



Introducing the Outcome Assessment and Complexity Collaborative Suite of Measures

A Brief Introduction - Version 2

Witt J, de Wolf-Linder S, Dawkins M, Daveson BA, Higginson IJ, Murtagh FEM

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Introduction

Health services and health care professionals are increasingly being required to demonstrate that they meet the needs of individual patients and their families, and that they do this in an effective and efficient way.

To achieve this, and to strive towards higher standards of care, services and staff must be able to show that they are making a measurable and positive difference to patients and families receiving their care. The Outcome Assessment and Complexity Collaborative (The OACC project) has collated a suite of fit-for-purpose measures designed to capture and demonstrate this difference for palliative care services. These measures can be used to improve team working, drive quality improvement, deliver evidence on the impact of services, inform commissioning and, most importantly, achieve better results for patients and families¹. In this booklet, the suite of measures is introduced. Subsequent chapters explain each measure in turn.

What is an outcome measure?

An outcome measure captures ‘change in health status’ as a consequence of health care or interventions.² The term ‘health status’ is used here in its broadest sense, and it relates to both patient and family (in keeping with the patient and family perspective of palliative care). Health status may not improve, but it may be maintained rather than allowed to decline. For example, quality of life may be maintained at a level for weeks or days longer than it would have been without palliative care interventions, or pain

may be controlled better, or families may be more supported and experience less strain. It is important to recognise that the experience of care is not the same as the outcomes of care. Experiences are likely to be better if outcomes are better, but the two do not always correspond. Experiences of care relate more closely to how individuals are respected, listened to and heard. Both outcome and experience measures are important, but this booklet concentrates predominantly on outcome measures

The move to commissioning services based on outcomes, rather than structure and process measures, is already under way. This means outcomes now serve an important function in palliative care.^{3,4} Previously, almost all assessments of the quality of palliative care in England focused on the structure and processes of care; for example, number of staff, number of admissions, length of stay and types of services provided,⁵ and they failed to routinely examine and report on outcomes for the patient and family, such as improvements or maintenance of functional status, reductions in symptom severity and alleviation of family strain.

Collecting patient and family outcomes routinely, using a set of standard assessment tools, has a number of advantages. Availability and feedback of outcome data has been shown to affect processes of care, leading to improved symptom identification and better communication.⁶⁻⁸ Regularly collected outcome data provide a consistent clinical picture of each patient and can help ensure that person-centred care is delivered. Outcome scores can provide

a common language amongst health care professionals; for example, at staff handovers and multidisciplinary meetings, supporting rapid decision-making, rational allocation of workload, and coordinated discharge processes. Outcome measures facilitate communication between service users and staff.⁶

This booklet introduces the OACC suite of outcome measures, along with one added question to help understanding of the patient's living situation. This suite of measures has been carefully selected to monitor changes in the key domains relevant for patients receiving palliative care. The combination of these measures fulfils the outcome measurement requirements recommended by the European Association of Palliative Care Taskforce on Outcome Measurement and supports measures most likely to be adopted for tariff development and national data and outcomes work in England (the Palliative Care Clinical Data Set). If used routinely, these measures will enable services to demonstrate that they provide effective and efficient care, and, most importantly, improve outcomes for patients and families.

References

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Frequently asked questions

When should I use these measures?

This booklet provides information about when to use the measures. Generally, it is recommended that the measures are collected at first assessment in the palliative care service and that there is at least one subsequent assessment. However, it is better if they are used continuously to inform and improve care. Depending on the frequency of subsequent assessments, you may wish to collect measures at all assessments or only at some; for example, if assessments are daily, you may not wish to collect all measures on a daily basis and you may choose to collect measures at first assessment and at phase change, collecting only phase daily. OACC-registered services are asked to collect measures at first assessment and on at least one additional occasion (except for the Living Situation question, which should only be updated if living circumstances change). The recommended interval for using the whole suite of measures is when phase changes or, if phase remains unchanged for a longer time, 3–5 days after first assessment for inpatients and 7–21 days after first assessment for community patients. This allows for variation in follow-up according to individual patient needs and differences in team working according to size of team and geography, etc. It is important that the timing of measures is driven by clinical need, not by the measures.

Do I have to change my clinical practice to use the OACC suite of measures?

If you don't already use these measures you will need to modify your practice to allow time to use the measures in a way that adds value to your work. The measures quite naturally map onto the holistic common assessment¹ and can be incorporated into clinical routines to help focus on issues important to patients. Some measures, such as the Phase of Illness or AKPS, are already routinely used in many services. Others may be new additions, but they should not change your practice with the patient and their family. However, the information from these measures will inform your clinical reasoning and the goals of care you establish. When used correctly, they have the potential to streamline your practice, save you time in the long term and improve outcomes for the patients and families with whom you work.

How do I know if worse scores reflect poor management for the patient as opposed to the patient deteriorating as a result of their illness?

It is important to acknowledge that patients will, over time, become less well. This means that symptoms may get worse, functional ability may deteriorate, and other concerns, such as anxiety, may increase. It is especially important for managers and commissioners to understand this; it is futile to expect everything to always improve. It won't. Using outcome measures is not about seeking the unachievable: it is about demonstrating the quality of care that palliative care teams provide. It is possible to prevent deterioration in pain scores or worsening of mobility, for instance. Families can be supported so that the strain on them lessens and anxiety decreases and it is possible to enable a patient to be more peaceful as they approach the end of life.

The real challenge in measurement is when someone expects a standard (or benchmark) to be delivered, which is not informed by close knowledge of the patients and families concerned. This is why it is of paramount importance that outcome measurement is 'owned' and managed by clinicians, and not imposed by those managing or commissioning services. The OACC project team are closely involved in the development of case-mix classification, so that, in the longer

term, case-mix adjustment of outcome measurement becomes possible, and this will enable realistic benchmarking of similar services useful to both palliative services and commissioners alike - such as already occurs in Australia through the Palliative Care Outcomes Collaboration.

References

- 1 Richardson A, Palin J, Henry C, Hayes A, Morris C, Dewar S. Holistic common assessment of supportive and palliative care needs for adults requiring end of life care. National End of Life Care Programme: Improving end of life care. 2010 (available at: www.nhs.uk/resource-search/publications)

Websites

Cicely Saunders Institute:
www.kcl.ac.uk/palliative

Palliative care Outcome Scale:
<http://pos-pal.org/>

Palliative Care Outcomes Collaboration (PCOC) in Australia:
<http://ahsri.uow.edu.au/pcoc/index.html>

Hospice UK:
www.hospiceuk.org

CLAHRC South London:
www.clahrc-southlondon.nihr.ac.uk

Registering with OACC

The OACC project team collaborates closely with clinical teams enrolled in OACC to achieve and monitor the implementation of outcome measures into routine clinical care. It is important that they are chosen, implemented and used in an evidence-based way. OACC

therefore draws on existing psychometric study of outcome measures in palliative care, and believes that strong academic and clinical partnerships help provide solutions to many challenges faced in implementing outcome measures. Launched in 2013 and led by the Cicely

Saunders Institute and Hospice UK, we welcome you to contact us if you would like to become an OACC-registered service or if you would like further information about what we offer and how we can work with you to achieve better outcomes for patients and families.

Contact details

The OACC Project team
Cicely Saunders Institute
King's College London
6 Bessemer Road
Denmark Hill
London SE5 9PJ

Phone: 020 7848 0753 or 020 7848 0096
Email: oacc@kcl.ac.uk

Antonia Bunnin
Director of Hospice Support and Development
Hospice UK
Hospice House
34-44 Britannia Street
London WC1X 9JG

Phone: 020 7520 8200
Email: a.bunnin@hospiceuk.org