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More Required on the Patient Role and Standardization

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represent these preferences using the QALY (quality-adjusted life year) measure. The QALY measure provides a single number evaluation of the value of health care outcomes derived from what people would prefer regarding the quantity and quality of life they could expect to live under those outcomes. Crucially, it assumes people's preferences are stable and given. But in the capabilities approach people's preferences are not hardwired and given but are instead the product of their continual efforts to develop who they think they are in terms of their "person-al" capabilities. The QALY measure thus has two weaknesses for a person-centered care account: It ignores the process by which preferences are constructed in the clinician-patient relationship, and it employs an inadequate proxy for what people fundamentally value, namely, their "person-al" capabilities.

The implication of this is that new "person-al" capabilities-based metrics need to be created in order to determine care priorities. Their emphasis would not be on standardized disease management protocols and assumed stable patient preferences but on people's shared participation in determining their health self-management needs. If the most important thing to people is their ability to function as persons—something that varies according to one's circumstances in life—then they should be able to register what this involves—indeed have responsibility to do so—in communication with clinicians, and with family members, in determining the care they receive. This means there is no "one-size-fits-all" solution to health care provision. A capabilities-based metric is not a simple set of rules but rather guidelines for investigating and identifying people's values regarding their sense of themselves as persons.

THE CAPABILITY APPROACH

Finally, not to be overlooked is that Entwistle and Watt not only make a valuable contribution to person-centered care thinking, but also make an important contribution to the ca-

pability approach as well. One of the main disputes between proponents of the capability approach concerns whether there ought to be a basic list of universal capabilities as guidelines for human development (Nussbaum 2003), or whether human capability development ought to be seen as a more pluralistic, open-ended process (Sen 2004). In the health care context, the former view risks treating people as patients in the passive sense of the term because it sets out what capabilities people ought to pursue, while the latter gives emphasis to the idea that people are agents of their own capability development. Entwistle and Watt's emphasis on "person-al" capabilities provides a further way of understanding the latter position in tying the question of which capabilities people would seek to develop to their personal identity self-narratives. In this view, when we accord people dignity as distinct beings, we cannot say what they might believe would provide them their personal identities. Thus, it seems that people's capability development needs to be a relatively open-ended affair, including in the crucial domain of health care. ■

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More Required on the Patient Role and Standardization

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It is critically important that deep and original thinking is applied to the concept of patient-centered care, not least when this is gaining international traction and might (at

last) effect change; for example in the United States, within the Institute on Medicine (IOM) report (IOM 2001) and, most recently, in the United Kingdom following the Francis

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Report identifying a saddening lack of patient-centered care in the Mid Staffordshire NHS Foundation Trust (Francis 2013).

As Entwistle and Watt (2013) state, agreement on a clear definition of the term “patient-centered care” eludes us. Hence it has been adopted by a range of parties and, deliberately or otherwise, used in a variety of ways. Meaning different things to different people, aligned with the undeniable nature of the concept—who could deny the importance of patient-centered care or that they want to deliver it?—allows it to be both widely supported and widely ignored. *Person-centered care* offers a potential route out of this impasse. We want to comment on this thought-provoking article by addressing two issues, with particular reference to our experience of engagement of patients in decision making and patient safety.

THE ROLE OF THE PATIENT

The first issue relates to the role of the patient in co-production of person-centered care. As Entwistle and Watt suggest, there are many important senses in which the ways people treat each other enable them (or not) to feel and/or to be seen as “ethically significant beings.” Within the context of enabling person-centered care, it is widely recognized that health care professionals (HCPs) hold a prime position in “permitting” patient involvement in health care (Ward et al. 2012).

Patient Safety

That patients have a key role to play in improving safety is now well accepted internationally (Ward et al. 2012). Our recent work exploring how best to support this patient role has led to the development of an approach that includes a responsibility for HCPs to actively foster engagement and enquiring behaviors in patients. This offers a means to redress the power imbalance that is inherently prevalent within health care systems, in order to facilitate a dynamic, collaborative, patient–HCP approach to reducing risk of harm. This resonates well with a capabilities approach, in that it addresses a significant barrier to achieving a valued functionality—the prevention of harm. As well as identifying patient (and family) support needs, our findings further showed that HCPs also need support in adapting to the culture and practice changes that this new “activated” patient style demands. These findings demonstrate how capabilities (of both patients and HCPs) are dynamically shaped by interactions between individuals and their environments.

It is perhaps therefore surprising that, while arguing for “equality–mutuality” within person-centered care, Entwistle and Watt fundamentally emphasize the role of the HCP. An active role for the patient is not readily apparent, at least not one that isn’t substantially orchestrated by the HCP. This demand on HCPs is a very tall order that not only risks marginalizing the patient role but also assumes that the HCP can deliver on this (which itself requires the HCP to have important *inter-personal* as well as reflective capabilities). Becoming a doctor or nurse is no more an abandon-

ment of being a person than becoming a patient. Thus, both professionals and patients have a need for personal capabilities to realize patient-centered care. In the context of patient safety (and in other areas, such as self-management of chronic illness) patients often possess expertise about their condition and its management that surpasses that of their HCPs. Hence, the patient is, arguably, in a position to both recognize and cultivate HCPs’ capabilities. Person-centered care is therefore perhaps better reframed as “*inter-person-centered care*.” This then takes us into a consideration of *inter-personal* capabilities, as well as further exploring the respective roles of the patient and professional in promoting and inhibiting the development or expression of mutual capabilities.

Decision Making

Entwistle and Watt say much less about the capabilities required by patients to engage in decision making: important given that expression of capabilities is framed within a relational context. While much has been done to support patients to better engage in consultations—for example, question prompts—bringing out what is important to patients is both interactional and emergent. Thus, in the context of shared decision making (SDM), patients often understand what is important to them in selecting the right treatment option only after they have explored and understood the risks, benefits, and consequences of the alternative options.¹ Partly this comes from the need for relevant knowledge, but also from the interactional nature of the consultation and the relational nature of decision making that often goes beyond the consultation (linking to Entwistle’s concept of relational autonomy [Entwistle et al. 2010] and Rapley’s concept of distributed decision making [Rapley 2008]). In the face of an often new diagnosis, and facing treatment options that are completely new to them, patients are initially ill prepared. Hence, they often only get to surface and test their preferences to support informed choice, helped by their clinicians, through emerging knowledge and understanding of the implications of the different options. Thus both patients and clinicians need *inter-personal* capabilities for the delivery of truly person-centered care in the setting of SDM.

Another problem with placing primary responsibility on the HCP is that of promoting a new form of paternalism. As part of this, we need to explore a new conceptualization of a patient’s best interest, which is already too often used as a smokescreen for denying engagement in decision making, by helping the patient to avoid making the “wrong decision,” as perceived by the clinician, drawing upon the clinician’s own values rather than those of the patient. We need to recognize that it is in the patients’ best interest to support them in active engagement, focused upon what is important to them. This also includes the recognition that SDM is not about delegating unsupported decision making to ill-informed and ill-prepared patients.

1. We agree with the authors that patient preferences are not equivalent to wants/likes, but need framing in the context of appropriate understanding of the implications of their decisions.

STANDARDIZATION

The second issue relates to standardization: The authors suggest that checklist approaches or standardized ways of working with patients are limiting to the context-sensitive application of person-centered care. However, drawing upon our experience of SDM and patient safety, we argue that standardization should not be too readily dismissed.

Supporting Behavior Change

Recent work on risk communication in acute stroke treatment reveals a tension between standardization and clinical adaptability to circumstances (Murtagh et al. 2012). On the one hand, standardization was valued in the sense that it allows consistent information to be conveyed to patients by members of the clinical team, and ready access to reliable, evidence-based information at the right time; on the other, concerns were expressed that this would detract from higher level communication/consultation skills that cannot be readily codified.

Guidelines and structured approaches are valued differently dependent upon levels of expertise, for example, as clinicians move from unconscious incompetence (novice) to unconscious competence (expert). Arguably, there are few clinicians who are currently expert in SDM (and fewer still, in the wider skills demanded by Entwistle and Watt). This implies that some form of standardization has a role, at least at the stage of embedding new ways of working for some (if not many) clinicians, but also for patients.

Let us draw upon three examples. As part of the MAGIC SDM implementation program, we developed brief in-consultation decision aids (brief decision aids and option grids; Brief Decision Aids 2013; Elwyn et al. 2013). They differ from traditional more extensive patient decision aids (PtDAs), which can only be effectively used outside the consultation. Brief tools have several benefits, including standardization of risk/benefit information, accessibility at the time it is required, and their capacity to impact upon the dynamics of the consultation—bringing the patient and clinician together over a shared artifact and task. In our experience these are most valued by nonexpert, generalist clinicians (e.g., general practitioners) and junior doctors (novices), and least valued by specialists (experts).

Another example comes from advanced SDM skills training, which we have based on a conceptual model (Figure 1) (Elwyn et al. 2012)—by definition, a simplification of a complex process. The linear model represents a much more fluid reality. Nonetheless, this standardization helps clinicians understand the component parts of an SDM consultation and supports them in applying a new approach in practice. A key element of the training is a checklist of phrases for the choice, option, and decision talk elements of the model, which works not as a recipe to be slavishly followed, but as a set of ingredients that can be used as appropriate to the individual consultation. These are elements of standardization that have a positive role—nuanced by an important understanding of their limitations as well as

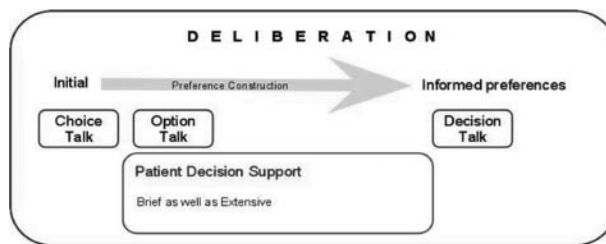


Figure 1. Shared decision making: a model for clinical practice.

their strengths. Dependence on such tools will decrease as clinicians become more skilled in SDM.

Furthermore, in the aforementioned work on patient safety, patients and families identified checklists and question prompts as tools that they would find helpful in supporting them to take an active role in improving their safety and, ultimately, a new way of interacting with HCPs and the “routinization” of involvement and information sharing.

CONCLUSIONS

Entwistle and Watt’s excellent article is an important contribution to unpacking the complexities of patient-centered care, and furthermore basing this in the context of capabilities thinking. The patient as person helps expand an important but challenging concept. The importance of words in shaping thinking is greater than we sometimes acknowledge, such that using the term “person” in the context of understanding patients is potentially very powerful, and may even help with the rather frustrating debates around terms such as patient, client, or customer. Perhaps we should also find a better term than “consultation”?

As the authors indicate, this article aims to stimulate debate. We propose that key elements for refining and furthering this approach include a greater recognition (in the spirit of equality–mutuality) of the role of the patient in the human interactions that constitute the core of health care—hence the need to consider the concept of *inter*-personal capabilities, alongside understanding the importance of developing capabilities in both patients and clinicians.

Furthermore, given the recognized burden that this will place upon clinicians, we have argued that there is a current need for elements of standardization, albeit nuanced, in order to support novice behaviors and interpersonal skills in both clinicians and patients.

Undoubtedly, this important article merits wide dissemination and debate, and in time could well be seen as a paradigm shift in our thinking about patient-centered care. ■

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