in concrete terms, it is not thought of as a momentary "fix" of isolated problems, but as an ongoing process in which the patient narrative can be added to, revised and reinterpreted, and collaboration around decision making and planning can be continuously revisited based on that.

The general motivation for the use of patient narratives in health care is the idea that knowing more about people than how the body functions is important both for having an adequate diagnosis and treatment, and for avoiding to treat people sub-optimally in other respects (e.g. in terms of long-term health, psychological well-being and autonomy). The component of collaboration, in effect, is about the need for handling the information transmitted through the narrative in a way that helps secure the achievement of these objectives. We will return to what using patient narratives and collaboration may mean in more concrete terms and which goals the use of these components may be taken to serve.

Obviously, the generic components of PCC/SDM assume that people 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. They moreover assume 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. In order to find reasons for advancing PCC/SDM there must, of course, also be the case that such an inclusion is desirable.

However, none of this implies any more particular theory of human nature, the moral importance of people or the ethical foundations of health care. The necessary assumptions of PCC/SDM are reconcilable with all philosophical and ethical theories that provide reasons for us to be considerate towards other people and recognise that they may have different and changing experiences, needs and wants worthy of consideration. Depending on which of those theories is taken as the motive for pursuing PCC/SDM, there will follow different objectives of such pursuits and different concrete variants of implementing PCC/SDM will appear more or less warranted in light of these (Sandman & Munthe, 2010).

This is both good and bad news for PCC/SDM. On the one hand, if it had indeed been true that introducing the three generic components would have meant necessarily pressing some specific worldview or ethical idea onto staff, patients and society, this would have complicated the issue of the supposed desirability of PCC/SDM. On the other hand, the openness of the notions of PCC and SDM as to what is supposed to be the ultimate goal of applying the generic components creates some uncertainty on how to ethically assess such applications. The remainder of this paper outlines various aspects of this uncertainty and the research-needs that it implies.

3. Immediate Effects on Patient Well-being

One of the most straightforward ideas found in the PCC/SDM movement has to do with making better room for the *patient narrative* in the routine organisation of health care. This means, in concrete terms, for caregivers to routinely initiate having patients talk about their general situation, listening and responding to them and participate in an ensuing dialogue that has to be allowed to take its time. Already this element may serve a number of

uncontroversial caring objectives related to the immediate well-being of the patient (Sandman and Munthe, 2010).

However, making room for the patient narrative also increases the risk of caregivers mishandling this process so that the patient is harmed rather than benefited in terms of immediate well-being. Introducing an organisational scheme where collection of a patient narrative is the default may make people feel pressed to talk more about their personal affairs than they would otherwise have liked, giving rise to retrospective regret and unease. The way in which the caregiver responds to the patient in the ensuing dialogue may similarly induce harm in many different ways, e.g., offending patients, making them feel insecure, effect feelings of abandonment, confusion and powerlessness, awake negative affective reactions, and so on. Having patients relate more about their personal troubles in broad terms may also emotionally burden caregivers – as is well known from many areas of counselling – and such harm may, in turn, negatively influence how they interact with patients, particularly if there is a lack of any special training or organisational processes for managing the effects, such as supportive staff counselling or debriefing.

All of these possibilities (good as well as bad) are, as has been pointed out (Haigh, 2000), well-known from the history of clinical practice in the form of a tradition of taking a broad anamnesis, as well as counselling in many other areas, and do not seem to be necessarily connected to the application of any particular decision making model. Rather, they are about subtleties in the person to person interaction that occurs when caregivers and patients talk and listen to each other. It is a recurring motive of PCC/SDM that the tradition of broad anamnesis-taking has been crumbling due to the increased reliance on biomedical testing and rigid, evidence based treatment regimes built on the results of such tests. However, it is easy

to forget that the traditional practice of broad anamnesis-taking also played host to many examples of what in retrospect has been held out as questionable tendencies of victimisation, domination and manipulation of patients. Simply put, there are many ways of listening to, talking to and interacting with people, and expanding the room for this between caregivers and patients in a systematic way – in the form of routine organisations for PCC/SDM – thus needs monitoring, evaluation and designs built on that to assure that the benefits are not accompanied by the reintroduction of old downsides. If some downsides are inescapable, assessment is needed as to whether or not these are balanced by benefits in other terms.

Since the patient narrative is supposed to be ‘holistic’ – i.e., potentially including all aspects of the patient’s situation, from biomedical, over psychological to social and existential aspects or problems – collecting this narrative also raises questions about the competence of caregivers to deal with such ‘holistic’ problem complexes and what resources are needed for securing that these problems are managed appropriately (Mead and Bower, 2000). This, in turn, can be related to issues of health care education and staffing, as well as the prioritisation of health care resources (see below).

4. Confidentiality and Patient Integrity

Besides immediate effects on the well-being of patients, the patient narrative also raises issues with regard to the integrity of patients that go beyond the immediate situation where the narrative is collected. This since the narrative may many times be assumed to include embarrassing or otherwise sensitive details about personal feelings and history, social relationships, and related aspects. Just as with somatic details, it is a plausible presumption that people will want to restrict access to this information and that failure to protect it from spreading beyond what is motivated on strict medical grounds brings risks of harm to patients

as well as reduced trust in health care institutions and staff. This is elementary as well as familiar ground in health care ethics.

However, PCC/SDM could be argued to sharpen the ethical challenge of respecting patient integrity. This since, *a priori*, the more information that is assembled in any sort of system (everything from the mind of a person or a group, over traditional archives to digital databases), the higher the risk that some sensitive information will leak. Moreover, it may very well be that much of the 'extra' information acquired through collecting the patient narrative (compared to when there is just some brief questioning, physical examination and biomedical testing) is *more* sensitive in integrity terms than details about bodily morphology and function. For instance, while a patient may not object to having a health professional discuss relevant physiological details of hers in relation to questions regarding diagnosis and treatment with other members of staff, relaying details about her personal life, intimate feelings or troubles in social relationships is probably seen as less appropriate for such sharing. Especially if the health professional is not seen as obviously competent to help with these problems. Thus, PCC/SDM brings an increased vulnerability to integrity breaches, not only in terms of probability, but also in terms of severity. This issue embodies some complexity due to the fact that one objective of PCC/SDM may be to find ways of supporting the patient with regard to problems revealed by the expanded information and therefore actualising needs for wider sharing among staff. That is, the situation in health care is less clear-cut than in, e.g., psychological counselling and therapy, where a strict principle of confidentiality with regard to individual caregivers is applied.

This issue is added to by the component of continuity – since that requires PCC/SDM to involve a system of documentation that allows relevant details of the patient narrative to be

recorded, revisited and transported through the health care organisation (Luxford et al, 2010). Nowadays, such documentation may be assumed to involve digitalised medical records and the various means for accessing and disseminating these. In addition, a number of IT measures (such as smartphones and social media applications) are presently considered for combining the continuity of PCC/SDM with increased opportunity for patients to be supported in self-care and the wider management of the impact of their condition on their daily life.² Also an increased complexity of the very system for disseminating information brings integrity related risks of a sort similar to those already mentioned. This is further highlighted by the general ethics discussion around "e-health", as well as the wider use of the internet and wireless communication technology in general (Silverman, 2003, Kluge, 2007).

5. Paternalism, Autonomy and Beyond

The *collaboration* component of PCC/SDM will actualise similar issues as those touched upon earlier. Just as a patient may be harmed by the way in which caregivers respond to the patient narrative, or their integrity being invaded when this narrative is disseminated, the process of collaborating in the making of decisions on the objectives of care, choice of treatments and further plans and the documentation and dissemination of the outcomes of such processes may lead to similar results. However, the collaboration component also gives rise to peculiar issues, all connected to the general question of what SDM or any other sort of collaboration in PCC will and should imply in terms of paternalism and respect or promotion of autonomy. Recent analysis has pointed to the fact that the general characterisations of SDM found in the literature are rather open in this respect (Sandman and Munthe, 2009, 2010). While, in the early days of theorising about SDM, it was believed that ensuring a deliberative dialogue between caregivers and patients would by itself safeguard against paternalism and promote patient autonomy in a way clearly desirable from a health care ethics

perspective (Emanuel and Emanuel, 1992), the picture has revealed itself to be more complex and problematic in both theoretical and practical terms (Charles et al, 1997, 2000, Clarke et al, 2004, Mead and Bower, 2000, Sandman and Munthe, 2010). At the same time, empirical studies indicate that in several areas where health care staff claim that they apply some form of SDM, patients are not in fact involved in discussing different treatment options and/or are not being notably assisted in understanding the meaning of different options (Breitsameter, 2010, Ågård et al, 2007, Thomson et al, 2006).

This highlights, first, the crucial distinction between *theoretical modelling* of PCC/SDM and *a priori* ethical arguments based on that, on the one hand, and, on the other, *empirical studies* of what actually happens when some model of PCC/SDM is implemented in clinical practice. Studying actual outcomes concerns, of course, health effects, but may also include different factors highlighted by health care ethical ideals as well as more well-defined success criteria built on that, e.g., regarding autonomy and paternalism. Further quality indicators, to be elaborated on below, may take into consideration effects on public health and health care expenditure. This actualises the need for having ethical ideals with regard to paternalism and autonomy being clearly spelt out in a way that is possible to apply in empirical studies where actual PCC/SDM attempts are evaluated. In spite of this, most of the instruments applied in empirical studies so far do not seem to capture very well those aspects of communication and decision making which are highlighted in ethical ideals regarding autonomy and paternalism connected to PCC/SDM. This regards e.g. instruments for measuring people's *views on* autonomy and paternalism (Stiggelbout et al, 2004), studies looking at *adherence, compliance or health output* (van Dam et al 2003), instruments measuring patient '*satisfaction*' or '*perception*' (Wolf et al, 2008, Epstein et al, 1996 and Bokhour et al, 2009), and assessments of degrees of *participation or interaction* (van Dam et al, 2003).

Second, there is, as indicated earlier, the normative ethical issue of *which* more exact goals *should* be strived for in PCC/SDM and what restrictions are set by these goals and further normative considerations. Just as the collection, documentation and dissemination of the patient narrative may benefit as well as harm patients, this narrative may be put to use in decision making in ways that promote and protect patient autonomy, but also in ways that have the opposite tendency (Sandman and Munthe, 2009). Knowing more about a person, of course, enables us to better assist and support her in clarifying her own ideas about her life, deciding on strategies to form her life in accordance with her plans, and find good ways to execute these strategies. However, this knowledge equally provides a richer palette of opportunities for manipulating patients into making decisions according to the ideas of other people, confusing them and otherwise interfering with their decision making in ways that reduce autonomy. This need not be the result of a conscious paternalist strategy, but may just as well result from lack of skill and knowledge about how to manage the patient narrative and subsequent dialogue and decision making (Elwyn et al, 1999, Coulter, 1999, Charles, Gafni and Whelan, 2000, Robinson and Thomson, 2001). There are many variants to choose from here, where considerations of autonomy and paternalism may be mixed in various ways, as well as being strived for in more purified versions, and some of these may even be argued to transcend the traditional opposition made in health care ethical thinking between autonomy oriented and paternalistic health care ideologies (Sandman and Munthe, 2009). Thus, the general advancement towards PCC/SDM makes it rather acute to debate and decide on these matters and to connect this work to empirically based evaluation and subsequent quality assurance work.

To the extent that promoting patient autonomy *is* considered to be a part of the point of PCC/SDM, a critical issue will be to what extent the fact that a process of SDM is designed to make patients better *informed* implies or effects that the decisions of patients are thereby made more *autonomous*. One aspect of this, well known from, e.g., genetic counselling, concerns how SDM should manage the risk of "information overload" (Juth, 2005), i.e., the effect of the communication of complex or unfamiliar information that people become confused or blocked in their decision making. This sort of problem extends further, since the transfer of the decision-making authority towards the patient is accompanied by a transfer of responsibility. In the envisioned PCC/SDM framework, the caregiver is not, by virtue of her profession, considered to be a specialist in the life and priorities of her patient, but is the patient thereby equipped to receive this transfer of decision authority and responsibility? It may seem unfair – or simply suboptimal from an autonomy point of view – to turn the patient into a co-decision maker without giving her adequate tools to match treatment options to personal preferences, probabilities, costs, risk balancing et cetera. In short, the connection between the capacity for autonomy that the patient is assumed to have, the information that she is given, and the degree to which the ensuing decisions are autonomous, is sensitive to disruption. Therefore, whatever assistance might be offered to guide caregivers in this process might also have to be provided to patients. This issue is similar to the one highlighted above about the need for taking care so that patient narrative and collaboration measures do not harm patients in terms of immediate well-being, only now reflected in an autonomy mirror.

Another aspect of information overload is that, ultimately, health professionals have to select among information anyway, often in relation to the perceived capacity for autonomy and general characteristics surrounding their patient: what she can afford financially, how those particular health risks and benefits stand in relation to her life (e.g. what is the weight of

information on small to moderate likelihoods of one or another genetic conditions affecting her fetus, for a woman who does not have the means to provide herself with adequate nutrition during the pregnancy) (Rapp, 2000). Such a selection of information may, in turn, be performed with varying paternalist or autonomy oriented tendencies, implying varying requirements regarding support for patients in managing this process.

Sometimes the difficulty of a person to make autonomous decisions is rather due to inescapable *internal* impediments – e.g., in the case of children or demented people. At the same time, the extent to which a person (rather than a decision) is autonomous – or, as it is often phrased, *decision competent* – is apparently a matter of degree (Sandman and Munthe, 2009). The question, then, is where the limits of PCC/SDM in relation to such an envisioned scale of decision competence are to be located. If the primary idea of PCC/SDM is to promote and protect autonomous decision making in a way that does not conflict with health related interests, it may be argued that PCC/SDM is only suitable for clearly decision competent patients. At the same time, many of the examples of care presented as PCC seem to regard patients not falling into this category. This indicates the presence of different ideas regarding the point of PCC/SDM with regard to autonomy, such as that there is value in letting whatever decision competence there is have an influence on clinical decision making, and that transferring decisional authority to decision incompetent patients may foster them to become more competent. Also, the idea may be that attending to autonomy is not really the point of care, but that letting the patient have her say may provide effects in terms of improved compliance or adherence (see below). All such suggestions actualise several of the critical issues already highlighted. However, the notion of involving decision incompetent patients in PCC/SDM complicates things, since it is highly likely that it necessitates the inclusion not only of the person cared for, but a number of other people, such as the parents of children,

adult children of demented elderly people, and so on (thus, the rising popularity of the notions of family- and relationship-centred care). Moreover, of course, the more people that are involved, the more complex the potential conflicts that may occur – of interests, of wants, of values, of power and of the interpretation of information (Segall, 2007). This complication will also affect the last two types of issues with regard to autonomy and paternalism, to which we now turn.

One of the chief arguments for SDM has been the idea that a collaboration between caregivers and patients may serve to avoid having considerations of autonomy and health conflict in clinical reality – sometimes expressed in terms of empowering or supporting patients for the sake of better adherence. In a recent analysis, it is argued that if SDM is to have a good chance of achieving such an objective, it has to involve "high level dynamics" – i.e. a process of dialogic deliberation, where both parties have authority, room and incentives to question not only the suggestions and arguments of each other, but the underlying value premises of these arguments (Sandman and Munthe, 2010). Further in this article, we will address the issue of what that implies for caregivers in terms of making concessions to patient demands. However, high level dynamics SDM also provides room for caregivers to apply some pressure on patients to revise their objectives and values so that conflicts between patient autonomy and health considerations are avoided or become less sharp. This actualises the question of how far a caregiver may go in terms of persuasion, pressures and incentives (what Thaler and Sunstein, 2008, have recently dubbed "nudging") in order to influence the decisions of patients, while still keeping within the bounds of plausible consideration of autonomy. While not new, this issue acquires amplified importance in light of scenarios where high level dynamics SDM is introduced on a broad basis as a standard model for caregiver-patient interaction and clinical decision making.

Moreover, we must not lose track of the fact that parties are manifold: the caretakers closest to the patients are most often nurses, counsellors and social workers, and not physicians. And, as we have seen, patients often bring with them a variety of entanglements, of which family, community and cultural connections are only a part. The degree of autonomy of the patient as well as of her decisions will therefore be sensitive to her relationships with all of these other parties. Indeed, as has been pointed out (McLeod, 2002), these relationships often have a determinant impact on the patient's trust in her caretakers, on her self-trust (in her own capacities and choices) and, implicitly, on her autonomy (and vice versa). To the extent that patient autonomy is taken to be a central value of PCC/SDM, it is a challenge to find ways of helping patients handle such webs of relations in ways benefitting them in terms of both decision capacity and autonomous decision making.

This all takes us to the last and, perhaps, most fundamental autonomy-paternalism related issue: how should the idea of a standardised PCC/SDM routine procedure be interpreted in the first place? It could be viewed as one of those caring and treatment options that patients may choose to embark on. It could, however, just as well be viewed as a necessary condition for further steps to be taken in the health care chain – in technical terms, having gone through PCC/SDM is then seen as an indication for subsequent measures to be motivated. From an autonomy perspective, the former conception seems easy to reconcile with the apparent fact that not all patients want to talk much about themselves, engage much in dialogues, collaborate much in decision making, and so on (Charles, Gafni and Whelan, 1997, Clarke, Hall and Rosencrance, 2004, Coulter, 1999, Joffe et al, 2003, Robinson and Thomson, 2001, Ågård et al, 2007). The latter conception, in contrast, seems to imply a sort of meta-paternalism: the idea that patients need to engage in PCC/SDM procedures to access further

care seems to mean forcing, pressing or manipulating some people to engage in (allegedly) autonomy and/or health promoting procedures against their wishes (a sort of paternalism that would remain even if the goal of PCC/SDM was assumed to be entirely focused on autonomy promotion). This highlights further the lack of basic ethical clarity regarding what are supposed to be the point and limits of PCC/SDM in autonomy and paternalism terms. It also makes salient the existence of different autonomy ideals that PCC/SDM may be related to.

6. The Allocation and Limits of Responsibility

Above, we pointed to the inherent idea of PCC/SDM of transferring responsibility for the choice and outcome of care to patients. This idea connects to a recent reorientation of the familiar issue of how (and how far to go) to secure patient compliance, where an increased emphasis on patient autonomy and SDM has led to the adoption of the new notion of *adherence* (Pitkala, 2007, Broyle et al, 2005, WHO, 2003, Russell et al, 2003, Lutfey and Wishner, 1999, Timms and Lowes, 1999, Marland, 1998). This notion captures the idea of caregivers allowing patients to take part in clinical decision-making and to adjust their clinical judgement in accordance with that. Thus, the outcome of care in terms of patient behaviour is to be assessed in relation not to a clinically predefined standard of best treatment (i.e. compliance) (Haynes, Taylor and Sacket, 1979), but an agreement between caregiver and patient. Since the patient has had some influence on this agreement, it may be assumed that adherence may be boosted by PCC/SDM if only the collaboration component is implemented in a way that allows for such influence. Furthermore, since adherence is more about honouring an agreement than submitting to external advice or instruction, responsibility seems to split between caregiver and patient – at least to the extent that the patient has managed to influence the agreement. In the context of PCC/SDM with its key component of continuity, to the extent that adherence is not secured by one agreement, this would seem to

actualise a new round of collaboration, leading up to a new agreement where those factors making the patient non-adherent are taken into account in order to secure future adherence (relative to the new agreement).

Obviously, if any of this is to be realistic at all, in view of the far-reaching unclarity involved, just talking loosely about PCC/SDM will not do. True, some versions of PCC/SDM emphasise strongly an increase of patient power, influence and involvement in clinical decision making. However, as noted, other versions stay firmly rooted in paternalist views of the goals of health care. Thus, whether or not a shift from compliance to adherence and an accompanying transfer of responsibility from caregivers to patients is to be seen as tangential to PCC/SDM would seem to depend on the issues mentioned earlier regarding what PCC/SDM *should* amount to in terms of autonomy and paternalism (the relationships between the concepts of adherence, autonomy, compliance and patient best interest are analysed more closely in Sandman et al, 2011).

Besides these questions, a basic issue for ethicists to ponder is to what extent transfers of responsibility from caregivers to patients of the sort sketched are desirable in their own right. In the preceding sections, we pointed to risks of harming patients in the immediate interaction implied by PCC/SDM and of burdening them with responsibilities without providing tools for managing this burden in connection to the collaboration component. But it is also possible that handing over responsibilities may serve to empower patients in terms of decision competence and control (Sandman and Munthe, 2009). Beyond such worries, however, lies a deeper issue about how such transfers would square with standard views on the professional responsibility of caregivers, the institutionalised version of this in terms of best treatment standards and the traditional notion of a duty of care.

In the traditional compliance paradigm, the behaviour of the patient is matched against the best treatment standard for her medical condition, this standard in turn being preset on a biomedical basis. The PCC/SDM motivated shift towards an adherence paradigm raises questions about how to view such a standard and if it is still motivated. It has been pointed out that if a high level dynamics SDM is to be possible, there has to be room for caregivers to make concessions to patient wants and values that may not conform to the best treatment standard (Sandman & Munthe, 2010). This since, in such versions of PCC/SDM, clinical decision with regard to a specific patient becomes highly individualised, taking into account all sorts of information (relayed through the patient narrative) besides biomedical data and predictions. In the individual case, the caregiver may thus accept decisions and plans that she knows will jeopardize the health of the patient, just to keep the latter "on board" or to "have something rather than nothing". How far can the caregiver go in making such pragmatic adaptations before she reaches the limits of her professional responsibility and, possibly, transgresses her duty of care?

There are possibilities, of course, to reshape the traditional notion of a best treatment standard, for instance, by instead connecting caregiver professional responsibility and the duty of care to a standard of *minimally reasonable treatment* that sets a lower threshold in terms of risks and expected health outcomes. While implying a relaxation of the ethical ambitions of health care in terms of risk-benefit, such a notion would provide the sort of safeguard against inefficient or unnecessary risky medical procedures that has been the main rationale behind the best treatment standard, only now adjusted to be compatible with substantial shifts in power between caregivers and patients. From an ethical point of view, this again connects to the need for further discussion of how to balance different notions of patient

autonomy and caregiver perspectives on patient best interest. However, it also raises issues of a more structural nature, to which we now turn.

7. Structural Issues

All of the questions taken up so far reside within a familiar framework of clinical ethics and its theoretical underpinnings. Basically, they all concern what PCC/SDM will and should imply for the relationship between individual caregivers and patients in clinical reality, what risks and potential benefits attach to that and what sort of empirical information is needed to assess PCC/SDM attempts from this point of view. Besides this, however, the broad advocacy of PCC/SDM as an aspiring 'over-ideology' of clinical decision making gives rise to a number of structural issues. Some of these arise as an effect of clinical ethical problems already noted taking on new shapes when viewed as parts of a broad pattern or movement that will influence not only patient-caregiver interaction, but the functioning of the very institution of health care. Others, instead, point to the well-known fact that collections of actions that may seem well motivated in each individual case may sum up to a structural pattern that is much less appealing.

An obvious vantage point to these issues is the question of how ideas on the fair distribution of health care resources apply to PCC/SDM. Implicitly, implementing PCC/SDM would effect a rather substantial expansion of the costs for delivering health care (e.g. in terms of the time and competence needed for properly collecting patient narratives and conducting SDM). The magnitude of this expansion would, in turn, depend on what more exact version of PCC/SDM and its underlying ambitions, e.g. in terms of patient autonomy. This highlights the need for making clear what the benefits of various PCC/SDM attempts are supposed to be, to what extent they are forthcoming and how the resulting cost-benefit balance fits into an

argument supporting that allocating resources for the implementation of PCC/SDM makes for a fair distribution when other needs and objectives of health care are weighted into the balance.

While many versions of PCC/SDM may have a prospect of promoting a more fair distribution of power, influence and opportunity (since they allow patients a more equal standing in relation to caregivers and may better empower them to deal with their health problems), whether or not such effects would be forthcoming seems to depend a lot on exactly which variant of PCC and SDM is implemented (and how this variant can be demonstrated to work in clinical reality in view of the various issues mentioned earlier). Moreover, to the extent that there would be such effects, giving patients the opportunity and means to influence care may result in even more differentiated health outcomes than can presently be observed, since patients will bring their diverse experiences, competences and ambitions into the decision-making situation. For instance, allowing patients to adapt treatment and care according to preferences and circumstances would risk benefiting patients with more sophisticated preferences and life-styles at the cost of patients with lower expectations.

Most Western health-care systems employ the guiding principle that resources should be used in proportion to the needs of patients, as assessed from a biomedical perspective by caregivers. PCC/SDM with its emphasis on taking into account the patient's subjective perspective and preferences, however, would seem either to considerably expand the notion of need thus applied or complicate the guiding principle just mentioned. Actual distributions of health care, as well as outputs in terms of health states, will be influenced by what sort of concessions and demands are made by caregivers and patients. The distinction between the needs of patients and the demands made by patients thereby becomes less clear-cut,

something that might impact on the possibilities to ration publicly funded health care spending, thus possibly posing a long-term threat to national health services. A move from a system where health care is allocated according to need towards a more demand-driven system can furthermore lead to increased inequalities in terms of health, due to strong patient groups pressing for access to various treatments that would have been easier for caregivers to resist in a system with more clear-cut limits.

Presumably, even in a more demand-driven health care system there would have to be some form of professional assessment of health care need, but what sort of balancing between this need and other considerations this would imply is far from clear. What has just been described is a possible structural effect of PCC/SDM of having the institutions of health care work more and more in the manner of any sort of business. This in spite of the fact that early work on PCC/SDM stressed it as a way of increasing patient influence on clinical decision making without sliding into a consumerist model (Emanuel and Emanuel, 1992). More lately, the rather popular idea of SDM as a form of *negotiation* aiming for a compromise between competing private interests has attracted criticism (Sandman, 2009). Nevertheless, a significant part of the movement towards PCC/SDM seems to be continuously oriented towards the idea of "consumer centred care", as well as the modelling of SDM as analogous to a business negotiation. At the same time, as indicated earlier, the tradition of applying a rigid limit (e.g. in the form of a best treatment standard) for what services health care may offer would seem to have to be abandoned on exactly those versions of PCC/SDM that aim for a substantial increase of patient influence on clinical decision making. This applies regardless of whether health care is funded privately or through public channels. In countries where the former sort of system is dominant, at the very least, some concern about the possible effects on population health and the distribution of access to health care resources in

the population seems to be apt. Countries employing a mostly publicly funded health care system, however, face a more multifaceted complex of issues.

In order to consistently distribute scarce health-care resources within a publicly funded system, there must be some idea of how to prioritise at a high institutional level, resulting in guidelines for what to offer (and not to offer) patients, that are applied by responsible agencies, hospitals, clinics, and so on. Whatever other principles are applied to this effect (such as allocation of resources according to need), *cost-efficiency* of treatments is a fundamental factor in such a prioritising scheme. Cost-efficiency, in turn, is assessed as a ratio between the cost of the treatment and its effects, using biomedical effect-studies of standardised treatment strategies. Thus, if the patient is allowed to modify the standard treatment plan – the cost-effect ratio of actual care will be affected. In the extreme case, patient demand will steer resources away from procedures proven to be best, thus producing a deteriorating process in terms of not only rational use of health care resources, but also the health of the population. Such effects may occur due to the facts that people care about many other things than their health, that their preferences may be influenced by powerful parties (such as pharmaceutical companies) (Segall, 2007), or that wide variations among patient preferences result in caregivers encountering difficulties in keeping up speciality skills in the lack of broadly applied standard procedures.³

Worries of this sort are further complicated by the connection between PCC/SDM and the issue of compliance/adherence. On the one hand, since lack of compliance with prescribed standard treatments is already today a problem, if PCC/SDM can use the shift towards adherence for having patients "on board" to a greater extent, this may affect population health for the better. Thus, it may be tempting to counter the just observed threats by redefining

health care efficiency in terms of adherence, thereby securing that if only PCC/SDM secures good adherence, cost-efficiency will not be in jeopardy. Indeed, this would seem like the logical thing to do on those versions of PCC/SDM where the idea of the patient as consumer is held out as the focal point. On the other hand, the concept of adherence in itself sets no limit to how far patient demand may have caregivers depart from best treatment standards. Having adherence as the novel primary goal of health care in the PCC/SDM context would thus seem to equal surrendering the basic authority on what health care is supposed to be doing to patients. Moreover, one of the bearing thoughts behind those versions of PCC/SDM that aspire to increase patient influence of and involvement in clinical decision making (thus being well-suited to sponsor a shift from compliance to adherence) is that patients have many interests besides health, and that health care – by employing PCC/SDM – should allow those interests to influence clinical decisions. Redefining efficiency in terms of adherence to clinical decisions, achieved through versions of PCC/SDM leaning towards the consumer model of the patient, may thereby make the threats towards population health and the financial basis of publicly funded health care even worse.

There are two further twists to this issue that becomes salient through, once again, noting the connection between the "consumer centred" versions of PCC/SDM, the idea of adherence as a primary goal of health care, and the ambition of transferring responsibility for clinical decisions and health outcomes from health care to patients. One reaction to the sort of threats just mentioned that seems congenial to the connection between PCC/SDM, adherence and responsibility-transfer to patients at this level is to revise general societal ambitions with regard to the health of the population in accordance with such a transfer. Simply put, if people choose to make deals with health care that results in deteriorating population health, this is a problem for the people and not for society. A rhetorically less draconian way of advancing

this sort of position comes in terms of trust: if patients are trusted to manage their own lives, we could also allow more of the responsibility for care, treatment and resulting health states to be transferred to patients. But how far should such a structural transfer of responsibility go, i.e. what is a proper distribution of responsibility between the people and society given a health care organisation built on this sort of PCC/SDM? This take on the structural effects of PCC/SDM is open for the view that health states resulting from people "betraying" the trust of society should have to carry the resulting burden themselves. After all, they have been given the power to influence clinical decisions and have made their choices with the support of SDM. Thus, PCC/SDM may function as a lever for the view that so-called option luck (in distinction to brute luck), should be given some weight in the distribution of health care resources (Segall, 2010). If patients are trusted to be involved in SDM and given the means to make well-founded decision adapted to their situation and thus make choices with detrimental effects to their health – should they not have to take responsibility for these effects to some extent? When such effects occur as a structural result of a broad organisational change towards PCC/SDM, this idea becomes exactly the thought sketched earlier: society has reasons to care about deteriorating population health only to the extent that it does not result from free and well-informed decisions of people.

The second twist is that such a structural process may affect not only the health of the population but their future autonomy as well. First, deteriorating health tends to affect decision capacity in a rather straightforward manner. Second, the sort of structural process described, where society provide less and less health promoting resources to individuals (as an outcome of transferring responsibility for health to individual people and having adherence as the ultimate goal of health care) affects many people's *ability to access* such resources. In this way, a PCC/SDM with far-reaching consumerist ambitions in terms of autonomy, may

end up in a totality of health care decisions that produces a situation where people's autonomy is less promoted than would have otherwise been the case. While each singular decision may be autonomy promoting within the frames set by its context, the sum of these decisions may be the opposite of liberating through its effects on the mentioned context and frames. Instead of having a classic *invisible hand* effect securing that the best decisions of each sum up to the best mass of decisions for all, we get a classic market failure where the exercise of freedom by each of us limits the freedom of all of us.

To close this section, we should make clear that – as mentioned earlier – there is no necessity in having PCC/SDM in any of the versions that actualise the sort of worries taken up here. Indeed, as remarked, PCC/SDM may very well be designed in ways that conforms to a paternalist health care ideology – even more so than what has been known before. However, many supporters of PCC/SDM seem to be particularly attracted to those versions that are intended to strengthen patient power over clinical decision making. In preceding sections, we have pointed out a number of clinical ethical issues arising on such an assumption. In addition, there is the basic issue of which underlying values *should* be driving PCC/SDM (determining which version – if any – of PCC/SDM should be implemented). What has transpired in this last section is that both of these layers of the ethics of PCC/SDM have salient health policy and public health ethical dimensions. The sort of troubles highlighted in this section correspond to well-known value tensions in public health policy between caring for population health, a fair distribution of health and autonomy with regard to health (Munthe 2008). Thus, settling the issues of the desirable mix of autonomy and paternalism, the allocation of responsibility between caregivers and patients, the importance of compliance and/or adherence and the proper allocation of resources to PCC/SDM (to name some of the central ones), necessitates that the implications of taking public health ethical aspects into

account (thus lifting the view above the particularities of clinical reality) are thoroughly explored.

8. Conclusions and a Program for Ethics Research

The broad advocacy of PCC/SDM tends to rather uncritically assume it to be an unequivocally good thing. Closer analysis from an ethics perspective reveals this to be far from settled. Thus, the advance of the PCC/SDM movement creates some urgency for bio-, health care and medical ethics researchers to take part in and critically assess this development in a number of ways. In fact, such participation seems to be essential for any serious scheme of quality assurance attached to transformations of clinical practice and health care policy in the PCC/SDM direction. We will close this article by outlining some of the major areas that need to be addressed.

- Clarification of the central *concepts* of PCC/SDM: their diverse meanings and internal relationships, facilitating ethical analysis *as well as empirical study*. The latter requires substantial work in order to facilitate making ethically relevant concepts operational (without loss of validity) in empirical studies using established methods from, e.g. linguistics, psychology and sociology.

- Clarification of what ethical objectives PCC/SDM are supposed to further and their dependence on specific ethical theories or perspectives giving rise to different PCC/SDM versions and ethical objectives concerning:
 - o Patient narratives
 - o Collaboration
 - o Continuity

- Development of these different versions of PCC/SDM into clinically testable praxis, calling for:
 - Empirical studies of participant experiences of different aspects of ethical relevance, e.g. regarding well-being, decision capacity, decision making.
 - Ditto of the communicative and interactive aspects of ethical relevance, e.g. regarding autonomy and responsibility.
 - Ditto regarding surrounding aspects, e.g. integrity and methods for securing continuity.
 - Development of quantitative assessment tools for large scale comparative assessment of different PCC/SDM variants

- At least, the following aspects need to be further explored in moving through the above steps:
 - The immediate and long-terms effect of PCC/SDM as to aspects like:
 - Integrity
 - Patient and professional well-being
 - Power-relationships
 - Professional responsibility
 - Professional competence
 - Based on existing research on the relationship between SDM and paternalism /autonomy, further clarification of how different versions of SDM relates to:
 - Manipulation vs. autonomy
 - Provision of information vs. autonomy
 - Persons lacking in decisional competence

- Autonomy vs. third-parties
 - Autonomy vs. compliance/adherence vs. best treatment standards
 - The transfer of responsibility from professional to patient
 - The standing of PCC/SDM in standard care
- In a broader perspective, clarification and further ethical analysis of the structural effects of different versions of PCC/SDM are needed, as to:
- The distribution of health care resources
 - The distribution of health and population health
 - Patients taking responsibility for their own health and health-outcomes
 - Long term access to health and health care resources

¹ See also, as examples, the following webpages where PCC is framed in rather missionary as well as entrepreneurial contexts: Eric Haider (<http://www.personcenteredcare.com>), The Person Centered Care Advocate (<http://www.personcenteredcareadvocate.org/>), Ohio Person-Centered Care Coalition (<http://www.centeredcare.org/>), Institute for Patient- and Family-Centered Care (<http://www.ipfcc.org/>) and Foundation for Informed Medical Decision Making (<http://www.informedmedicaldecisions.org/>).

² Several such ideas are presently being developed and tested in projects at the University of Gothenburg Center for Person Centered Care (GPCC).

³ Lack of consistently and regularly applied standard treatments also threatens making the cost-efficiency instrument itself inapplicable, or at least blunter than it is today, thus making it difficult to apply any sort of cost-

efficiency requirement in the prioritisation of health care resources. A possible remedy for this effects may be to develop more sensitive cost-efficiency instruments that relate to a minimally reasonable treatment standard and rate a number of modifications to be found in between this lower level and the best treatment standard. Presumably, such instruments would have to take into account statistics on compliance and adherence.

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