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POS

KING'S College LONDON

A user's guide to the *Palliative care Outcome Scale*

Fiona Aspinal
Rhidian Hughes
Irene Higginson
Jayne Chidgey
Uta Drescher and
Margaret Thompson
on behalf of the Palliative care Outcome Scale Action Partnership

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Introduction

Health services today are required to demonstrate that they meet the needs of individual patients and their families and do this in an effective and efficient way[1]. To achieve this, and to strive towards higher standards of care, services must measure the quality of care they provide. However, measuring need, the quality of care and its effects in palliative care is not straightforward. The important effects, such as pain, symptom control and alleviation of psychological problems all need to be captured in a sufficiently simple format to be useable in the clinical setting, when patients are often very sick.

The Palliative care Outcome Scale (POS) is an assessment and measurement tool designed to meet the needs for simple, appropriate assessment. It is a short, easy-to-use questionnaire designed to prospectively assess clinical practice, with regards to patients' palliative care needs and palliative care outcomes. This booklet provides a practical guide to using POS. Part I discusses key issues in measuring outcomes in health and palliative care. Part II covers the background to the tool. Part III explores issues around implementing the POS. Part IV considers data analysis and interpretation. Finally, Part V illustrates POS in practice.

Part I: Measuring outcomes

Measuring outcomes in health care

Monitoring health care outcomes is an important mechanism for developing and maintaining high quality health care systems worldwide[2]. Within the United Kingdom this is enshrined within the 1999 Health Act[3], which stipulates:

'It is the duty of each Health Authority, Primary Care Trust and NHS Trust to put and keep in place arrangements for the purpose of monitoring and improving the quality of health care which it provides to individuals'.

Closely allied to these legislative requirements is the notion of clinical governance[1]. Similar measures are in place in many other countries. Health care professionals are now required to embrace quality control, base clinical practice on evidence, and to set out clear protocols and standards for clinical practice. Most importantly, financial resources are increasingly being distributed to those service areas that can demonstrate efficiency and effectiveness. Thus, in the drive towards improving service quality, monitoring intervention practice and provision is becoming an increasingly integral part of the health care system. These health care issues are mirrored, and sometimes even magnified, within palliative care policy and practice.

Measuring outcomes in palliative care

Palliative care aims to meet the physical, psychological, social and spiritual needs of individuals at the end-of-life. Equally, palliative care recognises the needs of patients' family, friends and other people close to the patient. The holistic nature of palliative care requires that services be provided by a range of organisations, and by staff working in multi-disciplinary teams. Assessment and measurement of palliative care services must therefore reflect the issues which surround patient care, the services provided to family, friends and people close to the patient, and the complex relationship between different service providers.

Part II: Background to the POS

The development of the POS

The POS was developed following a systematic review of palliative care outcome measures[4]. The review concluded that no single measure addressed all key domains of palliative care. Furthermore, issues of validity, reliability, responsiveness and appropriateness were only partially met by the measures reviewed. The POS was developed to overcome some of the limitations associated with existing outcome measurement scales in palliative care[5]. The POS includes questions that had been used effectively in other outcome measurement scales and that encapsulate the central tenets of palliative care. Notably, the POS covers:

- Physical symptoms
- Psychological symptoms
- Spiritual considerations
- Practical concerns
- Emotional concerns – personal and familial
- Psychosocial needs – personal and familial

The POS, therefore, offers an opportunity for all symptoms affecting the patient to be raised. This seeks to ensure that each patient's problems are identified and enables staff to provide a more individualised care package.

The POS questionnaires

The POS comprises two complementary questionnaires. One for patients and one for staff. Staff can also make use of a scoring sheet. The questionnaire structure, format and style are similar for both patient and staff versions with most questions scored on Likert scales. In addition there are standard questions. The main difference between patient and staff questionnaires is that staff are asked to assess and record patients' functional status.

Scoring the POS

The physical, psychological, spiritual, practical, emotional and psychosocial domains represented in the POS are scored using a 0 – 4 (Likert) scale, with numerical and descriptive labels. Patients are asked to mark the box that best represents their condition. Staff, on the other hand, mark the box closest that they think most accurately

represents patients' conditions.

Once patients have completed the questionnaire there are many possible interpretations. These interpretations will all be guided by clinical experience and patients' general condition. For example, a patient who describes themself as 'slightly' affected by pain, is indicating that their pain may not be significant enough to warrant further administration of analgesia. It may also suggest that pain limits some activities but does not impair them enough to affect everyday living and associated quality of life. This prevents the patient from describing their pain as 'moderate'.

The POS enables two types of scores to be generated. First, scores can relate to individual question items. Individual item scores can enable staff to monitor change over time and allows a focus on particular POS items, such as anxiety, as pertinent to particular patients. Such procedures allow staff to assess and measure change in patients' conditions against interventions adopted.

Second, scores can be summarised. The summary score is generated by totalling scores from each question. The maximum overall summary score possible, which would only be generated when interventions had not made any significant impact, is 40 for the patient version and 44 for the staff version of the POS. Differences in these maximum scores between patient and staff versions is due to one extra question on the staff POS regarding patients' functional status; the Eastern Cooperative Oncology Group (ECOG) performance status.

Validity and reliability

The POS has been shown to be a credible clinical, research and audit tool, which is acceptable to both patients and staff[5]. Individual POS question items are all valid and the POS is equally valid when used as a summary scale. The POS is sensitive to change over time. Notably, it is responsive to changes in patients' conditions and will generate different results accordingly. Thus, the POS can detect clinically significant changes. The POS has acceptable internal consistency, which refers to the extent POS items tap into different aspects of the same attribute. The POS is reliable as it can yield similar results with different observers and when administered at different points in time. However, training in using the POS, and practice within a team is needed to achieve this. Part III gives training guidance.

Questionnaire completion times

The POS validation study found patients and staff took no more than ten minutes to complete the questionnaire[5]. On the first assessment it takes approximately six minutes for staff to complete the POS form and eight minutes for patients. However, in subsequent assessments, the time required for both patients and staff completions reduced. By the third assessment, for example, the average assessment time for each group was around four minutes. Subsequent interviews with professional users of the POS reinforced these initial findings demonstrating that the tool is very quick for both patients and staff to complete[6]. However, patients were found to take longer to complete questionnaires when staff are present[5]. Longer completion times are associated with the POS being used as a basis for valuable discussion between patients and staff.

Utility

The POS was developed for, and is now widely used with, people in receipt of specialist palliative care services. Specialist palliative care settings that use the POS include, for example, specialist hospital teams, specialist community teams, hospice day centres and in-patient units.

The POS has primarily been used with English speaking patients and their professional carers. However, the POS has been translated into other languages including, for example, Dutch, Punjabi, Spanish and Urdu. However, translated versions of the POS require testing to ensure it remains a valid tool.

The POS provides a very effective means of monitoring service interventions. The results from POS can be harnessed to improve patients' quality of care. To achieve this, the POS has been used as:

- a clinical tool
- an audit tool
- a research tool
- a teaching aid.

Part III: Implementation considerations

Education and training

Clinical tools will be most effective when accepted fully by the clinical team. Using the POS is most effective when staff at all levels have been consulted about its usefulness in their clinical setting. It is also essential that staff be involved in the decision making process as a whole, and especially with regards to methods of implementation. It is essential that implementation is supported by an integral education and training package. Such a package should enable staff to feel confident about using the POS, appreciate its underlying rationale and purpose, and understand the ways results can be used to improve care for patients. A culture of individual blame must be avoided: the team will need to see solutions to problems identified. Equally, staff need to be equipped with the skills and knowledge to enable them to act upon any questions or problems that arise from the POS. For example, should a patient score four (most severe) on the question for anxiety, it is vitally important that staff know how to fully respond.

In order to sustain staff commitment to the POS, it is important for those responsible for analysis of the data to share results with all team members. This will help to ensure that patients, staff and services as a whole benefit from patient feedback. Ultimately, the POS should be regarded as an integral component of routine clinical care. However, for this to take place requires continuing education and training.

Adapting the POS

In some clinical settings it can be appropriate to adapt the POS questions to better reflect particular clinical environments and patients' needs. For example, some POS questions may not apply to particular patient groups and more relevant information could be elicited when questions are adapted. Questionnaire adaptation is one important implementation consideration for professional users of the POS[6]. For example, some of the descriptive labels attached to questions have been altered in some organisations to better reflect local needs. It is important to remember, however, that testing will be required to ensure that the adapted questionnaire will yield meaningful and accurate results.

When the POS is used for audit it is necessary to collect demographic information in order that meaningful comparisons can be made between groups. Key demographic characteristics that should be included are patients' gender, age, diagnosis, occupation, marital status, living arrangements and ethnic origin. Other important information includes, for example, place of care, place of death and date of death. Information about drugs and treatments used will also allow comparison of outcomes of different treatments.

When the POS is used to collect information in non-specialist palliative care settings, some organisations have adapted the name from the Palliative care Outcome Scale to the Patient Outcome Scale. In these non-specialist settings, some people may associate palliative care with terminal cancer, which could cause anxiety and distress for some patients and their close ones.

Assessment frequency

Concurrent and complementary POS assessments from patient and staff perspectives can yield valuable information about patients' needs over time. The POS asks for assessments based on the last three days. In the POS validation study, patients receiving in-patient care were assessed every three days and patients receiving outpatient or home care were assessed at every contact, which was usually once a week[5]. In practice, professional POS users may adopt a flexible approach to assessment frequency to closely reflect their own service[6]. Some organisations, for example, use the POS every three days, others administer the POS weekly, and some assess at every face-to-face visit.

The frequency of POS administration can be influenced by a number of factors including organisational setting, patient group and clinical need. For example, an in-patient unit may use the POS once a week to inform ward round discussions, providing a summary of patient conditions and to assess clinical interventions. However, when patients' conditions become critical, or particular symptoms become acute, the POS can be administered more frequently to help assess rapidly changing patient conditions and the appropriateness of clinical interventions. The frequency of POS assessments can be decided during the implementation phase. However, it must be made clear what decision has been reached about frequency before POS use starts.

Part IV: Data analysis and interpretation

Storing the POS data

POS scores can be stored in a number of ways, including within patients' clinical notes or in a computerised database. From the outset, it is important to recognise that methods of storing confidential POS data should conform to the legal requirements of the Data Protection Act[7].

Analysing and interpreting the POS data

The reasons for using the POS will influence the methods used to analyse POS data. For many purposes, analysis of POS data can be based on ongoing comparison of scores on a case-by-case basis. In these situations, the POS can help to identify individual patients' needs and to inform clinical decisions. Scores can also be analysed to monitor patients' clinical change over time for each item.

Equally, a global score, generated by summing all the scores for each patient, can be useful. This approach provides an insight into the patient's overall condition. Furthermore, when compared between different assessments these data can also demonstrate changes in general condition over a period of time.

Differences in scores between patients and staff can highlight issues for staff to follow up with patients. More generally, differences in scores for particular items can help to identify areas for practice development, staff education and training.

POS scores can be analysed on a case-by-case basis, which enables comparisons between different POS scores at a particular point in time, and over a period of time. For group analysis – particularly when POS is used for audit and research purposes – a database should be used to facilitate data analysis.

Complementary information

When setting up a database it is worth considering what additional data might be included. For example, recording admission and readmission dates and dates of POS assessments can be useful.

When demographic data have been collected for patients, graphs and summary statistics should be obtained to describe the characteristics of the patient group. The principal focus of further analysis would usually be on the individual question domains covered by the POS and, for some purposes, on the summary score. As an example, it would be of interest to look at whether POS scores for individual questions vary according to facts such as age-group, diagnosis or the setting in which palliative care is being given. Variation over time could be looked at over an admission period or, if there were enough data, over more than one admission period. Both univariate and multivariate analyses can be appropriate for these types of analysis.

Part V: POS in practice: Case studies

The following two case studies, Mrs Annie Barlow and Mr Gordon Bradbury (names have been changed), exemplify some of the ways in which POS has been incorporated into routine clinical practices.

Case study A: Mrs Annie Barlow

Mrs Annie Barlow, an 86 year old lady with acute myeloid leukaemia was first assessed by the home care team in April. On this visit, patient anxiety, information and sharing feelings were scored as two. It was identified that Mrs Barlow was "keen to discuss practical aspects of coping with a terminal illness". The clinical nurse specialist documented that Mrs Barlow "feels her family and friends are reluctant to discuss poor prognosis and practical issues and she does not want to upset them". The community nurse specialist recorded a score of one for emotional support for Mrs Barlow and her family. A score of two was recorded for weakness, fatigue and potential for infection and haemorrhage as the care problems. On the community nurse specialist's next visit anxiety, information needs and sharing feelings were scored at zero.

Four months later the symptoms, breathlessness and weakness, were scored at three, this was the highest they had been. POS therefore, showed that a significant change in clinical condition had occurred, which, following further investigations, led to a diagnosis of anaemia. As a result, it was suggested that Mrs Barlow entered her local hospice for further assessment and possible blood transfusion. This was arranged and during her admission Mrs Barlow was transfused with four units of blood. On the community nurse specialist's next visit she documented that Mrs Barlow was feeling much better, had more energy and was able to care for herself independently. Breathlessness score was scored at one and weakness scored at two.

Mrs Barlow had one further admission during which she was given a transfusion to correct her anaemia. However, her condition continued to deteriorate, weakness and ECOG score increased to four, and pain previously scored zero was now two. Later, Mrs Barlow died peacefully at home with her family present and with symptoms and other problems well controlled.

Case study B: Mr Gordon Bradbury

Using POS with Mr Bradbury proved to be useful in terms of the information that he needed. The first time he scored himself four, it was clear that he wanted more information and the chance to ask some questions. This prompted the nurse involved to gather all the available information and then spend some time going through it all with him and his wife. Although it was felt that he had understood and absorbed the information he went on to score himself quite highly (two to three) the next three times that he used the tool. If POS had not been there as an indicator the nurse involved would have assumed that he had all the information that he wanted. In response to his self-scoring, the nurse made time to repeatedly go over the information with him. The fifth time that he used the tool he scored himself at zero when asked about information needed. This indicates that Mr Bradbury now thought he had all the information he required.

Frequently asked questions

Do I have to change my clinical practice to use the POS?

You do not have to alter your practice to use the POS. It can be used and incorporated into clinical routines to help focus on issues relevant to patients in receipt of palliative care.

If I am with my patient when they complete their POS questionnaire is there any point in me completing my assessment?

It is useful to collect data from both patients and staff perspectives. This produces complementary data that can be used for comparison. In order to reduce bias, it is important for staff to take steps to minimise staff influencing patients' responses. Thus, staff should aim to complete their assessment prior to facilitating patient completion.

What should I score if I cannot make an assessment for a patient? For example, I have patients who are too confused to self-complete and I do not know if they have had their information needs met.

In order to provide a meaningful interpretation of results, especially when larger numbers of patients are assessed, it is important to qualify the reasons for these missing data. In this instance, a note would be made that the patient was too confused to complete the questions themselves. Subsequent data analysis and interpretation can be informed by these reasons for missing data.

How do I interpret a patient giving a low score on pain, even though they have some signs of distress?

The POS can help identify issues most relevant to patients at the time of their assessments. As palliative care patients live with their condition, expectations can change as will the priority they attach to particular issues. The POS can capture patients' shifting perspective, which may appear contradictory, yet POS does not assume that particular symptoms or issues will always remain constant.

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

When POS is used regularly, resulting scores can be compared with patients' clinical condition regularly and reported in medical notes. However, should POS be used for audit purposes, when the POS data may not be analysed immediately, or when access to medical records is difficult, it is important to document patients' clinical condition and their demographic characteristics alongside the POS scores.

Is there a help line to address any question we might have?

The POS was developed by Irene Higginson and colleagues. Requests for further information, queries and suggestions for developing the POS should be directed to the POS development team:

POS Development Team
Department of Palliative Care & Policy
Guy's, King's & St Thomas' School of Medicine
King's College London
Weston Education Centre
Cutcombe Road
London SE5 9RJ
United Kingdom

Telephone: + 44 (0)20-7848 5584
Facsimile: + 44 (0)20-7848 5517

Electronic mail: pos-development@kcl.ac.uk

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