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SCIENTIFIC CONTRIBUTION

Towards self-determination in quality of life research: a dialogic approach

Leah McClimans

Abstract Health-related quality of life measures aim to assess patients' subjective experience in order to gauge an increasingly wide variety of health care issues such as patient needs; satisfaction; side effects; quality of care; disease progression and cost effectiveness. Their popularity is undoubtedly due to a larger initiative to provide patient-centered care. The use of patient perspectives to guide health care improvements and spending is rooted in the idea that we must respect patients as self-determining agents. In this paper I look at the two main orientations to quality of life measurement: standardized and individualized measures. I argue that while these measures are attempts to provide for patient self-determination, they both fail to do so. In their place I suggest a new approach which overcomes their respective difficulties: a dialogic approach.

Keywords Quality of life · Self-determination · Health · Health care · Measurement

The purpose of health-related quality of life[1] measurement is to assess the subjective experience of patients' health and well being (Schwartz and Rapkin 2004). Indeed, one of the motivations behind collecting information on patient-reported outcomes, such as quality of life, is to provide a venue for patients' different experiences and perspectives to impact healthcare provision.[2] The increasing popularity of quality of life measures is no doubt part of a larger initiative to provide patient-centered health care. But if they are to do this job, then these measures must faithfully provide patients with a voice. Thus it is important that they treat patients as individuals who create and follow different life plans; it is important that these measures treat patients as self-determining agents.

In this paper, I look at the two main orientations to quality of life research: standardized and individualized measures (Browne et al. 1997). Although I show that both types of measures are attempts to provide for patient self-determination, I argue that they both fail to do so. In their place I begin to introduce a new approach to quality of life research, one that avoids their respective difficulties.

I

In 'Quality of Life Measures in Health Care and Medical Ethics' Dan Brock examines two aspects of clinical ethics: informed consent and standardized health-related quality of life measures. His aim is to draw from these concrete practices an account of quality of life that might motivate them. This task is important since the standardized approach does not itself provide us with an explicit theory

L. McClimans (✉)
Department of Philosophy, University of South Carolina,
Columbia, SC 29208, USA
e-mail: mccliman@mailbox.sc.edu

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[1] For characterizations of the notion of quality of life and welfare see Griffin (1986), Sen (1993), Nordenfelt (1993) and Sumner (1996). The concern of these authors is whether quality of life or welfare is 'subjective' or 'objective'; related to happiness or capabilities or preferences. In this paper I am less interested in how we should define quality of life and welfare than whether the quality of life measures that clinicians already use promote self-determination. Indeed, as I argue in other work, I think the meaning of quality of life can only be determined dialogically and in an open-ended, developmental way.

[2] The most recent aspect of healthcare to be affected by patient-reported outcomes is hospital compensation. See NHS (2008, pp. 41–42).

to explain the logic of the measures it uses (Cummins 2005). Moreover, unlike some recent efforts to introduce new quality of life measures based on different theoretical approaches (Bramston et al. 2005; Cummins 2005; Ferrans et al. 2005; Hajiran 2006), Brock's project is helpful in providing an evaluative framework for measures that are currently in use.

Although I am most interested in Brock's analysis of standardized quality of life measures, in order to appreciate fully the picture of quality of life that he takes to motivate them, it is important to attend briefly to some of his comments on ethical frameworks for medical decision-making. Brock takes the dominant mode of medical decision-making to be one in which the patient and the physician share decision-making, but in which the patient is ultimately responsible for the decision to accept or reject treatment (Brock 1993). This method of decision-making is usually referred to as the doctrine of informed consent. Informed consent reflects a relatively recent change in health care, one that Brock takes to be motivated by new developments in technology which provide for the possibility of extending lives indefinitely, but with uncertain benefit (Brock 1993). Informed consent reflects the view that what counts as "health' is no longer merely the purview of physicians—it is no longer simply a biological fact. New technologies that blur the line between health and mere existence mean that patients have a right to shape their treatment in line with particular goals, values and life plans.

But what grounds the right to informed consent? Even if health is no longer understood as simply a biological fact we still might see clinicians as our best guide to therapeutic practice. Why must we involve individuals and their broad concerns to bear on what are still essentially medical decisions? If we turn to the literature in bioethics informed consent is typically justified on the basis of two values: the protection from harm and the protection of individual autonomy (Beauchamp and Childress 1983).

Historically, informed consent became essential to medical practice following public outrage over cases of patient exploitation for the purposes of medical experimentation. For instance, the Nuremberg Code laid out guidelines for informed consent after the experimentation on non-consenting individuals in concentration camps during World War II (Beauchamp and Childress 1983). In this context voluntary informed consent was understood as indispensable to the protection of individual safety and well being for it was thought unlikely that individuals would consent to procedures violating their own self-interest. For those who understand protection from harm as the primary justification of informed consent an individual's informed and uncoerced decision ought to promote well being.

But it is sometimes the case—especially as technology increases our ability to prolong life—that one's informed decision is contrary to one's well being. We might think of cases in which a patient refuses treatment for a potentially curable illness. Discrepancies of this kind have led to legal questions regarding the scope of an individual's decision-making power and to justifications of informed consent on the basis of individual autonomy. Take for instance the landmark 1960 case of *Natanson* v. *Kline* where the judge found that,

> Anglo-American law starts with the premise of thoroughgoing self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of lifesaving surgery, or other medical treatment. (Beauchamp and Childress 1983)

Following some interpretations of Kant, supporters of this justification understand respect for persons to be the same as a respect for their choices and different life plans: to be a person is to develop a plan and choose a course of action; it is to be self-determining (Beauchamp and Childress 1983).[3] On this view informed consent is usually understood as a necessary condition for respecting patients as persons. To withhold information from a patient or to make decisions in a patient's best interest is to treat them with something less than the respect owed to equals; it is to treat them paternalistically. Brock echoes this view when he writes that self-determination is what is required in order to recognize an individual as a person (Brock 1993). Moreover, he writes that self-determination is 'a central source of human dignity' (Brock 2005). Brock goes on to suggest that if self-determination is central to personhood and human dignity, then a life of choice is *part* of a good quality life (Brock 1993). In turning from informed consent to standardized measures of health-related quality of life Brock further develops his position that a good quality of life involves self-determination.

He begins by directing our attention to the way standardized measures typically assess quality of life, namely with respect to what he calls primary functions (Brock 1993). Primary functions refer to centrally important activities which, when missing from one's life, significantly *limit* one's choices or opportunities in creating and pursuing different life plans (Brock 1993). As we will see, limitations on opportunities are taken to adversely affect patients' quality of life. This framework for interpreting health-related quality of life measures closely resembles Amartya Sen and Martha Nussbaum's capabilities approach to quality of life, which was originally applied to

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[3] For a different interpretation of Kant and the importance of choice see, O'Neill (2002).

welfare economics (Sen 1993, 2001; Nussbaum 1999). To be sure, there are some differences between them, for instance, Brock sometimes uses different terminology than Sen or Nussbaum and the list of primary functions that Brock identifies as central to health-related quality of life are different from the capabilities that Nussbaum recognizes for quality of life more generally and they seem to be more narrow in scope than the achievement of ‘doings’ and ‘beings’ that Sen seems to imagine (Sen 1993). Nonetheless, I take Brock’s analysis as an attempt to translate Sen and Nussbaum’s work in development into the area of health care.

According to Brock, primary functions are represented by the different dimensions in a measure; the questions within the dimensions then assess the impact of disease or illness on an individual’s subjective experience by gathering information about how well an individual feels he or she is able to perform the requisite function (Brock 1993). To illustrate, the Sickness Impact Profile (SIP) asks respondents questions such as, ‘I am going out for entertainment less’; ‘I laugh or cry suddenly’; ‘I do not bathe myself at all, but am bathed by someone else’ (Brock 1993). These questions relate to the dimensions or primary functions of ‘Recreation and Pastimes’, ‘Emotional Behavior’ and ‘Body Care and Movement’ respectively. Respondents are given dimension specific scores based on their answers. These scores are meant to tell researchers about the respondents’ subjective functioning level within each dimension. The logic of these measures suggests that as one’s functioning decreases so does one’s quality of life.[4]

Recall from the discussion on informed consent that the value of self-determination is grounded in an account of persons whereby respect for persons is procured when we respect their decisions in accord with a self-chosen life plan. The value of self-determination highlights the value of personal choice. Nevertheless, for Brock the integrity of this value requires that individuals have a certain minimal array of valuable choices or opportunities from which to choose, for without such an array, self-determination is at best an empty promise.[5] For Brock the dimensions represented in standardized measures like the SIP capture the functionings that represent the minimal array of options one must have in order for self-determination to fulfill its promise of treating patients as persons. Thus quality of life measures do not evaluate the particular life plans that patients have chosen to follow, rather they assess whether or not a cohort of patients are adequately equipped to chose such a plan; whether their options are sufficiently pluralistic.

Following the methodology of standardized measures Brock takes these primary functions to be objective—individuals with a loss of primary functioning have a lower quality of life even in light of individual accounts of satisfaction and happiness. For Brock the objectivity of these judgments correctly redresses the danger of adaptive preferences. As he puts it, “To be satisfied or happy with getting much less from life, because one has come to expect much less, is still to get *less* from life or to have a less good life” (Brock 1993). He formally justifies this position with reference to Norman Daniels’ notion of a “normal opportunity range” (Brock 1993). Echoing the idea that self-determination requires a certain array of valuable choices Brock uses Daniels to argue that individuals whose disability or illness restricts the activities that they would otherwise be able to perform have a lower quality of life than individuals without such restrictions, because certain basic choices or normal opportunities are curtailed.

In Brock’s analysis of standardized quality of life measures, he emphasizes their focus on a person’s functionings as opposed to, what he calls, a person’s disability or illness. This distinction is based on the difference between a physical or mental impairment—a ‘disability’—as opposed to the things that an individual can choose to do—their functionings. Quality of life measures do not ask respondents to disclose their physical or mental circumstances—what we might think of as their biological condition. Instead they ask respondents about what they feel they can and cannot do. It is the *loss* of these functions that is taken to reduce opportunity range and hence quality of life, not the *presence* of disability.

This emphasis on functions makes sense since not all disabilities affect functioning levels. Brock’s example is a *60 Minutes* program from 1988 that interviewed individuals whose mothers had taken Thalidomide during their pregnancy. These individuals were born with a variety of physical deformities, but they had so completely adjusted to their condition that they were able to perform all the normal primary functions, albeit in unique and creative ways. According to Brock, in these cases quality of life may not be diminished (Brock 1993).

In a more recent paper Brock clarifies his position on this point: for a physical deformity or illness to have little or no impact on quality of life individuals must be able to perform the *same* primary functions as those without such problems. He gives the counterexample of deafness where

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[4] To be sure, some standardized measures of health-related quality of life combine functional assessments with questions regarding personal satisfaction and health perception. But in standardized measures answers to the latter kinds of questions cannot wholly override the results of the former although they are often taken into account. The Short Form-36 (SF-36), for instance, gives questions regarding satisfaction and health perception the same priority as functional ones.

[5] For instance, giving people the right to vote, but only placing one person or party on the ballot; giving women the right to make choices concerning their lives, but making it materially difficult for them to work outside the home.

in spite of claims that sign language and deaf culture allow individuals a rich and functional life he argues that there are valuable human activities such as listening to music, which they cannot choose to do. As a result their quality of life is objectively less than those who can hear (Brock 2005). Nonetheless, notice that according to Brock's analysis of standardized measures it is not the physical impairment associated with being deaf—it is not their inability to hear—that is supposed to make their quality of life worse, rather it is their inability to choose to participate in certain valuable functions.

If, as Brock suggests at the end of his discussion on informed consent, self-determined choice is a part of the good life, then significant limitations on an individual's ability to choose how they will live or limitations on the opportunities they have will make for a worse life. The objectivity embodied by standardized health-related quality of life measures appears to operationalize this point and thus meshes with Brock's suggestion. On this account standardized measures aim to promote substantive choices and thus self-determination; they reflect negatively on any disease or illness that limits these choices.

From his discussion of informed consent and standardized measures Dan Brock draws support for three conclusions about a good quality of life. First, self-determination is central to quality of life; second, we need a sufficient number of valuable choices if we are to fulfill the goal of self-determination and third, an individual's primary functions can give us information about their quality of life. In the next section I turn to examine the kind of primary functions that are employed by these measures and query Brock's second and third conclusion.

II

As we have seen on Dan Brock's account of standardized measures disabled or ill individuals have an objectively lower quality of life if their disability or illness reduces their opportunity to choose to partake in major life activities. Brock uses the American Disabilities Act (ADA) to support this claim, citing its definition of a disability as a physical or mental impairment that substantially limits at least one major activity (Brock 2005). Brock thinks that if one has a limitation in a major activity, then one necessarily has a lower quality of life. But why?

The link between unlimited major life activities and a good quality of life is due, at least in part, to the commitment to self-determination and the scope of valuable choices necessary to meet this goal. Nonetheless, we can still challenge the notion that maximizing a set of valuable choices necessarily increases the scope for self-determination and thus quality of life. Rather, in some cases restrictions on valuable opportunities enable certain kinds of life plans and identities which are otherwise unavailable and which also enhance quality of life. For instance, we may take oral communication to be a valuable functioning. Nevertheless, it is only in virtue of the *inability* to communicate orally that the deaf community and the notion of a deaf identity exist. Moreover, according to many deaf advocates living a life as a member of the deaf community can be a valuable life plan and it is so in virtue of the valuable opportunities open only to those who are deaf. For instance, deaf individuals have the opportunity to experience the world in a predominately visual and spatial framework; they have the opportunity to attend deaf schools and form friendships with other deaf individuals and be part of a community with a specific culture, history and political agenda.

Thus, we might say that the ability to communicate orally, to listen to music and so on—the ability to participate in certain valuable functionings—militate against a life lived as a member of the deaf community, a life which represents a different set of valuable functions. To be sure, it is often the case that having choices is important to self-determination and thus a good quality of life, but in arguing for the value of certain limitations in primary functions proponents of deaf culture need not take themselves to be limiting their opportunities, but rather protecting the opportunities that only some of us have.

According to Brock, one of the assumptions built into standardized measures is that one's quality of life is better if one has more valuable options from which to choose. But if there are genuine incompatibilities among some of our valuable choices, then we might think that the very idea of maximizing our valuable options is misguided. On this view quality of life is not simply a matter of having more valuable options from which to choose, but first requires that we make substantive decisions regarding what options are most valuable to us.[6] These decisions, however, will depend on a vision of the good in which an option or set of options is deemed valuable. For instance, oral communication may not be taken as particularly valuable given certain understandings of community, friendship, culture and bodily integrity. If Brock is right, then standardized measures do not attend to the variable conditions in which different choices are considered valuable, instead they assume that certain primary functionings are equally valuable for everyone; they assume that certain functionings act as a threshold below which quality of life can only be worse.

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[6] Amartya Sen has recognized this point with respect to the capabilities approach to quality of life. For his discussion of the topic see, for instance, Sen (1999).

From the point of view of the deaf community this assumption can have adverse consequences for deaf individuals and may adversely affect how others perceive their quality of life. For example, one of the dimensions or primary functions found in the Sickness Impact Profile (SIP) is ‘Communication’. In this dimension respondents are asked questions regarding trouble writing or typing and whether they speak clearly when under stress. A yes answer to any of these questions is taken to reflect negatively on quality of life since difficulty in writing, typing or speaking is taken to hinder communication and thus the ability to perform a primary function. Although deaf people may not be able to write or speak clearly—especially when stressed—deaf advocates argue that their quality of life can be as good as people who can hear (Lane 1993). Nonetheless the SIP is a generic measure, it is meant to be applicable to a wide range of individuals independent of their specific disability or illness.

If we accept the point made by the deaf community and indeed other disability activists that at least some life plans are valuable in spite of, or even because of restrictions to certain valuable functions, then we can argue that standardized quality of life measures embody an illegitimate bias against certain kinds of valuable lives. Thus these measures are not sufficiently self-determining.

To explore the root of this bias a bit further, consider again the primary function ‘Communication’ from the SIP. ‘Communication’ is taken to be, in part, oral communication, but oral communication almost always presupposes that one can hear. Moreover, recall from the previous section that the SIP also takes ‘Body Care and Movement’ to be a valuable functioning and asks respondents if they can bathe themselves. This question, however, presupposes at least partial use of one’s arms and legs. Although Brock emphasizes the fact that quality of life measures focus on what individuals are able to accomplish and not on their physical or mental impairment, if primary functions require certain biological ‘normalities’, then for practical purposes a good quality of life is only open to certain bodies.[7] Indeed Brock comes close to endorsing this view, at least for some conditions, when he writes that, “…serious disabilities…remain significant disadvantages for common human pursuits even after the goal of achieving reasonable and just social accommodation to disabilities has been reached; they are not “mere” or solely social constructions or socially constructed disadvantages” (Brock 2005).

In this passage Brock’s use of the term “serious disabilities” refers to physical or mental impairments which limit a major life activity, no matter what kind of social adjustments are made. For Brock some disabilities remain disabilities and no amount of social resources can change the fact that some individuals just cannot participate in all of life’s valuable functionings. Indeed, research suggests that no amount of surgical or technological resources will provide deaf individuals with the level of oral communication which hearing people enjoy (Kaplan et al. 2003). Moreover, it is because deaf people cannot hear and blind people cannot see that they are unable to listen to music or watch the sun set.

Nonetheless, we might argue that these “disabilities” *are* “socially constructed” for limitations only count as disadvantages given a certain view of a good life and with that, a view about what options are most valuable to us. We need not accept that a good quality of life requires options such as the ability to communicate orally or to view scenery. Put differently, we need not accept that a good quality of life always requires certain biological prerequisites. To be sure, it is possible to define opportunity and thus a good quality of life so narrowly that certain inabilities by definition limit our opportunities. But such a move is too restrictive (Amundson 2005): men lack the opportunity to bear children, but this fact is not typically taken to objectively limit *their* quality of life.[8] Instead, we tend to think that men have a different, but nonetheless valuable set of opportunities as opposed to women; these differences need not reduce either gender’s capacity for self-determination or their quality of life. If this is the case with men and women’s different sets of opportunities, then why does the inability to communicate orally objectively decrease quality of life for the deaf?

This question is not merely rhetorical; I suggest that the answer to it is two-fold. The inability to communicate orally theoretically limits quality of life when, for instance, quality of life measures embody a vision of the good life that requires the ability to hear. In this case individuals who cannot speak clearly are understood to have a worse quality of life than those who can. Disability activists sometimes target their arguments at this level of the debate contending that in principle the deaf and disabled *can* live lives of good quality. But practically the inability to communicate orally begins to limit quality of life when social and environmental circumstances are such that the inability to speak clearly limits forms of communication or community. Activists thus argue that while a deaf person’s quality of life may not be good, this assessment has nothing to do with hearing per se. Rather it reflects inequality of opportunity and a biased management of social resources. Disability and deaf activists therefore argue that we ought to recognize that some individuals live different, but

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[7] Ron Amundson makes a similar point in Amundson (2005).

[8] On the contrary, the inability to bear children has historically improved men’s quality of life and we could argue that this too is the result of certain notions of the good that prioritize independence, detachment and individuality.

nonetheless valuable lives and provide resources to help them achieve their vision of the good.

My criticism of Brock's analysis is not meant to imply that all disabilities make for a good quality of life nor that just any vision of the good is legitimate. Rather it is directed at the assumption that the absence of certain valuable opportunities—opportunities which often presuppose biological norms—necessarily reduces quality of life (Amundson 2005). Moreover, if self-determination is *part* of a good quality of life as Brock suggests, then standardized measures do not represent this principle.

III

This criticism of standardized measures is similar to the criticism that some social scientists and philosophers have made of the same measures. They argue that there are at least two problems with standardized measures, both of which unduly influence what can count as a good quality life. First, the dimensions or primary functions into which the quality of life construct is deconstructed are pre-determined on the standardized approach. It is argued that these pre-determined dimensions represent unwarranted assumptions as to the most important determinants of quality of life. These dimensions or primary functions may not represent those areas of an individual's life, which are most important to them or in fact areas that are even applicable to everyone in the cohort (Hickey 1999; Nordenfelt 1993).

Secondly, the scoring techniques of standardized measures are criticized in that the pre-determined weightings are biased (Nordenfelt 1993). For example, measures whose weightings come from averaging the preferences of sample populations ignore the inter-individual variability that exists if individuals are asked to weight these items themselves (Browne et al. 1997). Both of these criticisms suggest that standardized measures limit the extent to which individuals can substantively express what makes for a good quality of life. In making their criticisms social scientists critical of this approach suggest that standardized measures are not genuinely self-determining.

To redress the systematic bias inherent in standardized measures some social scientists have introduced an individualized approach to quality of life. This measure allows respondents to nominate the areas of their life that are most important to good quality and then individually weigh each dimension or primary function according to their own values and vision of the good. This kind of measure eliminates predetermined dimensions and weightings and thus provides respondents with more freedom to determine for themselves what makes for a good quality of life.

Although both standardized and individualized approaches are attempts to provide for patient self-determination, they differ in the model that they take to fulfill this ideal. While proponents of standardized measures take self-determination to be best fulfilled via maintaining certain thresholds, proponents of individualized measures take self-determination to be best fulfilled by opening up the opportunities for idiosyncratic self-expression. Moreover, it is in virtue of this difference that proponents of individualized measures take their approach to avoid the inherent bias of standardized measures. In the words of one proponent of the individualized approach, 'It seems clear that the method [of individualized quality of life] is culture-free'[9] (Hickey 1999). But are individualized measures really 'culture-free'?

To answer this question I turn to the practice of Female Genital Mutilation (FGM). FGM is the practice of cutting or removing the clitoris and sometimes part of the labia minora. Although condemned by the UN Commission on Human Rights and others it remains a common practice in some parts of the world (Nussbaum 1999). It is performed on young girls usually aged four to seven for reasons of beauty, purity and social continuity. FGM is linked to a variety of medical conditions, some of which include decreased sexual functioning due to pain during intercourse; infertility; and insensitivity (Nussbaum 1999).

Imagine that we interview a genitally mutilated woman to determine her individualized quality of life. Now let us imagine that despite the areas of life she nominates—whether they include sexual functioning or not—her quality of life is quite high. Are we justified in concluding that for this woman, FGM is unproblematic?

The difficulty here is that human beings *can* get used to a huge variety of conditions and learn to live rich and meaningful lives within them. But just because we *can* get used to a lot of things does not mean that we should do so. In fact modern democracies tend to support certain thresholds below which no one should function. This idea is captured in Brock's analysis of standardized measures and it reflects the understanding that to be a self-determining agent certain material conditions must be met. The United Nations' condemnation of FGM suggests that the freedom to fashion a life for oneself presupposes the ability

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[9] Dieter Birnbacher also raises a similar point (Birnbacher 1999). His idea seems to be that by taking an individual's assessment of quality of life at face value we avoid evaluative bias and thus individualized measures are independent of social and cultural ideals. Part of what motivates this point is Birnbacher's conviction that quality of life outcomes ought to be understood descriptively—we ought not attempt to evaluate them. As a result he is not concerned with the social and cultural factors that influence respondents' answers. Because I will argue that evaluating quality of life outcomes is part of what is required to promote self-determination, I am concerned both with evaluative bias and, as I discuss in this section, the social and cultural factors that frame respondent answers.

to participate in certain sexual functionings without undue pain or insensitivity.

To be sure, the support for a ban on FGM does imply that this practice and the social values it expresses are not part of a good quality of life just as the SIP stipulates that a life without oral communication adversely affects quality of life. But while in some circumstances we might find these thresholds paternalistic, is individualism the appropriate response? As Nussbaum (1999) notes in *Sex and Social Justice*, victims of FGM tend to live in communities that promulgate beliefs about female impurity and the second-class status of women; as a result these women often lack education and basic literacy skills. Can conditions such as these lead to self-determined choices about what is and is not a good quality of life? Far from self-determination these situations begin to look manipulative; they look like a systematic bias in favor of internalized gender hierarchies.

The individualized approach is not culture-free. When individuals express their quality of life these expressions are always grounded in cultural norms, norms which we may well wish to challenge. The individualized approach tells us that quality of life is whatever an individual says it is, but we can be wrong in our assessment of our lives. After all, our vision in these matters is always only partial and the orientation of the individualized approach, by insisting that our appraisal is always legitimate, limits our opportunities to expand that vision and create perhaps better lives for ourselves. But as we have also seen, to define the dimensions of quality of life in advance, to predetermine the conditions for the possibility of self-determination with respect to a particular vision of the good also potentially limits our opportunities, because it can blind us to the genuine quality of different lives.

IV

These criticisms of both the standardized and the individualized approach stem from a common problem: in neither case can we adequately challenge the assumptions—the vision of the good—against which quality of life is measured; neither measure uses an adequate model of self-determination to capture both the flexibility and critical reflection necessary to an account of quality of life. Self-determination requires something more than the presumption embodied by standardized measures when we evaluate respondent answers in light of a fixed range of valuable opportunities; it also requires more than the quick acquiescence of individualized measures to different expressions of quality. A new approach to self-determination is needed in quality of life research.

This new approach should be able to acknowledge that different sets of valuable opportunities can sometimes lead to good quality lives, as I suggested was the case with the inability to communicate orally. Moreover, this approach should be able to accommodate new insights into quality of life; we should be able to *learn* about quality of life through patient reports. But at the same time it should not be uncritical; it should not be an "anything goes" approach to quality of life. By reflecting on different sets of functionings this approach should be able to provide good reasons for when they do not embody quality of life. To be sure these reasons are subject to revision, nonetheless this approach should be able to provide them. With the aim of achieving these ends I suggest that this new approach ought to be a dialogic one.

A dialogic approach: learning from quality of life measures

A dialogic approach conceptualizes quality of life measures as a kind of text. Moreover, it suggests that when researchers analyze quality of life data, they are 'reading' these measures to understand better the quality of life of a particular cohort of respondents. The idea here is that we should read measures to understand quality of life similarly to the way we read books to understand their subject matter. The approach is dialogic, in part, because when we come to a text we come to it with questions, whether well-articulated or not that we think or hope the book will be able to answer. In looking for our answers the text may raise further questions thus creating an on-going conversation with the text. This dialogue is already analogous to how quality of life researchers relate to their measures: they come to them with questions concerning the quality of life of a certain cohort—sometimes well-articulated, sometimes not—and hope that respondent responses will provide them with answers.

Because we come to a book with questions we are already oriented to it in certain ways; we have certain assumptions and expectations about what it is about, we look for certain themes and so on. In the same way, researchers come to quality of life measures with assumptions about what a good quality of life comprises, expectations about how respondents will answer, what their answers mean and so on. The problem with standardized measures, however, is that these assumptions that orient researchers to the measures over-determine the content of respondent answers. We saw this possible over-determination in Section II with regard to the quality of life of deaf people. The assumption that quality of life requires opportunities for oral communication or even listening to music may adversely affect not only how *we* understand the quality of life of those without these opportunities, but may also affect the quality of life they have open to them.

In textual analysis, however, we do not allow our assumptions about a text's subject matter to blind us to the content or orientation of the book; instead, we treat the text as something from which we might learn, that is we consider how it might teach us something new. By treating the text in this way we allow it to question our assumptions and expectations and in doing so we create a dialogue between our previous orientations and the text. For instance, we might begin reading a text with the expectation that the plot will follow the pattern of exposition, climax and denouement. But as we read on we may fail to recognize a climax and begin to wonder if the text has a plot. Thus we might begin with the question: 'Does this book have a plot?' But in opening ourselves up to what the book may teach us our question becomes: 'Does this scene count as a climax?' or 'Can a plot lack a climax?' As this kind of dialogue goes on we become better educated, either because we come to understand the text's subject matter differently or because, while we maintain our previous assumptions, they are now more transparent and less reliant on unexamined interests. For instance, we may come to understand that a climax can include a wider variety of events than we previously recognized; or we may conclude that the book did not have a climax, but now we are more aware of what we are looking for when we read a story.

If in textual analysis we can allow a text to challenge our assumptions, might we not find ways to let respondent answers do the same? Consider two studies assessing the impact of cochlear implantation on quality of life in prelingually deafened adults. One study found that prelingually deafened adults, contrary to expectations, are not only seeking implantation, but also receiving some measure of benefit. Researchers at the University of Toronto found that independent of variable audiologic outcomes—the actual benefit to hearing in terms of speech perception—the quality of life data from 44 prelingually deafened cochlear implant recipients approached that of the quality of life data from postlingually deafened implant recipients from the same program (Kaplan et al. 2003). This result was surprising because while the postlingually deafened recipients could recognize speech after their implantation, the prelingually deafened recipients could not.

In another study it was found that this improvement in quality of life is mainly due to more confidence in communication via lip reading ability, better environmental awareness and greater independence (Chee 2004). Moreover, when the prelingually deafened participants were asked about their personal satisfaction with the implant 66.7% were 'very satisfied' and when asked if they would go through the same process again 93.3% said they would (Chee 2004).

Before this study it was generally thought that cochlear implants had little to offer prelingually deafened adults since the ability to understand speech was supposed to be their main benefit (Kaplan et al. 2003). But in this study hearing improves quality of life in lieu of speech perception and sentence recognition. Thus researchers took from these studies a new appreciation for what cochlear implants can offer as well as a new appreciation of the importance of hearing to quality of life. Hearing, this evidence seems to suggest, is important to quality of life not only because it allows for word discrimination and sentence recognition, but also when it simply enables one to hear indiscriminate sounds.

But what happens if we treat the measures in this study as a text and allow the responses from these prelingually deafened adults to challenge our assumptions? Instead of reading into their responses the importance of hearing to quality of life, we might ask how the ability to hear indiscriminate sound is linked to independence or confidence? Is hearing sound *essentially* tied to these characteristics? Or as Lane (1993) points out: do mainstreamed deaf schoolchildren who lack a deaf community and deaf role models and who are taught oral skills that they only poorly acquire become adults who *are* isolated, *are* unconfident, and *are* insecure? If the latter, then findings from the Toronto study may not represent an endorsement of cochlear implants so much as they do a social critique: even given a relatively insignificant ability to hear prelingually deafened adults find that life gets much better.

Whether or not hearing is essentially tied to independence and confidence when we enter into a dialogue with our measure we come to understand the quality of life of deaf people better. For one thing our assumptions about the connection between hearing and independence and confidence become more explicit. From this fact we may come to see that this connection is not straightforward—current social and education circumstances work to maintain it; or we may acknowledge deaf activists' concerns in this regard, but decide that in the context of our study hearing and confidence are synonymous. But even if we take these studies to promote cochlear implants, such a dialogue with the measure helps us to better understand quality of life: now we understand how and in what way hearing and independence or confidence are tied together.

The dialogic approach provides the tools with which we might learn from patient responses; that we might not simply read into their responses that for which we are ready to hear. In doing so this approach promotes patient self-determination. By taking patient responses seriously, the dialogic approach treats patients as equals in a mutual inquiry into the multiple meanings of the construct 'quality of life'. Unlike standardized measures, this approach does not set pre-determined thresholds below which one has a worse life. Instead the dialogic approach recognizes that quality of life is a contingent concept, one whose content may change in different concrete circumstances.

A dialogic approach: taking a critical stance

But what of the acquiesce of individualized measures? How might a dialogic approach maintain a critical stance? Returning to the analogy with textual analysis, not every interpretation of a book is a good one and not every "interpretation" of quality of life measures will be valid. To flesh out the difference between valid and invalid interpretations I turn to part of Gadamer's framework for textual analysis in *Truth and Method*. Here Gadamer introduces two criteria for evaluating texts and text-analogues: interpretations must be coherent and truth-sensitive (Gadamer 2003).

With regard to coherence, valid interpretations must find a way to unify the parts of a text into a coherent whole; they must be successful in seeing the text as a unity of meaning. Conversely invalid interpretations will be unable to make the various parts of the text cohere. For example, in Adichie's (2006) novel *Half of a Yellow Sun* three characters are profiled as they come to terms with the events that led up to and comprised the Nigeria-Biafra war from 1967 to 1970. It is a complex novel with many themes and thus although it is about the tragedy and waste of war and the suffering of the Igbo people, such an interpretation falls short of considering the text in the unity of its parts. It is also about the strength and fragility of love; how class shapes individual lives and the long-standing effects of African colonialism. A valid interpretation of this text must account for the way in which these different aspects of the novel cohere and we may criticize interpretations that fail to do so.

Similarly, we may criticize interpretations of quality of life that fail to see it in the unity of *its* meaning. Thus we may question an interpretation of quality of life that identifies it with FGM since this identification fails to consider other aspects of quality of life such as education; equality of opportunity; freedom from coercion; and bodily integrity. This critical aspect of the dialogic approach begins to overcome the individualized approach's acquiescence to idiosyncratic accounts of quality of life. It does this by basing challenges to individual accounts of a good life in their incoherence with other accounts of a good life. The point of departure for these challenges is the idea that different accounts of a good quality of life are not hermetic; rather they are permeable and as such allow for and are able to respond to criticism. In making these criticisms the dialogic approach further promotes self-determination by providing a means to widen our horizons and better understand the quality of our own lives.

Nonetheless, the criterion of coherence is not enough to guard against invalid interpretations: it is possible to make a text or measure coherent in light of certain assumptions and yet also potentially misunderstand it (Warnke 1987). In fact this is the situation we find with respect to the outcomes data on deaf people: researchers understand the data as forming a coherent whole in light of their assumptions about what makes for a good quality of life (the ability to hear; the ability to communicate orally) and yet I argue that they still potentially misunderstand it. It is Gadamer's second criterion—that we assume a text or its analogue is possibly true—which helps to overcome these kinds of misunderstandings.

In discussing how the dialogic approach may overcome the presumption of standardized measures I already touched on the importance of considering a text or a text-analogue as something from which we might learn; in treating a text or measure as something from which we might learn we treat it as though it were possibly true. It is this second criterion of validity that urges us to question our assumptions and remain open to new ways of understanding the subject matter and thus new ways of seeing the fit between parts and whole. To be sure, this openness risks new appreciations of the subject matter or measure at hand. For instance, we may come to see how certain aspects of FGM do cohere with quality of life. We might come to see certain forms of FGM as similar to male circumcision or on a par with certain understandings of beauty equivalent to tattooing, ear piercing or surgically assigning a sex to ambiguously sexed infants. We might even come to understand FGM as having a role in a good life, although we might also try to encourage measures that retain the solidarity and bonding aspects of FGM without the medical harms to which it often leads.

But if the dialogic approach 'risks' new appreciations of quality of life it does not appreciate just any interpretation. Valid interpretations must be coherent and truth sensitive. Nonetheless, applying these criteria to our understanding of quality of life measures is more of an art than a science. This does not mean that quality of life research must give way to qualitative interviews; on the contrary, this approach is meant to be applied to quantitative measures. But it does mean that our understanding of quality of life is contingent and tied to particular contexts; practically speaking the questions and answers in these measures will always be open to challenges and revisions. It also means that researchers will have to learn the skills of interpretation, skills that I venture to suggest might best be acquired through an emphasis on critical thinking. For a dialogic approach to quality of life research primarily requires researchers to learn how to continue asking questions—questions about how we might best understand a measure's outcomes.[10]

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[10] On a dialogic account of quality of life research, it is not the job of the researcher to pronounce what is or is not a good quality of life. Rather it is her job to further our understanding of quality of life. Even when researchers criticize certain accounts of a good life, for instance FGM, these criticisms would ideally occur in the form of further research that challenge proponents of FGM to reflect on the coherence of this view.

Certainly, the implementation of the dialogic approach would require changes in how we administer these measures and changes in how we understand them. No longer would we think of them as determinate assessments of quality of life, but rather as tools to enhance communication about quality of life. But if quality of life research is meant to provide an outlet for the patients' perspective, so that it might be more sensitive to their needs and so they might have more control over the health care services provided to them; if a good quality life is part of a self-determining life, then we might do well to consider such modifications.

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