



Outcome Measurement in Palliative Care

The Essentials

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PRISM



PRISMA

Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care



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Palliativmedizin e.V.

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WHO Collaborating Centre for
Palliative Care and Older People



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Foreword

Outcome measurement in palliative care: how to assess what is in the patient's heart and mind

"I only want what is in your mind and in your heart", is what David Tasma, a patient dying from cancer, said to Dame Cicely Saunders in 1949. This may also be used to summarise what we need in order to treat palliative care patients well. We need knowledge about symptom control, good communication skills and empathy, and in exchange we need to know what the patient is feeling (in their heart) and thinking (in their mind).

Surely this cannot be measured. One of the major differences between palliative care and other areas of healthcare is the holistic approach it takes, including psychosocial and spiritual dimensions in addition to the physical suffering. This also presents a major challenge: how to assess concepts such as suffering, dignity and spirituality? These concepts are less well defined and more difficult to measure than, for example, blood pressure or body weight. Measurement of physical symptoms such as pain is well established, but palliative care workers might challenge these assessments with the argument that feedback from the patient on how they are feeling today is more important than the score on a symptom scale. This is reflected by the lack of widely accepted standards for outcome measurement, and the wide scope of different instruments and scales that have been summarised in several recent reviews.

However, 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. We have to prove the quality of the care that we deliver,

account for the resources that are allocated and verify that patients are receiving the best possible care in relation to these resources.

This means that palliative care services have to measure the outcome of their interventions, and be prepared to compare them to other models of care or to other types of service delivery. Outcome measurement of palliative care will become even more important as new players enter the game. Specialists such as geriatricians or neurologists are treating other patient groups, and a public health approach for palliative care has been recommended in addition to specialist palliative care, exposing, for example, general practitioners to palliative care issues. Recently, a workgroup from Boston has demonstrated the benefit of early access to palliative care, which improved not only the quality of life and reduced the costs of treatment, but also increased survival times. This has reinforced the need to start palliative care early, and not restrict it to end-of-life care.

All this adds to the need to provide expert guidance on symptom assessment and measurement in palliative care. Healthcare professionals starting to work in palliative care have to be trained on what measurement instruments to use, how to use them and what to do with the results.

This booklet provides the practical guidance that is needed for patient-reported outcome measurement in palliative care. It is based on the experiences of the PRISMA project, funded by the European Commission's Seventh Framework Programme. The booklet does not focus on specific instruments, but rather explains the background and the meaning of outcome measurement, and

then proceeds with step-by-step training on how to do it. The booklet is suitable for training specialist and non-specialist staff in palliative care outcome measurement. It can be used as basic training material for a research collaborative to agree on a common understanding, as well as for new model services introducing palliative care in unusual settings or for new patient groups.

The authors are to be highly commended for their contribution to the improvement of palliative care. Following the guidance provided by this booklet, the next step should be the development of a framework for the selection of outcome measurement instruments according to the setting and dimensions that have to be covered. For this purpose, a Task Force of the European Association for Palliative Care (EAPC) has recently been established, led by the authors of this booklet. I hope that the basis provided here, and the results that can be expected from the EAPC Task Force, will lead to the continuous development and improvement of palliative care outcome measurement and thereby, finally, to an on-going improvement of patient care across Europe.



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for Palliative Care (EAPC)*



Introduction

More and more people are living with a chronic disease near the end of their life, in Europe as well as the rest of the world.

Palliative care needs are therefore increasing, and they are also becoming more complex because of the range of illnesses patients are suffering from. Furthermore, the integration of palliative care within the healthcare system, and across countries, varies greatly, which adds to the challenge of providing high-quality palliative care.

Outcome measurement has a major role to play in improving the quality, efficiency and availability of palliative care. Measuring changes in a patient's health over time, and finding out the reasons for those changes, can help service providers focus on learning and improving the quality of services. Outcome measures, specifically Patient-Reported Outcome Measures (PROMs), are tools that can effectively be used in palliative care to assess and monitor care, either for individual patients, or across populations. PROMs put the patient at the centre of care and focus on what matters to them.

There is an extensive range of different types of outcome measures for

use in clinical care, audit and research, and it can be difficult to know which to choose and how to effectively use them. This guidance gives palliative care clinicians information about what outcome measurement is and how it can be used to improve care plus guidance on choosing and using outcome measures. This booklet will be useful for anyone working with those requiring palliative care, including nurses, doctors, psychologists, social workers, those providing spiritual care and therapists.

The PRISMA project, funded within the European Commission's Seventh Framework Programme, aims to inform best practice and harmonise research and outcome measurement in end-of-life care across Europe. As part of PRISMA, an online survey on the use and experiences of professionals with outcome measurement in palliative care, and an expert workshop about outcome measurement in palliative care, were conducted. Both emphasised the need for more guidance and training on outcome measurement. In response to that, this guidance was developed to inform palliative care clinicians involved in patient care, audit or research, who want to know more about the practice of outcome measurement.

Chapter 1

Outcome measurement and palliative care

What outcome measurement is

Outcome measurement is a way of measuring changes in a patient's health over time. An outcome can be described as "the change in a patient's current and future health status that can be attributed to preceding healthcare".¹ Outcome measurement involves the use of a measure to establish a patient's baseline health status, and then evaluating changes over time against that baseline. Outcome measures help to record these changes. By using these measures it is also possible to measure the structure, process and output of care. However, outcome is what directly affects the patient and their family (Figure 1.1), and this is what we focus on in this guidance.

Why it is important to measure outcomes

Outcome measures are widely used in health research to describe patient populations or to assess the effectiveness of interventions, but they are not, as yet, always incorporated into routine clinical practice.³ However, with the increasing focus on patient autonomy, equitable service delivery and transparent information compelling service providers, healthcare commissioners and funders to demonstrate effectiveness and value for money, outcome measurement is becoming a more important procedure to consider. In addition, funding from governments or commissioners is becoming more often a condition for on-

going provision of outcomes data.⁴ The use of outcome measurement is therefore becoming increasingly important in healthcare, both in general and in palliative care in particular.

Accountability to patients, funders and governments is another driving force in terms of outcome measurement activity in healthcare, with service providers being required to demonstrate efficiency and high-quality care. Palliative care services need to have a genuine interest in using outcome measures in order to enhance quality assurance, maintain on-going quality improvement and strengthen the learning capacity of the organisation. Service providers, commissioners and funders also have an

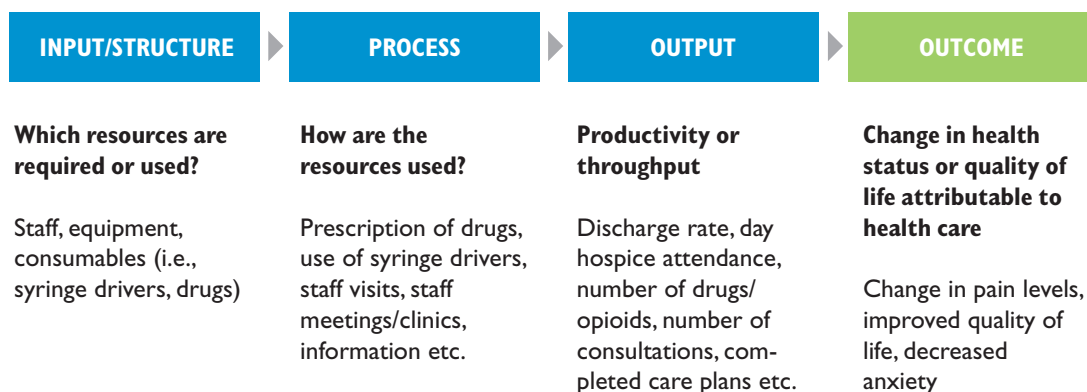


Figure 1.1 A palliative care example regarding the sequence involved in outcome measurement (adapted from Higginson and Harding 2007²)

ethical responsibility to ensure that vulnerable patients and their families, such as those requiring palliative care, receive services that effectively contribute to their well-being and quality of life, despite advanced disease.

How outcomes are measured

As outcomes in healthcare are related to patients' experiences, patients are the main source of information concerning changes in their health status, quality of life or symptoms. These outcomes can be measured using a variety of tools, for example Patient-Reported Outcome Measures (PROMs or PROs), which are questionnaires or instruments used to capture these changes.

How outcome measures are used in palliative care

Outcome measures are used for assessing, measuring, evaluating or monitoring a range of different aspects of healthcare. There are three main purposes behind the use of outcome measures: clinical care, audit and research. The type of outcome measure used will be dictated by the purpose.

In clinical care, outcome measures can be used to:

- ▶ establish patients' baselines (for example, baseline pain level, existential distress or spirituality);
- ▶ assess patients' symptoms, as well as families' and patients' needs/problems;
- ▶ monitor changes in patients' health status or quality of life;
- ▶ facilitate communication with patients/families and the healthcare team;
- ▶ aid clinical decision making;
- ▶ evaluate the effect of interventions, care or services.

For clinical purposes, outcome data are usually recorded in the patient's clinical record and shared amongst team members to promote cohesive, co-ordinated patient-centred care (see Chapter 4). This type of data may also feature in case study reports and publications, or within reports to funders in relation to funding care for individual patients.

Audit is a systematic approach to evaluating quality or performance in

healthcare. It involves setting or establishing standards, monitoring or observing performance or practice, and then evaluating what was done in relation to the standard identified. A clinical audit focuses specifically on clinical care, but audit projects can also be broader in their focus, for example, the practices within organisations or departments may be examined in an organisational audit.

For the purposes of audit, outcome measures can be used to:

- ▶ establish standards of practice in particular departments (for example, in medicine, nursing, social work, physiotherapy or music therapy departments), or within palliative care teams or organisations;
- ▶ assess the care given against established standards, with the view to improving standards;
- ▶ determine uptake of service;
- ▶ benchmark or compare standards of practice in one organisation with another organisation.

The main aim of research is to understand the patients' situations better and improve their care. To demonstrate results, measurement of outcomes is crucial. Therefore, the use of outcome measures and, increasingly, patient-reported outcomes is an intrinsic part of research and researchers are often much more familiar than clinicians with the use of outcome measures.

For the purposes of research, outcome measures can be used to:

- ▶ screen whether patients meet inclusion criteria for a study;
- ▶ assess patients' functional status;
- ▶ measure or describe patients' symptoms, quality of life and quality of care;
- ▶ monitor changes in patients' health status or quality of life;
- ▶ evaluate the effect of interventions, care or services.

Outcome measurement data for research are usually presented in a summed or aggregated manner. Patients and organisations are not usually identified, and findings may be published for wide dissemination.

Outcome is what directly affects the patient and is what we focus on in this guidance

Practical and ethical challenges of outcome measurement in palliative care

Patients in palliative care have unique needs. The illness trajectory in palliative care, for example, poses a challenge to outcome measurement as patients' health will deteriorate and symptoms will probably worsen. This deterioration makes the detection of health-related outcomes challenging. At the very least, deterioration in physical health is expected, and changes in cognitive abilities are also likely to occur closer to the time of death. These challenges influence what type of outcome measure can be used, who they can be used with and when they can be used. For example, PROMs are impossible to use closer to the time of death once the patient becomes unconscious.

Ethical considerations also play an important role in enabling outcome measurement in palliative care. For example, is outcome measurement data sufficient for determining what care is needed for patients at the end of life? Should outcome measures be used for symptoms that are difficult to report? How often should symptoms be measured when patients might rather spend time with loved ones before their death? If there is no valid outcome measure to use, should we just not measure at all?

To aid the development and implementation of outcome measurement in palliative care, an international expert meeting was convened in 2010 by PRISMA⁵ (see Introduction). The group agreed on the following:

- ▶ Standardisation and agreement of a core set of tools in palliative care needs to be based on rigorous scientific criteria, rather than by consensus only. Standardisation needs to be balanced with diversity and flexibility.
- ▶ Training, support and resources for outcome measurement for clinical care, audit and research are required for palliative care clinicians and researchers. These could be web-based, printed materials or face-to-face training sessions. The training needs to include how to

choose an outcome measure, along with information and practical strategies on implementing outcome measures in organisations, and how to analyse and interpret findings.

- ▶ When translating outcome measures for use in other countries, it should not simply be a literal translation of the tool. Instead it should encompass the process of learning what things mean: the heuristic process of meaning. The measures need to have the same meaning and impact in different cultures and languages. Cultural competencies and local differences must be taken into account when translating outcome measures for use in palliative care.
- ▶ A multi-professional approach is required in outcome measurement in palliative care, and the different competencies of the professional groups involved in palliative care must be acknowledged. Nurses should be involved in the development of outcome measures in order to aid successful implementation of the measures in clinical care.

KEY POINTS

- ▶ Outcome measurement is a way of measuring changes in a patient's health (which can be attributed to preceding healthcare) over time.
- ▶ It can be used to improve the quality of healthcare services.
- ▶ Outcome measurement can be used for clinical care, audit and research purposes.
- ▶ There is an increasing need for robust outcome measurement in the field of palliative care, but this poses particular challenges and requires special consideration with regard to patients' situations at the end of life.

Further reading

Palliative care

- ▶ Davies E, Higginson IJ, eds. *Palliative care: the solid facts*. Copenhagen, WHO Regional Office for Europe, 2004 (www.euro.who.int/InformationSources/Publications/Catalogue/20050118_2, accessed 1 December 2010).
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Use of outcome measures

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Chapter 2

Choosing and using outcome measures

Choosing an outcome measure

A huge variety of outcome measures exist in palliative care. They differ in the domains and dimensions they measure, and in their length, accessibility and cost. This diversity makes the selection of a measure challenging. Ideally, original literature (for example, publications about the development of the measure) about a specific outcome measure and studies on the validation of that measure should be reviewed to inform one's choice. However, as this is often not practical for clinicians, review articles (which systematically identify, appraise and synthesise the evidence) about outcome measures can help to get an overview of the necessary information.

When deciding which measure to use, the aims and the reason for using an outcome measure should be taken into consideration. This includes considering the context of the outcome measurement, that is, whether data will be routinely collected in clinical care, for audit purposes or within a research study (see Chapter 1). For example, for clinical care, short, widely accepted measures might be more practical; whereas in research, a series of measures may be needed. Relevant questions to ask when choosing an outcome measure are shown in Figure 2.1.



Figure 2.1 What to consider when choosing an outcome measure

Types of PROMs in palliative care

Generic versus specific

Generic or specific outcome measures can be used within palliative care. Generic measures are multidimensional measures that include physical, psychological and social health components. They are able to be used on a large range of health and quality of life concepts, and in various health conditions, populations and interventions. Specific measures are specially designed for particular domains, health conditions, signs and symptoms, body parts or populations (see Table 2.1).

Single item versus multiple items

Outcome measures that use single-item scales measure a concept of interest using a single question. For example, the severity of a symptom such as pain can be measured by asking a patient to rate the severity on a scale from 0 ('no pain') to 10 ('worst pain I can imagine'). The endpoints, which are also called 'anchors', need to be clearly defined but can vary in the wording. If just two endpoints are provided on a continuous line (normally 10 cm), this is called a visual analogue scale (VAS). When using a VAS, the patient marks a point between the two endpoints where the patient rates the pain (see Example 2.1). The actual value is then

Table 2.1 Type of outcome measures

	Generic measures	Specific measures
Advantages	<ul style="list-style-type: none"> ▶ applicable across a broad population for comparing different conditions; ▶ large range of domains; ▶ can compare palliative treatment with other treatments. 	<ul style="list-style-type: none"> ▶ specifically developed to measure outcomes in palliative care; ▶ for use in specific conditions or domains (for example, symptoms, function, palliative care needs); ▶ more responsive to clinically meaningful changes.
Disadvantages	<ul style="list-style-type: none"> ▶ often lack responsiveness to change; ▶ not validated in palliative care; ▶ do not allow specific problems to be identified. 	<ul style="list-style-type: none"> ▶ do not allow direct comparison with data collected from another patient group.
Examples	<ul style="list-style-type: none"> ▶ SF-36¹ ▶ EuroQol (EQ-5D)² ▶ General Health Questionnaire (GHQ)³ ▶ Sickness Impact Profile⁴ 	<ul style="list-style-type: none"> ▶ Palliative care Outcome Scale (POS)⁵ ▶ Hospital Anxiety and Depression Scale (HADS)⁶ ▶ Edmonton Symptom Assessment Scale (ESAS)⁷

Example 2.1 - Visual analogue scale (VAS)



Example 2.2 Numerical rating scale (NRS)



measured using a ruler. If the line has numbers in between (for example, from 0 to 10, as shown in Example 2.2), this is called a numerical rating scale (NRS).

There can sometimes be problems using a VAS with palliative care patients who are very ill, as they need to be able to see the scale. Patients may need to put glasses on and sit up to fill in the VAS. Using numerical scales can mean more patients can take part as they do not need to see the scale in order to answer the question.

Outcome measures that use multiple-item scales combine various questions on a specific area. They are more complex to develop, and can be more burdensome for patients but they are often more effective in describing a multidimensional phenomenon.

Domains and dimensions

Most outcome measures cover various domains and dimensions. Domains describe the scope of an area of interest; dimensions relate to measurable quantities or particular aspects of a problem. Outcome measures in palliative care can cover several domains, for example, the patient, family and carers, or quality of care, as well as physical,

psychological, social or spiritual dimensions (see Figure 2.2). The choice of a measure depends on which outcome needs to be measured, for example, individual symptoms, palliative care needs or quality of life.

The patient

A patient's experience can be related to physical (for example, symptoms and functional status), psychological (for example, cognition and emotions), social and cultural (for example, family and friends, organisational and financial), and spiritual (for example, beliefs, meaning and religion) domains, which are all interlinked. As palliative care aims to provide holistic care for patients and families, an outcome measure should ideally cover several of these domains, as well as aspects of care. Some examples for this are given in Table 2.2.

A large number of outcome measures have been developed to measure specific physical dimensions, for example, symptoms such as pain, breathlessness or fatigue. These measures give a more in-depth view of the problem and, as they are very specific, it is likely that they are more often used in research rather than clinical care. Psychological symptoms, such as

Outcome measures in palliative care can cover several domains

Example 2.3 Domains and dimensions of outcome measures in palliative care (adapted from Mularski et al 2007⁸)

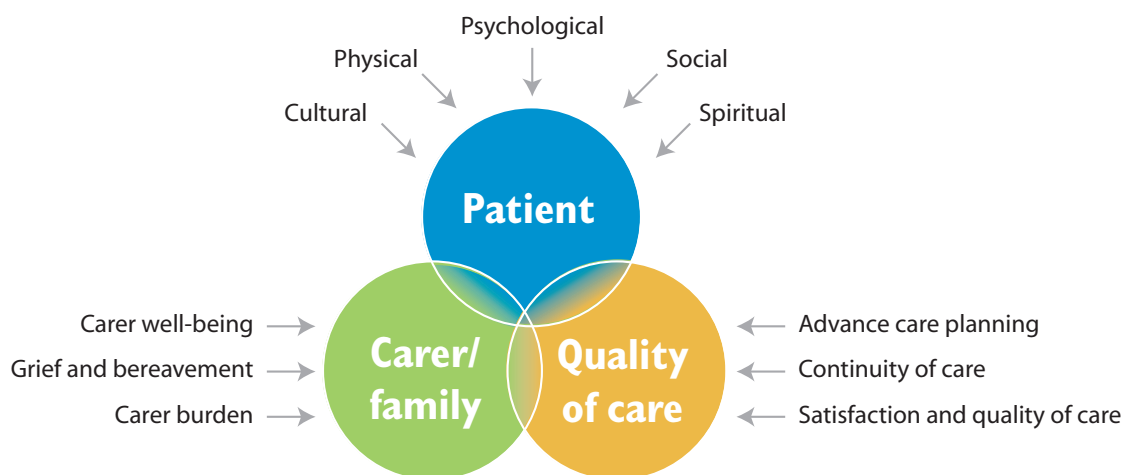


Table 2.2 Examples of multidimensional outcome measures in palliative care

Outcome measure	Number of items	Completion time	Additional comments
Palliative care Outcome Scale (POS) ⁵	10 items on physical symptoms, emotional, psychological and spiritual needs, provision of information and support 1 open question on main problems	mean time 6.9 min (patients) and 5.7 min (staff); repeated assessments of patients and staff mean time < 4 min ⁵	scores from 0 ('no effect') to 4 ('overwhelming'); patient, staff and carer version; widely used palliative care measure freely available after registration
POS-S Symptom list	10 symptoms 2 questions about the symptom that affected the patient the most and that has improved the most	few minutes	scores from 0 ('no effect') to 4 ('overwhelming'); additional symptom versions available for other conditions (POS-S MS, POS-S renal); freely available after registration
Distress Thermometer ⁹	overall distress score 20 symptoms, 5 items on practical problems, 4 on family problems, 5 on emotional problems, 2 on spiritual concerns	median length of time 5 min, with 75% taking no more than 10 min ¹⁰	distress score 0-10; other items yes/no
Edmonton Symptom Assessment Scale (ESAS) ⁶	9 symptoms and 1 "other problem"	approximately 5 min ¹¹	each symptom with NRS 0-10 developed to measure the most commonly experienced symptoms in cancer patients; freely available
Memorial Symptom Assessment Scale (MSAS) ¹²	28 physical and 4 psychological symptoms	20-60 min, ¹³ short form < 5 min	measuring presence, frequency, severity and distress of symptoms; short form version available (MSAS-SF); only presence and distress of symptoms; developed for cancer patients but also used in other conditions
Hospital Anxiety and Depression Scale (HADS) ⁷	14 items (7 depression, 7 anxiety)	2-6 min ¹⁴	developed to assess depression and anxiety for people with physical illness; not freely available
EORTC QLQ-C30 ¹⁵	5 functional scales (physical, role, emotional, social, and cognitive), 3 symptom scales (fatigue, nausea/vomiting and pain), a global health status/QoL scale and six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties)	first assessment 12 min (SD 7.5 min), second assessment 11 min (SD 6.5 min) ¹⁵	not freely available, widely used in cancer research; modular supplement available for a range of malignancies (lung, breast, gastric, brain etc.)
EORTC QLQ-C15-PAL ¹⁶	pain, physical function (3 items), emotional function (2 items), fatigue (2 items), QoL (1 item), symptoms (6 items)	< 20 min ¹⁷	not freely available, shortened version of the EORTC QLQ-C30 for palliative care patients

depression or anxiety, are either measured using separate measures or are included in the symptom measures.

Besides symptoms, most patients experience gradual, abrupt or intermittent functional decline during the course of their disease and towards the end of life. Functional status refers to the patients' mobility and the ability to perform certain routine tasks. These are also called activities of daily living (ADL), for example bathing, dressing and preparing meals. The widely used Karnofsky Performance Status (KPS) describes 10 levels of function.¹⁸ A modified version for palliative care is the Australia-modified Karnofsky Performance Status (AKPS). The AKPS is more appropriate for clinical settings and includes multiple care settings such as palliative care.¹⁹ Another example is the Palliative Performance Scale (PPS) which uses five observer-rated domains that are correlated to the KPS.²⁰

Advanced disease also has an impact on a patient's personal life. Social needs and cultural aspects should be assessed as they will influence the experience of symptoms and can cause psychological distress. Practical needs, such as organisation of care or financial constraints, will add to a patient's burden, as can family dynamics and communication problems. Only a few outcome measures cover practical and social needs, for example the POS has one question on practical matters, and the Distress Thermometer has five items on practical problems.

The concept of spirituality is difficult to define. Some authors refer to it as including meaning of life and death, transcendence and forgiveness, as well as a patient's interpretation of their illness.^{21,22} The measurement of spirituality is multi-faceted. For example, some outcome measures focus entirely on spirituality, whereas other tools include spirituality-related items as part of assessing quality of life and religiosity. Spirituality is often not considered when assessing a patient's situation, nor is it often covered in normal conversations, and it can therefore be missed. Using an outcome measure that includes at least one or two items relating to the spiritual dimension can help identify areas for further investigation and support. For example, the POS includes a question about 'feeling good about oneself' or 'whether life is worthwhile'. The Qual-E

includes three (out of 31) items on spiritual aspects of quality of life,²³ and the McGill Quality of Life Questionnaire (MQOL) includes four (out of 17) items on the meaning and purpose of life, life worth, feelings about oneself, and value of life.²⁴

Carers and family

Carers and families often experience burden and have their own personal needs (for example, social, emotional and financial needs). Outcome measures for palliative care often focus on the degree of burden and strain experienced by carers, especially their physical and mental health, finances, and social life. Some outcome measures specifically examine the needs and experiences directly related to carer tasks, such as giving medication, providing physical care, or managing time. Other instruments are designed for carers of patients with specific diseases, such as dementia or stroke. The Zarit Burden Inventory (ZBI) was originally designed for carers of dementia patients, but has now also been validated and used in relation to other conditions and in palliative care.⁹ Although originally developed with 22 items, the 12-item and six-item versions are widely used, and a short version with four items can be used as a screening tool.¹⁹ The POS includes one question on family anxiety,⁵ and the CAMPAS-R has two items on carer anxiety and depression.²⁰

Quality of care

Patients' and carers' perceptions of, and preferences for care (place; information) and place of death are important domains in outcome measurement. This includes their perceptions of the amount of information provided, the level of communication with themselves and their families, and their satisfaction with the overall care. Assessing the quality of care can highlight areas that need to be improved. Ideally, a combination of measures should be used to measure quality of care, including process measures (that measure the performance of a process), measures that look at the structure that supports the care that is being delivered, and outcome measures.

Disease group and conditions

Some outcome measures have been developed and validated for specific

conditions or disease groups, for example, cancer or respiratory disease. Strictly speaking, a measure should only be used with the patient group with which it has been validated. As palliative care is provided for people with a wide range of conditions, outcome measures that have been validated across different conditions are useful and important. Some measures such as the EORTC-QLQ C30 or FACIT (Functional Assessment of Chronic Illness Therapy) have sub-sections or modules that are disease-specific, for example they include specific symptom lists.^{27,28} Networks such as interRAI (www.interrai.org), which draw together researchers committed to improving healthcare for elderly, frail or disabled people, have agreed and tested a set of tools for use with specific patient or disease groups (especially for cognitively impaired patients or those with dementia).

Completing the outcome measure

The gold standard for reporting outcomes is normally considered to be information collected directly from the patient. PROMs can either be self-completed or facilitated by an interviewer, personally, or over the telephone. In a clinical setting, self-administration will be the most practical way to get information from patients. However, this poses a challenge in palliative care when patients are deteriorating and may not be able to answer questionnaires, especially towards the end of life. Although it is best for patients to fill in the questionnaire on their own, in reality they are often helped by professionals if they are too weak or too tired. Research has shown that professionals tend to underestimate rather than overestimate patients' symptoms.²⁹ Underestimation of symptoms has been particularly reported for drowsiness, shortness of breath, pain, fatigue and anorexia.^{29,30} It is therefore important that professionals score only what the patient reports, rather than using their own assumptions of what they think the patient would score.

If patients are unable to answer the questionnaire, proxies such as relatives or healthcare providers can be used to fill in the measures for the patients. However, there has been a debate about how accurate these ratings are, and how much

they reflect patients' views. Some outcome measures include a special proxy or family version, for example the POS. Ideally, ratings from both patients and proxies should be collected and compared. This allows for the adjusting of proxy ratings if the patient is not able to complete the measure as their disease progresses. Measures such as the POS allow for this.

How often to use an outcome measure

The frequency that an outcome measure should be used depends on the aim of the measurement, for example whether it is an assessment of change in symptoms, or an evaluation of an intervention, and what is being measured and how quickly it is changing. Symptoms should be assessed frequently, for example on a daily basis, to allow review of their management. In contrast, quality of life, a more complex construct, might only change over a longer period of time, or in response to a significant event (for example related to disease progression or a change in social support network), and therefore measurement regularity should take this into account.

The time it takes to complete a measure is also a consideration when determining how frequently to use an outcome measure. If a measure is to be used regularly, it should be short and able to be completed within minutes. Measures that take longer to complete, for example, half an hour or an hour, can be tiring for patients and this may lead to patient burden and missing data. Longer measures should be used with greater intervals between use. Longer measures are often used for research, rather than for routine clinical use.

It is important to establish an early baseline assessment with patients as changes will occur earlier in their care rather than later³¹, and changes in patients' symptoms or palliative care needs will be missed if there is no baseline assessment. Collecting data on an on-going basis can be challenging as patients and staff may not recognise why it is important. Repeated data collection not only captures changes, but also helps to identify new problems that need timely interventions. Explaining to the patient and staff members why the same outcome measure needs to be filled

in repeatedly is therefore vital. Repeated data collection will become more challenging as palliative care patients deteriorate over time. Using the data in the presence of the patient and referring to the answers they gave previously will increase compliance as patients will feel that filling in the outcome measure is not a waste of time, but an investment in their own care.

Outcome measures often pre-define a period called a 'measurement window' which the questions relate to, for example, the last week or the last three days. This is occasionally changed by users. Strictly speaking such a change affects the validity of the measure, but trials have shown that this is more relevant when a measure assesses the presence/absence of a symptom, rather than the severity of the symptom. Nevertheless, the practice of changing the measurement window when using tools should be approached with caution, and ideally the measure should be used as it was designed to be used.

What to do with the data

If data are collected for clinical purposes, the questionnaires need to go into the clinical notes, be brought to the attention of clinicians, shared with patients, and used to influence care and clinical decision making. It has been shown that feedback of PROMs results to clinicians has greater impact on discussion and detection of patients' problems, rather than on subsequent management of these problems.³² Teams should develop a routine for how patient reports are used in ward rounds, team meetings, or other consultations. In some organisations, patients enter their answers using computer touchscreens and results are directly presented to clinicians in the consultation. If the data are used for additional purposes, such as audit or research, they should go to a central place where they can be entered into the computer or used otherwise. How results are fed back to the clinical team to inform their work should be considered.

Steps to take before starting outcome measurement

- ▶ Familiarise yourself with the requirements of the chosen outcome measure. In particular, determine whether the dimensions

and the measurement window fit your needs.

- ▶ Complete any available training and read the guidance regarding the use of the outcome measure.
- ▶ Determine beforehand why you are using the measure. Is it going to be used for assessment or screening purposes or both?
- ▶ Determine when the measure will be used. Will it be used at certain points to monitor treatment?
- ▶ Pilot the measure with a few patients. This can help determine whether or not the measure is suitable for the intended purpose.
- ▶ Involve patients in the process: explain why PROMs are helpful, how they are used and how they can make a difference to their care.
- ▶ Determine how the data will be stored and reported upon. For example, this might involve filing the completed outcome measure in the patient's records, and reporting the patient's aggregated score to the multidisciplinary team.

KEY POINTS

- ▶ Many types of outcome measures are available for use in palliative care including PROMs, generic and specific measures, and single-item and multidimensional measures.
- ▶ PROMs can and should be used for clinical, audit and research purposes. They are helpful with assessment, monitoring and reporting.
- ▶ The number of existing outcome measures in palliative care makes the choice of the right measure difficult, but there are certain questions to ask that can help you to select the most appropriate measure.
- ▶ The measures that are available are designed to be used in certain ways; ideally clinicians should stick to the recommendations for use. Adaptations are possible, but adapting their use in practice should be done cautiously, as this may invalidate their use.
- ▶ Use of established outcome measures is preferable to developing new measures.

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Chapter 3

What makes a good measure

How useful an outcome measure is can be determined by its psychometric properties, and how well these relate to its aim. A measure is 'good' if it can be shown to have validity, reliability, appropriateness and acceptability, the ability to be translated into different languages, responsiveness to change, and interpretability of results.

Validity

Validity is one of the most important aspects of an outcome measure.¹ It refers to what a tool is measuring and whether it is measuring what it should be measuring.² The most important types of validity are face, content, criterion and construct validity.

Face and content validity

Face and content validity are closely linked concepts that describe whether a measure is assessing the relevant aspects for the purpose, and whether the domains covered are appropriate, important and sufficient.¹ The quality criteria for these two areas are not standardised and assessment is based on the subjective views of experts. For palliative care, the experts are patients, families and healthcare professionals. Therefore, their views on the content of a measure are paramount.

Face and content validity are of central importance to the choice of PROMs for routine clinical practice, as they highlight the extent to which the measure captures the views of patients and other key stakeholders.³

Using an outcome measure with high face validity can (adapted from Nevo 1985)⁴:

- ▶ increase the co-operation and motivation of the patient, family or carer during and after the measure administration;
- ▶ reduce dissatisfaction among patients with low scores;
- ▶ increase the co-operation of employees, administrators, commissioners and policy makers to implement or use the outcome measure.

Criterion and construct validity

Criterion validity refers to whether the measure correlates with another instrument that measures similar aspects. Preferably, the other instrument is the 'gold standard', meaning it has been validated, and is widely used and accepted in the field. For a new measure, the correlation with the gold standard is expected to be between 0.4–0.8 for it to have an acceptable criterion validity.² If no other measure or gold standard exists for comparison, the measure must be linked to a theory or hypothesis in order to show construct validity. Construct validity is the extent to which a measurement corresponds to the theoretical concepts or constructs that it was designed to measure. If the relationship between the measure and theory that it is testing cannot be shown, the problem can be either with the measure or with the theory that was used.



Reliability

The reliability of an outcome measure refers to whether the measure produces the same or similar results when administered in unchanged conditions. Reliability is important as it can reduce measurement error or errors that are related to the process of measurement. Providing clear definitions for the scores from an outcome measure helps to make it more reliable. Fewer points on the scale also improves reliability.

Inter-rater reliability

Inter-rater reliability assesses whether similar results are reached when different observers are used to rate the same situation or patient. Normally, inter-rater reliability is calculated with Cohen's kappa statistical test, which takes into account the proportion of agreement between the two raters in relation to the proportion of responses that could be expected by chance.² Cohen's kappa can have a value between 0 and 1, with levels of 0.21–0.4 indicating fair agreement, 0.41–0.6 moderate agreement, and 0.61–0.8 substantial agreement.²

Test-retest reliability

Test-retest reliability assesses whether similar results are reached over two distinct periods of time in unchanged conditions. The time intervals chosen depend on the variability of the domain being measured and the potential for change over time.⁵ Test-retest reliability is

assessed by Cohen's kappa statistical test, which is controlling for chance agreement.¹

Internal consistency

Internal consistency evaluates how individual items of the outcome measure correlate with each other. The quality criteria to assess internal consistency is Cronbach's alpha, which reports the average of correlations between all possible halves of the scale.¹ A very high internal consistency (>0.9) suggests that many items of the measure are capturing similar aspects.¹ Internal consistency is important if an outcome measure is used to monitor a single underlying concept with multiple items. However, if the underlying clinical phenomenon is complex, internal consistency is not so relevant.⁶

Appropriateness and acceptability

Many PROMs have been primarily developed for use in research, with the emphasis on psychometric properties. However, a psychometrically-sound measure may not always be very practical for clinical use. Therefore, appropriateness and acceptability are also used to indicate whether a measure is suitable for its intended use.¹ Barriers for use in clinical care include measures that are too long for patients to answer, or that require a lot of time for administration; complicated scoring systems; costs related to the use of the measure; or poor accessibility (that is, they may not be fully published, fully

A measure is 'good' if it can be shown to have validity, reliability, responsiveness to change, appropriateness & acceptability

available or access may be restricted). These aspects are particularly important in the context of palliative care, where patients are cared for in different settings, such as at home, in hospital or in a hospice; patients' time is limited; and their condition, which may involve cognitive impairment and frailty, poses a challenge to the use of outcome measurement. Therefore, there needs to be a balance between sound psychometrics and the feasibility of a measure for clinical use.

Responsiveness to change

Responsiveness to change refers to whether the measure can detect clinically important changes over time that are related to the course of the disease or to an intervention, such as symptom management. This is particularly important in outcome measurement as, by definition, outcomes are related to change (see Chapter 1), whereas assessment of health status is related to a particular point in time.³

The quality criteria to assess responsiveness to change are multiple. Important questions to answer when assessing the responsiveness of an outcome measure are:¹

- ▶ Does the change detected by the outcome measure correlate with the change measured by a gold standard?
- ▶ Does the detected change compare with what the patient or clinician has identified as an important change?
- ▶ Is the detected change associated with changes in treatment or care?

When an outcome measure has proven to be responsive to change, the minimally clinically important difference (MCID) needs to be determined. The MCID is defined as the smallest change or difference in an outcome measure that is perceived as beneficial.¹⁰ This change can either be retrieved by asking patients about differences or by calculating it using mathematical criteria.¹¹ MCID are available for many measures but, in general, a difference of about 0.5 standard deviations of the endpoint being assessed is a useful estimate.¹¹ Having too few points on a scale (for example, 0, 1 and 2) often makes the measure less responsive

to change. Floor and ceiling effects occur when scores from an outcome measure are not discriminated below or above a certain level (meaning that they will not detect change).

Interpretability

The interpretability of an outcome measure refers to whether the results (which are often a number) can be translated into something more meaningful to the patient, the family or clinician. An interpretable tool should enable a response to these questions: What is severe? What is the cut-off point when the outcome measure is used for diagnosis? How many points correlate with a symptom change?¹ Terwee et al highlighted a range of scores that are helpful in assessing the interpretability of a tool:⁶

- ▶ means and standard deviations (SD*) of scores of (subgroups of) a reference population (norm values);
- ▶ means and SD of scores of relevant subgroups of patients whose scores are expected to differ (for example, groups with different clinical diagnoses, age groups, gender groups or primary versus secondary care setting);
- ▶ means and SD of scores of patients before and after treatment(s) of known efficacy;
- ▶ means and SD of scores of subgroups of patients based on patients' global ratings of change.

**standard deviation is a measure of the spread of values of a variable around a population mean value (see Chapter 4).*

Translation into other languages

To be able to use outcome measures with different groups to compare results between countries, outcome measures need to be translated into other languages by following a formal process and the same rigorous validation process also applies as for the original measure. Even though this is lengthy and costly,⁷ it is an important procedure to ensure accurate scores when outcome measures are used and compared. Much research has been conducted on translating certain tools (for example the POS), and there are also guidelines regarding how questionnaires

Example 3.1 Validation and translation of the POS in Argentina adapted from Eisenclas et al⁹

In order to be able to use the POS in Argentina, Eisenclas et al⁹ carried out a cross-cultural adaptation and psychometric analysis of a Spanish (Argentine) translation of the POS. In this case study we will focus on the cross-cultural adaptation, which has been divided into three steps:

Appraisal of conceptual equivalence

was performed to ensure that the content of the POS covers the needs of Argentinian palliative care patients and is relevant to them. The authors carried out a literature review of health-related quality of life issues in palliative care patients in Argentina; interviewed local palliative care professionals; and asked patients in two focus groups about issues they expected to be addressed. This process assured the conceptual equivalence of the POS in the Argentinian culture.

Intermediate forward and backward translation, followed by an expert committee review:

Two forward and two backward translations were undertaken by two independent translators at each phase. Several versions of the POS in Spanish were produced, and the expert committee agreed on a single version.

Qualitative pre-testing: The newly created Argentinian POS was tested with a sample of 65 palliative care patients and 20 palliative care professionals. Following the completion of the POS, both groups participated in individual, semi-structured interviews. Questions around the relevance, length, comprehension and interpretability of the POS were asked. After pre-testing, seven POS questions were changed.

The POS version developed after this process of cross-cultural adaptation was then psychometrically tested and validated.

should be translated.⁸

Translation involves the consideration of semantic and conceptual meaning and procedures to ensure equivalence between cultures. Both forward (translation into the new language) and backward translation (translation of the new language version back into the original language) are important elements of this process. In addition to the meaning of terms used in outcome measures, accuracy in the translation requires translation in relation to the sense of those terms. Also, the same language might have different meanings in different cultures.⁹

Informal translation without validation in the new language might lead to loss of measurement properties. Therefore, considering whether the outcome measure has been translated adequately is an important step in assessing the quality of the outcome measure, and this may influence whether or not the tool can be used with certain groups of patients or in certain countries.

KEY POINTS

- ▶ Validity and reliability are vital elements of a high-quality outcome measure.
- ▶ When using an outcome measure, you need to be sure that the measure is valid, reliable, acceptable and responsive to change.
- ▶ Some outcome measures lack key information on reliability, sensitivity to change and interpretability.
- ▶ Outcome measures need to be appropriate and acceptable to patients, and to the circumstances they are used in.
- ▶ Translation of outcome measures into different languages must follow the same rigorous process as used for the development of a new measure.
- ▶ An outcome measure has to show responsiveness to change if change over time is to be evaluated.

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Chapter 4

Scores of outcome measures and their analysis

Outcome measures produce different types of scores or numbers which can be attributed to individual questions or summarise all the questions. These scores can be helpful and can be used in different ways either for an individual patient or for a group of patients.

Assessment and screening: individual patient scores

Outcome measures can be used to assess and screen individual patients, and multidimensional and uni-dimensional measures can assist with this. For example, the Karnofsky Performance Status (KPS), which involves the assessment of three dimensions of health status (activity, work and self-care), can be administered by any healthcare professional to quickly assess patients' level of functioning. With a KPS score of 60 or higher, a patient may be eligible for attending day hospice services. Alternatively, those scoring 60–40 may be eligible for attending the same service, but with carer support. Those scoring 40 or less may be too ill to attend the day hospice but, if they need symptom control, either a home care service, a hospice or an inpatient unit might be more appropriate for them. In addition to assessment, outcome measures can also be used to screen patients. For example, a single item on mood in an outcome measure might highlight that a patient is depressed. To assess this further, a more specific questionnaire on depression (for example the HADS or the Beck Depression Inventory (BDI)) or a psychiatric assessment might be necessary.

When using an outcome measure, each patient's answer usually has a

numerical value attached to it, or a numerical value which can be assigned to the answer option if answers are categorised. For example, single-item measures such as a VAS or an NRS, which are often used to measure the severity of a symptom, result in one overall score. No calculations are then required for an individual patient.

Example 4.1 Use of a single-item instrument for scoring symptoms

A patient is attending a breathlessness clinic.
The severity of breathlessness is assessed with the following NRS.

'On a scale from 0 to 10, indicate how much shortness of breath you had on average over the last 24 hours'



No shortness
of breath

Shortness of breath
is as bad as it can be

The patient circled 6 on the NRS, indicating moderate to severe breathlessness for this patient.

Unlike single-item measures, multi-item outcome measures sum scores of individual questions to an overall aggregated score. Sometimes these scores need to be divided by the number of questions, or more complicated adjustments of the scores are necessary. The relevant information needs to be found from the user guide of the

outcome measure. For clinical purposes, outcome measures that do not require further and more complicated calculations are more practical.

Some outcome measures give important information both from individual items and overall scores which

can be used to inform clinical decisions, as shown in Example 4.2. In this case, the total POS score is useful in getting the broad picture, whereas individual scores such as pain and depression give important information on key aspects of the patient's situation.

Example 4.2 Using POS individual and overall scores, and the related clinical meaning

Patient admitted to palliative care unit with severe pain

POS	Score/description	Clinical meaning	Team members input required
Pain	4 Overwhelmingly	Not responding well to opioids	Palliative care physician and nurse
Other symptoms	1 Slightly	Nausea, constipation	Palliative care physician and nurse
Anxiety	2 Sometimes	Occasionally anxious about pain getting worse	Palliative care physician, nurse, therapist, and chaplain
Family anxiety	4 Always preoccupied	Family anxious about deterioration and patient not getting better	Nurse, social worker
Information	1 Hard to understand	Did not understand why opioids are not working	Explanation by palliative care physician
Support	0 As much as I wanted	Feels supported	No action currently necessary, continue with volunteer input
Depressed	3 Occasionally	Risk of clinically relevant depression	Physician
Self-worth	3 Occasionally	Risk of clinically relevant depression	Further assessment and potential referral to psychologist
Wasted time	0 None at all	Just admitted	No action currently necessary
Personal affairs	2 Practical problems in the process of being addressed	Financial issues, advance care planning	Social worker
Total score (0-40)	20	Overall moderate palliative care needs	

Monitoring change: patient scores over time

Using outcome measures more than once with the same patient enables changes and treatment effects to be monitored, and can provide useful information regarding patient trajectories over time (improvement or worsening). For many outcome measures, minimal changes in scores (or MCID) are described, indicating how much difference in a score there needs to be in order for it to be clinically meaningful. For example, for the POS, a variation of one point in individual items is linked to clinical meaningful change.^{1,2} If information about change scores does not exist, clinical judgement

should be used to determine the relevance of the change in relation to the individual patient.

There are different ways of making patients' scores that are collected over time more useful to clinicians and patients. This can be either in the form of tables (as in Example 4.3), or by visually plotting or mapping the scores. An Excel spreadsheet can provide both a table and a graphical version of the scores. Presenting the information in this way can aid the monitoring of treatment and the identification of any patterns in relation to responses to treatment, the timing of interventions or other salient factors (see Example 4.4 overleaf).

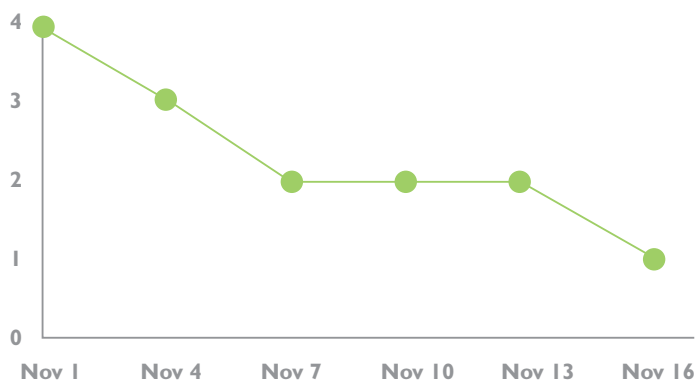
Example 4.3 Comparing POS individual and overall scores over time, and their clinical meaning

POS question	1st May	8th May	15th May	Clinical meaning
Pain	4	3	2	Improvement
Other symptoms	1	1	1	Stable and adequate
Anxiety	2	1	3	Fluctuating, possibly increasing
Family anxiety	4	3	3	Slight improvement
Information	1	0	0	Improvement
Support	0	0	0	Stable
Depressed	3	2	2	Slight improvement, requires monitoring
Self-worth	3	1	0	Improvement
Wasted time	0	3	3	Deterioration, requires follow-up
Personal affairs	2	2	0	Slight improvement
Total score	20	16	14	Overall improvement, however some areas need follow-up

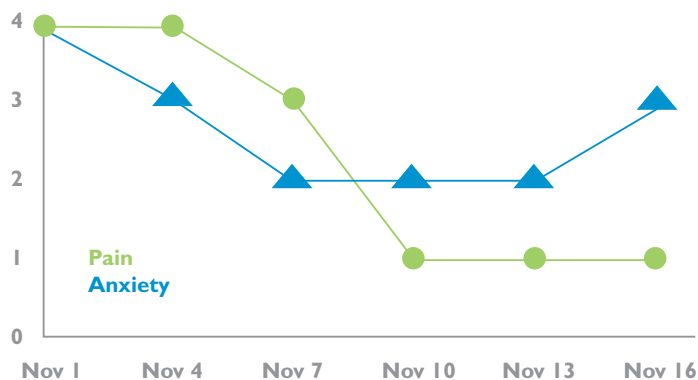
Example 4.4 Pain scores over time using the POS patient version (question 1)

Q1 - Over the past 3 days, have you been affected by pain?

- 0 Not at all, no effect
- 1 Slightly – but not bothered to be rid of it
- 2 Moderately – pain limits some activity
- 3 Severely – activities or concentration markedly affected
- 4 Overwhelmingly – unable to think of anything else



Example 4.5 Pain and anxiety scores using two items of the POS (question 1 and 3)



This type of visual mapping can be completed in relation to single items (as shown in relation to pain in Example 4.4), or in relation to a number of items (as shown in Example 4.5). Displaying information in this way can aid understanding of the relationship between different symptoms, and also complement discussions with patients on determining which symptoms require the most attention.

Analysing data from several patients

If a team is interested in the characteristics of a whole patient group, rather than one individual patient, data can be analysed in a more sophisticated way. For larger amounts of data, the use of computer software is inevitable. For this, data need to be entered into a computer, which is time consuming and can be liable to mistakes as the data need to be transferred from a hard copy to an electronic format. Alternatively, some organisations use electronic formats for data collection where patients enter their answers directly into wireless tablet computers. This saves time and reduces the risk of mistakes.

Occasionally, when working with larger sets of patient scores, data might be missing: questions might be skipped by mistake; the patient may not have wanted to reply, may not have understood the question, or may not have been well enough to answer the question; or staff may have lacked time to use the questionnaire. Although it is difficult to avoid missing data when working with patients with advanced disease who are frail or close to the end of life³, the best way to avoid missing data is to have quality control procedures in place (for example, double checking of data, availability of questionnaires in a large font size, the provision of training on how to use the outcome measure, and raising the issue of missing data with staff).

Data analysis: common descriptive statistics

For clinical purposes, the use of statistics is not always required when outcome measures are used. However, common descriptive statistics may be useful in certain circumstances, for example, when comparing two different patient groups on two different wards. Calculating the mean, median or SD may be useful at times.

The mean, also known as average, is the sum of all the scores divided by the



number of scores. The mean is a measure of the centre of a distribution if the values being summarised have a symmetrical distribution.⁴ This is not the case if most of the values are distributed towards one end of the scale or if there are many extreme values. In the context of outcome measurement, it is a common and simple calculation to do.

$$\text{Mean, } \bar{\chi} = \frac{\sum \chi}{n} = \frac{\text{sum of values}}{\text{number of values}}$$

Example 4.6 Calculating a group of patients' mean breathlessness scores using the NRS

Description: Two groups of patients, one with COPD and one with lung cancer, have the following NRS scores for distress due to breathlessness.

How much distress did you have due to your breathlessness (0 = no distress at all; 10 = maximum distress I can imagine)?

	COPD	Lung cancer
Patient 1	10	-
Patient 2	-	3
Patient 3	6	-
Patient 4	9	-
Patient 5	-	8
Patient 6	8	-
Patient 7	-	7
Patient 8	-	1
Patient 9	7	-
Patient 10	-	2
Mean	8	4.2

The average distress score for the COPD group is $(10+6+9+8+7)/5 = 8$; for the lung cancer group it is $(3+8+7+1+2)/5 = 4.2$. By calculating the mean, we can see that these two patient groups differ in their average distress levels, and that COPD patients have, on average, severe distress levels (NRS=8) and lung cancer patients have moderate distress levels (NRS=4.2). Nevertheless, there are two lung cancer patients experiencing severe distress levels.

The median is another measure of the centre of distribution. The median is more robust as it is not affected by extreme values.⁴ Data are arranged in increasing order. The median is the middle value which divides the data in half; 50% of observations are lower and 50% of observations are higher than the median. If there is an even number of values, the median is the average between the two middle values.

Median = value of order $\frac{(n+1)}{2}$ in an ordered sequence

Example 4.7 Calculating the median distress score of COPD and lung cancer patients (from Example 4.6)

Distress due to breathlessness in COPD and lung cancer patients, measured using an NRS

	COPD	Lung cancer
Patient 1	10	-
Patient 2	-	3
Patient 3	6	-
Patient 4	9	-
Patient 5	-	6
Patient 6	8	-
Patient 7	-	8
Patient 8	-	1
Patient 9	7	-
Patient 10	-	2
Median	8	3

To calculate the median, the different values need to be ordered:

COPD group	6	7	8	9	10
Lung cancer	1	2	3	7	8

The median in each group is the middle value.

Median = $(n+1)/2 = (5 \text{ values} + 1)/2 = 6/2 = 3$ rd value

The median for COPD is 8 and for lung cancer 3.

Example 4.6 and 4.7 also highlight the importance of working with both individual and group scores. If only groups scores were used, patients 5 and 7 in the lung cancer group would have been missed.

In addition to mean and median, the spread of values or variation of data can be described by the SD or the interquartile range. The SD is the average distance from the mean of every value. It can be used if the data are symmetrically distributed around the mean. The SD will help you to see how homogenous (same) or heterogeneous (different) your data are. The smaller the SD, the less spread are the data (see Example 4.8).

$$SD, s = \sqrt{\frac{\sum(x - \bar{x})^2}{(n-1)}}$$

Example 4.8 Calculating SD using the POS total score

A group of patients using the POS have the following sum scores at admission:

POS sum score at admission	
Patient 1	36
Patient 2	31
Patient 3	15
Patient 4	36
Mean (SD)	29.5 (9.95)

Calculating the SD of the POS sum scores of four patients at admission shows that the patient total scores are relatively widely spread (SD 9.9). The mean of all scores for the time of admission is 29.5.

$$SD = \sqrt{\frac{\sum(x - \bar{x})^2}{(n-1)}}$$

$$SD = \sqrt{\frac{(36-29.5)^2 + (31-29.5)^2 + (15-29.5)^2 + (36-29.5)^2}{(4-1)}}$$

$$SD = \sqrt{\frac{(6.5)^2 + (1.5)^2 + (-14.5)^2 + (6.5)^2}{3}}$$

$$SD = \sqrt{\frac{297}{3}}$$

$$SD = 9.95$$

If there are too many extreme values, and therefore SD is not appropriate, the interquartile range is an alternative measure to reflect the distribution of data. It is used in combination with the median and describes the interval between the 25th and 75th percentile; meaning that 25% of all the scores are below that score, and 75% of all the scores are above that score (see Example 4.9).

Example 4.9 The 25th and 75th percentile using the POS scores shown in Example 4.8

Ordered POS scores	Percentile
15	25 th = 23
31	Median 33.5
36	75 th = 36
36	

Key points

- ▶ Single-item scales for individual patients require no further calculations.
- ▶ For multi-item scales, sum scores can usually be calculated, but individual scores might also give relevant information and are important to consider.
- ▶ Scores over time from the same patient enable changes to be monitored and provide information on individual patients' trajectories.
- ▶ To compare groups of scores, simple descriptive statistics are useful, such as mean, median, SD and quartiles.

Further reading

- ▶ Kirkwood BR, Sterne JAC. *Essential Medical Statistics*. 2nd ed. Malden, Mass.: Blackwell Science; 2003.

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Chapter 5

Quality improvement and organisational change

Even though research has shown that clinicians and researchers are generally willing to use outcome measures within healthcare,¹ and specifically within palliative care², barriers within organisations continue to prevent or hinder their routine use.²

Implementation of outcome measurement requires facilitation, change and communication. This chapter is designed to equip clinicians, researchers and managers with ideas, tools and strategies to enable the regular use of outcome measures. A widely used quality improvement cycle (audit) is explained, and resources that can aid outcome measurement implementation are highlighted. Change management and organisational theory are covered here to ensure that implementation dimensions are considered, pitfalls are avoided and successful implementation of outcome measurement occurs, regardless of the organisational context.

Change in organisations: types of change and enabling change

Change management has the potential to aid quality improvement within healthcare generally.³ Change is an essential component of implementing outcome measurement, and can vary in size, scope and type (for example, staggered/gradual/sharp/immediate change) (see Example 5.1).

Understanding the factors, processes and forces that drive change within organisations can aid the management and facilitation of outcome measurement implementation. “Facilitation is a technique by which one person makes things easier for others”.⁴ Facilitation involves providing support to help change attitudes, habits, skills, and ways of thinking and working. Good facilitation aids change by helping clinicians, researchers and managers understand what needs to change, how this change can occur, and what the outcome and impact of the change will

Change is an essential component of implementing outcome measurement

Example 5.1 Change in size and scope



A clinician's choice to change from the patient POS version to the carer POS version with one patient

Implementation of routine use of PROMs in a palliative care unit, hospice and home care service

Implementation of an end-of-life care strategy within a national healthcare system that relies on PROMs to determine healthcare provider payments

be. There are three core dimensions in relation to the role of a facilitator: characteristics (for example, respect and empathy), role (for example, access to facilitator and negotiation), and style (for example, flexibility and presence).⁴ When good facilitation is evident, alongside good evidence and the right environment, successful implementation of evidence-based practice can occur.⁴

An easy-to-use and quick method to help analyse external and internal forces involved in change is the PESTLE method of analysis. In essence, the PESTLE method involves identifying the political (P), economic (E), social (S), technological (T), legal (L) and environmental (E) factors that drive and inhibit change. This method helps identify forces that can prompt change; helps determine whether a change is required and how urgent it is; and helps identify the resources that might be required for the change to occur (see Example 5.2, opposite).

Although the history of the development of this method is difficult to establish, it is a method that can be used very simply, or in a very complex way, to help one think practically about the need for change. A PESTLE analysis can be completed from many different perspectives, for example from the

perspective of an individual clinician, a multi- or inter-disciplinary team, a department or service, an organisation, a region, or from a national perspective.

Acceptance or reluctance to use outcome measures is influenced by many factors. For example, medical doctors and physiotherapists may be more inclined to accept and use outcome measures, as components of their work are directly related to dimensions that are easily measurable (for example, range of movement, intensity of pain). However, other professionals, who focus on more emotional, psychological or spiritual dimensions, may find it more challenging to embrace the use of outcome measures in practice. There are arguments for both using and not using outcome measures clinically in palliative care, as illustrated in Table 5.1.

Considering the level of evidence that supports the change is also important. Successful implementation of evidence-based practice requires consideration of three core elements: the level and nature of the evidence to support the change; the context or environment into which the change is to be put in place; and the method or way in which the change process is facilitated. Successful implementation is more likely to occur

Table 5.1 Arguments for and against the use of outcome measures in palliative care

Arguments for outcome measures	Arguments against outcome measures
Helps assess and screen patients and symptoms.	Restricts creativity in practice.
Supports the evidence-based medicine movement in order to ensure service quality, effectiveness and accountability.	Does not fit with the ethos of palliative care as it detracts from patient-centred care.
Enables identification of what works and what does not work in terms of clinical interventions.	Detracts from the benefits of interventions.

Description of a fictitious service

St Barnaby's is a long-established hospice in the UK comprising 16 beds for palliative care patients. The majority of its funding comes from charitable sources, however, a third of the funding comes from the National Health Service (NHS) in England. St Barnaby's offers a broad range of services to patients and their families using a multidisciplinary approach to care, that is provided by palliative care specialist doctors, nurses (locums and permanently-employed nurses), an occupational therapist, a music therapist, a chaplain and several volunteers.

Description of change context

Recently, the quality of UK hospice services has received a lot of attention in the media; prompted by a recent high-profile case highlighting symptom management issues with a cancer patient. In response to this, numerous letters to a national newspaper's editor were published. An overwhelming feeling of the importance of the need for adequate symptom control of all dying patients was clear from those who wrote in. This high-profile case happened to correspond with the release of the new Government's White Paper which also featured in the media. This paper highlighted that funds for NHS-funded service providers will soon be reliant on their performance, and that their performance will, in part, be measured by provider reports detailing PROMs. These events prompted the manager of the hospice to complete a PESTLE method of analysis about whether or not to formally introduce the use of outcome measures within the hospice.

PESTLE analysis

Forces to support formal introduction of outcome measurement

- ▶ White Paper focusing on the need for outcome measures (Political).
- ▶ Payment to service providers will soon be driven by PROMs findings (Economic).
- ▶ Pressure from patients and their families for measurement of symptoms to ensure adequate symptom control (Social).
- ▶ A new computerised patient record is about to be used in the hospice and this could be developed to include outcome measurement data (Technological).
- ▶ A recently introduced Carers Equal Opportunities Act requires carer assessments by healthcare providers (Legal).
- ▶ Shared rooms in the hospice means that patients and families are aware of symptom issues and that it is important to ensure all patients' symptoms are adequately controlled (Environmental).

Forces against the formal introduction of outcome measurement

- ▶ Introduction of outcome measurement will require training and additional resources such as time, and cover for locum staff involved in providing and receiving the training (Economic).
- ▶ Some staff are resistant to using outcome measures with patients as it is not always viewed as being conducive to good patient experience of palliative care (Social).
- ▶ Outcome measurement may create additional paperwork for staff and this may reduce patient contact hours (Economic).
- ▶ The nurses' station is small and outcome measurement paperwork will mean that staff need more space to complete paperwork (Environmental).

when: (a) there is high-quality evidence to underpin the change; (b) the context or organisation is able to cope with change; and (c) effective facilitation is in place.⁴

Facilitation methods to help implement outcome measurement are:

- ▶ A cascade management approach that involves the promotion of autonomy in staff regarding their use of outcome measures;
- ▶ Staff involvement in decision making;
- ▶ The use of measures that can be analysed within existing resources;
- ▶ Advice regarding data analysis;
- ▶ The use of measures that are relevant to clinical care;
- ▶ The use of staff training to complement implementation;
- ▶ Encouraging staff to view outcome measures as an integral component of clinical care.⁵

Understanding perspectives within organisational contexts

Understanding the culture of an organisation, or an organisation's value system, including the dominant values, visions, perspectives, standards and behaviours^{6,7} is important when implementing outcome measurement. This involves understanding the relationships within the organisation (usually understood through leadership roles) and the organisation's approach to measurement (for example, monitoring systems).⁴ A useful framework for understanding the culture of organisations was highlighted by Charles Handy, who proposed four types of organisational culture (see Example 5.4, opposite).⁸ Consideration of these different cultures in attempting to implement outcome measurement may aid the development of strategies to support the implementation of measures within an organisation.

As organisations are made up of individuals, understanding the individual within their organisational context can also help understand individual responses to change that involves outcome measurement. This understanding can then be used to help enable change in individual staff that are resistant to change (see Example 5.3).

Determining what is needed and by whom: agreeing a data collection plan

During the process of implementing outcome measures, discussions about what data to collect, for what reasons, and by whom, need to occur. Systems mapping can help with this task. This consists of developing a pictorial representation of the organisation (or local area) and links within and between identified components, as illustrated in Example 5.5. Systems mapping can also be used to identify links between those components within and those outside of an organisation. Systems maps are helpful in determining what type of information is required and by whom.

Example 5.3 Tips for a data collection plan

Questions to consider, and to discuss with others, when agreeing a data collection plan:

- ▶ What do we want to collect?
- ▶ What do we need to collect?
- ▶ How can we improve the return rate of outcome measurement data?
- ▶ What do people want from the data?
- ▶ What do people need from the data?
- ▶ How can we present findings in a meaningful way?
- ▶ What systems can we put in place to make the data collection, inputting and reporting process easy, and to minimise the impact of these tasks on other duties?

Power culture

- ▶ Influence and control within an organisation is centred on a central figure or group.
- ▶ The relationships with people in that central group matter more than informal titles or positions within organisations.
- ▶ Influencing the key opinion leaders and power holders is required for outcome measurement implementation.
- ▶ Implementation might not succeed without their endorsement.

Role culture

- ▶ Delegation of authority is based on organisational structure or formal roles. For example, the role of the clinical nurse might be very important in terms of determining the work of other nurses in the palliative care unit, or the role of the palliative care consultant may be very important in terms of identifying key clinical areas of specialty within a hospice.
- ▶ It is important to recruit the most senior staff of all the clinical disciplines to the implementation task as they ultimately hold responsibility for introducing outcome measures across the organisation, and to more junior staff. For example, implementation of outcome measures might automatically fall to the most senior nurse on the ward.

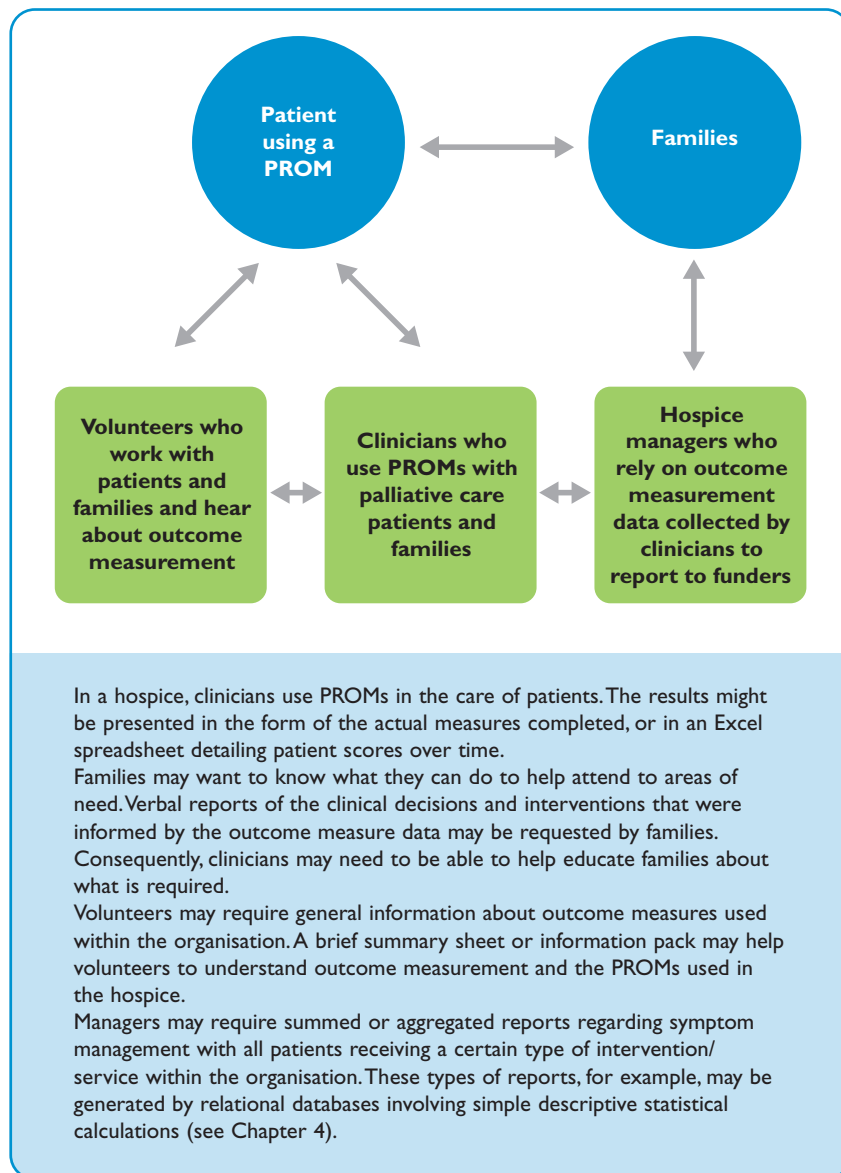
Task culture

- ▶ Involves an emphasis on the task at hand, rather than the roles of the people required to complete the task.
- ▶ Teams are formed to solve particular problems within the organisation.
- ▶ Clinical staff that hold outcome measurement competencies and knowledge, and service managers with change management expertise, might be enlisted to construct and deliver an outcome measurement implementation programme within these types of organisations.
- ▶ An outcome measurement team involving various members from different professions and rankings within an organisation might be established to introduce outcome measures within the organisation.

Person culture

- ▶ Involves scenarios where individuals or groups of individuals exercise great control and influence within the organisation.
- ▶ Less common or relevant to healthcare environments, and more relevant to business/private sector organisations.

Example 5.5 An example of a hospice systems map in relation to use of PROMs



Equipping organisations for outcome measurement success

Once it has been agreed that outcome measures will be implemented and used within an organisation, a change management plan can be constructed to aid comprehensive implementation. Ideally, this type of plan should be constructed with those involved in the change; be developed with knowledge about the resources that are available; and informed by the outcome that is required.

Considering these perspectives is useful as it helps determine how people may perceive, respond, become involved and embrace the change ahead.⁸ Change perceived as being owned by oneself or one's organisation (active change), in contrast to a change that is perceived as imposed (reactive change), may require fewer resources and less time to implement. Considering change in this way may lead to the identification of the best way to enable outcome measurement implementation and, importantly, it will help identify corresponding communication strategies that may help with the change. Example 5.6 sets out some principles for understanding organisational change and Example 5.7 lists some rules for managing change.

Developing a good communication strategy will involve creating opportunities for stakeholders to have ownership of the change process and to express their thoughts about what is required and how the change can be implemented. Keeping in mind the things that drive people (for example, clinical care for clinicians, governance for managers, and accountability and quality for commissioners) can help shape the content of communication with them. For example, when highlighting the benefits of outcome measurement in discussions with clinicians, the potential of the measures to improve assessment and care might be emphasised. While for managers the notion of how outcome measurement can help streamline and improve services is important.

Making a real difference through audit and achieving successful outcomes

An audit can be completed once the change has been implemented and outcome measurement is being used

Example 5.6 Understanding organisational change?

Principles for understanding organisational change (quoted from Pugh 1993⁹)

- 1 Organisations are organisms.
- 2 Organisations are occupational and political systems.
- 3 All members of an organisation operate simultaneously in three systems – the rational, the occupational, and the political.
- 4 Change in people may occur differently:
 - ▶ Those who are successful yet are also experiencing tension in certain parts of their work may have confidence in their ability and the motivation to change;
 - ▶ Those who are successful may have the confidence to change but might also need to be motivated to change;
 - ▶ Those who are not experiencing success may resist change as they may feel they need to protect themselves and that staying the same might help them do this.

Example 5.7 Rules for managing change?

Six rules for managing change (quoted from Pugh 1993⁹)

- 1 Work hard at establishing the need for change.
- 2 Do not think out the change, think through it.
- 3 Initiate change through informal discussion to get feedback and participation.
- 4 Positively encourage those concerned to articulate their objectives.
- 5 Be prepared to change yourself.
- 6 Monitor the change and reinforce it.

within the organisation. Audits focus either on individual patient care (case audit), a service (for example at a department level) or an organisation. Audits can help identify major risks, reinforce implementation of evidence-based practice, influence improvements and ensure governance (or the accountability of services). Audits can also aid quality assurance. The audit cycle involves setting standards and goals; monitoring and observing practice; and then using the feedback or findings to improve quality (see Figure 5.2).

Figure 5.2 The audit cycle¹⁰



Importantly, where standards of care are not established, pre-audit activity can be completed to help establish standards. This type of audit activity is useful for new services that are being introduced and for new interventions. Pre-audit activity is similar to the usual audit cycle, however, instead of measuring performance in relation to already established standards, the first step is identifying what standards are currently being achieved, or ones that might be possible. Audit can be beneficial to patients, staff and organisations (see Example 5.8).

Similarly to change management, the process of audit implementation can be aided by engaging people with the audit process to ensure and enable their ownership of the process. Helping people to understand the relevance of the audit outcomes to their own work may aid data collection and result in the sustained use of outcome measures. Some useful tips for successful audit are given in Example 5.9.

Example 5.8 The benefits of audit to...

Patients

- ▶ Identifying and addressing practice-based problems.
- ▶ Identifying resource requirements for services and interventions so that patients get what they require.
- ▶ Identifying service use and service needs.

Palliative care staff and clinical departments

- ▶ Enabling the monitoring and review of the quality of care provided.
- ▶ Identifying systematic ways of addressing clinical problems or challenges.
- ▶ Identifying areas for improvement, and ensuring that difficulties are considered in more detail.

Organisations

- ▶ Providing data to measure the organisation's performance against palliative care standards.
- ▶ Identifying areas for service delivery improvement.
- ▶ Bringing together important information for reports to funders.
- ▶ Enabling comprehensive and summary reports for those working within the organisation to aid self-monitoring and quality improvement.

Example 5.9 Tips for successful audit in outcome measurement

- ▶ Each outcome measurement audit should form part of a structured audit programme.
- ▶ Various stakeholders (for example multidisciplinary team members) need to be involved in the audit and the actions that result from the audit. This includes service users and managers.
- ▶ Outcome measure audits should also include measures related to process (see Figure 1.1, page 8).
- ▶ The published evidence about outcome measurement should be considered in relation to what standard is being measured or established. This ensures that good standards are set and improved upon.
- ▶ Staff involvement in audit is key to promoting ownership.
- ▶ Establishing a culture of critical enquiry can be aided through encouraging staff to exercise autonomy in audit activities.¹¹

Benchmarking

Benchmarking is the process of comparing, sharing and developing practice in order to achieve and sustain best practice.¹²

Benchmarking is useful in establishing how similar organisations compare. As a consequence, best practice can be identified; beacon (leading) sites can become known and used to aid wider development; and national standards can be established. Similarly to the audit cycle, benchmarking involves a cyclical series of steps to identify and improve standards (see Figure 5.3).¹²

An excellent example of a national and voluntary programme where benchmarking of standards involves outcome measurement is the Palliative Care Outcome Collaboration (PCOC) in Australia. PCOC uses established standards of palliative care to develop and support a national benchmarking system that will contribute to improved outcomes. This national initiative allows for the collection, analysis and reporting of large sets of outcome measurement data. Information about PCOC and examples of their reports can be accessed via their website at <http://chsd.uow.edu.au/pcoc/>

As with all types of aggregated (or summed) outcome measurement data, the findings should always be interpreted with the following factors considered:

- ▶ What measures were used?
- ▶ What is the context of the data that were collected?
- ▶ Do the presented datasets compare, or do they require adjusting before comparison can take place?
- ▶ What is the response rate?
- ▶ Was there any bias in the responses that were provided?

Opinion leaders and facilitators are required for benchmarking programmes to be successful. Opinion leaders are similar to facilitators in that they can influence change, habits, practice and therefore outcomes. However, they can also be different from facilitators in that they may draw more upon their status and technical skills to influence change, rather than drawing upon the interpersonal and group skills that are required for successful facilitation. Social networking may also be more important in relation to the role of an opinion leader. Opinion leaders may operate as facilitators as there is overlap between these two roles.⁴

Figure 5.3 Cyclical approach to benchmarking¹²



Key points

- ▶ Improving quality and implementing outcome measurement inevitably involves change.
- ▶ Change is aided by understanding the type of change required; the forces inhibiting or encouraging the change; the resources required for the change; and the meaning of the change to the various stakeholders and participants.
- ▶ Promoting outcome measures, establishing the benefits and relevance of outcome measurement, and good communication are key to the implementation of outcome measurement in palliative care.
- ▶ Audit and benchmarking are important in identifying standards of outcome measurement practice, areas of good measurement practice and areas to improve.
- ▶ Opinion leaders and facilitators are central to these processes.

Further reading

- ▶ Dunckley M, Aspinall F, Addington-Hall J, Hughes R, Higginson IJ. A research study to identify facilitators and barriers to outcome measure implementation. *Int. J. Palliat. Nurs.* 2005;11(5):218-25.
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- 9 Pugh D. Understanding and managing organisational change In: Mabey C, Mayon-White B, editors. *Managing change.* 2nd edition: Paul Chapman; 1993.
- 10 Benjamin A. Practice: The Competent novice: audit - how to do it in practice. *Br. Med. J.* 2008;336(7655):1241-5.
- 11 Cooper J, Pettifer A. Promoting ownership in palliative care audit. *Int. J. Palliat. Nurs.* 2004;10(3):119-22.
- 12 Department of Health. *Essence of Care: Patient-focused benchmarks for clinical governance.* London: Department of Health; 2001.



Chapter 6

Where to find more information

In this chapter we provide a wide range of resources for the use of outcome measures in palliative care. The list is not conclusive, but is aimed at helping those who want to find out more about outcome measurement in general, or about specific outcome measures.

Websites

There are a variety of websites that provide information on outcome measurement in palliative care, either as part of a general website or sites that are specifically designed for palliative care. No single website contains all the relevant information on all existing outcome measures; however, there are websites that contain all the relevant information about specific individual outcome measures.

www.csi.kcl.ac.uk/tools.html

Irene Higginson, Department of Palliative Care, Policy and Rehabilitation, King's College London, UK – regular updates
Detailed information on the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS)

www.palliative.org

Robert Fainsinger, Edmonton, Canada – up-to-date
Website of the Palliative Care Program in Edmonton; primarily ESAS

www.facit.org

FACIT measurement system
FACIT with specific measures for different tumour entities, different symptoms and non-cancer specific scales (including palliative care); variety of language versions available

www.dyingwell.com/MVQOLI.htm

Ira Byrock, USA – regular updates
Missoula-VITAS Quality of Life Index (MVQOLI) – with Guide to use the MVQOLI

www.iqola.org/instruments.aspx

www.sf-36.org

USA – regular updates
International quality of life assessment project to validate and translate the SF-8/12/36; Short form Health Survey SF-8/12/36

www.proqolid.org

PRO and QoL database = PROQOLID
Mapi-Research-Trust, France – regular updates

Search in: alphabetic, generic, population (including 'terminal patients'), dimension, disease, author's name, language, type of instrument, mode of application; 690 instruments, >1100 translations, 82 databases are included, with short descriptions and links 15 outcome measures under 'terminal patients'

www.caresearch.com.au/caresearch/ClinicalPractice/ServiceIssues/Audit/POS/tabid/247/Default.aspx

CareSearch: palliative care knowledge network (Flinders University, Australia) – regular updates
Different sections (for example, clinical practice, finding evidence) with a presentation of tools; a variety of tools for different purposes (clinical practice, research, audit); Detailed information on CAMPAS-R, ESAS; LCP, POS, PCOC, STAS

www.chcr.brown.edu/pcoc/toolkit.htm

TIME – Toolkit for instruments to measure end of life care; Joan Teno, USA – last update 2004
Range of outcome measures are presented and reviewed, with advice on how to choose and use them (audit, research); 188 instruments

including: advance care planning, carer well-being, continuity of care, emotional symptoms, functional status, grief and bereavement, physical symptoms, quality of life, spirituality

<http://palliative.info/pages/Tools.htm>

Mike Harlos, Winnipeg, Manitoba, Canada – regular updates

Offers an organised, up-to-date collection of links to web-based palliative care resources, as well as locally-developed palliative care material; section with 'Assessment and Evaluation Tools' (links and PDFs); some instruments are presented/linked: Edmonton Functional Assessment Tool (EFAT), KPS, Palliative Performance Scale (PPS) - Version 2, MVQOLI, the Multidimensional Quality of Life Questionnaire for persons with HIV/AIDS (MQOL-HIV), Australian Government Department of Veterans' Affairs Pain and Symptom Control Measurement Tool, Edmonton Staging System (ESS), ESAS

www.promotingexcellence.org

Originally Robert Wood Foundation, now hosted by Growth House, Inc. – last update 2009

Sections: clinical care, educational, evaluation, organisational. Within evaluation: clinical quality, community assessment, cost/utilisation, education, organisational, programmatic, provider assessment, satisfaction/perception of care; key clinical assessment and research tools; 31 instruments are described and links provided

www.hospicecare.com/resources/pain-research.htm

International Association for Hospice and Palliative Care (IAHPC) official website, USA – regular updates

Official website of IAHPC; section with

'Assessment and Research Tools'; ~40 instruments are presented with links/PDFs

Systematic reviews

Over recent years, several systematic reviews have been published on various aspects of outcome measurement in palliative care (by year of publication)

Albers, G. et al. (2010) Evaluation of quality-of-life measures for use in palliative care: a systematic review, *Palliat. Med.*, 24(1), 17-37.

To make an inventory of all currently available QoL measurement tools suitable for use in the palliative care population and to assess the content and clinimetric quality of the instrument; PubMed, Embase, Cinahl, PsychInfo (engl.+dutch) (1990-2008); Inclusion: development/validation of the tool, QoL in non-curative treatment patients Identified: 2,015 references; Included: 33 tools (36 studies); e.g. ESAS, FACIT-PAL, MSAS, POS Ranking: 1. MQOL, 2. QUAL-E, 3. QODD; Conclusion: Many instruments were identified, but most were not yet evaluated. Evaluation of existing instruments with good content validity should have priority over development of new ones.

Vivat, B. (2008) Measures of spiritual issues for palliative care patients: a literature review, *Palliat. Med.*, 22(7), 859-868.

To discuss data from a literature review about measures of spiritual issues for palliative care patients (as part of a development process of an instrument); Medline, Cinahl, ClinPsyc (1996-2001/2001-2007) (terms: cancer AND spiritual) Identified: 1,066 references; Included: 29*

measures; 'functional' (spiritual health or spiritual well-being, function): e.g. FACT-Sp-Ex, MiLS, SpIRIT; 'substantive' (spiritual beliefs/experiences – content): e.g. INSPIRIT, SAS, SpS; Conclusion: none are entirely suitable for use with palliative care patients in the United Kingdom or continental Europe.

Jordhoy, M.S. et al (2007) Assessing physical functioning: a systematic review of quality of life measures developed for use in palliative care, *Palliat. Med.*, 21(8), 673-682.

How, and to what extent, physical functioning assessments have been included and performed in QoL instruments developed for palliative care in particular. Although they focussed on 'physical functioning', they did a general systematic review of QoL tools in palliative care. Medline (2005); Inclusion: life threatening illness/palliative care specific Identified: 1,326 references; Include: 224 instruments (general) – of these 39 as palliative care specific; uni-/bi-dimensional: e.g. ESAS, VAS; Multidimensional: e.g. QUAL-E, STAS, POS; Conclusion: Despite its importance, physical functioning assessment seems to be a minor part of palliative care QoL instruments.

Mularski, R.A., et al (2007) A Systematic Review of Measures of End-of-Life Care and Its Outcomes, *Health Serv. Res.*, 42(5), 1848-1870.

To identify psychometrically sound measures of outcomes in end-of-life care and to characterise their use in intervention studies; update of the systematic review conducted by Lorenz (see overleaf): 09/2004-11/2005

Identified: 24,423 articles; Included: (see below) 35+48+16 new = 99 tools; Conclusion: In general, most measures have not undergone rigorous development and testing. Measure development in end-of-life care should focus on areas with identified gaps, and testing should be done to facilitate comparability across the care settings, populations and clinical conditions. Intervention research should use robust measures that adhere to these standards.

Pearson, E. J., Todd, J. G. and Futcher, J. M. (2007) How can occupational therapists measure outcomes in palliative care?, *Palliat. Med.*, 21(6), 477-485.

To identify an outcome measure for occupational therapy interventions with palliative clients, in particular home assessments; Medline, Cinahl, PsychInfo, CareSearch, PROQoLID, DARE, PallCare Index (1980-2006); Inclusion: QoL, palliative care, occupational therapy
Identified: 45 tools; Included: 24 tools, e.g. EORTC-QOL-C30, FACT-G, PACA, POS; Conclusion: The research found that it may be feasible for occupational therapists to use a QoL tool as a routine part of assessing each palliative care patient, with the objective of focusing interventions on priority areas identified by the patient.

Richardson, A., Medina, J., Brown, V. and Sitzia, J. (2007) Patients' needs assessment in cancer care: a review of assessment tools, *Support. Care Cancer*, 15(10), 1125-1144.

To discuss the importance of systematic assessment of needs in routine care and the contribution tools can make to this process; Medline, Embase, BNI, ERIC, Cinahl (1984-2004); Inclusion: clinical purpose; Exclusion: research purpose, single domain, satisfaction (comprehensive list of in/exclusion)
Identified: 1,803 papers – 36 tools; Included: 15 tools

Kirkova, J., et al (2006) Cancer Symptom Assessment Instruments: A Systematic Review, *J. Clin. Oncol.*, 24(9), 1459-1473.

To evaluate currently available symptom assessment instruments for adult cancer patients. A secondary objective was to compare instruments by psychometric criteria; Medline, Embase, Cinahl, Cochrane Reviews, BIOSIS (1980/90-2004); Inclusion: symptom assessment; Exclusion: QoL

Identified: 76 articles + 2 conference papers; Included: 21 instruments; symptom-targeted (<5 symptoms): e.g. INV, HADS, NS; Multi-symptom (>5 symptoms): e.g. ESAS, MSAS + modified instruments; Conclusion: The instruments vary in symptom content and extent of psychometric validation. Both comprehensive and shorter instruments have been developed, and some instruments are intended for specific symptom assessment or symptoms related to treatment. There is no ideal instrument, and the wide variety of instruments reflects the different settings for symptom assessment.

Lorenz, K., et al. (2004) End-of-life care and outcomes. Summary, Evidence Report/Technology Assessment No. 110. (Prepared by the Southern California Evidence-based Practice Center), Rockville, MD: AHRQ Publication.

Lorenz, K. (2008) Progress in Measuring and Improving Palliative and End-of-Life Quality, *J. Palliat. Med.*, 11(5), 682-684.

Lorenz, K.A., et al (2008) Evidence for Improving Palliative Care at the End of Life: A Systematic Review, *Ann. Intern. Med.*, 148(2), 147-159.

Lorenz, K.A. et al (2006) Quality Measures for Symptoms and Advance Care Planning in Cancer: A Systematic Review, *J. Clin. Oncol.*, 24(30), 4933-4938.

Focusing on the outcomes: patient and family satisfaction; pain, dyspnoea, depression and anxiety, and behavioural problems in dementia; continuity; caregiving burden other than bereavement; and advance care planning. A systematic review was conducted to evaluate:

- 1 The scope of the end-of-life population.
- 2 Outcome variables that are valid indicators of the quality of the end-of-life experience for the dying person and surviving loved ones.
- 3 Patient, family and healthcare system associated with better or worse outcomes at end-of-life.
- 4 Processes and interventions associated with improved or worsened outcomes.
- 5 Future research directions for improving end-of-life care.

Medline, DARE, NICE, NLM (1990-2004)
Inclusion: published, English, humans
Identified: 21,745 articles; Include: 35 tools (from TIME - Toolkit of Instruments to Measure End of

Life Care; up to the year 2000) + 48 new instruments (200-2004) = 83 tools in total, e.g. ESAS, EORTC-QOL-C30, FACT, MSAS, POS, QODD, STAS; Conclusion: With regard to measures, the review identified one high-quality, widely-recognised resource. Measure development is most advanced for cancer populations or mixed populations that consist largely of cancer patients. The largest number of measures evaluated quality of life, quality of care, and symptoms. The literature documents many measurement challenges including proxy respondents, timing of interviews, and cognitive thresholds.

Bruley, D. K. (1999) Beyond Reliability and Validity: Analysis of Selected Quality-of-Life Instruments for Use in Palliative Care, *J. Palliat. Med.*, 2(3), 299-309.

To review quality of life instruments for their potential usefulness in the palliative care setting. Conceptualisations of quality of life throughout history, and contemporary conceptualisations of quality of life are briefly discussed. Medline (1992-1998), Cinahl (1982-1997)
Inclusion: multidimensional, self-reported, appropriateness in palliative care
Identified: 20 instruments; Included: 6 instruments; SF-36, EORTC-QOL-C30, QLI, HQLI, MQOL, MVQOL; Conclusion: The researcher or clinician should consider all of these factors when choosing the quality of life instrument that best fits the purpose.

Hearn, J. and Higginson, I. J. (1997) Outcome measures in palliative care for advanced cancer patients: a review, *J. Public Health*, 19(2), 193-199.

To identify and examine outcome measures that have been used, or proposed for use, in the clinical audit of palliative care of patients with advanced cancer, and to systematically assess these using well-defined criteria; Medline, Cancerlit, Healthplan, Oncolink (1985/ 1991-1995); Inclusion: cancer, measure contained more than one domain

Identified: 41 measures (list of excluded is given); Included: 12 measures (5-56 items) e.g. ESAS, EORTC QLQ-C30, PACA, STAS; Conclusion: Each measure meets some, but not all, of the objectives of measurements in palliative care, and fulfills some, but not all, of the criteria for validity, reliability, responsiveness and appropriateness.

Books

Most major textbooks on palliative care include chapters or sections on outcome measures.

Addington-Hall J., et al. Research Methods in Palliative Care. Oxford: Oxford University Press; 2007

Chapter 7: Outcome Measurement (Irene Higginson, Richard Harding)

7 measures in more detail (POS, STAS, ESAS, Zarit Burden etc.)

Bruera, E., Higginson, I.J., Robb, S.D., von Gunten, C.F. Textbook of Palliative Medicine. 1 ed. London: Hodder Arnold; 2006

Chapter 40: Tools for pain and symptom assessment in palliative care; Chapter 41:

QoL assessment in palliative care

Several symptom assessment tools are described, only a few QoL measures are mentioned

Hanks, G., Cherny, N., Christakis, N.A., Fallon, M., Kaasa, S., Portenoy, R.. Oxford Textbook of Palliative Medicine. 4 ed. Oxford: Oxford University Press; 2010

6.3 QoL in palliative care - principles and practice; 7.7 The measurement of pain and other symptoms; 7.10 Clinical and organisational audit and quality improvement in palliative medicine;

6.3: several measures are described; (e.g. EORTC QOL-C30, FACT-G, SEIQOL, MQOL)

Walsh, D., et al. Palliative Medicine. 1st edition. Philadelphia: Saunders Elsevier; 2009

Chapter 63: Clinical symptom assessment;

Chapter 64: Qualitative and quantitative symptom assessment; Chapter 65:

Measuring QoL

Several instruments of symptom assessment and QoL are described and linked

List of acronyms

ADL	Activities of Daily Living
AKPS	Australia-modified Karnofsky Performance Status
BDI	Beck Depression Inventory
CAMPAS-R	Cambridge Palliative Audit Schedule
EAPC	European Association for Palliative Care
EFAT	Edmonton Functional Assessment Tool
EORTC-QLQ C30	European Organisation for Research and Treatment of Cancer Core Questionnaire – Quality of Life
ESAS	Edmonton Symptom Assessment Scale
ESS	Edmonton Staging System
FACIT	Functional Assessment of Chronic Illness Therapy
FACT-G	Functional Assessment Cancer Therapy–General
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
IAHPC	International Association for Hospice and Palliative Care
KPS	Karnofsky Performance Status
LCP	Liverpool Care Pathway
MCID	Minimally clinically important difference
MQOL	McGill Quality of Life Questionnaire
MQOL-HIV	Multidimensional Quality of Life Questionnaire for persons with HIV/AIDS
MS	Multiple sclerosis
MSAS	Memorial Symptom Assessment Scale
MSAS-SF	Memorial Symptom Assessment Scale - Short Form
MVQOLI	Missoula-Vitas Quality Of Life Index
NHS	National Health Service (UK)
NRS	Numerical rating scale
PACA	Palliative Care Assessment tool
PCOC	Palliative Care Outcome Collaboration
POS	Palliative care Outcome Scale
PPS	Palliative Performance Scale
PRISMA	Reflecting the P ositive D ive R sities of European P riorities for R e S earch and M easurement in End-of-Life C Are
PROMs/PROs	Patient-Reported Outcome Measures
QODD	Quality of Death and Dying (measure)
QoL	Quality of life
QUAL-E	Quality of Life at End of Life (measure)
SD	Standard deviation
SEIQoL-DW	Schedule for the Evaluation of Individual Quality of Life-Direct Weighting
STAS	Support Team Assessment Schedule
VAS	Visual analogue scale
ZBI	Zarit Burden Inventory

PRISMA partners



www.prismafp7.eu

