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Using and implementing individual-level outcome measures in palliative care settings: a reflective commentary

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Summary. Individual-level outcome measures are an important aspect of palliative care. They are tools that can drive high-quality, person-centred care through providing healthcare professionals and services with valuable information about the patients we see, supporting us in making important decisions on patient care, and helping us to evaluate the effectiveness of clinical interventions. By reflecting on contemporary evidence from within palliative care, this commentary has three purposes. Firstly, we describe what individual-level outcome measures are and make the case for their importance within palliative care. Secondly, we highlight how we may get the most out of these outcome measures through using them in different ways. Finally, we reflect on the challenges to implementing outcome measures and advocate for the adoption of a 'whole-systems' approach that is complemented by implementation science when integrating them into practice. We provide practical advice and considerations on how this approach may be adopted. Accordingly, we hope that researchers working in this area, as well as those in clinical practice who are involved in using or implementing outcome measures across different settings of care, will reflect and critically engage with these suggestions in order to inform their implementation efforts and use of outcome measures.

Key words. Outcome measures, implementation science, palliative care.

Utilizzo e implementazione di misure di esito individuale nei contesti di cure palliative: una riflessione.

Le misure di outcome a livello individuale sono un aspetto importante delle cure palliative. Sono strumenti che possono favorire un'assistenza di alta qualità e incentrata sulla persona. Da una parte possono fornire agli operatori e ai servizi sanitari informazioni preziose sui pazienti che assistiamo, dall'altra possono supportare nelle decisioni importanti sulla cura dei pazienti, oltre ad aiutare nel valutare l'efficacia degli interventi clinici. Partendo dalle attuali evidenze derivanti dalle cure palliative, questa riflessione ha tre obiettivi. In primo luogo, descrivere quali sono le misure di esito a livello individuale e confermare la loro importanza all'interno delle cure palliative; in secondo luogo, indicare come ottenere il massimo da queste misure di esito utilizzandole in diversi modi; e infine, riflettere sulle sfide per l'attuazione di tali misure e sostenere l'adozione di un approccio di sistema che sia complementare all'esercizio della scienza quando integrato nella pratica. Si riportano di seguito consigli pratici e considerazioni su come adottare un simile approccio. L'augurio è che i ricercatori che lavorano in quest'area, così come quelli che si occupano di pratica clinica, e che sono coinvolti nell'uso o nell'implementazione di misure di esito nei diversi contesti di cura, riflettano e raccolgano criticamente questi suggerimenti al fine di implementare e utilizzare le misure di esito.

Parole chiave. Misure di esito, scienza dell'implementazione, cure palliative.

Introduction

By 2060, the global need for palliative care is projected to increase by 87%[1]. To meet the needs of this increased number of patients, it is essential that we are able to systematically identify, monitor, and address their symptoms and concerns. One way of achieving this is through using patient-level outcome measures. In this commentary, we demonstrate the value of outcome measures for palliative care and suggest how to implement them into routine clinical practice. As such, this article is split into three sections. The first section outlines what outcome measures are within palliative care and draws on available evidence in demonstrating the value of using them to inform patient care. The second section builds on the first by highlighting how we may collect outcome measures appropriately and then use them in different ways in order to get the most out of them. The final section outlines some common implementation challenges associated with integrating outcome measures into everyday clinical practice, and argues for the importance of adopting a whole-systems approach when attempting to implement them.

What are outcome measures?

Within healthcare, an outcome is defined as 'the change in a patient's current and future health status that can be attributed to preceding healthcare'[2]. In capturing *change*, therefore, outcomes require individual-level information about patients to be collected at two or more timepoints (figure 1). To collect this information, measurement tools are needed. In ensuring that clinical decision-making is driven by a person-centred approach, it is advocated that these

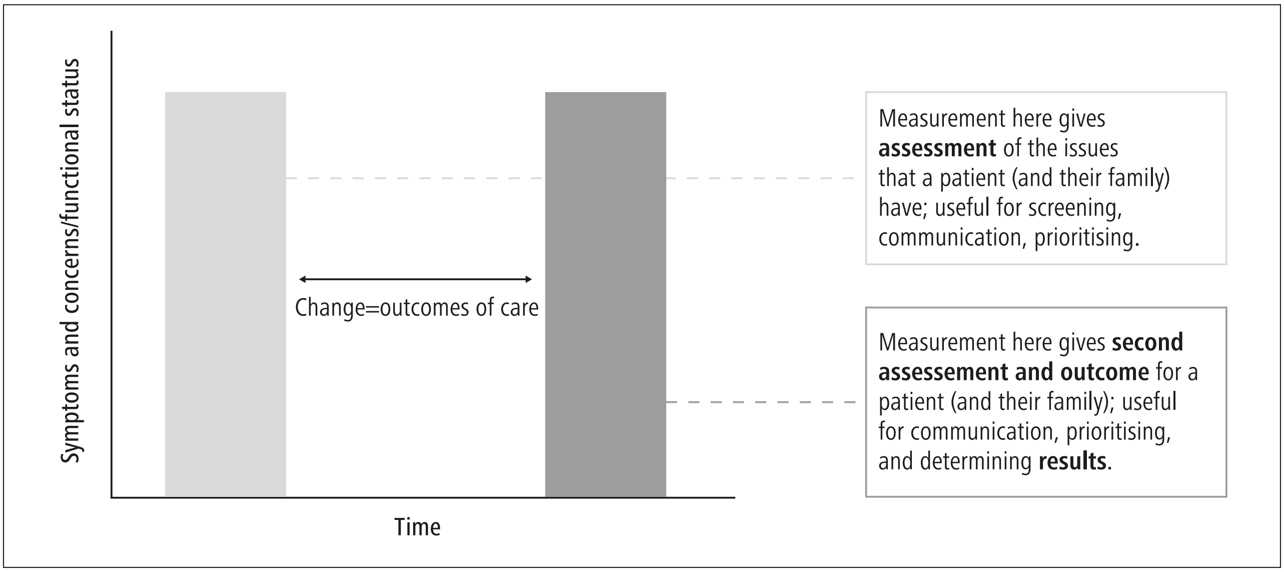

Figura 1. The difference between assessment and outcomes.

measurement tools are designed in ways that assesses the perspectives of patients directly[3-5]. In achieving this, Patient-Reported Outcome Measures (PROMs) are considered as the ‘gold standard’ for outcome measurement within palliative care[6]. PROMs require patients to fill out standardised and validated questionnaires which provide health-care professionals with information regarding their own perceptions of their health status and well-being[7]. It is often the case, however, that many patients with palliative care needs lack the capacity to complete outcome measures (due to impaired cognition or being too unwell)[8], and so patient-centered outcome measures (PCOMs) are often used in clinical practice. Whilst these include PROMs, they also include proxy-reported ratings which, whilst still endeavor to focus on and evaluate concerns most important to patients, are completed by others (e.g., by healthcare professionals and/or a patient’s family member)[7].

Within palliative care, most core outcome measures that are used can be split into two types: (i) functional status measures; and (ii) symptom measures. Functional status measures assess the physical performance/functional status of an individual, and often are centred on their ability to perform common activities of daily living. The most commonly used functional status measures in palliative care are the Australia-modified Karnofsky Performance Status (AKPS)[9] and The Modified Barthel Score for Palliative care[10-12]. Symptom measures aim to assess the different illness-related physical, psychological, social, and spiritual symptoms that a person may experience. A multitude of symptom measures are used within palliative care, including the palliative Phase of Illness[13], the Edmonton Symptom Assessment Scale (ESAS)[14], the Memorial Symptom Assessment Scale (MSAS)[15], the Palliative Care Problem Severity Score (PCPSS)[16], the Symptom Assessment Scale (SAS)[17-19], the European Organization for Research and Treatment of Cancer Quality of Life 15 items Questionnaire for Palliative Care (EORTC QLQ-C15-PAL)[20, 21], and the Integrated Palliative care Outcome Scale (IPOS)[22,23]. Some of these measures focus exclusively on symptoms, and others focus on the wider range of symptoms and other concerns which affect those with advanced progressive illness. IPOS is a particularly good example of a measure which assesses the full range of concerns that a person may have (not just their symptoms). It also has both patient and proxy versions; it can be completed by patients themselves (via the self-reported version) or healthcare staff (via the proxy-reported version)[23].

Why are outcome measures important?

To improve the standard of palliative care that is provided to patients and their families, measurement is important. This is so that we are able to understand whether or not current practice is working or getting better, or whether it is not[24]. In assessing the quality of healthcare, the Donabedian framework is the most widely adopted model. This framework consists of three components: structures, processes, and outcomes[25,26]. Assessing structures allows us to understand the effectiveness of resources, people, equipment, and buildings, whereas measuring processes assesses the effectiveness of how these structures/resources are used[24]. Most research within palliative care has focused on examining structures and processes of care[6,24]. Whilst these are necessary prerequisites for good palliative care, neither can guarantee, nor provide indicators of, good quality care. This is because they do not tell us anything about the patients we see (i.e., their needs or concerns) or whether the interventions that we use in clinical practice are effective at addressing these.

Thus, measuring outcomes is important because they provide healthcare professionals with valuable information about the patients we see, support us in making important decisions on their care, and help us to evaluate if the clinical interventions that we use are effective or not[3,27]. Indeed, there is strong evidence[7,24,28-31] to support the use of PCOMs in routine palliative care. At a patient level, they act as tools that can support:

- Improved communication between patients and clinicians.
- The identification of unrecognised symptoms.
- Monitoring of symptoms and concerns.
- Increase the amount of clinical action taken based on data.
- Improve patient satisfaction and experience.
- Reduce reports of debilitating physical symptoms at subsequent visits.

Moreover, aggregating data from individual PCOMs also allows for benchmarking and auditing (i.e., setting standards to compare the quality of care to) so that we are able to highlight areas in which health services/organisations are doing well and identify areas for improvement and refinement[32]. An example of this can be seen from the Australia Palliative Care Outcome Collaboration, who have demonstrated the value of benchmarking and auditing to systematically improve clinical outcomes at a service level through routine outcomes data collection and feedback to hospice services[33].

For these reasons, in working towards high quality palliative care, the European Association for Palliative Care recommended that PCOMs are implemented into routine clinical practice across all settings in which palliative care is delivered. [6] Moreover, they also advocate for the 'establishment of National and international outcome collaborations that work towards benchmarking to establish and improve care standards.' Despite these recommendations, PCOMs are not always used in clinical practice. One reason for this may be that healthcare professionals often report difficulties in understanding what they are and how they should best be used to benefit patient care[3,34-36].

Getting the most out of outcome measures

Whilst there are numerous potential benefits of using outcome measures, their value is not derived through simply using them more often. Rather, in getting the most out of outcome measures, using them *appropriately* is crucial. This entails two major considerations: (i) collecting outcome measures correctly; and (ii) using the data we have collected effectively.

COLLECTING OUTCOME MEASURES CORRECTLY

Collecting outcome measures correctly involves understanding how to collect data using the right measures, at the right time, and in the right settings. Many of the outcome measures that have been developed and designed specifically for use in palliative care contain 'rules' with regards to how and when they should be collected across different settings of care. For example, in the UK and much of Europe, a core set of outcomes measures (palliative Phase of Illness, AKPS, and IPOS) are used in clinical practice. These measures inter-relate with one another, and the frequency and timing of their use depends on whether they are being used within inpatient hospice or community settings (table 1 for an example). Collecting

Table 1. An overview of the core set of 'OACC' measures37, including their definitions and timings of collection across different settings of care.

Measure	Description	Frequency/timing of collection
Palliative Phase of Illness	Palliative Phase of Illness is a measure which describes the urgency of care needs for a person receiving palliative care. It does so by describing four distinct phases of a patient's illness, including: stable, unstable, deteriorating, dying, and deceased. These Phases are measured through determining the care needs of a patient and/or their family and provide a clinical indication of a patient's Phase of Illness which can be used to inform care planning.	Inpatients (hospice) ■ Daily Community ■ Each contact
Integrated Palliative care Outcome Scale	A holistic, well-validated, and global measure of symptom burden that uses 10 questions (scored on a 0-4 Likert type scale) to assess the most important symptoms and concerns of patients affected by life-limiting illnesses across physical, psychological, social, and existential domains of well-being. There are two forms of IPOS; patient-IPOS (where patients complete the questionnaire as a self-report) and staff-IPOS (a proxy version which is completed by staff).	Inpatients (hospice) ■ Initial assessment ■ Change in Phase of Illness ■ End of episode Community ■ Each contact
Australia-modified Karnofsky Performance Status	Assesses a patient' overall performance/functional status across 3 dimensions: activity, work, and self-care. Healthcare professionals use their observations of patients' ability to perform everyday tasks and scores them at 10% increments between 0% (i.e., the patient is dead) and 100% (i.e., no complaints or evidence of disease).	

each outcome measure appropriately within the setting they are being used is important; failing to do so means that the data collected is less likely to be helpful in guiding clinical decisions or facilitating service development. Conversely, ensuring the appropriate methods of collection of outcomes information is achieved provides the foundation on which these measures may be used to inform clinical practice in meaningful ways.

USING OUTCOMES INFORMATION EFFECTIVELY

Getting the most out of outcome measures, however, requires much more than simply collecting them correctly. The real value of collecting this information is dependent on the different ways in which we *use* this data. A helpful way to understand the different types of value that we may achieve through using outcomes data is through the application of Greenhalgh's framework[38]. Greenhalgh describes how we may use individual level patient data, or the aggregation of this into group data, either directly with or away from patients. Table 2 provides an adaptation of this framework that has been contextualised within palliative care. It provides four 'quadrants', each of which summarises the different ways in which outcome measures may be used.

One way in which we may apply outcome measures is through using and discussing individual level outcomes data directly with patients and their families (quadrant 1). This may be through using them as part of our initial assessments or as a conversation opener to create a person-centred dialogue about the things that matter to individual's the most. We may also use outcome measures at this level to screen for a wide range of symptoms and concerns that cover multiple domains of well-being (physical, psychological, social, spiritual), alongside monitor whether the interventions that we use help to improve them over time.

Another application of outcome measures is through using individual level outcomes data but away from the patient interface (i.e., at a team and/or organisation level; quadrant 2). Within multidisciplinary teams, using measures in these ways can facilitate communication and more efficient working through providing a common language. This may efficiently focus discussions or help in prioritising time and resources on the symptoms and concerns that are most important to patients and their families. Moreover, at this level, outcomes data can also be used between teams and organisations as a way of passing on important information during referrals, handovers, and discharge.

The third way in which we may apply outcome measures is through using group level data with patients (third quadrant). This refers to applying a standard approach to the whole group of patients seen, usually to screen the group of patients for a specific issue or to trigger a specific action once a symptom or concern is identified. Examples might be to formally assess for depression (with a full clinical assessment of mood and mental state) any patients who reports 'depressed mood' above a certain level within a measure. Another example might be that all patients below a certain level of function (or with deterioration in function) might be automatically reviewed by a physiotherapist or an occupational therapist. Electronic scoring can also readily be used to embed decision aids for the professionals or to 'trigger' automatic alerts or referrals, although it is important to understand how such decision aids or alert systems might work and if they are effective, including their safety.

The final way in which we may apply outcome measures is through using group level data away from the patient interface (quadrant 4). Using data in these ways is particularly helpful in assessing quality of care. This is through using aggregated data to monitor who accesses services and assess the impact of these services through demonstrating whether or

Table 2. A summary of the different ways in which outcome measures may be used within palliative care.

	Level of aggregation of outcomes data	
	Individual	Group
Used at the clinician-patient interface	Quadrant 1: ▪ Assessment ▪ Monitoring ▪ Promoting patient-centredness	Quadrant 3: ▪ Cohort screening ▪ Use of alerts and decision aids
Used away from the clinician-patient interface (i.e., within and between teams and/or organisations)	Quadrant 2: ▪ Facilitating within-team communication and team working ▪ Assessing workload ▪ Working with other organisations or teams (e.g., for referrals, handovers, providing discharge information)	Quadrant 4: ▪ Annual reports ▪ Service development; assessing and improving quality of care ▪ Business intelligence and business cases for new/sustained resourcing of services ▪ Population monitoring (who accesses and uses care/services) ▪ Financial resources/tariff

This table is an adaptation of Greenhalgh's[38] matrix on the applications of person reported outcomes in clinical practice.

not they are effective at improving/managing patient symptoms and concerns. Moreover, using data in this way is helpful for developing business cases either for highlighting to funders that more resources and funding is needed either to improve and/or maintain already-existing services, or make funding cases for developing newer and better services.

Despite the potential value of using outcome measures in different ways, they are used inconsistently (if at all). Some palliative care organisations do not collect outcomes data, and many that do often only apply them in ways that algin with only one or two of these quadrants. Whilst this can support patient care, to maximise the value of using outcome measures, it is crucial that they are used across *all* of these quadrants. One reason for the inconsistent collection and use of outcome measures within palliative care is that they are often difficult to implement.

Whole-systems approach to implementation

THE CHALLENGES OF IMPLEMENTING OUTCOME MEASURES INTO PRACTICE

There is a growing body of work within palliative care that has explored the barriers/facilitators that underpin the implementation of outcome measures[3,34-36,39,40]. Common barriers that affect implementation include:

- perceived time constraints
- lack of training and education
- tools being perceived as burdensome
- negative attitudes towards outcome measures
- fear of added work
- top-down approach to implementation
- lack of i.t. infrastructure within organisations
- no feedback of outcomes data
- availability of champions to drive change.

When viewed in silo, each of these issues represents individual, interpersonal, team, or organisational factors that impact implementation. Each of these factors interact in different, and often complex, ways that are important to understand and address when implementing outcome measures into routine practice. For example, our recent study exploring the processes underpinning the successful implementation of outcome measures in palliative care found that efficient I.T. systems that allowed staff to easily input, view, and extract outcomes data (so that they could be fed back to those that used them) were fundamental to successful implementation [34]. When combined with strong leaders who championed their use, this allowed healthcare professionals to see the different values of using outcome measures to inform patient care, helped them to feel involved in implementation, and motivated them to continue learning about and using outcome measures as part of their everyday practice. Conversely, when these systems were not in place, and outcome measures were collected without feedback, many saw them as a ‘tickbox’ exercise. Understanding and addressing these challenges is important if PCOMs are to be implemented into practice and their benefits realised.

A WHOLE-SYSTEMS APPROACH TO IMPLEMENTATION

Effective implementation requires an understanding of how to integrate PCOMs in a systematic, skilled, and consistent manner across the different settings in which palliative care is delivered. To do this involves consideration of the different ‘wrap-around’ factors that underpin implementation. These include thinking about how to demonstrate the importance and purposes of PCOMs to those who are using them, using the right measures at the right time, ensuring follow-up assessments, involving all teams/team members, having efficient feedback systems in place, and embedding PCOMs into the ‘cultural fabric’ of how teams and services operate. Given that these factors exist at multiple levels of practice, we argue that adopting a ‘whole-systems approach’ to implementation is essential in the planning and rollout phases of implementing outcome measures.

A whole systems approach to implementation appreciates the relationships between individual, interpersonal, team, and organisational factors that impact the scale-up and diffusion of complex interventions (such as PCOMs) into specific/local contexts. In adopting this ethos, those interested in implementation may wish to draw on the ideas of Hawe[41], Lanham[42], May[43], McLeroy[44], and Sallis[45]. A central feature that unifies these the theories and models proposed by these scholars is the appreciation that the implementation of PCOMs is affected by complex sociocultural processes, structures, and contexts that are likely to naturally evolve over time. However, rather than attempting to iron out and remove complexity within these contexts, it is important that complexity is accepted and embraced as an unavoidable feature of working within ‘real-world’ settings.

To complement the adoption of a whole-systems approach to implementation, we argue that there is merit in drawing on the principles and methods of implementation science. Implementation science is the systematic study of methods that are used to facilitate the integration of evidence-based practices/interventions (such as PCOMs) into routine clinical practice[46, 47]. This area of study comes equipped with a menu of different theories and frameworks that may be selected to provide a theoretical foundation on which to plan and perform the implementation of PCOMs. This is through drawing on specific theories and frameworks as a basis through which we can make evidence-based and theoretically informed assumptions on how, why, and in which contexts our implementation strategies/efforts are likely to work[46].

There are a few examples from within the palliative care literature of where a whole-systems approach has been complemented by different implementation theories and frameworks. For example, in their systematic review, Antunes et al.[3] drew on Promoting Action on Research Implementation in Health Services’ (PARIHS) framework to highlight the facilitators and barriers to implementing PCOMs that existed across individual, management/organisational, and setting specific levels. Moreover, Pinto et al [36] used the Consolidated Framework for Implementation Research (CFIR) to explore how the implementation of PCOMs across different palliative care settings were affected by individual-level factors (i.e., attitudes, beliefs, and knowledge) alongside the structural, political and cultural context within and outside of the organisations in which implementation occurred. Whilst the specific theories or frameworks that are adopted in research or clinical practice will depend on which is the best fit for answering our research questions, or which is likely to be most helpful in the context that implementation will occur, they ensure a robust and informed way of capturing and considering the multilevel factors that impact implementation.

Using existing evidence on the most important factors that underpin the implementation of PCOMs into palliative care, table 3 provides a summary (yet not exhaustive) set of questions that are designed to help those using PCOMs, or those who are involved in their rollout, to embrace complexity through reflecting on the multilevel factors that should be considered before and during attempts to implement PCOMs across different palliative care settings.

Summary

To summarise, outcome measures are an important part of evidence-based palliative care. The aim of this commentary article was to describe what outcome measures are, make the case for their importance within palliative care, demonstrate the different ways through which they can be used to better the quality of care that we provide to patients, and provide practical advice and considerations on how we may successfully implement them into routine practice*. We hope that researchers working in this area, as well as those in clinical practice who are involved in using or implementing outcome measures across different settings of care, will reflect and critically engage with this article in order to inform their implementation efforts and use of outcome measures.

Notes. For those interested, as part of the RESOLVE project, we have developed a set of training resources (including instructional videos, handbooks, and interactive quizzes) that have been designed to help healthcare professionals in their understandings of what outcome measures are, why they are important, and how they should be used across different settings of care. These may be found through following this link: https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve/resolve-training-resources

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Table 3. A guide to using a 'whole systems approach' to implementing outcome measures into routine practice.

Level of practice	Questions to consider
Individual (e.g., ability, motivations, beliefs, attitudes towards PCOMs)	■ Within the setting that you work (inpatient, outpatient/day therapy, homebased/ community), do you: ■ Understand which outcome measures to use, when to use them, and why you are using them? ■ Know how to input, view, and extract outcomes information into (and out of) your service's electronic system? ■ Understand how to clinically act on/respond to information collected through outcome measures? ■ Know where to go for additional help and advice on how to use outcome measures?
Interpersonal (relationships between staff, patients, and families)	■ Do you know how to deal with scenarios in which patients are too ill to complete PCOMs themselves (i.e., the use of proxy-reported version of outcome measures)?
Team (using PCOMs within and between teams)	■ How will you include your team in the implementation of outcome measures? ■ Have you planned on how to integrate the use of outcome measures into everyday clinical practice and team working (e.g., at multi-disciplinary team meetings, ward rounds, handovers, etc.)?
Organisational (the setting/institutions in which people work and opportunities/resources to support PCOMs use within them)	■ Is there up-to-date and regular training/education in place for new and existing staff using outcome measures (including what PCOMs are, how to use them, and why they are used)? ■ Do you have electronic systems and support in place that allows staff to easily input, view, share, and extract outcomes data? ■ Have you considered how to feedback outcomes information to staff (in supportive and constructive ways where staff do not feel this information is being used to critique clinical practice)? ■ Can you identify staff members within your service/organisation who would be an appropriate outcomes champion/leader (usually people who are experienced in using PCOMs and passionate about their use)? ■ Have you considered a stepwise approach to implementation?

Note: The questions posed in this table are derived from evidence-based solutions provided by studies that have been conducted[3,34-36,39,40].

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