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Representing disabling experiences: Rethinking quality of life when evaluating public health interventions

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Abstract

Interventions that promote public health have the potential to transform lives, particularly for those who experience disability, where marked social and material inequalities occur across the life-course. When evaluating such interventions, health-related quality-of-life is regarded as a primary outcome and used to inform evidence-based practice. Quality-of-life measures, however, are not straightforward heuristic devices but express technologies of epistemic power. By prioritizing methodological certainty over the credibility of personal testimonies, those experiencing disability can find themselves excluded from the evidence base on which public health interventions are based. Our study explores how disability is represented by tools informing evaluative public health research and establishes the possibility of alternate practices, including the potential for more appropriate measures better suited to representing experiences. We conclude by considering how discussions about "flourishing" can create more inclusive and empowering practices able to challenge inequalities and discrimination consistent with a commitment to social justice.

KEYWORDS
disability, discourse, discrimination, epistemic injustice, evidence-based practice, global health, health care, health policy, inequalities, public health, quality-of-life

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Interventions that promote public health have the potential to challenge inequalities—particularly for those who experience disability—where marked social gradients occur across the life-course (WHO, 2011). Such interventions regard health-related quality-of-life (QoL) as a primary outcome measure and the basis of evidence-based practice. Evaluative research, however, struggles to offer a meaningful analysis of disability (Berghs et al., 2016). Integrative and inclusive approaches sensitive to disablement are rare and consequently those experiencing disability can find their voice misrepresented or disregarded (Barnes, 2016). This creates the potential for epistemic injustice as interventions encouraging healthy lifestyles are insufficiently responsive to testimonial experience and unable to empower people as they negotiate responsibility for their well-being (see Fricker, 2007).

To explain this, our study examines the use of QoL measures, when representing disability in research evaluating (complex) public health interventions. Measuring QoL enables an assessment of an interventions effectiveness (connecting sensitivity to individual experience with whether an intervention works) and efficiency (aiming to ensure scarce resources are appropriately allocated as a means of managing competing priorities, of which cost is a consideration). As advances in public health delay mortality, assessing population health relative to the number of lives saved is no longer sufficient. QoL ensures public health can reconcile personal experience within population domains and facilitate (cost-effective) interventions aimed at improving individual and collective well-being. By proposing solutions to complex and politically contested dilemmas, the reassuring certainty offered by measuring QoL is attractive and explains why the World Health Organization (WHO, 2012), World Bank (2022), and national organizations (Bowling, 2014; CDC, 2018) recommend their use. Popular QoL measures such as EQ-5D and SF36 provide a shared universal language in which collective experiences can become quantified and aggregated into composite standardized scores. These "objective" scores can be compared over time and across different socio-political contexts, thereby establishing authoritative international benchmarks. QoL challenge narrow measures of morbidity or mortality—embedded in bio-medical approaches—and offer a possible counterbalance to ideological (and political) decision making (Maynard, 2005). However, the certainty invested in these measures encourages their uncritical acceptance. This includes avoiding questions about how they reproduce underlying normative assumptions.

As in any research, rarefying experience through methodological application presents a testimonial language that is not entirely a person's own. This heuristic risk, with the potential to deny (see Derrida, 2016), provides our initial theoretical orientation as we examine how QoL represents experiences of disability. However, rather than provide a counter-set of definite "right answers," which endanger superficiality, especially given the subject's complexity, we suggest establishing "better questions to ask" (Fassin & Das, 2021, p. 7) as a more appropriate starting point. This includes identifying why change is necessary before speculating on what change may look like. When exploring the limitations of QoL measures as a policy tool, presenting disability as a case study enables us to consider alternatives. Our interest, however, is with how disability is represented, rather than an account of how health-care systems use research. We begin by exploring how historically grounded discursive practices, although creating possibilities consistent with the improving aspirations of public health, reproduce technologies of power which become reflected in our sense of the modern. In negotiating this, QoL generate an explanatory tension that, by prioritizing an impaired body that generates personal risk, struggles to recognize disability as a collectively negotiated identity with the potential to generate social disadvantage. This is a problem of measurement and interpretation. We conclude by assessing the extent evaluative public health research (and its design) can develop inclusive practices, including the potential to represent "flourishing" experiences as the basis of challenging social inequalities.

REPRODUCING QUALITY OF LIFE

Evidence-based decision making on the basis of evaluative research is reasonable when facilitating optimal public health. There remains, however, a continual and negotiable tension between an analysis and presentation of "truth"—where knowledge is regarded as possible—and using "truth" to reproduce received ideas to create representations of who we are (see Foucault, 1970). Reflexive engagement is therefore required to disentangle "problems of knowledge" from "solutions to the problems of the social order" (see Meloni, 2016, p. 10) in which "matters of concern" become confused with "matters of fact" (see Latour, 2009). This creates a risk of individual experience becoming colonized by ideological inscriptions that, by imposing an analysis (and solution) consistent with power relationships concerned with realizing current normative (and political) priorities, disregard empowering agency (see Foucault, 1994).

For example, in response to the industrialization of the nineteenth century, the origins of public health struggled to reconcile the relationship between ill-health and poverty, initially explaining ill-health relative to individual circumstances—or as Edwin Chadwick (1842) described it, "improvidence" and "profligacy"—rather than structural inequality created by emerging market relationships and urbanization (see Hamlin, 1998, p. 112). Consequently, a personally realized ill-health generated poverty. Poverty, however, did not generate ill-health. To suggest otherwise would have challenged the progress associated with industrialization (Porter, 1997). Modern-day public health negotiates similar struggles when attempting to reconcile a neoliberal market economy with a commitment to health for all. Policy on obesity, for example, prioritizes individual behavior over the role of industry in mediating food choices (Walvin, 2017). Interventions focus on personalized behavioral change, although ironically this makes it easier for industry to resist state intervention by presenting it as a threat to personal liberties and consumer choice (see BBC News, 2022). Furthermore, the U.S. food industry—mindful that tobacco companies used a similar discredited justification—sought protection through "The Personal Responsibility in Food Consumption Act (2005)." The Act, a trade-off between constitutional rights and the protection of business interests, prevents consumers suing food companies for their obesity.

"Black Lives Matter," by identifying racism as a public health issue (García & Sharif, 2015), raises comparable discursive challenges when explaining the impact of COVID-19. Racial and ethnic minorities experienced a disproportionate number of infections, more severe complications, and higher mortality rates than majority groups (see Reyes, 2020; Touchton et al., 2021). Locating the problem within cultural and social behaviors, state-sponsored explanations disregarded the consequences of racism which, by generating poverty, impacting on employment patterns, and mediating access to appropriate health care, increased the COVID-19 risk (see Commission on Race and Ethnic Disparities, 2021). Locating "problems" within the practices of marginalized groups, which are then "blamed" for their own misfortune, is longstanding (Chattoo & Atkin, 2019). As with other disadvantaged groups, such as older people, the immunocompromised, and those living in poverty, public health protections assume populations have sufficient freedoms (and access to resources) to enable them to take responsibility. Some, however, find it easier to manage risk. Interventions emphasizing individual behavior disguise how social divisions become transformed into sites of injustice as experience becomes detached from its social realization. As we shall see, disability connects to these practices when represented by QoL measures.

Throughout public health emerges as a political concern (see Rosen, 1957). Health can become located within the individual who becomes responsible for their own "vulnerability," rather than identified with socio-political structures that reproduce this "vulnerability" (see Foucault, 1994). As they become co-produced and cultivated through public health, socio-political arrangements risk reproduction through research (see Epstein, 2021). QoL enables research to sustain its commitment to improving future health (Rosen, 1957), while reflecting assumptions about what it is to be healthy, fit, and able (Armstrong & Caldwell, 2004). This creates expectations about collective well-being, against which individual behavior is assessed (Rose, 2009). Consequently, individuals participating in public health research cannot help but become organized within and inscribed by the society in which they live (see Shilling, 2001). The possibility of epistemic contingency, consistent with testimonial experience, is juxtaposed against an imperative to establish measurement able to improve well-being when expected standards are not met (see Foucault, 1994). For example, by capturing the experience of "productive bodies," statistical calculations are used to "improve" societies by mitigating any identified threat (see Wahlberg & Rose, 2015). In seeking to quantify and objectify experience, QoL measures can therefore conflate the "lifeworld" with the tools designed to understand it (see Habermas, 1987).

Public health research is sensitive to negotiating a role in which critical questioning has to be balanced against invalidating the credibility of interpretation. However, discussions about QoL accompanied by a narrowly defined account of equipoise largely discount the normative context in which research is located (see Schneider, 2022). Critique tends to be self-referential, concerned with solutions that refine methodological application through an introspective quality appraisal that focuses on internal proprieties and the practical application of measures (see Fayers & Machin, 2015). This reinforces their utility as a research instrument, rather than as a framing device able to convey ideological meaning. The context in which research takes place and the type of knowledge it generates is rarely questioned, including how QoL projects moral worth. Theoretical assumptions framing research questions remain unchallenged while the inability of randomization to generate inclusive and representative samples is regarded as a methodological artifact rather than an expression of social exclusion (see Kennedy-Martin et al., 2015).

Despite a longstanding commitment to equitable health outcomes, public health seems especially reluctant to engage with more critical readings of disability (McDonald & Raymaker, 2013). QoL measures the struggle to accommodate contingency, including how disability represents a socially negotiated experience realized within a particular environment, rather than a deviation from an expected and standardized norm (Berghs et al., 2016). QoL offers and reinforces an *a priori* definition of disability rather than gives expression to it. This is a challenge when generating empirical evidence to improve public health, particularly when the "politics of certainty" favored by governments and international agencies entail the "vehement search for social confirmation of truth, in the face of the irredeemable pluralism of the patterns on offer. … Each formula … however carefully selected … is one of the many and always until further notice" (Bauman, 1994, p. 200).

Embracing ambiguity—and incorporating this into the methodological designs that produce evidence-based practice—is a reminder that understanding the contextual assumptions informing research practices is as important as assessing methodological integrity when representing and interpreting experience. The operationalization of QoL reflects this.

Operationalizing quality-of-life

In the twentieth century, improved living conditions and advances in clinical medicine reduced the threat of mortality from infectious disease, especially in the global North. At the beginning of twenty-first century, around 15 percent of the world's population had a life-limiting condition, most of whom are located in middle- and low-income countries. However, in the global North, nearly half of those aged 60 years live with an impairment (WHO, 2011). Morbid living (and its impact) competes with morbid death (and its distribution) as an appropriate focus for government policy interested in fostering life and bringing "its mechanisms into the explicit realm of calculations" (Foucault, 1970, p. 162). By becoming synonymous with well-being, more inclusive definitions of health challenge previous approaches that understood health as the absence of disease or infirmity (WHO, 1948).

Healthy living, once defined as a human right and a global political aspiration, commits governments to improving the well-being of citizens as the basis of generating "health for all" (WHO, 1978). QoL emerged in response to this and provided opportunities for developing public health interventions that moved away from reductionist forms of bodily pathology "into territory more directly relevant to patients themselves, their well-being, comfort and satisfaction" (National Institute of Clinical Excellence, 2008, p. 6). De Sardan and others (2017, p. 73), however, explain the opacity this engenders: "International standardisation certainly has economic or managerial justifications, but it is also based on a belief in the intrinsic effectiveness [of] an increasing 'protocolisation' of care, which is inseparable from the bureaucratisation of health and of all public services."

This "protocolization" has particular consequences for how disability is defined, counter-intuitively reinforcing the potential for reductionism, disfranchisement, and estrangement by struggling to escape the imposition of normative values (Connell, 2011) in which impairment is undesirable. This is the context in which QoL measures acquire utility (and assume validity). By enabling public health to assess collective health outcomes (Murray et al., 2013), QoL measures generate quantifiable scores that can be compared with standardized population norms (Szende et al., 2014). Important global examples include EQ-5D (EuroQol, 2022) and SF36/SF12/SF8 (Rand Corporation, 2022a). The SF36 is especially influential in assessing quality-of-life adjusted life years (QALY) and disability adjusted life years (DALYs) (see Table 1).

When generating measurement, what appear to be straightforward questions disguise underlying normative values about what it is to be disabled (Laurie, 2015). To illustrate this, we cite empirical research that operationalizes QoL instruments to capture disabling consequences. Exclusion, for example, raises an immediate challenge in which inclusion is subordinated to a methodological inflexibility committed to reproducing consistency in accordance with predefined, formulaic outcomes. Those who cannot complete measures in their accepted standard form find themselves excluded in study exclusion criteria. The adaptability of measures for use by individuals with a broad range of disabilities experienced in different health-care and

TABLE 1 EQ-5D and SF36 health-related quality-of-life (domains and scales)

EQ-5D		**SF-36/SF-12/SF-8**	
Domain	**Scale**	**Domain**	**Scale**
Mobility	No problems	Vitality	Yes, limited a lot
Self-care	Slight problems	Physical functioning	Yes, limited a little
Usual activities	Moderate problems	Bodily pain	No, not limited at all
Pain/discomfort	Severe problems	General health perceptions	
Anxiety depression	Extreme problems	Physical role functioning	
		Emotional role functioning	
		Social role functioning	
		Mental health	
Self-assessment of health	0 to 100		

socio-economic (and international) contexts is underdeveloped (Russell et al., 2018). QoL measures, for example, continue to be informed by oral and written practices, remaining slow to adapt to more visual or sensory representations of experience. Current measures also assume a communitive competence, premised on memory and associated with shared linguistic, cognitive, and cultural understanding (Berghs et al., 2016). Furthermore, attempts to decolonize disability by promoting non-Western conceptual definitions and quantification have yet to be translated into agreed international standards (Connell, 2011).

When used, EQ-5D and SF36 are required to fix an experience in time and assume a person is either disabled or not. Disability, therefore, becomes a binary variable (Hays et al., 2002). It is rarely represented on a continuum or understood as contingent (Robinson et al., 2009). Multiple sclerosis (MS) and sickle cell disease (SCD), where QoL measures assess disabling consequences, demonstrate the limitations of locating experience spatially with little regard for trajectory (see Rezapour et al., 2017). MS can fluctuate in severity over the life course, having periods of remission and/or being progressive. Depending on the day EQ-5D or SF36 is administrated, questions may generate a different response (see Berghs et al., 2016). QoL measures attempt to accommodate this by assuming that any possible individual variation is balanced out by accumulated collective responses. This, however, can overlook how disability finds expression in people's lives. For those with SCD, for example, negotiating uncertainty relative to a highly variable condition is a defining feature of their well-being. Health outcomes thus assume a contingency rather than representing a fixed experience. For example, some studies have misunderstood the impact of SCD on child mental health by failing to recognize the fluidity of experience. Using measures that assume experience is static also generates confusion as an individual cannot match their experience to the invited responses (Dyson et al., 2021).

The conflation of personal functioning (impairment) with well-being represents a more fundamental tension, particularly since QoL is seen as an expression of what a person can (or cannot) do, with little consideration of how the social, political, and economic circumstances in which people live create disability (Armstrong & Caldwell, 2004). Questions about self-care ask how "independently" a person can perform self-care activities as a way of assessing their health. EQ-5D includes statement such as: "I have no problems with self-care"; "I have some problems with washing or dressing myself"; and "I am unable to wash or dress myself." Self-care is, therefore, identified relative to a functional deficit caused by bodily impairment with no exploration of how support may facilitate independence (see Riegel et al., 2021). Questions about mobility are equally predicated on functionality. EQ-5D includes the following prompts: "I have no problems in walking about"; "I have some problems in walking about"; and "I am confined to bed." Mobility, however, is a socially realized activity. These prompts/statements are not simply an indication of impaired bodily function, but also a representation of disablement. Leaving aside the association of walking with mobility, such questions assume that there is somewhere suitable to go, which may not be the case in urbanized inner-city, crowded locations where a person may also feel unsafe. For someone with dementia immobility may be an expression of a person's anxiety about getting lost rather than physical incapacity (see Cross et al., 2018). Those with mental health problems or a learning disability may have no difficulties with mobility, but due to socially generated stigma may be reluctant to venture out (Boardman, 2011). However, for those with physical impairment, the difficulties with mobility may be more to do with negotiating an inaccessible built environment (Oliver, 2013).

Questions about "routine" and "usual" activities similarly foreground individual impairment and fail to acknowledge how independence in social activities is likely to be connected to the availability of care, access to technology and transport, accessibility of accommodation, or facilitated participation (Berghs et al., 2016). Questions about usual activities may also be negatively interpreted as creating a norm about what should be regarded as usual. This may seem at best confusing, at worst, pejorative (Kras, 2009). People with autistic spectrum conditions, for example, may experience difficulties with social interactions but enjoy meaningful activities by having intensive and specific fulfilling hobbies that fall outside what is considered "usual" (Reynolds, 2016). Families of children born with life-limiting conditions may have a different sense of what is regarded as "usual" (Papworth et al., 2021). This, however, reflects a more invidious problem. Participation in "usual activities" is an outcome of cultural negotiation that does not have the same meaning for everyone (Rapp & Ginsburg, 2017)—variations of the SF12, for example, including prompts about pushing a vacuum cleaner or playing golf. Other questions ask whether a person feels "down-hearted" or "blue" (see Rand Corporation, 2022b). Questions about pain and discomfort reinforce this by ascribing a universal meaning to functional and physical limitations created by pain, which foreground individual discomfort, impacting on a person's activities (see Hadi et al., 2018). The social or emotional consequences of pain—including the response of others or how the socio-culture and the political environment mediates the experience of discomfort associated with pain to generate barriers to participation—remain unexplored (Wailoo, 2016).

Asking about autonomy and independence cannot help but privilege certain values that are often insensitive to intersectional differences associated with say, culture, age, or gender (Battles & Manderson, 2008). An inbuilt logic reinforces this by establishing the experiences of "able-bodied" and "sane" people as the norm when offering standardized definitions of well-being with which a person must compare their experience. Role limitation, for example, becomes associated with embodied physical or emotional impairment (see SF12) that, by imposing "corporeal standards," represent an ideal—and culturally loaded— sense of what a body (and mind) are expected to do, such as "move a table," "walk upstairs," or "feel full of pep" (see Campbell, 2009). An impairment located within a body creates a person with a disability rather than the normative response to that impairment (see Goodley et al., 2019). Few measures, for instance, explore how those who experience disability contribute productively to the societies in which they live (Albrecht & Devlieger, 1999). There are also various states of impairment, which "healthy" participants rate worse than death, according to a numerical QoL scale. However, those who live with such conditions report only slightly lower levels of well-being when compared to "healthy" counterparts (see Dolan, 1997). This is why more critical approaches to disability challenge assumptions about how a functional impairment is assumed to generate disablement. Oliver (2013), for example, offers alternative questions to explore QoL. Rather than ask whether health impacts on one's ability to work (see SF36), he suggests that questions should enquire about whether the discriminatory behaviors of others make it difficult for an individual to do their job. Instead of asking whether personal health restricts daily activities, questioning should more appropriately focus on the extent inadequacies in support and in the lived environment restrict daily activities.

The operationalization of QoL through the development of measures can appear somehow independent of what it guarantees. It has the potential to disadvantage by (re)defining experience as personally negotiated rather than socially conditioned. QoL generates assumptions about the kind of life a person can expect to live. This creates moral value (see Millar, 2017). Representation and reproduction become entangled, each reinforcing the other (see Epstein, 2021). To understand this, we explore the explanatory power of QoL scores relative to the social (and political) context in which they are used. This establishes a historical continuity, reflected in our sense of "the modern," of which QoL measures are a part.

Explaining quality-of-life

By emphasizing the role of social obligation and individual responsibility (Mead, 1986), neoliberalism has a particular discursive influence on how QoL scores have developed and become interpretated. This includes how the "art of government" creates expectations about state accountability for mending "broken bodies" (Porter, 1997, p. 298). A commitment to preference and choice as the basis for active engagement with one's environment, generates an "entrepreneurial-self" obliged to successfully navigate current circumstances, independent of reliance on the state (Zizek, 2015, p. 42). Quality-of-life offers an opportunity to assess the success (or otherwise) of this navigation by creating assumptive lifestyles, to which an individual can aspire and be judged against. The interpretative process circumscribes the "kind of life, worth living" that, by privatizing risk management, legitimates the body politic and creates social stability (Fassin, 2009). By anticipating threats individuals become architects of their own future (Taylor, 2018). Well-being is actively and purposively achieved; an act of responsible citizenship that enables the successful rationalization of social life (Petersen, 1997).

This, however, has social consequences. "Fitness," for which an individual assumes personal responsibility, becomes an affirmative and protective attribute of a resilient self-identity (Marsland & Prince, 2012). It also creates a social and depersonalized category of "unfit" against which individuals can be judged (Tajfel, 1970). While bolstering the self-worth of those who are regarded as "fit," it has detrimental consequences on the identity of those who are not (Islam, 2014). Establishing group-based cognitive attachment, which encourages definitional judgments and exaggerates (aspirational) difference, reinforces stereotypes that generate discrimination (Hogg & Williams, 2000). By institutionalizing this process, normative expectations ensure positive self-identification has the potential to polarize in which disability becomes a predefined "other" rather than a negotiable and contingent circumstance.

Under the influence of the World Bank (1993, p. 26, emphasis added) the "impact" of disability on daily living led to a general assessment of the "demands" disabled populations placed on governments: "There are … many diseases or conditions that are not fatal but that are responsible for *a great loss of healthy life*. These conditions are common, can last a long time and frequently lead to *significant demands* on health systems."

This explains why QALYs and DALYs, generated by SF36 scores, often associate functionality with economic productivity, valuation, and cost; or with personal (and family) impact in terms of productivity (see Madans et al., 2011; The United Nations [UN] Sustainable Development Goal 2016, SDG 3). Disability signifies "deviance" and "burden" and a threat to collective well-being. This reinforces the norms and expectations of an able-bodied and economically productive population (Mont & Loeb, 2008). By unsettling normative expectations, disability therefore creates the possibility of unfulfilled life (Moola & Norman, 2011). As QoL measures focus on what a person cannot do relative to expected social norms, they sustain this. Positive trajectories are seemingly closed off (Gibson et al., 2009), including a sense that "individuals … cannot age successfully" (Molton & Yorkston, 2017, p. 291). An individual is expected to "salvage" a meaningful life from the "ruins" of disability (Dyson et al., 2021; Tsing, 2013). This has implications for what are regarded as appropriate policy responses. They also define what is considered appropriate support. The ability of social institutions to accommodate difference, while facilitating social achievement, is rarely considered.

Inscriptive confessional practices (see Martin & Waring, 2018)—such as those associated with talking therapies and, in particular, cognitive behavioral therapy (CBT)—demonstrate this. CBT is justified through evaluative research in which improvements in QoL inform the evidence base (see National Institute for Health and Clinical Excellence, 2014). Personally negotiated impairment, captured through QoL scores, becomes the basis of intervention that is reinforced through further evaluative research (see David et al., 2018). QoL defines what is regarded as successful adaptation, which measurement then goes on to confirm. This evidence base is rarely questioned, despite concerns that it confuses short-term impact with sustainable long-term effectiveness (Dalal, 2015). This, however, is not a straightforward problem of measurement. Encouraging individuals to develop "resilience" to enable them to "cope" with the consequences of impairment discourages an interest in the social context that transforms impairment into long-term disability. Talking therapies promote personal accountability and responsibility, encouraging individual adaptation to current circumstances by facilitating a reflexive insight able to mobilize available, supportive networks and resources (Craciun, 2017). Consequently, QoL is associated with negotiating an unquestioning (dis)able bodied "norm" rather than a site where contested norms defining the "normal" are instituted (Atkin et al., 2010). There is a risk, for example, that an inability to "cope" becomes a personal failing, with discrimination becoming internalized rather than regarded as contingent and changeable. Choice, for example, is constrained by the environments inhabited by individuals (Stephens, 2006). Networks are not always facilitative but connect to broader structural factors able to challenge individual negotiations (Neckerman & Torche, 2007). Not everyone has the same opportunity to realize their preferred QoL. Disability is associated with multi-dimensional poverty, educational attainment, employment opportunities, disadvantage, discrimination, and medical and social care costs (Mitra, 2018). This highlights the importance of interrogating how social context predisposes individuals to a certain experience (Grech & Soldatic, 2016). Questioning how context defines experience is as important as understanding how a person experiences that context. Disentangling the epistemic justice this generates begins to establish the basis of different types of measures.

EPISTEMIC INJUSTICE

Quantifying disability through QoL measures gives voice to a particular aspect of disabling testimonies; a voice that may not reflect what disabled people regard as normatively important (Shakespeare, 2013). By representing a site where assumptions are enacted and projected, QoL renders experience visible. It lays open the constraining and predisposing aspects of disablement in which an undesirable present seems an inevitable manifestation of current circumstances. Disability disrupts expectations, which an individual is then required to negotiate. Consequently, a personally realized deficit experienced in relation to a functional impairment vies with socially undesired consequences to define QoL. This assumes precedence over a lived experience negotiated relative to a context where the future is undone by social injustice (see Rose, 2009). A functionally able body becomes a norm and a comparator, generating a sense of what could have been as disability is defined relative to cost and burden that, if not managed, poses a collective social threat. QoL measures, therefore, represent an epistemic tool through which an idealized ethos of self-care not readily available to everyone becomes the accepted standard on which to judge well-being (Laurie, 2015). Scientifically validated QoL classifications generate an "afflictive gaze" that transforms disablement into a dividing practice, reinforced through stratified social divisions. It also creates a silencing process that denies epistemic agency by inhibiting (and clouding) possibilities (see Scully, 2018).

The knower—on whose behalf QoL measures claim to speak—is disempowered and struggles to be heard, as their own credibility is doubted, when articulating experiences outside the frameworks defining QoL. This testimonial injustice is accompanied by a more specific hermeneutic injustice (Fricker, 2007), making it difficult for individuals to access a vocabulary, to voice their experiences, without reproducing the potential for disruption (Tremain, 2017). Attempts to express a meaningful life are interpreted relative to an "undesired" precarity. Consequently, realizing subjectivities (and their transformative potential) occur alongside normative conditions that ascribe experiences a marginal (and problematic) status that, to become part of polity, require management (see Scully, 2018). By encouraging internalization of these conditions, QoL measures prevent alternatives able to challenge the generation of disablist practices. This "requires special efforts to identity it (and) protest it" (Fricker, 2007, p. 145).

Establishing alternative measures

In reinforcing expected norms, QoL measures require individuals to legitimate experience against the continuous possibility of exclusion (Shakespeare, 2013). Socio-political factors, however, act on the body, which is as much a site for realizing social practices that generate disability as it is for understanding embodied experience (Oliver, 2013). The possibility of a nonfunctioning body, by representing a threat to active agency, creates the potential for estrangement that an individual has to confront when accounting for the precarity of their experience. However, in defining precarity, QoL measures struggle to explain how social environments create disability, despite disadvantage and discrimination representing fundamental expressions of a negotiated "disabled" identity (Goodley et al., 2019). This "hinders [the] full and effective participation in society on an equal basis with others" (United Nations, 2007, p. 1). Disability rather than a personal realized risk is a socially negotiated situation (Allen & Feigl, 2017). Rather than asking how a functional impairment prevents individuals from realizing normative expectations, QoL measures could more appropriately explore how cultural, economic, and social resources (and processes), facilitate participation. This includes encouraging individuals to reflect on how relationships mediate their experiences (Thomas, 2007) and, in particular, how negotiating an acceptable QoL requires interdependency and reciprocity (Willen et al., 2022). Understanding social inclusion, for example, while exploring the conditions that facilitate social opportunity, offers alternate explorations consistent with these ideas of interdependence (Krahn et al., 2009).

Outcome measures exploring how interventions enable or encourage inclusion when presenting an aggregative measure of effectiveness are likely to be more consistent with the priorities of those experiencing disability (see Dalin & Rosenberg, 2010). This is because our responsiveness to changing environments gives form to an adaptable experience (Braidotti, 2019) able to generate a positive self-identification on which to establish more affirmative social expectations (Islam, 2014). Consequently, interrogating the normative assumptions that prevent inclusion offers a more suitable initial engagement. Operationalizing the social determinants of public health support enables this by focusing on "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems" (WHO, 2022).

Social determinants, as we have seen, have a negative influence on expressions of disability, although they can be empowered to generate a more positive impact. The potential for precarity is recognized but becomes accessible in a way that avoids the inherent liabilities associated with constantly reproducing social exclusion. Generating purposeful insights, which reconcile potential with inevitability, enables research to use QoL to critically evaluate—and, if necessary, confront and resist—the choices required of us (see Foucault, 1994). This is the basis of a collective conversation on which to question (and challenge) the normative expectations associated with disability which, as they become realized by social, political, and economic structures, shape and define an individual's life chances (VanderWeele, 2017).

By promoting definitions of human development consistent with collective well-being (Nussbaum & Sen, 1993), "capability" offers an especially influential framework to realize this collective conversation (Mitra, 2018). Positive relationships, social integration, and social contribution (Huppert & So, 2013) align with personal growth, self-esteem, autonomy, and life satisfaction to enable "flourishing" as individuals utilize their lived environment to generate a "good life" (Keyes, 2002). Pursing a "good life," however, is a dynamic pursuit rather than a fixed state (Garland-Thomson, 2019). Identifying factors that facilitate an individual's values within the context of their family and social networks, while accessing how inequalities impact on the social detriments of health, offers a different exploration of QoL. This includes developing outcome measures able to identify intersectional, institutional, interpersonal, and internalized discrimination, including how educational and employment opportunities, poverty, poor housing, and access to care mediate disability (Willen et al., 2022). When considered alongside the extent interventions (and policies) can generate equity through creating more inclusive environments on the basis of equality (rather than despite of), alternative ways of understanding in which active agency can be understood relative to the social context in which it is realized are established. Challenging disabling environments that generate inequalities, while creating the circumstances that enable an individual to "flourish," is likely to generate a more appropriate evidence base on which to base interventions. This includes valuing the experience of those living with disability; understanding how discrimination impacts on their lives; and the extent they feel included and able to access cultural and social resources that enable them to realize their (future) preferences (see Table 2).

DISCUSSION

The ways in which we know and represent the world are inseparable from the ways in which we live in it (Jassanoff, 2004). Public health has to negotiate this tension. In aligning methodological considerations with broader debate about the social circumstances which reproduce disability, this article questions the extent QoL represents disablement when conducting evaluative research. It highlights how cultivated coproduction (Epstein, 2021) in which a constitutive link between research activity and socio-political arrangements define conventions that give interpretative meaning to QoL. Consequently, QoL measures reproduce and constitute social life as much as they offer an analysis of it.

Classification reflects prevailing power relationships that serve to shape the moral and social order (Foucault, 1970). By representing a series of interconnected technical, social, and economic decisions (Bowker & Star, 1999) under the guise of an authoritative and normative objectivity, a definition of disability is generated in which the "politics" has been "scrubbed away" (Epstein, 2021, p. 659). Boundaries are established (and policed) as QoL scores become indistinguishable from the concept with which they are associated. Any criticism, beyond methodological refinement, is discounted on the basis that it undermines utility (see Meloni, 2016). Validity is presupposed rather than a hypothesis that must constantly remain open. This "can lead you to miss noticing other things that are going on" (Halley, 2008, p. 191).

Acknowledging the transactional coproduction of evidence—in which evaluative research is entangled with the political—offers the basis of alternative practices (see Latour, 2009). Experience is necessarily and inevitably reified during the process of presentation, as individual behavior is reconciled within the collective domain of public health. This requires public health to engage reflexively with how knowledge occurs. Asking "does an intervention work?" "what does it fix?" and "is it sustainable?" are legitimate questions. Allocation of resources requires prioritization and having a sense of whether an intervention improves a person's QoL can challenge rhetorical (political) decision making. However, establishing reliability relative to the psychometric properties of an instrument without reference to the broader context in which they become enacted confuses accuracy of calculation with validity of conclusion. Furthermore, attempts to aggregate "burden" at a collective level do not remove its prerogative meaning nor its connection to expressions of "defectiveness." QoL is not an outcome of a disinterested heuristic engagement; it represents the potential for epistemic injustice in which embedded technologies of normative power, by reinforcing discursive practices through which that experience is recreated, place a moral value on a "life worth living" that is inherently ableist and reductionist.

Current use of QoL measures creates the risk of representing disablement as a stratified and rarefied "functional deficit" generated through an embodied impairment, rather than a consequence of environmental and structural determinants that shape the experiences. This undermines public health's commitment to improving future health. Any claims to be working in accordance with an established evidence base can also be questioned. Addressing this injustice requires a reimagining of how disabled voices are accorded testimonial credibility. Situating a knowing subject who is creatively responsive relative to a context in which others attempt to define their experience, can expose entrenched definitions of disability implicit in QoL and make alternative testimonial languages accessible (Thomas, 2007).

TABLE 2 Principles informing the development of alternate measures

Principle	Operational meaning	Domain	Indicative questions
Respect and dignity	Assess active agency and autonomy, including the freedom to make choices and realize independence and self-determination	Societal status/standing	Do you feel your independence is respected? Do you feel listened to you by others? Does the response of others make it difficult for you to have the life you want? Are you supported to make the decisions you want? Would you describe your family/social relationships as positive?
Full and effective participation and inclusion	Assess how discrimination prevents participation and denies normative opportunities Assess the extent institution barriers prevent inclusion/others' attitudes deny opportunities/social networks facilitate inclusion?	Societal accessibility/inclusion Social enablement/emancipation	To what extent are you able to lead the life you want? Do you feel you have the same opportunities as other people? Do you feel part of your neighborhood/community? Are you able to have the family relationships you want? Are you able to realize the reciprocity you expect when negotiating family and social relationships? To what extent do you feel your experience is valued by others? To what extent do you feel you have the best opportunities to enjoy life and do well?
Equality and equity	Assess sustainability and impact of inequality	Social, cultural, and material capital Social empowerment	Are you able to make choices about the kind of life you want to lead? Do you have access to resources and networks to enable you to live well? How well are you able to access the support you need to lead the life you want? Are you able to realize your choices and preferences? Do you feel empowered to make the decisions that are right for you? How do you rate your life satisfaction? Are you confident that your future aspirations are likely to be met? Do you feel positive about your future?

These alternative languages imply a more sensitive and critical regard for the "art of living," which, by articulating strategic and ethical intent, can decipher our sense of the forthcoming and ensure it does not become the basis of an inevitable inequality (see Rose, 2009). Locating lived experience within the socio-political environment in which it is realized enables discussions about QoL to redefine the "choice to survive" as the outcome of an ongoing and continuous struggle. This is "inclusive," creating an alterity through which disabling consequences are conceptualized as a "nomadic" continuum (rather than an outcome with a fixed meaning) from which change can be generated (Braidotti, 2019). Reconciling this fluid continuity creates the possibility of a different gaze able to challenge the credibility "excess" accorded to the use of QoL measures (Fricker, 2007). In practical terms, this includes an interest in capturing the extent that interventions facilitate inclusion, emancipation, and empowerment by promoting definitions of human development consistent with the original and positive intent associated with "capability" and "flourishing" (Robeyns, 2005). This offers an opportunity to reimagine current approaches by presenting a vocabulary in which individuals can articulate their priorities (Willen et al., 2022), while epistemically challenging the contributory injustice (Dotson, 2012) and the associated hermeneutical ignorance that denies alternative explanations (Pohlhaus, 2012). Generating epistemic resources and repertoires empowers a socially aware concept of "flourishing." Reconciling individual aspiration with the potentially detrimental impact of structural inequalities that transform impairment into disability offers the possibility of measures able to assess an intervention's value when: developing positive relationships free from disadvantage and discrimination; facilitating social inclusion and engagement in which an individual is accepted and valued; and sustaining autonomy without reference to deficit, burden, or loss. This also broadens understandings of utility.

Nonetheless, while different evaluative tools are needed to assess QoL, the threat of "protocolization" remains (see Connell, 2011). "Capability" and "flourishing" struggle to escape historical concerns that locate individual experience within prescriptive "healthy" norms that become a problem when not met. Realizing the social determinants of health, when making sense of QoL, faces similar discursive challenges. This creates a continual tension for public health as the theoretical potential associated with the social determinants struggles to find expression in an account of disability that reproduces personalized risk. Questioning the context of interpretation is, therefore, as important as establishing different measures. Otherwise, there is a risk that measurement continually reproduces the "entrepreneurial self" and generate an explanatory framework that associate QoL with individualized risk. Current social and cultural imaginations, for example, reproduce a social standing in which disability as an undesirable condition that threatens self-realization and generates a collective burden that requires intervention. As we have seen, critical identity theory explains how creating positive stereotypes associated with "fitness" disguises judgments that generate social exclusion. This, however, reflects a more fundamental theoretical tension. The detrimental impact of structural inequalities of health is continual and requires an evaluation of interventions able to connect with "the broader structures and dynamics—historical, political, socio-cultural and ideological—that shape and constrain individual and collective chances of flourishing" (Willen et al., 2022, p. 2). This is a matter for social justice. An individual's capacity to flourish depends on the circumstances in which they live: "for individuals to flourish, they must be situated in societies that promote their flourishing" (Roberts, 2019, p. 201). This necessitates questioning the "hostile environments" (Garland-Thomson, 2019, p. 24) that create disability by denying agency and restricting an individual's potential (Willen et al., 2022).

To represent experience is not a neutral process. Negotiating contingency is ongoing; an intrinsic part of generating research evidence. As Foucault (1994) observed, the task of truth telling is endless. This is why the promotion (and defense) of testimonial experience can be as important as its presentation. Injustice is inevitably generated by discursive practices and expressed through power relationships (Fricker, 2007). Choices are always required and intentionality remains continual as life carries within it possible futures not realized (see Derrida, 2016). Individuals need to recognize themselves in the decisions they make. This provides ethical purpose.

It is also the basis of resistance (Mishler, 2005). Interrogating the normative assumptions that constrain and colonize disabling futures enables a more engaged and reflexive account of how QoL represents and reproduces moral value. Our preparation for an occurring future enables us to question the conditions which define our QoL. This raises the possibility of an evidence base more consistent with the lived experience of disability and on which a more "trustful" conversation can be built as a basis for challenging inequality and social injustice (Fricker, 2007).

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