The American Journal of Bioethics

Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/ujbj20

Person-Centered Care, Autonomy, and the Definition of Health

Lily Frank

City University of New York

Published online: 17 Jul 2013.

To cite this article: Lily Frank (2013) Person-Centered Care, Autonomy, and the Definition of Health, The American Journal of Bioethics, 13:8, 59-61, DOI: 10.1080/15265161.2013.802068

To link to this article: http://dx.doi.org/10.1080/15265161.2013.802068

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the “Content”) contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at http://www.tandfonline.com/page/terms-and-conditions
HEALTH AS A CAPABILITY

Despite my skepticism about the improvements that the capabilities approach to PCC offers over autonomy-focused definitions of PCC, especially in solving practical problems, there is an important theoretical role for the capabilities approach in understanding the nature of health itself. As the authors acknowledge, early attempts have been made to redefine health in terms of human capabilities (Law and Widdows 2008; Venkatapuram 2012). This definition makes health the “meta-capability ... to achieve a cluster of basic capabilities and functionings” that are essential for human beings to be free and to achieve well-being (Venkatapuram 2012, 6; also see Law and Widdows 2008). Nussbaum’s capabilities theory specifies a list of core capabilities necessary for human freedom, including, for example, the ability to live a normal life span, to use one’s senses and imagination, to enjoy recreation, and so on (Nussbaum 2001, 78–80).

The capabilities definition of health can avoid criticisms that other prominent definitions of health, for example, the bio-statistical model or well-being account of health (Law and Widdows 2008, 311) cannot. The biostatistical definition of health faces criticism from normativists and constructivists who claim that it falsely assumes that a definition of health can be free of normative elements (Law and Widdows 2008). The broader well-being definition, used by the World Health Organization, escapes that problem. But it has been widely criticized as being too vague to measure public health outcomes (Jadad and O’Grady 2008) and conflating the distinct concepts of health and happiness (Callahan 1973).

One of the virtues of the capabilities approach definition of health is that it incorporates personal and social factors into the measure of a person’s level of health (Law and Widdows 2008). For example, in an environment in which public accommodations are available for the disabled, the disabled will be able to exercise more capabilities and functionings and thus enjoy greater health than in an environment where they are not accommodated (Law and Widdows 2008, 313). Defining health in this way is consistent with the authors’ overall project because it implies that when physicians aim at promoting health they inherently aim at the promotion of essential human capabilities and functions needed for human flourishing.

PERSON-AL CAPABILITIES

The authors do not use the capabilities approach to redefine health. Instead, they suggest that the capabilities approach, specifically “person-al capabilities,” provides a basis for understanding the meaning and application of PCC. In their view, PCC is a kind of care that promotes patients’ personal capabilities, which are “a subset of human capabilities ... those associated with the concepts of persons and being treated as persons” (34). In contrast, autonomy-focused PCC poses several ethically significant problems in clinical practice that person-al capabilities PCC can uniquely solve.

Imagine physicians treating an elderly patient who cannot decide about whether or not to have a lifesaving, non-urgent procedure with complex risks. Physicians taking themselves to be acting based on autonomy-focused PCC would simply give the patient the necessary information about risks and benefits and insist the patient make her or his own decision. They may make little effort to establish a relationship with the patient. Instead, they would keep their distance so that the patient can make an independent decision. Furthermore, if the patient cannot communicate a choice, they may decide that the patient is not autonomous...
(lacks capacity) and manage the patient’s care according to their priorities. This would open up the possibility of objectifying the patient and ultimately denying the patient the respect owed to persons. In contrast, the person-al capabilities approach stresses strengthening physician–patient relationships and enabling the patient’s autonomy capabilities.

RESPECT FOR AUTONOMY

Physicians may routinely fail to treat patients respectfully, but the authors do not convincingly make the case that this is traceable to autonomy-focused PCC. It seems that what the authors call positively “enabling the development of person-al capabilities” (34) and connect uniquely to their person-al capabilities approach is exactly what many accounts of the principle of respect for autonomy mandate for ethical care. In the following, I explain how the principle of respect for autonomy can already accommodate the problems the authors list.

The claim that autonomy-focused PCC involves merely providing patients with information and insistence that they independently choose their treatment, even when unwilling to, misses its mark. Respect for autonomy, properly understood, dictates that part of respecting a patient with decisional capacity involves allowing them to choose to make or not to make their own decisions, to relegate their medical decisions to a surrogate, or to simply follow their physician’s recommendations. Patients also have the right not to know varying degrees of information about their diagnosis, prognosis, or treatment options (Beauchamp and Childress 2001, 63).

The authors contend that when put into practice, autonomy-focused PCC leads physicians to prioritize task-oriented communication and information provision over supportive physician–patient relationships. But respect for autonomy casts informed consent, for example, as a process, not an event, that should involve careful listening and a dialogue that takes patients’ concerns seriously (Brody 1989). This entails using effective evidence-based communication techniques and tailoring them to the needs of individual patients or populations. Although it takes more than effective communication to build a supportive physician–patient relationship, this is foundational.

The authors observe that autonomy-focused PCC does not consider the support patients may need in realizing their autonomy capability and neglects the fact that patients’ “preferences” may not be “well informed, stable, strong, or good” (31). They claim their view requires investigating whether confidence in a “patient’s autonomy capability” is warranted. Respect for patient autonomy overcomes these obstacles in several ways. What the authors neglect is that decisional capacity is decision specific. Physicians are obligated out of respect for autonomy to assess patients’ decisional capacity, maximize it if it exists, and try to restore it when it does not. Part of respecting autonomy involves the recognition that just because a patient lacks the capacity to make one decision does not mean that the patient lacks the capacity to make others.

In addition to more widely discussed barriers to decisional capacity, such as delirium or brain injury, there is a growing body of empirical literature on barriers due to cognitive distortions, framing effects, and affective forecasting (Schwab 2006). Respect for autonomy requires that clinicians be aware of these barriers and strive to overcome them when possible, enhancing patients’ decisional capacity. Understood this way, respect for autonomy is almost identical to the authors’ emphasis on the “development of person-al capabilities” (34).

Finally, the authors claim autonomy-focused PCC leads physicians to unethical attitudes toward those who have “limited competence,” by either assuming that their autonomy capability cannot be enhanced or by failing to acknowledge them as persons worthy of respect. Importantly, valuing or prioritizing respect for autonomy does not mean that autonomy is the only ethically relevant feature of persons.

The authors discuss real and troubling gaps in the provision of ethical care, but the root of these gaps is not autonomy-focused PCC. A myriad of other plausible (and indeed likely) explanations for these gaps should be considered. Suggestions include inadequate training in medical ethics and communication skills during undergraduate medical education or residency, the influence of the hidden curriculum (Hafferty and Franks 1994), time constraints and high patient load, compassion fatigue (Bellini and Shea 2005), and burnout. While the authors do not make the case that autonomy-focused PCC is the source of these ethical deficiencies, the capabilities approach offers a new and fruitful rethinking of the nature of health and the goals of health care.

REFERENCES


Entwistle and Watt (2013) make an important contribution to the person-centered view of health care by reframing past thinking on the subject in terms of the capability approach. Past thinking about person-centered care, often rather characterized as patient-centered care (see their Table 1), employs a range of normative values that are arguably supportive of the concept of a person. But ironically these values are not clearly grounded in any account of what the person is. Thus, it is not clear what anchors these values and how they are to be interpreted in concrete care settings. Suppose clinicians believe they respect the dignity of their patients. What should they look for to determine whether the way they deliver care actually does treat their patients as persons?

The capability approach employs a fairly specific conception of what persons are, namely, that they are agents of their own capability development (where capabilities are their opportunities to achieve different functionings to do and be what they value). This view of the person as an active being contrasts with the emphasis in many person-centered conceptions of care framed as patient-centered care. As the word itself indicates (derived from to wait, bear, or suffer), “patients” are recipients of care, therefore passively involved in their care, albeit seen in patient-centered accounts of care as deserving of respect and invested with dignity in that capacity. It is true that person-centered conceptions of care formulated as patient-centered often invoke personal responsibility and self-determination. But absent a way of seeing people as agents who are actively involved in their own care, they often employ a narrow understanding of autonomy as noninterference. As Entwistle and Watt note, this can generate paradoxical views of clinician practice where those with expert knowledge are expected to defer care decisions to their patients in preference-sensitive circumstances to allow them to maintain their “independence.” Patient personal responsibility and self-determination have little meaning in this framework.

THE PERSON AND “PERSON-AL” CAPABILITIES
What Entwistle and Watt then offer is a way of understanding how people actively determine their health and care preferences in interaction with clinicians in terms of the idea of people developing their “person-al” capabilities. This gives one key part of how they ground the idea of a person as an agent, namely, their relational autonomy view of personal identity. In contrast to the noninterference view of autonomy, when people’s identities are relational and derive from their interaction with others, that active interaction requires that others recognize them as agents. The person-centered value of respect that clinicians pursue is then tied to recognition of their patients as agents. Adam Smith (1790 [1976]) long ago explained recognition using the impartial spectator idea, or here the idea that clinicians understand the point of view of their patients as their patients understand it. How they would actually do this goes to the second key part of how Entwistle and Watt explain “person-al” capabilities.

Consider what one might find when imagining oneself in someone else’s place. As Entwistle and Watt explain, it is essentially the narratives people keep about themselves regarding why they are doing what they are doing, what their goals are, and what their views of their past are—all components of ongoing stories people maintain about how they see themselves as distinct persons, whether rightly or wrongly. Thus, when we respect people as relatively autonomous, their “person-al” capabilities are what might be called their personal identity capabilities (Davis 2011), ones that they actively pursue to achieve who they each think they individually are, and around which they organize their broader capability development in terms of all the particular opportunities they pursue in life.

QALYS?
Many person-centered, or patient-centered, care accounts emphasize the need to respect patients’ preferences, and...