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A capabilities approach to person-centered care: response to Open Peer Commentaries

Our suggestion that the aspects of healthcare quality associated with ‘person-centered care’ can be understood as a matter of health services and staff recognising and cultivating a subset of capabilities that we called ‘person-al’ (Entwistle and Watt 2013) attracted a diverse set of open peer commentaries. Taken together, we think these commentaries highlight the strong potential of the guiding idea to illuminate and help address a range of issues of ethical concern across diverse healthcare domains. They also offer some helpful suggestions for the further development and investigation of applications of capabilities thinking in relation to person-centered care and healthcare delivery more generally.

Several commentaries identify specific concerns about, and challenges for, our approach. Some of the concerns rely on interpretations of our position that we do not share. They prompt us to try to clarify some key points before responding briefly to some of the suggestions about additional implications and applications.

Points of clarification

We start by strongly disagreeing with Rebecca Levine’s assertions that our “model... focuses on medically ‘improving’ individuals’ bodies to achieve an ‘ethical status’” and that the fact that we did not indicate how to measure capabilities “can reinforce an oppressive status quo” that excludes people with disabilities from participation in the social mainstream (Levine 2013). In part, Levine’s concerns about our capabilities-based idea about person-centered care appear to stem from her assumptions and concerns about a capabilities approach more generally. We align ourselves with the scholars and advocates who, as Sara Bergstresser’s commentary illustrates, believe that a capabilities approach has significant positive potential to promote participation and social justice for people with disabilities (Bergstresser 2013). We think the approach’s recognition of human diversity, pluralism about what matters, and valuing of individual freedom, together with the social ontology of capabilities, work *against* the imposition of oppressive requirements to conform to particular bodily norms, medical treatment regimes or ways of life.

Levine’s concerns also seem to reflect some difficulty in accepting that our guiding idea can require *both* that everyone should benefit from person-centered care *and* that person-centered care should be appropriately responsive to the diversity of human bodies and values. Sem de Maagt and Ingrid Robeyns usefully provide and prompt some further clarification here. Their commentary distinguishes between the *moral status* of individuals (which should be equal for all) and morally appropriate *treatment* (which may differ from person to person) (de Maagt and Robeyns 2013). This helps us explain that in our paper, we rejected criterialism for the assessment of moral status (so

moral status is equal for all), and encouraged the use of “individually appropriate ways of recognising and cultivating what person-al capabilities [different people] do and can have” as a flexible guide to morally appropriate treatment (which may differ across people).

In other words we are trying to say that, while healthcare provision should be person-ally respectful and person-ally supportive for everyone, this doesn't have to be (indeed cannot be) achieved by having health services and staff work with everyone in identical ways. Some differences between people justify (or require) that they are treated differently to achieve person-al respect and support. This idea has parallels with the distinction that economists make between horizontal and vertical equity for situations of similar and different need (Culyer 1995). It can help, as Suzanne van de Vathorst and her colleagues point out in their commentary, to reconcile commitments to be both non-discriminatory and culturally competent when interacting with ethnically diverse people (van de Vathorst et al 2013).

De Maagt and Robeyns reasonably noted that our original paper did not offer much guidance on how, when and why to treat a person differently (de Maagt and Robeyns 2013). We agree with them that some kind of criteria or assessment must play a role in answering these questions, and also that the capabilities approach has theoretical tools that can help. The distinction that they mention between internal and external constituents of capabilities can indeed be useful (this is one reason for highlighting the value of the social ontology of the capabilities approach). We also think it will be possible to develop criteria relating to the person-al capabilities themselves to inform judgements about *which* differences between people do and do not justify interacting with them in (which particular) different ways.

Although we are only just beginning this work (which will require participatory and empirical research as well as philosophical-theoretical development), we do want to say a little more about the person-al capabilities to help clarify our guiding idea and to explain why it could be useful in efforts to promote person-centered care and help to overcome injustices in healthcare more generally.

The person-al capabilities are a subset of capabilities associated with experiences of having the moral status of a person and of being a valued member of the human community. (As we're using the term, the person-al capabilities are not the particular subset of all possible capability sets that a specific person has or values).

As we said in our introductory paper, the person-al capabilities are not yet well specified. We did not think we had pinned them down quite as firmly as our paper suggested to de Maagt and Robeyns that we had. While we think that capabilities associated with *some* of the functionings that feature in historic criterialist accounts of personhood *could* be among the person-al capabilities, and we used some of these to illustrate in principle what person-centered care could entail when it is understood as care that recognises and cultivates the person-al capabilities, we do still think that “further questions need to be asked, for example about the identification and perhaps prioritisation of what we are calling person-al capabilities [and] about how these capabilities can and should be cultivated... for particular patient groups”. John Davis' ideas about capabilities for personal identity narratives seem particularly promising and will warrant careful attention in this regard (Davis 2011, 2013).

Although it should be possible to identify a set of person-al capabilities (or domains of person-al capabilities) that are generally associated with experiences of having the moral status of a person and of being a valued member of the human community, both the potential to 'have' particular person-al capabilities and the value of particular person-al capabilities will vary across individuals and situations. Thus the recognition and/or cultivation of particular person-al capabilities might be more or less of a priority for particular individuals and at particular times.

In saying this, we rely on several linked features of person-al capabilities *as* capabilities that matter for considerations of how we can appropriately recognise and cultivate each other's person-al capabilities. These are important for thinking about the implications of our guiding idea and the concerns some commentators raised. First, the person-al capabilities are, in varying ways and to varying extents, socially and situationally shaped. When we say that people vary in terms of the person-al capabilities they have and can have, it is important, as de Maagt and Robeyns suggest, to consider what combination of more 'internal' and more 'external' factors are contributing to this, and which of the external factors (e.g. social aspects of healthcare provision) might be modifiable and contribute to the enhancement of valued person-al capabilities). Second, the person-al capabilities are dynamic. They can evolve over the course of individuals' lives (Ballet et al 2011) and be affected by both illness and healthcare situations. Third, particular person-al capabilities can be had to varying degrees (rather than in all or nothing ways), and this again can depend on 'external' as well as more 'internal' or individual factors.

Reflecting these points, a wordier version of our guiding idea (for healthcare staff) could be that person-centered care involves:

(a) recognising

- (i) what valued person-al capabilities each individual does have in the particular situation in which you encounter them,
- (ii) what personal-capabilities are important for them, and
- (iii) what scope there is for them to exercise, and for healthcare provision (including your own interactions with the person) to enhance (or conversely to undermine) their person-al capabilities and

(b) finding ways of cultivating (or at least not undermining) their person-al capabilities, both in the current situation and for their future, by

- (i) enabling them to exercise their more internal(ised) person-al capabilities and
- (ii) ensuring that healthcare provision contributes to the development or expansion rather than contraction of those person-al capabilities that matter for them and that can be externally influenced.

We see a person's person-al capabilities as enabling them to be and become their own particular and valued person, and in some sense *on their own terms*. They are capabilities to engage in the social world and to have others interact with us in ways that give due regard to our own perspective and agency.

Implications for autonomy and shared decision-making

Several commentators disagreed about whether our idea does too little or too much in relation to autonomy and shared decision-making in health care. We were particularly disappointed and

somewhat perplexed that Lily Frank thought that we had contrasted our account of person-centered care with (what she calls) “autonomy focused PCC” (Frank 2013): we identified a requirement that healthcare supports capabilities for autonomy among the likely implications of our guiding idea. Our critique of the ways autonomy featured in some current interpretations of person-centered care focused on the problematic ways that a principle of respect for autonomy is sometimes understood – a concern which Frank seems to share.

In response to comments from Sara Bergstresser (Bergstresser 2013) and Rebecca Levine (Levine 2013), we stress that we do not think that the provision of information and the offering of choice are unimportant. Our concerns are: (a) that information and choice are sometimes inappropriately assumed to be all that is necessary (and so sufficient) to ‘respect’ patients’ autonomy; (b) that if this assumption is combined with a view that healthcare staff should not influence patients’ choices, it can lead to a neglect of the broader kinds of support that (as several other commentaries illustrate - de Maagt and Robeyns 2013; Epstein 2013; Hrisos and Thomson 2013) people sometimes need to enable them to engage in and influence their care; (e.g. friendly encouragement, a ‘sounding board’, reassurance or the kind of recommendation that Ron Epstein illustrated (Epstein 2013); and (c) that the provision of information and choice are sometimes over-emphasised to the neglect of other issues that, in some circumstances, can be more important for what people need to feel they have been treated appropriately as a person.

Just what is needed to work with individuals as (potentially) autonomous agents will differ because people have varying capabilities for autonomy, and these capabilities are constituted in different ways. Some, for example, are constrained by congenital intellectual disabilities, and some have been socially suppressed in ways that may or may not be modifiable within a healthcare episode. We don’t disagree with Sara Bergstresser that when people seem unable or disinclined to make their own decisions after being informed about their healthcare options “this should be recognised as a frequent product of consistently negative past interactions with healthcare providers” (Bergstresser 2013). Our guiding idea would judge those past interactions inconsistent with person-centered care because they undermined capabilities associated with participating in important decisions about one’s own care and life. It would also encourage healthcare staff to find ways to overcome such a negative historic legacy, to recognise people’s ‘internal’ potential, and to ensure that current and future healthcare interactions cultivate or support the expression of those capabilities moving forward.

Similarly, we do not disagree with de Maagt and Robeyns that it would be inappropriate to give a four year old a choice whether to take medication. Our guiding idea would encourage ensuring that the ‘gentle coercion’ that they identify as necessary is done in such a way as to cultivate rather than undermine the child’s reasoning and decision-making skills and self-confidence in these for the future. We have said more elsewhere about sharing decisions in ways that involve more than ‘stand back’ respect, and that positively develop rather than deny or undermine autonomy capabilities, especially in people whose decision-making capacity may be limited (Entwistle et al 2010a; 2012).

Choice-related capabilities are clearly very important in many healthcare situations, but they are not the only important personal capabilities, and for some people at some times (e.g. in advanced stages of dementia) it may be appropriate to focus on others.

Additional implications and different emphases

In our introductory paper, we focused on the implications of our capabilities-based idea about treating people as persons for thinking about the ways healthcare staff work with patients. The idea that treating people as persons involves recognising and cultivating their personal capabilities can, of course, also have implications for thinking about other relationships. We will briefly respond here to a few suggestions from commentators, especially those who were concerned that we had under-emphasised key issues.

The significance of social structures

We don't disagree with Alex Neitzke that structural aspects of health care provision are important for the delivery of person-centered care (Neitzke 2013). They can indeed have important implications for the recognition and cultivation (or otherwise) of people's personal capabilities, as we briefly and occasionally acknowledged in our piece. However, many of patients' experiences of being treated as a person (or not) are experiences of interpersonal interaction, and healthcare staff are explicitly asked to provide more person-centered care, so need useful ways to think about this. Our guiding idea could help staff and others reflect on how healthcare (and broader social) systems and cultures affect people -by impacting on their personal capabilities. The social ontology that we adopt from capabilities approach is an important theoretical resource that could help pinpoint structural as well as interpersonal problems.

Patients' recognition and cultivation of their own (and others') capabilities

Susan Hrisos and Richard Thomson fairly point out that because we focused on what healthcare staff do, an active role for patients in healthcare "is not readily apparent" (Hrisos and Thomson 2013). Of course we do not wish to deny that patients often can and arguably often should contribute actively to key aspects of their healthcare. And as John Davis points out, Sen's capabilities approach in particular "gives emphasis to the idea that people are agents of their own capability development" (Davis 2013). We have been concerned previously to highlight the ways that features of healthcare provision sometimes fail to give practical support for the implementation of policies that advocate more active contributions by patients to their safety and to decision-making about their care because they impair patients' capabilities to contribute (Entwistle et al 2010a, 2010b). Hrisos and Thomson's observation raises questions about both the relationships between personal capabilities and other (perhaps overlapping) capabilities relating to participation in healthcare. We have associated the personal capabilities particularly with the 'person-centered' aspect of healthcare quality, and prevailing frameworks for thinking about healthcare quality often treat 'safety' and 'effectiveness' as distinct from this (IOM 2000). However there are important links, as Michael Millar's commentary relating to healthcare acquired infection (Millar 2013), and Robert McMaster's and John Davis's commentaries relating to the implications of the idea for health economics highlight (McMaster 2013; Davis 2013). Questions about the boundaries and intersects between these need attention.

Hrisos and Thomson's point also reminds us that there is important theoretical and empirical work to be done to investigate capabilities for personal capability development.

Future work

Finally, we think Miles Little has rightly and eloquently highlighted important practical challenges to the sharing and adoption of our guiding idea, as well as to the promotion of far-reaching improvements to healthcare more generally. (Little 2013) We appreciate the encouragement he and others give us to persist, however, and plan to move forward by working (1) to develop the theoretical underpinnings of the idea that we have shown in principle to have value, (2) to examine in detail the practical implications of the idea in particular contexts, and (3) to find ways to communicate the key ideas more simply and more clearly to support their use (including via approaches that incorporate some degree of standardisation, which, as Hrisos and Thomson point out, may be practically important even to promote appropriately individualised approaches to care (Hrisos and Thomson 2013)) .

This broad programme of work will need to be a collaborative endeavour, involving people with practical and experiential insights from diverse healthcare settings, people from the various disciplinary backgrounds who work on the evaluation and improvement of service provision, and people willing to grapple with complex philosophical issues. We look forward to further conversations with those interested.

Ballet, J., M. Biggeri, F. Comim. 2013. Children's agency and the capability approach: a conceptual framework. In: Biggeri, M., J. Ballet, and F. Comim (Eds) *Children and the capability approach*. London: Palgrave-Macmillan. Pp22-45.

Bergstresser, S. The person at the center. *American Journal of Bioethics* ****

Culyer, A. 1995. Need: the idea won't do – but we still need it. *Social Science and Medicine*; 40 (6): 727-30.

Davis, J.B. 2011. *Individuals and identity in economics*. Cambridge: Cambridge University Press.

Davis, J.B. 2013. People-centered health care: capabilities and identity. *American Journal of Bioethics* ****

De Maagt, S., I. Robeyns. 2013. Can person-centered care deal with atypical persons? *American Journal of Bioethics* ****

Entwistle V.A., S.M. Carter, A. Cribb, K.M. McCaffery. 2010a. Supporting patient autonomy: the importance of clinical relationships. *Journal of General Internal Medicine*, 25 (7): 741-5.

Entwistle, V.A., D. McCaughan, I.S. Watt, Y. Birks, J. Hall, M. Peat. et al. 2010b. Speaking up about safety concerns: Multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*, 19(6): e33-e33.

Entwistle V.A., A. Cribb, I.S. Watt. 2012. Shared decision making: enhancing clinical relevance. *Journal of the Royal Society of Medicine* **105**: 416-421.

Entwistle, V.A., Watt, I.S. 2013. Treating patients as persons: a capabilities approach to support delivery of person-centered care. *American Journal of Bioethics* ****

Epstein, R.M. 2013. The ambiguity of personhood. *American Journal of Bioethics* ****

- Frank, L. 2013. The definition of health, goals of medical care, and patient centered care. *American Journal of Bioethics* ****
- Hrisos, S., R.Thomson. More required on the patient role and standardisation. *American Journal of Bioethics* ****
- IOM (Institute of Medicine). 2001. *Crossing the quality chasm: A new health system for the 21st century*. Washington DC: National Academy Press.
- Levine, R.L. 2013. Disable the patient by incorporating the capabilities approach into person-centered care. *American Journal of Bioethics* ****
- Little, M. 2013. Comment on Entwistle and Watt. *American Journal of Bioethics* ****
- McMaster, R. 2013. Capabilities and patients as persons: ethical implications for health economics. *American Journal of Bioethics* ****
- Millar, M.R. 2013. A capabilities perspective on healthcare associated infection. *American Journal of Bioethics* ****
- Neitzke, A.B. 2013. Bringing a structural frame to person-centered care. *American Journal of Bioethics* ****
- Van de Vathorst, S., D. Willems, M.L. Essink-Bot. 2013. The contribution of the capabilities approach to reconciling culturally competent care and non-discrimination. *American Journal of Bioethics* ****