

## ORIGINAL ARTICLE

# Relating person-centredness to quality-of-life assessments and patient-reported outcomes in healthcare: A critical theoretical discussion

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## Abstract

Engagement with the historical and theoretical underpinnings of measuring quality of life (QoL) and patient-reported outcomes (PROs) in healthcare is important. Ideas and values that shape such practices—and in the endgame, people's lives—might otherwise remain unexamined, be taken for granted or even essentialized. Our aim is to explicate and theoretically discuss the philosophical tenets underlying the practices of QoL assessment and PRO measurement in relation to the notion of person-centredness. First, we engage with the late-modern history of the concept of QoL and the act of assessing and measuring it. Working with the historical method of genealogy, we describe the development of both QoL assessments and PRO measures (PROMs) within healthcare by accounting for the contextual conditions for their possibility. In this way, the historical and philosophical underpinnings of these measurement practices are highlighted. We move on to analyse theoretical and philosophical underpinnings regarding the use of PROMs and QoL assessments in clinical practice, as demonstrated in review studies thereof. Finally, we offer a critical analysis regarding the state of theory in the literature and conclude that, although improved person-centredness is an implied driver of QoL assessments and PROMs in clinical practice, enhanced theoretical underpinning of the development of QoL assessments is called for.

## KEYWORDS

health-related quality-of-life, measurement, patient-centred care, patient-reported outcomes, personhood, philosophy

## 1 | INTRODUCTION

Engagement with the historical and theoretical foundations of healthcare practices is important. Ideas and values that shape such practices—and in the endgame, people's lives—might otherwise remain unexamined, be taken for granted or essentialized. One

practice that has become increasingly common and influential in modern healthcare settings is the assessment and measurement of patients' quality of life (QoL). QoL measures are increasingly applied as an integrated part of clinical practice (J. Greenhalgh, Gooding, et al., 2018; Porter et al., 2016, 2021). Moreover, they are used by healthcare providers and regulators to monitor and evaluate

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healthcare service quality and 'value for money' (Calvert et al., 2019; Rapley, 2003; Schick-Makaroff et al., 2021). Considering the potential impact these practices have on how we understand health, healthcare quality and value—and thereby how resources are distributed and roles shaped on all scales of healthcare systems—it is increasingly important to address the question of what ideas are embedded in these measures. To that purpose, we attempt to explicate and discuss some of the philosophical tenets underlying the practices of QoL assessments and patient-reported outcome measures (PROMs). We view this as an important analytical investigation of conceptual issues related to these practices. Since ideas and concepts condition the formulation, usage, and interpretation of these measures, they also have very real consequences. Thus, our discussion is undertaken from the standpoint that theorizing the subject is closely intertwined with practice and action.

The theoretical discussion is structured in three parts. First, we engage with the (primarily late-modern) history of the concept of QoL and the practice of assessing it within healthcare settings; we try to elucidate some traditions of thought and ideas that the construct is entangled with in different ways. Several historical and philosophical underpinnings of these measurement practices are highlighted. Second, we analyse theoretical and philosophical underpinnings regarding the use of PROMs and QoL assessments in clinical practice, as demonstrated in review studies thereof. Finally, we offer a critical analysis regarding the state of theory in the literature and its potential consequences.

## 2 | CRITICAL APPROACH

We intend to critically reflect on the practices of QoL assessment and the use of PROMs as societal and discursive phenomena. Our discussion starts in an attempt to *historicize* QoL as a construct and the practices of measuring and assessing it. Inspired by the historical method of genealogy, we provide an account of the development of QoL assessments within healthcare by highlighting some of the contextual conditions for their possibility. Contextualizing in this way means accounting for some of the cultural, political and economic ideas and values that influence and condition these practices and their discourse. However, we do *not* attempt to lay out a teleological chain of events to explain the history of QoL in its totality. Instead, we sketch out an array of contexts and ideas that can exemplify how different strands of philosophical and political values and tensions have underpinned and shaped this construct and how it continues to be understood and operationalized. The historical research and the empirical literature that we mobilize here is geographically limited to Europe and North America, and only includes publications in English and Swedish. Clearly, our discussion is itself conditioned by our backgrounds and languages and does not reflect universal processes within healthcare; it does however engage with some widespread phenomena and common ideas and tensions within healthcare today.

This examination will also differentiate between the history of QoL as a construct and the procedure of assessing and measuring

that construct in healthcare. PROMs are examples of tools that are used for QoL assessment. Historically, the practice of assessing QoL precedes PROMs but they do share important philosophical underpinnings and are therefore open to be theorized in relation to similar historical conditions. PROMs are communal with the assessment of QoL in that they reflect indicators within healthcare that are based on *quality* of outcomes and impacts of health conditions and interventions from the perspective of the person experiencing them. Here, quality has to do with a person's expression of the state and value of something, particularly their life or part of that life (in the form of outcomes of a healthcare procedure). There are many different instruments for measuring QoL in healthcare, including many different PROMs, with questions covering a wide range of life domains (a.k.a. dimensions)—physical as well as psychosocial—that are typically answered using a numerical scale. Though the term Health-related quality of life (HRQoL) has been inconsistently defined (Costa et al., 2021), it is generally used to demarcate a difference between aspects of QoL that are viewed as related to health and other areas that are not (Ebrahim, 1995). However, this demarcation of QoL and HRQoL as distinct constructs has been critiqued (Karimi & Brazier, 2016; Michalos, 2017; Sawatzky & Cohen, 2021). Despite this controversy, the term HRQoL has been widely used to describe a field of research and measurement that provides an important historical foundation for the development of PROMs, with a focus on patients' views on their health as reflective of outcomes of their healthcare (e.g., symptoms, well-being and various aspects of functioning).<sup>1</sup> Moreover, it is useful to distinguish between *assessment* and *measurement* of QoL; in this context measurement pertains to a patient's score that is based on a tool (e.g., a PROM), while the assessment could be understood as the interpretation of that score, which can be aided by dialoguing with the patient and through awareness of possible limitations and particularities of the tools used. In this sense, the use of a measurement tool is preferably viewed as a facilitator of an assessment (Sawatzky & Cohen, 2021).

While the first part of our discussion focuses on historicizing, the second part is an attempt at interpreting the discourse regarding the use of both QoL assessments and PROMs in clinical practice. With the intention of performing a narrative review (T. Greenhalgh, Thorne, et al., 2018), we turned to review articles on the subject, specifically regarding patients with life-limiting or life-threatening conditions where a palliative approach to care could be appropriate. The use of review articles was motivated by the assumption that theoretical underpinning should be explicated in this type of studies, while a clinical context was selected because the inclusion of a palliative oriented approach to care actualizes needs to elaborate on rationales for clinical procedures beyond survival. It is also a field with a strong history of QoL assessments in which knowledge about patients' QoL perspectives is utterly important for quality practice. Since we expand on the logic of QoL assessments in general in both the historically oriented segment and the discussion, the applicability of our analysis is not restricted to palliative care contexts alone. However, those contexts can serve to crystalize the present rationales and the issues at stake. Our intention is not to scrutinize

all existing related literature, but to draw on illustrative examples evident in review studies. Our final section expands from the historical analysis and the account of the contemporary discourse to articulate a philosophical and ethical critique of discourses about QoL and PROMs in healthcare. This positions us as authors in that we are laying out what we believe to be at stake and why it matters, taking the ethical imperative of person-centredness as a ground for a reflexive critique of measurement practices which often avow to be driven by that same imperative.<sup>2</sup> Here, we relate the theoretically and ethical foundation of person-centeredness to philosophies of personalism and especially Ricoeur (1992) and its applications in healthcare and nursing (e.g., Britten et al., 2017; Öhlén et al., 2017).

### 3 | THE LATE-MODERN HISTORY OF QOL AND CRITIQUES OF THE ORGANIZATION OF HEALTHCARE

In healthcare, QoL is a concept with a varied history. Several narrative reviews on the history of QoL reveal the exact phrase seems to find its way into the healthcare discourse in the mid 1960s, first being mentioned in an article by physician Russell Elkinton (1966; Pennacchini et al., 2011; Post, 2014). Elkinton pointed out that physicians should wish for their patients 'not just the absence of death but life with a vibrant quality', and in that manner aspire towards a 'humanistic biology that is concerned, not with material mechanism alone, but with the wholeness of human life, with the spiritual quality that is unique to [the person]' (Elkinton, 1966 p. 713). This humanism was articulated as a correction to a field of medicine that Elkinton felt had sharpened its precision but faltered in regard to harmony. In a concrete example of how discourse of QoL is inscribed in historical conflicts and tensions stretched out diachronically, the author explicitly points back to the English early-modern philosopher Francis Bacon (1561–1626) and his empiricist take on medicine:

'The office of medicine', said Francis Bacon, 'is but to tune this curious harp of man's body and reduce it to harmony'. Almost four centuries later, in the accelerating scientific revolution that Francis Bacon fathered, medicine is doing the tuning with unprecedented skill but is having trouble with the harmony. What is the harmony within a man, and between a man and his world—the QoL—to which the patient, the physician, and society aspires? The need to continue to search for answers to these basic questions concerning the goals and values of human life daily becomes more pressing' (Elkinton, 1966, p. 711).

Resistance towards overtly rationalistic governance of societal functions and institutions are a key part of various critiques of modernity that run within an ever more expansive modern project during the 20th century (and now in the 21st). However, a division and conflict between measurement or objective description on the

one hand and the emphasis on holistic and humanistic viewpoints and the meaning of lived experience on the other has deep historical roots and is perhaps most clearly articulated in the aftermath of the 'scientific revolution' and its focus on standardization, pure description and logic.<sup>3</sup> These are the traditions against and into which Elkinton inscribes his discussion, through the notion that something has been lost. Such critiques of the biomedical paradigm can also be understood in relation to a gradual change in the understanding of sickness and health following the patterns described above. The Swedish historian Karin Johannisson researched the ideas of the body, health, and sickness as they evolved in Sweden and Europe during the 18th and 19th century. She highlighted how the experiential body was increasingly understood as an objective thing, bereft of meaning, and how the meaning of experience gradually became irrelevant to the different curative processes of medicine (Johannisson, 2001).<sup>4</sup> This is a backdrop against which the biomedical paradigm of the 20th century and onwards can be understood. Johannisson theorized the rationalized and empirical trend as a certain set of rules and ideas, a particular 'grammar' or culture of medicine she names 'scientific medicine'. The experiential element of health it serves to marginalize finds its expression and continued survival in other such grammars of medicine. We could here ask how the concept of QoL functions with regard to this 'grammar'. In one way, QoL can be understood to have introduced a complication in the tendencies of rationalized medicine; this is probably how Elkinton wanted to view addressing QoL—as a form of resistance.

The World Health Organization's (WHO) 1946 definition of health is often viewed as a key motivator for integrating a focus on QoL (as well its assessment) into healthcare. Health was described as a 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organization, 1946). Although a negative definition (in which health is marked against disease and by extension the crystal-clear limit of death) does not necessarily demand any normative judgements on the *quality* of the health in question (and therefore neither of the life), the move to a positive definition cracks open the box of philosophy. According to Bickenbach:

[the WHO definition] launched a highly productive debate about the nature of health in which two major strategies have dominated: a descriptive or naturalistic approach in which health is operationally defined in terms of normal functioning understood entirely in the language of the biological sciences and a normative approach which insists that health cannot be understood until the salient fact that health is a human good is explained (Bickenbach, 2017, p. 961).<sup>5</sup>

Of course, pre-existing philosophical discussions and debates about and within medicine and healthcare predate and provide the foreground for the WHO definition. Reflections on the qualitative state of both health and life and on their *meaning* are ancient and often inscribed in modern discussions. But the importance of these

qualitative dimensions gaining a clearer entry into the definition of health by such a universal agency as the WHO, and at that time, should not be underestimated. The concept of health is distinct from QoL, but this emphasis on the qualitative aspects of health opens up for questions about an individual's life and wellbeing. The definition arrives just a few years after the Second World War, in a climate of sharpened attention to the nature of human beings and a clear emphasis on their social aspects, possibly spurring the definition of health in a more qualitative direction. Brock Chisholm, the first director of the WHO and part of the group that formulated the 1946 definition wrote the same year that 'we have responsibility for social health, for being able to live in peace and contributing to the welfare of other people' (Larson, 1996, p. 181). At a time when the very nature of humans was contested and in doubt after the atrocities of two world wars, an inquiry into the state of the lives lived and tending to the harmony of human beings, as mentioned by Elkinton, could serve a vital function. This foregrounds Chisholm's universal ambitions and his statement that 'a new kind of citizen' was necessary for the survival of humanity (Larson, 1996, p. 181).

Understood in this way, the construct of QoL is framed by a discourse concerning morality. But clearly and crucially it is also profoundly political. Mark Rapley has argued that QoL is a key factor in the modern history of nation-state governance. He highlights a speech by Lyndon B. Johnson in 1964 where the former American president states the importance of measuring the progress or greatness of US society not by purely economic indicators but by the 'quality of the lives our people lead' (Campbell et al., 1976; Rapley, 2003). Rapley concludes that '[t]he idea of quality of life as a measurable indicator of the "great society's" achievements has, since its inception, been inseparable from the notion of progress' (Rapley, 2003, p. 4). Social indicators were a vital part of the evaluation of widespread governmental programmes during the 1950s and 1960s (Michalos, 2017). Hence, there are two sides to the story of the general struggle for social rather than economic wellbeing, especially during the 1950s and 1960s. One side might be characterized as a growing disillusionment with Western governmental power and governance, spurring political action from social movements in many parts of the world—movements that questioned the progress-narrative of liberal societies and the superficiality of quantity and money. The other one is that social indicators and measures were already and had long been an integrated part of governance—in fact, the collection of social and demographic information goes back at least to the Enlightenment (Rapley, 2003). Such integration pertains to healthcare as well. QoL could be viewed as an articulation against the function of capital by virtue of expressing other values than the objective and monetary. But as we shall see, it has also been subsumed into quantification and rationalization, and possibly also into what has been named and theorized as biopolitics, an inheritance of the work of Michel Foucault (Rapley, 2003).

Pennacchini et al. (2011) argue that healthcare incorporated a broadened focus in the 1960s and 70s, moving from primarily considering mortality versus life as its business to addressing QoL as

an aspect of health. QoL assessments became more and more prevalent within healthcare discourse and clinicians increasingly used them to guide decision-making in their practices. Thus far, we have mainly focused on the construct of QoL itself and less on the procedures of assessing or measuring it. Why then did this practice gain momentum at that time? One explanation is progressionist: the advancement of therapies and technological progression within medicine was lengthening the lives of citizens in the richer industrialized countries of particularly the global North and West (Pennacchini et al., 2011). Randall and Downie have put forward three other common reasons for the popularity of measuring QoL: (1) It serves as a standardized quality mark for comparing different services and treatments; (2) It enables practitioners to provide better care for individual patients by learning about their 'subjective symptoms'; and (3) At the time when these measures became more and more dispersed, there was a strong trend towards quantifying what is qualitative (Randall & Downie, 2006). This latter trend is particularly important to grasp if we are to provide a feasible account as to why the assessment and measurement of QoL became increasingly integrated into health care. The Swedish philosopher Jonna Bornemark (2018) has written about the desire to quantify as part of a deep-rooted idea in the modern world: that everything can potentially be known and *represented* in a number or by description. With the appropriate procedure, particularities can always be generalized. Thus, she sees an over-zealous use and embrace of measurements and documentation as an expression of the scientific and reductionist views of the globalized and accelerated 'late modernity'.<sup>6</sup>

This trend is clearly tied to the political and economic field. For Bornemark (2018), the organizational form of governance known as New Public Management (NPM) is largely constitutive of this 'profligation of documents'. NPM can be described as symptomatic of the neo-liberal policies that have dominated politics in many parts of the world since the Reagan and Thatcher administrations in the United States and Great Britain in the 1980s. These policies were and are heavily influenced by so called neo-classical economy, which sought to tie the state to the mast on the ship that is society. The neo-classicist and neo-liberal conception of value and just distribution is most importantly influenced by Friedrich Hayek's (1944, 1988) assertion that the price system of the market is the only just and non-partisan way of ordering resources collectively. Through NPM, more and more areas of life and society became governed by the same logic as procedures undertaken in a market. In such a system, everything must be clearly comparable—hence the need to quantify performance. The main incentive for the dispersion of NPM was to maximize efficiency in a way inspired by the lean model of production. We need to be careful here of conflating the assessment of QoL with this trend. As we have seen, QoL is partly situated in traditions of critiquing a reductionistic and quantified model of health and life. Moreover, healthcare governance is heterogenous and follows multiple rationales. Even so, we cannot ignore the overlap between quantification of quality and a marketized system of welfare services. Rapley (2003) and Rose (2007) are among those who have

made the point that the heightened individualization of healthcare is partly connected to the creation of the citizen as an active consumer, making rational decisions in the market. It should be remembered that practitioners at all levels operate within healthcare organizations that are dictated by a broad array of interests and goals. Assessments of QoL could, for example, be said to be operative within tensions and negotiations between the particular and the general or the standardized, where care takes place in a 'tension between individualized knowledge applicable in particular situations, versus standardization and measurement to secure organizational and quality efficiency' (Öhlén et al., 2017, p. 3).

Today, *person-centred care* and variants of the concept are widely circulated in healthcare discourse. It advocates that, for both moral and curative reasons, patients within healthcare need to be treated as more than bodies carrying a biological pathology. In many ways, it's contingent on some of the same holistic and humanistic philosophies that foregrounded QoL in health care. Crucially, person-centred care is also subject to a discussion where the critical discourse expands from only highlighting the way one person meets another—in the ethical encounter between health practitioner and patient—to acknowledging the environmental and contextual origins of the person's challenges in his/her life and what contributes to its quality (Leplege et al., 2007). Moreover, this discourse expands to organizational and structural realities and logics that condition encounters in healthcare. In Sweden, the sociologist Rolf Gustafsson has shown how the governance of healthcare in the latter part of the 20th century, through a continuation of long-lasting historical tendencies within hospital care, developed into hierarchical structures in which the patient was not only subordinate but also invisible (Gustafsson, 1987). From this perspective we can see how the practices of measurements and assessments of QoL operate within tensions:

Hospital clinicians' ability to assess and address QoL and care experiences are therefore shaped by systems that require them to simultaneously meet the needs of their patients, the patients' networks of relations, fellow health care providers, the institutions of care, their own professional regulatory bodies, and larger governmental interests. Due to this complexity, clinicians are often pulled in competing directions (Krawczyk et al., 2019, p. 517).

These tensions and different priorities are testament to the different ideas and contexts that QoL assessments have been formed by historically. To some extent, they mark out a difference between various scales of application, such as clinical practice and healthcare evaluation. Therefore, their use in clinical practice—and how that use is considered—cannot be understood in separation from the greater scale. Assessment of QoL holds different values and promises within itself. How we think about the premises, how we formulate the ways we perform these assessments and measurements, and when or where they should or should not be performed at all—all these

reflections can be enriched by an understanding of these tenets. We now move on to the discourse surrounding PROMs and QoL assessment tools to tease out what the perceived rationales, ideas and notions of these practices look like today.

## 4 | RATIONALES BEHIND PRACTISING QOL ASSESSMENTS

To identify potential theoretical and philosophical rationales and assumptions for using PROMs and QoL assessments in clinical practice, we sought explicit and implicit reasonings thereof in review articles pertaining to the use of QoL assessments and PROMs in healthcare where a palliative approach to care could be appropriate. A first observation was the tendency of many articles to phrase the information gathered by PROMs or QoL assessments as *subjective*. They thereby operate with a dichotomous epistemological notion where 'subjective' is placed in stark contrast to its conceptual opposite 'objective'. This commonly looks like this:

From a holistic perspective, QoL focuses on the subjective suffering of the patient and on his or her individual needs and wishes, depending on the context in which the patient lives (Singer et al, 2013, p. 230).

The nature of experience has been—and continues to be—a topic of complex philosophical discussions. Naming patients' experiences as 'subjective' speaks to the many premises underlying this discourse, and societal discourse at large, as well as to a lack of theory that is also noticeable in the literature. This void is especially distinct on the matter of *communication*. The perceived benefits of the measurement tools are generally articulated as a direction towards a greater focus on the individual and an improvement of patient-practitioner communication in health care (Antunes et al., 2014, 2018; Bausewein et al., 2016; Bennet et al., 2012; Donaldson, 2004; Finlay & Dunlop, 1994; J. Greenhalgh, Gooding, et al., 2018; Mizuno et al, 2017; O'Boyle & Waldron, 1997; Singer et al, 2013; van Roij et al, 2018). This is the most common form of reasoning expressed in this specific literature. However, as others have pointed to before (e.g., J. Greenhalgh, Gooding, et al., 2018), there are rarely any nuanced or deeper reflections made on *how* this sort of orientation towards the person and the improvement of communication should be understood; there is a lack of philosophy and theory and philosophical premises seems often to have stagnated into taken-for-granted assumptions. To exemplify: although 'the person's perspective' is sometimes expressed as an awareness of otherwise overlooked domains of health, there is little reasoning on the interrelations between these domains or other thoughts on how the perspectives of different 'persons' should be understood. The same applies to the generic conceptualization of 'communication'.

The most clearly stated expressions on the rationales for assessments and measurement tools in clinical practice, implying a greater focus on the person's perspective, are found in the reflection

on unmet 'physical, psychological, spiritual and social' needs (Antunes et al., 2018; D. Li & Madoff, 2017; McCall et al., 2016). This can be understood as a widening of aspects of *what the person is* in the healthcare situation. For example, Bausewein et al. (2016, p. 10) state that '[f]or the clinical setting, multiple symptoms should be included in the measure to assess the full experience and symptom burden of the patient'. By entering the variables of 'full experience' and 'symptom burden', this quote actualizes the experience of the patient as ethically and potentially clinically relevant.

As shown above, QoL is often negatively operationalized by focusing the measurements on notions of 'burden' and 'strain'. Additionally, the 'full experience' is conflated with the full symptom burden. However, there are exceptions of measures that focus both on a broader range of both positive and negative aspects of QoL, especially in contexts of palliative and end of life care. Measurement tools have also been described as a form of facilitators for dialogue and communication between patients, families and clinicians, as well as between clinical teams (Antunes et al., 2018; Catania et al., 2015). J. Greenhalgh, Gooding, et al. (2018) examine this difference between score and dialogue, showing how clinicians may adjust their usage of PROMs to the particular circumstances of their patients. Their article effectively theorizes the usage of PROMs by leaning on the theoretical work of Leah McClimans. 'How' is here understood as an opening of a space of reflection:

[T]he ways in which patients interpret questions and construct their answers is shaped by social and cultural factors and can affect the ways in which patients understand, frame or think about their condition. Drawing on the work of Gadamer, McClimans offers a theoretical account of the PROMs completion process that can explain our findings. She argues that PROMs ask 'genuine questions', that is, questions which open up inquiry into the subject matter at hand but also the meaning of that subject matter (J. Greenhalgh, Gooding, et al, 2018, p. 22).

Other articles mention the need to think through whether the domains of an outcome measure reflect the most relevant outcomes for a certain patient group (Granda-Cameron et al., 2008). In addition, a common theme is the intention to measure what matters most to most people, while individualized measures are a noticeable exception (Aburub & Mayo, 2017). A focus on improving shared decision-making and agency—the value of involving patients in their own care—is also present in the literature Antunes et al., 2018; (Bennet et al., 2012; Catania et al., 2015; Donaldson, 2004; L. Li & Yeo, 2017; van Roij et al, 2018). But there are also examples where authors voice concerns about this approach towards agency, for instance with regard to implementation in surgery settings (Pompili, 2015). Several reviews bring up specific rationales for using PROMs or QOL assessments in palliative care; this is described as a stage of disease management where aspects of health other than survival become important in a very concrete way, which is why PROMs can be an

important aid in attending to those other needs (Antunes et al., 2014; Bausewein et al., 2016; van Roij et al, 2018). Another perceived value of measurement tools, explicated in just a few places in the literature, is their use for measuring the needs of the patient's relatives and family members—an extension of the holistic ideals of person-centredness already highlighted as a common feature in the reviewed material (e.g., Bausewein et al., 2016).

The perceived benefit of implementing PROMs and QoL assessment tools in clinical practice is also often described in terms of efficiency and improved faster monitoring and follow-up of in-patients' symptom development (Bygum et al., 2017; Davis, 2004; MacKeigan & Pathak, 1992). There are several instances where some of the value of PROMs and QoL assessment tools is less tied to the tendencies of individualization of healthcare mentioned above, and more to this potential of closer monitoring and more frequent reporting on a disease's progression:

It is well recognized that physicians frequently under-report patient toxicities from treatment. There are multiple potential reasons for this, both patient and physician-related. One of which is the effect of time on patient recall of symptoms, for example, nausea may be worse during the first few days following treatment, but the patient may not be reviewed until a number of weeks later. A patient-led method of reporting toxicity that directly fed back to physicians could overcome this (Lewis et al., 2018, p. 36).

Tool usage is here largely legitimized by a logic that can be tentatively associated with rationalistic and biomedical tendencies in healthcare systems and societies at large. Several reviews are influenced by evidence-based medicine, and quantitative studies are often the foundational parts in the syntheses. This includes discourses that highlight communication and patient-orientation in clinical practice (e.g., Bjordal, 2004), as exemplified below concerning electronic PRO and HRQOL measures:

ePRO systems can improve patient-provider communication during clinic visits and alert clinicians to acute needs for symptom management between visits. [...] ePRO systems make it possible for clinicians to have systematically collected symptom data that can support clinical decision-making. These features have been found to improve patient satisfaction with their care and have the potential to improve symptom management (Bennet et al., 2012, p. 339).

Above we specifically see how an under-theorized form of communication—which rids itself of a mass of existing theory from fields such as communication theory, psychology, sociology, philosophy, ethics, etc.—sits next to or links with the biomedical language, and the quantifiable and observational aspects of measurement tools that facilitate data collection. There are some exceptions and nuances

to this pattern; different tendencies and ideas cross and contaminate each other. But the biomedical discourse is dominant and holds a clear legitimizing function. Implicitly, a more holistic view of health comes to the fore, but rarely in a theorized form. A few articles even address the paradigm-level, hence framing the potential of measurement tools as an important shift:

There is increasing disillusionment with the purely biomedical model of health assessment, and interest has grown in supplementing such data with patient-based evaluations, such as QoL (O'Boyle & Waldron, 1997, p. 19).

Another aspect of the discourse is a focus on the organizational benefits of using measurement tools in practice, as well as reflections on the conditions for either successful or negative implementation results. In these cases, the potential benefits of using measurement tools in clinical practice are described as heavily contingent on the specific circumstances of different healthcare organizations and institutions, mainly on a micro-level. To a degree, these notions thus form a perspective that at least indirectly ties the ideas of the value of PROMs and QoL assessments to questions of economy and politics, a move that is otherwise practically non-existent. These factors and circumstances are often described as 'facilitators' and 'barriers' to successful implementation:

Implementing PROMs in palliative care clinical practice is an ongoing interactive and continuous process. There is a need to identify and address potential barriers to a successful implementation of PROMs in clinical practice, using appropriate facilitators, tailored to the characteristics of each setting (Antunes et al., 2014, p. 172).

To summarize, the empirical literature on QoL assessments and PROMs in clinical practice exhibits ideas of addressing the person in holistic ways and of facilitating agency and authorship for patients within healthcare settings. However, this impulse often stops at a pragmatic level and thereby becomes equated with the measurement procedure. In general, there are few clear or elaborated ideas of *how* these practices facilitate a person-centred approach, or why such an approach matters. We will now move on to discuss why this lack of ideas and theoretical engagement needs to be addressed and challenged.

## 5 | CONCLUDING CONSIDERATIONS

Although a lot of work has been put into asserting some theoretical and conceptual grounding of QoL and PROMs (see McClimans, 2010), our review has identified a lack of explicit philosophical and theoretical work in the literature on the use of PROMs and QoL assessments in clinical practice. Why is that

problematic? The highly pragmatic characteristics of the literature are certainly due to the empirical nature of healthcare research, aiming to build evidence for practical solutions of benefit for patients. Also, generic statements on communication in the literature could build on notions that the actual practice of meeting a person will always be a singular and particular task that can neither fully be subjected to a standardized description of interaction or subsumed into the measurement outcome. If so, this pragmatism could be said to build on an implicit, experiential knowledge of this situation, both on the part of the researchers and interviewed practitioners as well as among patients and family members. But we would argue that there is no *necessary* opposition between 'abstract' theory and actionable practice. Pointing out theoretical foundations may sound like an attempt to abstract and slow down process, but that is an unfortunate understanding of what such an effort might imply. Here, theorizing is equivalent to opening up to what *can be* given rather than just complicating an experiential 'given'; it means initiating and accepting possibility and risk. By indicating what might be limited or missed with a certain way of structuring experience we open up to more constructive ways of understanding practice.

Thinking critically and theoretically about the procedures and their many possible forms and consequences is integral to being person-centred; otherwise, person-centredness risks becoming a stagnant, simplified and thereby emptied concept. Indeed, one could argue that in some regards it already is. As we have seen in the review studies, the proclaimed driver and benefit of using these measurement tools in clinical practice is either explicitly or implicitly enhanced person-centredness. But if we consider the historical fact that such procedures are inscribed in political and economic rationales, combined with the flat descriptions and high degree of pragmatism in the literature, it should be clear to us that things are not that simple. Practices, theoretical structures as well as practitioners aiming at person-centredness through QoL assessments must therefore be critical and self-critical, if they are to achieve it.

Understanding the underpinnings of measurement tools and the concepts involved in them is necessary because their outcomes might otherwise be viewed as free of values, which is not true and may have potentially harmful consequences. There is a tendency to objectify QoL as if it was body temperature or similar to a laboratory test result. Patient-reported outcomes naturalize the procedure even by their name: these are the outcomes reported by the patients themselves. Why could this be harmful? Because, (as we stated in our introduction) the practices of QoL assessment and PRO measurement have personal and societal consequences intertwined with underlying philosophies, assumptions, purposes and potential measurement biases (Sawatzky et al., 2017). For example, underlying conceptualizations of health and QoL result in some aspects of life being represented in the measurement, whereas others are not. This can result in clinicians not taking certain aspects—into account. In addition, measurement biases can be introduced. How individuals understand their QoL could change over time as a result of coping, adaptation or personal development. This may result in a phenomenon known as

response shift, where the meaning of a person's measurement scores change over time (Sprangers & Schwartz, 1999). For example, in palliative care, a response shift may occur as a result of coping or adapting to progressive symptoms, which can have implications for clinical practice and healthcare decision-making (Sawatzky et al., 2021). Furthermore, different people may not interpret and respond to questions about their health and QoL in the same way. By representing and mis-representing perspectives of different people there is a risk of creating biases and inequities. Normative notions that become recreated and rigid might further cement these sorts of inaccuracies and biases. Moreover, the naturalization of quantifying quality and rating well-being runs the risk of dispersing a banal idea of how people understand values, themselves, and their health.

A lack of critical perspectives—such as economic critique, communication theory, philosophies of personhood, intersectionality, postcolonial theory, etc.—may also inhibit us from understanding what the flaws of our measures might be, or from asking the sort of questions that might allow us to discover them. Additionally, potential biases may arise when patterns of inequality and power imbalances already present in contemporary societies are ignored. It is therefore important to consider how power dynamics and patterns of discrimination are played out in measuring QoL or patients' experiences. Let us recapitulate that healthcare institutions are torn by different logics. As things stand, they will continue to be complicit in both the systemic reproduction of intersectional marginalization and disempowerment, *as well as* in the counteracting movement aiming towards the principle of a just and unbiased right to healthcare. In this balance, critical perspectives are crucial to the analysis of what part a certain practice is playing, or to what extent and in what ways it is playing both parts.<sup>7</sup> We could here invoke the French philosopher Michel Foucault's sense of bio-power, where the power over life is not only destructive but also 'productive' in that it structures how people live their lives. This power is not sovereign or situated centrally in the traditional sense. Rather, it is decentralized through the dispersion of 'truth-regimes' (Foucault, 1980): the limits of how we think what could be true about something, such as how my life could be, what would constitute quality in my life, etc. In an important reading and recalibration of Foucault's notions, theorist Judith Butler proclaims *critique* to consist of interrogating our suppositions by asking the question: 'What is the relation of knowledge to power such that our epistemological certainties turn out to support a way of structuring the world that forecloses alternative possibilities of ordering?' (Butler, 2002, p. 214). What would considering that question mean in practice? Critiquing the aforementioned tendencies of objectification (as well as the dichotomization into the categories of objective and subjective) and pragmatism need not imply that we cannot or should not measure QoL or patients' experiences. However, it does have implications for how that assessment or measurement can or should be used, and for considering the profound limitations involved. It serves to remind us that a certain measure is always derived from a limited structure of quality, and of certain ideas of it. It is *always* limited because it is a practical structure, a certain *way of grasping*, understanding and

ordering how we can deem and evaluate the quality of our lives or experiences. This is not only the case for the quantitative structure of rating scales but also, in a more nuanced way, for all forms of expression, including 'open', 'semi-structured' and narrative ways of asking someone to deem something.<sup>8</sup> This does not mean that all measurements of experience are equally helplessly flawed and that we should abandon them altogether, but it means that we have to carefully consider how we assess and measure and what that those procedures allows us to say and do. This is what would be implied by a critical awareness along Butler's lines. If we are too quick to affirm what a certain measurement procedure makes possible, we might forget to analyse the potential insufficiencies that simultaneously make other important things impossible. On the level of both individual ethics and more large-scale societal ethics, the procedure of measuring and assessing quality and experience will benefit from factoring in this notion of critique.

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## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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## ENDNOTES

- <sup>1</sup> PROMs differ from person-reported experience measures (PREMs) which are used to assess patients' experiences of the care they received.
- <sup>2</sup> Person-centeredness is often based theoretically and ethically in philosophies of personalism. See Öhlén et al. (2017) and Britten et al. (2020).
- <sup>3</sup> For a detailed historical work on the mechanisms and narratives composing the sense of a 'scientific revolution', see Bowler and Morus (2005).
- <sup>4</sup> Johannisson (2001) contended that while there were Romanticist strands within medicine and philosophy in the 19th century that counteracted and complicated this momentum towards a 'rationalization' of the body, the overall trend remains relatively unequivocal. It became crystallized in the biological materialism of the latter part of that century.
- <sup>5</sup> Clearly, the 'descriptive or naturalistic' approach cannot be fully separated from the normative; what is considered 'normal functioning' is often contested and reframed.
- <sup>6</sup> The concept of late-modernity stems from the work of sociologist Anthony Giddens.



<sup>7</sup> Two interesting instances of such interrogations are Friberg et al. (2018), and Habran and Battard (2019). Friberg et al. evaluate how different logics were at play in the ways health professionals interpreted and applied a specific intervention, while Habran et al. analyse how care relationships are constructed differently in different care models.

<sup>8</sup> A process evaluation by Pettersson et al. (2018) provides a concrete example of how various communicational strategies have different consequences.

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