

Review Article

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Abstract

Objectives. Recent years have witnessed the rise of patient-reported outcome measures (PROMs) in palliative care (PC), particularly those focused on the standardized measurement of symptom burden. These measures seek to evaluate the quality of PC through the quantification of various aspects of potential suffering (e.g., sleeplessness, loss of appetite, and pain). Further, drawing on patient experience, they provide a framework for evaluating the effectiveness of, and at times expanding, PC services. The aim of this paper is to provide a theoretically informed normative critique of PROMS-PC through a critical engagement with heterogeneous literatures.

Methods. A hermeneutic narrative review underpinned by a view of “knowing” as an ongoing social accomplishment and inspired by complexity theory.

Results. This narrative review highlights some limitations to the development of PROMs, including the use of proxies to complete them, and how the outcomes may not always reflect either the character of PC or the key aspects of practice and experience therein.

Significance of results. In their current form, PROMs have the potential to skew understandings of service quality, for example, by privileging one aspect of quality, that is, physical symptoms over other aspects of quality such as communication with care providers.

Introduction

The history of the formal integration of patient outcomes into evaluations of health is relatively recent, with systematic ways of integrating patient experience, viewed as critical to the shift to value-based health (Porter 2009). In the United Kingdom, the Darzi review titled “High Quality Care for All” highlighted the need for patients’ views of their health and experience to be included as indicators of the quality of National Health Service care resulting in patient-reported outcomes (PROs) becoming a central feature. (Department of Health 2008) Patient-reported outcome measures (PROMs) are the tools or instruments used to measure PROs and are considered as: “core elements of a patient-centred, quality-oriented healthcare system” (Williams et al. 2016). A PRO is one “directly reported by the patient without interpretation of the patient’s response by a clinician or anyone else and pertains to the patient’s health, quality of life, or functional status associated with health care or treatment” (Food and Drug Administration 2009). They have developed over more than 2 decades and are widely used across most OECD countries (Etkind et al. 2015).

Standardized measurement and patient-reported measures in palliative care

The utilization of what from here forward, in this paper, referred to as PROMs-PC (PROMs used in palliative care) have historically been applied for research purposes and are now increasingly used in clinical practice. Further, PROM-PCs are increasingly center-stage in the evaluation of organizational performance. The purpose beyond the employment of PROMs-PC remains similar to the broader PROM agenda mentioned above, but with specificities in regard to the palliative care environment. In particular, PROMs-PC aim to improve patient care through *screening* for undetected problems in the physical, psychological, spiritual, and social domains; *monitoring* patients’ problems and response to therapies over time; *involving* the patient in

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decisions about their care; *improving* the appropriateness of the use of interventions; *promoting* quality improvement activities through benchmarking service provider performance; *facilitating* patient and/or family caregiver communication (Williams et al. 2016).

PROMs-PC are now employed for research, clinical and/or benchmarking purposes in multiple countries including the UK, Africa, Europe and Australia, Canada, and South East Asia and have become a standardized aspect of evaluation (Antunes et al. 2014; Bausewein et al. 2014, 2011; University of Wollongong 2022) as with health care more generally (Simon et al. 2012). It is also clear that PROMs-PC hold significant appeal in palliative care given the hitherto lack of systematic evaluations and evidence-base available for many practices. As Lukas Radbruch put it: “If we want palliative care to become part of the regular healthcare system so that it can be easily accessed by every patient that needs it, we have to comply with the rules” (Bausewein et al. 2014, iii).

The problem, as with other attempts at systematizing practice and evaluation in palliative care and death and dying, was what to include in seeking to garner patient perspectives in a complex, sensitive, multifactorial, and highly interprofessional clinical field. There was a recognized tension in determining how to ask enough without adding additional burden to patients. At a formative European workshop in 2012 participants agreed that an “ideal measure” PROMs-PC would “contain six to ten questions; cover all (complex) aspects and dimensions of palliative and end of life care; be easy to use and brief to administer; understandable for cognitively impaired patients; non-burdensome to patients, carers and staff; and produce relevant and comparable results” (Simon et al. 2012). A PROM-PC suite of measures that meets these ideals has not been identified or developed and it is questionable whether it is possible to do so. Increasing doubt is emerging about the capacity of a measure, or indeed, a single measure, to capture the complexity of palliative care interventions.

More recently PROMs-PC have been adopted into scaled-up programs. For example, in Australia, a national program funded by the Australian government incorporates PROMs-PC within a suite of tools (University of Wollongong 2022). The normative assumption of PROM-PC is that such techniques provide a systematic means of providing clinicians, service providers, funders, and other stakeholders with a means to appraise individual patient experiences, including developing a language shared between service providers, and indeed extending out to patients; instil routine collection of experience; and ensure benchmarking of care across settings thereby improving quality and supporting decisions about individuals, groups, and populations (Bausewein et al. 2014). PROMs-PC assumes that data collected are those defined as meaningful to people receiving care. These assumptions warrant further examination in light of the over 30 years’ experiences with PROMs-PC.

Methods

Review scope and purpose

This narrative review uses a hermeneutic approach with the aim of seeking a deeper understanding of the PROMs-PC literature and allowing: “diversions into unplanned areas” (MacLure 2005) in order to engage with the complexities and uncertainties of this field. Hermeneutics is concerned with the process of interpretive understanding (“Verstehen”) (Boell and Cecez-Kecmanovic 2014) and is

drawn from the philosophical theory of knowledge that new understandings arise from application as well as interpretation (Schmidt 2014).

A hermeneutics approach focuses on the process of furthering understanding to foster a dialogue between previous research, the researchers, and the readers, rather than achievement of a definitive understanding (Boell and Cecez-Kecmanovic 2014). This review of the literature was approached as hermeneutic cycles, as described by Boell and Cecez-Kecmanovic (2014). That is, our interpretations are based on the premise that parts are only understood from an understanding of the whole – and the whole is only understood from understanding parts (Schmidt 2014).

Our search commenced in 2019. In view of ongoing hermeneutic cycles, we did not predetermine the time frame for the literature search. First, led by AC, we identified review articles of PROMs-PC and searched the databases (CINAHL; PubMed; Web of Science; CareSearch palliative care knowledge network, Google Scholar; humanities abstracts and ProQuest social science database) using the following initial search terms palliative care: terminal care, patient reported outcome measures, PROMs, measurement, healthcare, suffering, patient experience. We also drew from associated grey literature. We then expanded our search using citation pearl growing strategies following the diversions described above. We then searched terms related to patient reported outcomes directly related to palliative care and in the way we describe above. Following the first read and analysis of articles, we expanded our search to include manuscripts that related to populations who may require palliative care but where the literature was not palliative care specific. Finally, we expanded our search to review literature in the fields of social science including science technology studies and organization and health-care management studies. We repeated this process several times, until no new elements were found.

Conceptual framework

With the widespread acceptance and implementation of PROMs-PC, there is a need for a theoretically informed review of the literature that is broader than the dominant biomedical research paradigm that privileges “objective measurement” (Cassell 1991, 2004). Instead, the theoretical framework in which our review is situated as one that recognizes social complexities (Greenhalgh and Papoutsi 2018) along with the limitations of researching “something as complex as suffering” (Dragojlovic and Broom 2018) using the scientific method alone” (Hallenbeck 2008). Instead, the philosophical underpinning of this review views the patient as a subject, and occupying a lived context in a world of social interactions embodied in space and time. Accordingly, “It is not bodies that suffer but people” (Cassell 1991, 2004). Second, as Orlikowski (2002) states, “knowing is not a static embedded capability or stable disposition of actors, but rather an ongoing social accomplishment, constituted and reconstituted as actors engage the world of practice” (Orlikowski 2002, 249). Thus the aim of this paper, rather than provide yet another formulized summary, is to provide a normative critique of PROMS-PC in a theoretically informed way through a critical engagement with heterogeneous literatures, i.e. a critique of the cultural norms, assumptions, beliefs and actions associated with PROMS-PC. Our focus is on underlying assumptions associated with PROMs-PC, drawing from critical social science and humanities scholarship as well as clinical literature.

Hermeneutic analysis

Aligned with Hermeneutics, we discussed the findings of each hermeneutics cycle reflexively and iteratively questioning each other's assumptions in relation to understandings and assumptions of PROMS-PC from the literature and from each of our individual disciplinary and practice lenses, i.e. medicine, nursing, and social science. In these discussions, face-to-face, online, and via email, we asked the question – what are these data telling us about PROMS-PC using Srivastava and Hopwood's framework for qualitative data analysis (Srivastava and Hopwood 2009). This analytical process resulted in the following themes: Proxies: Deficits: Symptom-centered Assessment in a Person-centered Process; PROMS-PC in Practice; Red-tape or Value-add? Measuring Bodies, Accommodating Persons? and Are We Measuring What We Think We Are Measuring?

Findings

Proxies

There are a significant number and variety of outcome measures in palliative care measuring different domains (Bausewein et al. 2014). The idea of PROMs more broadly is to derive knowledge of their symptoms as reported by the patient themselves. That is, ultimately, why PROMs were developed in the first instance. Proxies in palliative care however, whether clinicians or families, have been shown to be, to a large extent, involved in the reporting. For instance, a PROM-PC used nationally in Australia is the Symptom Assessment Scale (SAS). It asks patients to rate symptoms such as pain, breathlessness, fatigue, and bowel problems with a numerical score between 0 and 10 (0 = no distress–10 = worst possible distress) (Bausewein et al. 2014). A recent study of a population of mainly cancer patients (76%) found that service data entries where symptom distress was reported by patients using the SAS was 61% versus 39% reported by a proxy and that cancer patients were more likely than noncancer patients to self-report (Clapham et al. 2021). The issue of proxy reporting is evident in the literature showing that health-care professionals and family caregivers perceptions of suffering and care may be quite different to those of patients (Heyland et al. 2006; Virdun et al. 2015) and that there are regular and significant disparities between patient ratings of symptoms and that of health-care professionals (To et al. 2012). As such, and perhaps unsurprisingly, health-care professionals tend to underestimate the extent of symptoms when compared with patient's reports of symptoms (Laugsand et al. 2010). In the context of not being unable to communicate for a multitude of reasons, a significant proportion of patients are unable to indicate a numerical score for distress themselves (Etkind et al. 2015). For example, proxy scoring of the distress on behalf of an "other" is limited in the SAS domain of poor sleep when a person is asleep and/or semiconscious for much of the time in the terminal phase of illness. Despite the ambition of earlier referral to specialist palliative care, a UK study highlighted that more than half of all referrals occurred in the last 48 days of life and referral was especially late for those with a noncancer diagnosis (median of 27 days) (Allsop et al. 2018). The median length of survival in an Australia study was slightly higher (54 days) (Good et al. 2004). If PROMS-PC evaluation is the new and primary paradigm of evaluation of the quality of palliative care services, there is a risk of overlooking the very patients that account for a large proportion of the palliative care population.

Deficits

Herein lies a further conundrum and that is the negatively framed focus on problems, burden and distress, which are then encoded in PROMs, rather than what people *can* do or what they feel *positive* about at the end of life. This is highlighted in the growing body of public health and palliative care literature. Here the focus is on living when dying and on people's capacity to "live full and satisfying lives" even when facing death (Kellehear and Sallnow 2011, 9). By way of example of such a contradiction, in the last weeks or days of life, service users are advised that "normal" and "natural" dying encompasses an expected decrease of appetite and thirst, with little desire to eat or drink. On the one hand, as part of the rhetoric of reassurance of palliative care clinicians, patients and caregivers are informed that this is a normal part of a "natural" dying process and thus is not distressing for a person. Yet on the other, as a proxy for the dying person, a family member is expected to rate distress associated with loss of appetite. Thus, the finding that there is a decline in mean reported appetite-related distress around 7–10 days before death (Sousa et al. 2022), utilizing PROMS, is perhaps unsurprising given the likely extent of proxy rating by clinicians and caregivers in the days before death. (Clapham et al. 2021) This speaks to the normative lines between "natural" deterioration, and undue suffering, which inform proxy evaluations.

Symptom-centered assessment in a person-centered process

The PROMs movement in palliative care has, for the most part, focused on patients' reporting of *symptoms*. One of the core ontological issues faced in the clinical measurement literature is the issue of the extent to which a reduction of distress, as defined by symptom burden (and as articulated in the selected symptomatology), is reflective of high-quality palliative care. There is little doubt that symptoms – and patient reporting therein – is a useful indicator of some aspects of experience and can improve awareness of unmet need and assist professionals to act to address those needs (Etkind et al. 2015). The literature shows, however, that reducing particular facets of experience (e.g. pain, nausea, sleeplessness) does not always provide a holistic picture of what patients value most (McCaffery et al. 2016) or of overall suffering or the lack thereof, for people with palliative care needs. The selected measurement domains may not necessarily be the right ones, resulting in PROMS-PC failing to pick up the real impacts of health care in the life of patients and their families (Dolan et al. 2009). In a recent study of patients with heart failure, although receptive to using the PROM provided, participants expressed that the PROM did not adequately capture key issues such as mental health and social relationships. (Davis et al. 2022) A study of patients with lung cancer showed that the PROM did not capture the complexity of the symptom of breathlessness including experiential dimensions (Ji Hyun Sung et al. 2020). Thus, clinicians are at risk of not exploring distress more globally, including psycho-existential distress, and vice versa. Any chosen PROMS-PC may conceal much of the complexity of palliative care, as evident in its day-to-day practice. Current standardization measures may not accommodate the clinical reality that good palliative care for one person, may in fact depart considerably from that of another. Scaling quality risks concealing diversity.

A focus on symptoms may overshadow other important issues. Literature from the field of health communication, for example, shows that communication between clinicians and patients

is closely linked with health-outcomes (Street et al. 2009). Relationships between clinicians and those they care for have transformative potential (Kearney 2000). This is reflected in neuroscientific research whereby nocebo-related effects can produce unwanted side effects when health-care workers or medical interventions are distrusted and vice versa (Benedetti et al. 2007). Studies in the field of psycho-oncology show how psychosocial outcomes that are positive can be the direct result of relational encounters (including those with clinicians) in which patients are validated and feel that they are known (Street et al. 2009). Reducing evaluations of the quality and successes of palliative care to symptom measurement risks devaluing other fundamental aspects of palliative care (Kearney 1992).

PROMs-PC in practice

Research indicates that clinicians can find implementing PROMs in practice to be taxing due to the time and effort required (Bausewein et al. 2011). Importantly, clinicians report significant ambivalence in terms of their implementation of PROMs in everyday practice. This review has highlighted concerns about distraction from the clinical interaction (Krawczyk et al. 2018). A realist synthesis of highlighted how palliative care clinicians expressed that PROMs inhibited interactions with and minimized emotions failing to capture the complex and dynamic nature of issues important to patients (Greenhalgh et al. 2017).

The effectiveness and utility of PROMs in routine practice is influenced by how they are implemented (Bausewein et al. 2011). In an era of datification, clinicians and managers are inclined to develop work arounds or gaming practices whereby they ignore, adapt, or change data practices to reduce the burden of data collection and/or alter outcomes (Mannion and Braithwaite 2012; Wallenburg and Bal 2019). These strategies can compromise both the validity of the PROMs to support the care of patients and also their value as an indicator of the quality of care (Greenhalgh et al. 2017). Moreover, clinicians' agenda for collecting PROMs are often incompatible with those of other stakeholders and significant tensions occur between administering PROMs-PC for the purposes of clinical care and for audit, research and/or benchmarking purposes (Krawczyk et al. 2018). Clinicians are required 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. 2018, 517). PROMs-PC that clinicians find useful in screening patients are not necessarily useful as indicators of the quality of a service (Greenhalgh et al. 2017). Similarly, clinicians often focus on collecting and entering data rather than using PROMs-PC to identify patients' needs in real time, to inform and plan care (Aranha et al. 2018). An ethnographic study of breast cancer nurses showed how significant recontextualization work was required to make PRO data usable and meaningful in clinical practice (Torenholt and Tjørnhøj-Thomsen 2021).

Red-tape or value-add?

There are indications that in highly complex organizations where services are increasingly stretched with associated workforce challenges (World Health Organization 2022) and constrained health budgets, PROMs are not the only burgeoning "paperwork" requirement in the measurement agenda. Integrating PROMs into care requires substantial human resources and high-level skills

and is highly dependent on support of organizational structures (Torenholt and Tjørnhøj-Thomsen 2021). The available evaluative literature shows that the concern of clinicians about the time and effort involved in collecting and entering PROMs data may be, at least partially, justified. PROMs-PC, as part of routine measurement, raise ethical and moral implications, whereby certain objectives and practices are valued and others are concealed. (Mitchell et al. 2021)

Measuring bodies, accommodating persons?

Few studies reported patient and/or family experiences of PROMs-PC. A recent scoping review of patients' experiences of PROMs referenced several oncology studies but only 1 palliative care specific study (Carfora et al. 2022). Studies indicate, however, that patients and families regard safe and high-quality palliative and end-of-life care as much more than symptom management (Benedetti et al. 2007). Of significance and highlighted in the literature are: effective communication, continuity of care and shared decision-making; expert care; respectful and compassionate care, and trust and confidence in clinicians; an adequate environment for care; and minimization of burden to patients (Collier et al. 2016; Masson 2002; Sandsdalen 2016; Steinhauser et al. 2000; Virdun et al. 2015); avoidance of life support that is unwanted; and issues of life completion (Heyland et al. 2006).

A scoping review of PROMs in the context of cancer care found that to be successfully implemented, PROMs need to address issues of most importance to patients rather than those deemed to be so by designers (Howell et al. 2015). Patient reporting of selective issues, in particular, symptom burden not only falls short of offering a wider picture of quality of palliative care, but may also have unintended consequences and potentially may even contribute to iatrogenic harm heretofore not considered (Wolpert 2014). Coaching patients and families to construct their distress in a particular language and as a set of numerical signifiers whatever their circumstances could be problematic. Symptom scales are a decontextualized representation of the patient, in the sense that they are concerned only with the specific issues deemed important by the creator of the PROMs (Torenholt and Tjørnhøj-Thomsen 2021). The view of the person here is one in which the body is viewed, for the most part, as a scientific object, composed of parts made up of physiological systems that medical science aims to fix (Marcum 2008).

The self-monitoring of symptoms assumes that the concept of quality of life exists and is conceptually understood. Concepts such as quality of life and/or defining one's experience as a numerical list of scores, for the most part reflect Western definitions of health. However, Indigenous people across Australia, New Zealand, and Canada for example, tend toward holistic, multidimensional, and interconnected understandings of health and well-being unable to be separated into distinct individual units (Connolly 2017; Durie 1985). Annmarie Mol's thesis takes this even further arguing that judging one's life via tick boxes does not make sense because "you are inside your life, you live it and you cannot disentangle yourself from it and establish its quality from a distance" (Mol 2008). The second assumption is that patients and/or families want to have greater control of their health (Lupton 2013). Lupton's critique of digital engagement and patients, including in the setting of those with chronic illness, highlights how "empowerment" can become a "set of obligations" and agrees that not all people have the "economic or cultural capital to enact the "role" that is envisaged by discourses of symptom self-monitoring" (Lupton 2013).

In a study to investigate telehealth in palliative care, patients were asked to complete the SAS daily on an iPad. For some people, this was a reassuring and positive experience because they knew that their level of symptom distress was being monitored daily by a specialist palliative care nurse (Morgan *et al.* 2017). Similarly, day hospice patients felt that the palliative care outcome scale was useful in helping them to communicate their individual needs and concerns, especially in a shared space with little privacy (Slater and Freeman 2005). Community patients reported experiences of completing the integrated palliative care outcome scale was largely positive providing them the opportunity to reflect on their illness including how and to what extent it affected them (Högberg *et al.* 2019). Promoting self-reflection, however, assumes a desire for what Seale describes as “open awareness” and may risk further marginalizing those for whom such “open awareness” of illness and of dying is not a value or cultural norm (Seale *et al.* 1997). Moreover, patients, like clinicians are required to do “data work” involving approximation of their embodied experiences in order to classify themselves in predefined categories (Torenholt *et al.* 2020). For instance, in the Telehealth study, completion of the SAS, for some people, was a constant reminder of the level of distress as a result of symptoms and for whom answering the questions was in and of itself distressing (Slater and Freeman 2005). A recent study in the hospital palliative care setting also showed that patients found repeated questionnaires burdensome (Whitehurst *et al.* 2014). Moreover, people often wish to express the quality, nature, and impact of their symptoms beyond that which is possible via a numerical rating via an iPad (Morgan *et al.* 2017). When Watanabe *et al.* (2009) asked patients to examine cognitive processes in completing the Edmonton symptom assessment score, participants conveyed their difficulties in comprehending the terminology of the symptoms and would often translate the symptom term into their own words when “thinking aloud” (Watanabe *et al.* 2009). The work of Torenholt *et al.* (2020) shows how patients, like clinicians, filter completion of PROMS according to the perceived purpose and recipient of these data (Torenholt *et al.* 2020). Some patients manipulate PRO data to minimize stigma and/or influence their treatment as Dowrick *et al.* found in their study of people with depression (Dowrick *et al.* 2009). Therefore, by promoting the articulation of distress in a particular format and through PROMS-PC there may be at risk of further marginalizing or alienating those groups who have limited or no access to specialist palliative care services.

Are we measuring what we think we are measuring?

The assumption behind PROMS-PC is that the resulting data are solid, or valid, in the sense of reproducible and reliable (Davieson *et al.* 2021). This is in contrast to other types of data not deemed reliable or trustworthy. Measurement tools, including PROMS-PC must serve the purpose for which they are intended, *i.e.* to make health services better. That is, PROMS-PC needs to have teleological value (Mitchell *et al.* 2021). The somewhat “taken for granted” benefits of PROMS-PC are mostly articulated in the health and medical literature, as a positive focus on the individual and associated improvements of clinician–patient communication and health care. Yet these assumptions and subsequent consequences are rarely the focus of deeper reflection and study (Andersson *et al.* 2022). That PROMS’ numerical data are to be trusted more than other forms of data are debated in the literature. There is often an assumption that those collecting and entering

numerical data are doing so consistently and reliably, within-patient and across patients; within services and across different services. Numerical data assume a higher status over descriptive, simply by being numerical. A recently reported ethnographic analysis on The Liverpool Care Pathway for the Dying Patient (LCP) points to the need for a more nuanced understanding of how PROMs are used in practice. Despite assumptions of “standardization” how the values represented by the LCP were enacted in different national contexts, organizations and by different clinicians were significantly different in England and the Netherlands (Borgstrom and Lemos Dekker 2022).

While PROMs are often subjected to psychometric testing, contemporary validity theorists advocate a network of empirical evidence to support the intended interpretation and use of PROM scores for decision making in particular contexts (Hawkins *et al.* 2018). Few PROMs tools had been subjected to investigation to explore whether or not patients attributed the same meanings and interpretations to items that were intended by PROM designers (Greenhalgh *et al.* 2017). This qualitative evaluation of how people understand and interpret items is now advocated as integral to the development of new PROMs (Patrick *et al.* 2011).

Research reported in the health and clinical literature tends to make the assumption that the overall effects of data collection and analysis are positive, inherently “good” and not detrimental to either service delivery or expertise and experiences of patients and families as well as practitioners. Literature on PROMs-PC in the clinical field assumes, for the most part, implementation is incapable of leading to iatrogenic harms. This supposition may be misguided. For example, Wolpert posits the potential iatrogenic consequences of the use of PROMs for audit and research purposes (Wolpert 2014). For example, a study exploring changes in the content of the discussion in the consultation over time found that PROMs feedback increased the frequency of clinician’s discussion of symptoms with patients, but not psychosocial issues (Takeuchi *et al.* 2011). In an attempt to address this gap, a recent Australian paper reports the implementation of a PROMs-PC for what the authors refer to as psycho-existential “symptoms,” *i.e.* the Psycho-existential Symptom Assessment Scale (PeSAS). This scale asks patients to provide a numerical score for 10 items: anxiety; discouragement; trapped by illness, hopelessness, pointlessness, loss of control, loss of roles, depression, the wish to die, and confusion (Kissane *et al.* 2022). Here suffering is assumed to be a “symptom” of a pathology that is “fixable.” Extending the PROMs-PC benchmarking paradigm to include a scale such as PeSAS raises further paradigmatic concerns. Physical symptoms may lend themselves to such numerical reductionism to some degree. However, whether patients can engage in a similar fashion in enumerating their psychoexistential distress needs careful and objective evaluation. Further, evaluating psychoexistential experiences in this way may result in regarding professional care as low quality should scores in the aforementioned domains remain unchanged or worsen despite intervention. This assumes, first and as den Hartogh argues that emotional states such as grief and distress are inappropriate responses to the real circumstances of a person. Second and notwithstanding the important role of health-care professionals in providing psychosocial and spiritual support, this would mean conflating the professional role to one whereby psycho-existential “interventions” are expected to “cure” or “fix” a person. This, argues den Hartogh, crosses a boundary of what he refers to as “constraints of realism” (den Hartogh 2017) if suffering is understood as a threat to personhood as defined by Cassell (1991 2004). Ironically, as den Hartogh posits, to not be sad or even depressed in

response to certain circumstances in the face of death may in fact be pathological (den Hartogh 2017).

A further assumption is that palliative care clinicians and other stakeholders use PROMs-PC data to continually improve care for patients and their families and that this has resulted in service improvements. A recent systematic review noted that while PROMs-PC appears to have an impact on processes and outcomes of care in palliative care, feedback of PROMs-PC does not appear to improve overall health-related quality of life (Etkind et al. 2015). In addition, many PROMs-PC studies relate, for the most part, to an oncology population (Clapham et al. 2021). The authors conclude that investigations of other disease and other settings relevant to palliative care need further investigation (Etkind et al. 2015).

Discussion: evaluating and enhancing PROMs-PC

Acknowledging the aforementioned issues and limitations of PROMs-PC as well as the opportunities afforded to patients and families, there is a need to seek diversity of evidence to evaluate this assumption beyond the “evidence” characterized by PROMs themselves. As Greenhalgh and Papoutsis have argued a more pluralist approach and a wider range of evidence is needed to define what counts as “high-quality” evidence (Greenhalgh and Papoutsis 2018). As COVID-19 has made evident, the circumstances of the real-world often differ from the ones in which conventional approaches to research are used, for multiple social and behavioral reasons (Greenhalgh et al. 2022).

The diverse approaches would draw from already existing diverse bodies of evidence and investigate the currently opaque consequences of implementing PROMs-C as well as capturing data in a variety of forms and from the perspectives of all stakeholders, including patients and caregivers. It would take account of the messiness of interacting nonlinear systems and contexts given the practice of routine measurement can result in transformation of health care in unintended ways (Mitchell et al. 2021). As Seymour and Clarke (2018) argued in their critical analysis of the rise and demise of the Liverpool Care Pathway in England, the key lesson is about the need for “greater assessment of the wider risks involved and more careful consideration of the unintended consequences that might result from a given course of action” rather than the “dangers of scaling up clinical interventions that lack an evidence base” (Seymour and Clarke 2018). The potential of unintended consequences need to be better understood given data resulting from PROMs are rarely neutral. Rather they are “politicised, improvement efforts flounder, or targets and indicators have perverse effects. Indeed, public performance measures are not neutral assessments of performance, but can alter behaviour in unintended and dysfunctional ways” (Braithwaite and Mannion 2011). As well as service improvements, there is a widely held assumption that collecting PROMs-PC data provides services with meaningful information to support increases in resource allocation from government or other funding bodies. This assumption appears to be largely untested.

The palliative care movement espouses the need to clarify misunderstandings of what palliative care is to other clinicians, service providers, and service users. Notwithstanding intractable debates in the literature concerning the language of palliative care as well as the charge that it has now become biomedicalized (Clark 2002), privileging certain aspects of care and communicating these to the broader clinical community and public risks perpetuating unintended messages. By focusing on physical symptoms at the

expense of issues given high importance by patients and families there is a risk of erosion of those aspects of care (Mitchell et al. 2021). Reducing palliative care to what “can” be measured risks what is referred to by Holmstrom and Milgrom as “effort substitution” – in other words – a reduced performance where targets do not apply (Kearney 2000). This partial view, with its associated tendency to exclude the social complexities of people’s lives has the potential to undermine issues of most significance to people unless fully defined by patients, families, communities as well as other stakeholder recipients. Further, if the rhetoric that palliative care is “everyone’s business” is to move to reality then the question as to how PROMs-PC are best implemented and for who needs to be asked? For example, who gets to self-report and who doesn’t as well as what they do they get to self-report are surely important questions? For example, in Australia, only 40% people who could benefit from specialist palliative care receive it.

Conclusion

There continues to be a strong push for health care to integrate PROMs and palliative care is no exception. At the same time and within the wider health-care arena and the field of patient safety and quality, there is an increased promotion of patient, family, and service user experiences of care as a measure of quality. Historically the palliative care movement has led the way in person-centered care resisting a solely biomedical approach to care and treatment. This review has highlighted that PROMS-C alone are unlikely to produce person-centered care. If PROMs-PC are to be used then there is an imperative to study what they achieve (and don’t achieve) using diverse methodologies underpinned by latest evidence-based approaches, including qualitative evidence otherwise the “measurement” agenda risks delegitimizing the very voices of the patients and families palliative care aims to serve. Further, there is a need to research the effects of outcome measurement in palliative care using diverse methodologies and through different theoretical and disciplinary lens to fully understand their adoption and in different contexts. A research agenda that promotes a deeper and fuller understanding of what the effects of these measures are and that asks the kind of questions that might allow discovery of these effects is needed so that PROMS-PC can be better used to improve the care of patients and families.

Competing interests. None.

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