

**Report on Impact of the Palliative care Outcome Scale (POS):
A global perspective**

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November 2013**

The origins of the Palliative care Outcome Scale (POS)

The POS was developed in 1999 by Professor Irene Higginson, Head of the Department of Palliative Care and Director of the Cicely Saunders Institute, King's College London, for use with patients with advanced disease, and to improve outcome measurement by evaluating many essential and important outcomes in palliative care. The Support Team Assessment Schedule (STAS), developed in 1986, was the precursor to the POS. STAS was constructed to evaluate the work of palliative care support teams and consisted of 17 items, to be rated from zero (best) to four (worst) by a professional caring for the patient.

The POS builds on some of the strengths of the STAS, such as clinical application and ease of use. Importantly, POS also allows patients to use the POS themselves. This tool is therefore a patient reported outcome measure, when the patient version of POS is used. POS has demonstrated construct validity, acceptable test/re-test reliability for seven items and good internal consistency. POS takes less than 10 minutes to complete by staff or patients.

The POS has been translated into many languages including Chinese, Croatian, Dutch, French, German, Hebrew, Italian, Norwegian, Punjabi, Spanish and Urdu - though not all of these translations have been fully validated yet.

The Scope of this Report

The aim of this piece of work was to interview European and international healthcare practitioners on their use of the Palliative care Outcome Scale (POS) and its impact on the care of patients. A separate report had already looked at the use of the African POS and this is available on the POS website: www.pos-pal.org

Everybody who had registered on the POS website was contacted to ask if they would be available for a phone interview to talk about their use of the POS and its impact and challenges. Of those that responded, a large number had looked at the POS for various reasons including to aid research; to compare against other outcome scales; or simply out of interest, but were not currently using it. There was also a strict six week time schedule for the interviews, ending in June 2013.

20 people were interviewed, based on willingness and availability within the timescale. There was considerable diversity, both in the countries represented by the interviewees and settings in which the POS was used. Participants came from Brazil, Croatia, Germany, the Republic of Ireland, Israel, Italy, New Zealand, Norway, Singapore, USA, and the UK - countries where palliative care has been established for a number of years, except Croatia, where there is no formal organised palliative care. Seven used the POS in a hospice setting (inpatient, day hospice, in the community or a combination of these), seven in hospitals (POS in inpatient or outpatient palliative care consultancy service, and in a renal service and community outreach), one in nursing homes, two in research, one stand-alone community service, one in undergraduate and post-graduate nurse education, and one mobile community outreach service. Several organisations had chosen to use the POS after comparison with, and piloting, other tools.

Impact of the POS on Patient Care

As Dr Constantini of Regional Palliative Care Network, National Cancer Institute observed, in terms of overall impact, there is not one POS. It is administered with different aims in

different settings - for example screening, supporting clinical activity, checking the quality of work of staff, for staff training or as part of a complex intervention and quality of life assessment. The POS is a form and its efficacy as a tool depends entirely on the way it is used and the understanding of those administering it.

All interviewees considered that using the POS improved patient care. While they felt they identified most symptoms and clinical needs during routine patient assessments, the POS could help in highlighting these more quickly and exposing some that the patient did not think important, or was reluctant, to mention. Some of the benefits of using the POS were very specific. For example, at Paulistano Hospital, the initial focus was on responding to the questions on pain and information. A target was set that within six months, patients should have a pain score of one or less, 72 hours after admission. This target was achieved, as had their target on information.

The POS results could also challenge expectations about patients' symptoms. One hospice recorded an interesting result from using the POS. While the team expected pain, nausea and vomiting to be the most distressing symptoms, in fact patients identified fatigue and weakness, breathlessness and poor mobility as the worst - and often overwhelming - symptoms. These symptoms are more difficult to control. The team responded by running a six week course run by the OC, physiotherapist and complementary therapist to suggest some coping mechanisms (for example, breathlessness can be helped by hand-held fans). In the final week of the course, carers were invited in to be given some tools to help their loved ones. In terms of poor mobility, the team were able to help by ensuring assessments were made early, aids were given more quickly and making sure, for example, that the patient did not have to go up and down stairs so often.

Another hospice noted that, in their inpatient unit, the changes made as a result of using the POS could be small practical ones that increased patient dignity. For example, it had been discovered that patients found it difficult to reach the light switches and therefore had to call for help. The hospice responded by installing stand-alone lamps that could be turned on by touch. There were also changes made to the way patients could choose food.

A day hospice found that using the POS identified that constipation was a common problem. This problem had not been raised by patients before, perhaps, the interviewee suggested, because they felt it was not a problem with which doctors should be 'bothered'.

In one case, where the POS had been used for research purposes with heart failure patients discharged from a trauma hospital, quantitative findings were significant for pain, other symptoms and self-worth. It appeared that nurses were not rating patients' symptoms as severely as the patients themselves rated them, or were perhaps missing cues to severity of heart failure patient symptoms. There was also a strong need by patients for more information on self-management

Sometimes the POS identified symptoms that, for various reasons, it was not possible to solve. A renal supportive care co-ordinator, running the POS as a pilot, noted there were consistently reported problems with pain, weakness and depression. Pain and weakness were common problems for people on dialysis and symptoms could not be completely controlled. In terms of depression, while there were services available at the hospital to help patients, dialysis patients had to come to the hospital three times a week and were often reluctant to come to the hospital again for anything else, or to stay longer on one of their regular visits. A hospice found that scores for anxieties about family matters and low self-worth were highlighted on the POS, when patients hadn't reported this as a problem during face to face assessment. This reinforced the need for psychosocial and pastoral services within the hospice.

Psychosocial issues

All interviewees agreed that the POS was useful in identifying and talking about psychosocial issues. It was found to be important not only with regards to patients' answers to direct questions on the POS but because, as one person put it, "it provides the starting point for a discussion with patients".

As an example, Dr Tavares from Hospital Paulistano in Sao Paulo Brazil, described a patient who had not wanted to talk to anybody, but when a nurse started asking the POS questions, became very emotional and started to talk about his feelings. Dr Tavares considered that this was because the patient felt the nurse was paying attention to his needs.

Dr Aart Huurnick, who uses the POS in a nursing home in Norway, noted that the questions about family and relationships were helpful, not only in enabling the staff to understand the relationships but also for the patient, in initiating questions about their family relationships.

Using the POS was a way of starting a conversation with patients about subjects that they did not previously perceive a medical doctor would be interested in discussing with them. For example, Dr Alessandro Valle Medical Director of Fondazione Faro, Torino noted this was the case surrounding the item on financial problems. Consequently, they rarely discussed this problem and never spontaneously, despite financial problems potentially seriously affecting the quality of a patient's life and that of their family. The POS therefore created opportunities for these problems to be addressed with staff that patients previously perceived as irrelevant.

Impact on staff

Several interviewees mentioned the positive effect of administering the POS on staff. Scores lowering over time enabled staff to see that they were doing a good job in a field of work where it was often inevitable that patients' conditions would deteriorate. Dr Huurnick noted that the question about "feeling good about yourself as a person" was a challenge in Norwegian, but very important. It enabled staff to understand that while symptom scores may be increasing, the patient could also feel that they were doing well. It was an important existential point. Overall using the POS was felt to enable staff to do their jobs better. It acted as a check-list to ensure important areas of patient care were not forgotten, it was used in staff meetings and as an integral part of multi-disciplinary team meetings for deeper analysis of patients and specifically in one organisation the POS was now an integral part of the hand-over.

Using the POS could also indicate areas where further training or support for staff was required. For example, in one organisation it became clear that staff found it hard to talk about death to patients and their families, which prompted ways of supporting them in this to be investigated. In a day centre that was changing from a social care model to a specialist model, the POS had been very useful in educating the staff, who traditionally had not seen their role as clinical intervention. It proved there was more that needed to be done in patient care.

Clinical audit, quality improvement and governance

A number of interviewees used the POS for clinical audit and quality improvement within their organisations, though others did not currently have the staff or the expertise to do this at present. It was used in change management, from a social care to a specialist care

model for a day hospice and for a service looking to expand its work to other diseases beyond cancer. For UK organisations, the evidence base the POS could provide was also useful in negotiating with commissioners for funding and recognition of the wider role of palliative care. In one case, it was of significant use in a bid for capital funding. As a result of the POS showing many patients suffered from breathlessness and fatigue and needed physiotherapy, the new expanded facilities for the organisation will include a physiotherapy gymnasium. More generally, as one interviewee commented, over time the use of POS would make it possible to demonstrate that the importance of palliative care lies not only at the end of life, but also in handling 'trigger-points' in long-term non-curable diseases and coping across the range from intense care to self-management.

Nurse Education

A Senior Lecturer at the University of Glamorgan, Wales, used the POS as one example of performance status tools in the pre-registration nurses' course. The emphasis in discussing the POS was not on palliative care, but on discussing it as a tool that enabled an assessment of a patient from a number of perspectives; patient, family and health professional. It also provoked thought about how an assessment of a patient was not just about their physical condition and symptoms. The importance of this is that nurses were acquiring information about the palliative care approach, which would be helpful in their overall work. .

Adaptability of the POS

While some participants expressed concern about changing the questions in case it affected international comparisons and there were some difficulties in translating some concepts (feeling good about oneself as a person, for example), a number of people had adapted the POS. This included deleting, changing and adding questions as appropriate for their particular setting in which they worked, and around the cultural norms of their country. In practical terms for example, the three day time period of the POS did not suit all settings. In cultural terms, the Israeli interviewee said the question about how a patient felt about themselves would not elicit a useful answer. For the Israeli POS, a question had been added on Living Wills, as the right to have one had been made a statutory law five years previously, but had been minimally utilised so far..

In Croatia, the question "Over the past three days, have you felt that life was worthwhile?" was not considered easy to understand. Most people in Croatia define themselves as Catholics, and it was considered more appropriate to focus on who was providing spiritual care, and ensuring the patient had access to the sacraments.

In Italy, it was common for relatives to know more about a patient's illness than the patient themselves, and so, while retaining integrity in their relationships with the patient, palliative care staff had to tread carefully. However, the POS was useful in that it allowed some issues which may not normally be addressed to be discussed. Dr Edward Hong from Singapore felt that using the POS was particularly helpful in the Asian context in surfacing some of the psychosocial and spiritual issues, such as grief and loss, which are not so readily talked about.

Challenges and future possibilities for using the POS

All interviewees saw the value of the POS, although it had not always been easy to implement or integrate into existing systems. In some cases the problems were practical, for example there were difficulties in integrating the POS with other assessments or into an electronic patient record system.

A US interviewee noted that the metrics being asked for by the US government for hospital reimbursement were quite onerous, so the POS was seen as one more form to fill in. Time was also a problem in terms of analysing the overall results, as opposed to using for individual patient care. A number of interviewees also commented that at first there had been resistance from staff in using the POS, because of the extra time it consumed.. However, generally they became convinced of its value when they saw how useful the information in improving patient care was and, as mentioned above, because it demonstrated to them what they were achieving.

One interviewee commented that no current tool can capture everything, especially in cases where there is a high level of complexity, or where the patient is very unstable. Another noted that the POS did not encompass functionality and palliative rehabilitation.

Overall however, there was enthusiasm to continue using the POS and to extend its use and a demand for training in analysing the results. It is clear that it can be used effectively in many settings, including non-specialist palliative care settings and adapted to suit the cultural norms of different countries.