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Review Article

A Systematic Review of the Use of the Palliative Care Outcome Scale and the Support Team Assessment Schedule in Palliative Care

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Abstract

Context. The Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) are two outcome measures used in palliative care settings to assess palliative concerns, needs, and quality of care.

Objectives. This systematic review builds on the findings of a previous review to appraise the use of the POS and STAS since 2010, particularly the context and nature of their use.

Methods. MEDLINE, Embase, PsycINFO, British Nursing Index, and CINAHL were searched for studies published between February 2010 and June 2014. Relevant authors were contacted, and reference lists of included studies were searched. Studies reporting validation or the use of the POS or STAS were included, and data on sample population, how the outcome measure was being used, study design, study aim, and results of the study were extracted.

Results. Forty-three studies were included (POS $n = 35$, STAS $n = 8$). There was an increase in the use of the POS and STAS in Europe and Africa with the publication of 13 new translations of the POS. Most studies focused on the use, rather than further validation, of the POS and STAS. There has been increasing use of these measures within non-cancer patient groups.

Conclusion. The POS and STAS are now used in a wide variety of settings and countries. These tools may be used in the future to compare palliative care needs and quality of care across diverse contexts and patient groups. *J Pain Symptom Manage* 2015;50:842–853 © 2015 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Outcome measure (health care), palliative care, patient outcome assessment, hospice care, terminal care

Introduction

Outcome measures have an increasingly important role in health care. These are measures that help to record a patient's change in health over time, as a result of health care or interventions.¹ The implementation of outcome measures is important for improving the quality of service delivery and promoting accountability. In particular, patient-reported outcome measures (PROMs or PROs) are increasingly recognized as a good way to inform the delivery of health care

and promote patient-centered care, as outcomes directly reflect the difference made for the patient.²

The Support Team Assessment Schedule (STAS) and the Palliative care (or Patient) Outcome Scale (POS) are examples of outcome measures specifically developed for palliative care. The STAS was developed in 1986 as a standardized measure to evaluate the work of palliative care support teams. Its 17 items can be rated from 0 (best) to 4 (worst) by a patient's professional caregiver. These items measure patient

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symptoms, anxiety and insight, family anxiety and insight, quality of communication with health care professionals and carers, and the need for practical support. Cohen kappas for STAS items were greater than 0.48 (up to 0.87), with high correlation coefficients (Spearman rho ranged 0.65–0.94).^{3,4}

The POS was developed in 1999 following the success of the STAS. This measure was designed for use with advanced cancer patients and evaluates similar outcomes to the STAS, but with an additional patient-reported element. The POS demonstrated good construct validity (Spearman rho = 0.43–0.80), as well as test/retest reliability.⁵ Internal consistency of the different versions of the measure was also good (Cronbach alpha = 0.65 [patients], 0.70 [staff]).⁵ The 10 items of the POS assess physical symptoms, psychological, emotional, and spiritual needs, and the provision of information and practical support. Two versions of the original (“core”) POS are available for use in specialist and nonspecialist palliative care settings. The latter is also referred to as the “Patient Outcome Scale” in some studies.⁶ This is recommended when POS is used in a population that will not necessarily be familiar with or introduced to the term palliative care, such as screening those with long-term conditions for palliative care needs. The POS-S is a further development of the POS that incorporates a symptom list. Extended versions of the POS-S have been developed for use with those living with multiple sclerosis (POS-S-MS), parkinson disease (POS-S-PP), and end-stage renal disease (POS-S-renal). Additional POS measures (POS-S and Integrated Palliative care Outcome Scale [IPOS]) represent refinements of POS to capture more detail about symptoms (POS-S) or to integrate the core POS with the symptom module POS-S (IPOS). In addition, POS is being developed as a screening measure to assess needs of dementia patients residing in care homes.

One of the main challenges to the use of PROMs in palliative care is the high proportion of palliative care patients with impaired cognition or those who are otherwise too unwell to complete them. In some palliative care settings, nearly 60% of all patients were unable to complete PROMs unaided.⁷ It is helpful, therefore, to use the term “patient-centered outcome measures,”⁸ which refers to measures that encapsulate the priorities of patients themselves, but may include proxy reporting (i.e., they are completed with help from family or professionals, or directly by professionals themselves). Of note, the POS exists in patient, health professional, and carer versions, and so supports this approach.

A review was conducted in 2010 to appraise the use of the POS and STAS since their development. To

build on these findings, the present review aims to appraise the use of the POS and STAS, especially in the context and nature of their use and identify strengths and weaknesses, by identifying and analyzing publications about their use since 2010.

Methods

Design

We conducted a systematic literature review to update the previous review by Bausewein et al.,⁷ including references up to 2014. We followed standard review methodologies as outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement, which is an evidence-based minimum set of items for reporting systematic reviews.^{9,10}

Search Strategy

We used a predefined search strategy. Articles were identified by a comprehensive search of five electronic databases: MEDLINE, Embase, PsycINFO, British Nursing Index, and CINAHL. Databases were searched for articles published between January 1, 2010 and June 9, 2014. The following search terms were used in an advanced key word search, or an advanced abstract search where the key word search function was unavailable: “Support Team Assessment Schedule”; “STAS and palliative”; “Palliative Care Outcome Scale”; “Palliative Outcome Scale”; “Patient Outcome Scale”; and “POS and palliative.” To identify any further articles, the reference lists of relevant articles were reviewed, users registered to the POS website (www.pos-pal.org) were contacted for additional publications, and a list of publications from the Department of Palliative Care, Policy and Rehabilitation, King’s College London, was searched for relevant records from 2010 onward. Full details of the search strategy are presented in [Appendix I](#) (available at jpsmjournals.com).

Inclusion and Exclusion Criteria

Inclusion criteria were as follows: 1) those publications that focused on the validation of POS (and related measures, e.g., POS-S) or STAS; 2) reported psychometric testing or psychometric properties of the original measures or of translations; and 3) those publications that used the POS (and related measures, e.g., POS-S) or STAS to collect data. Exclusion criteria were as follows: 1) review articles; 2) publications before January 2010; and 3) publications already included in the previous review.⁷

Study Selection

Studies identified through the search were imported into Endnote X7 (Thomson Reuters, Philadelphia,

PA) and screened to remove duplicates, conference abstracts, reviews, and research agendas. The abstracts of the remaining studies were assessed, with eligible studies being further subjected to full-text screening before being included in the systematic review.

Data Extraction and Analysis

Data were extracted from included studies and tabulated in a spreadsheet. Data captured included year of publication, author, study location/country, sample population, how the outcome measure was being used, study design, study aim, and results of the study. Details are in [Appendix II](#) (available at jpsmjournal.com). Articles were then categorized by their main objective and purpose of the use of the outcome measure, for example, study of symptom prevalence within a population. Details are in [Appendix III](#) (available at jpsmjournal.com). Both of these processes were carried out by one researcher (E. C.) independently, with the process repeated for 10% of studies by another independent researcher (J. W.). Raters agreed on 68% of items. Any discrepancies were discussed with the senior authors until agreement was reached.

Data Synthesis

Extracted data from the studies were tabulated by classification according to their main objective. Data were then further synthesized into tables to show countries, translations, and populations in which the measures were used. These data were reported independently and in total with the data reported in the previous review by Bausewein et al.⁷

Results

Study Selection

Overall, 178 articles were identified from the database search, and 10 additional articles were identified through contacts, scanning of reference lists, and departmental publications ([Fig. 1](#)). After exclusion of duplicates and nonrelevant articles, 43 studies remained: 35 on one of the POS family of measures and eight on the STAS. Characteristics of the included studies may be found in [Appendices II and III](#) (available at jpsmjournal.com).

In addition, we were made aware of four ongoing studies that used or validated the POS, but these would not be ready for publication until after the publication of this review. Details of these studies can be found in [Appendix IV](#) (available at jpsmjournal.com).

Study Designs and Aims

Of the 35 POS studies included, 24 were observational^{6,11–33} and 11 were experimental.^{34–44} Of the observational studies, 10 were cross-

sectional,^{6,13,15,16,20,21,23,25,31,32} 11 were longitudinal,^{11,12,17–19,22,26,27,29,30,33} two were qualitative or mixed methods,^{24,28} and one was of part of a quality assurance program.¹⁴ Of the experimental studies, three were randomized controlled trials (RCTs)^{37,38,43} and the remainder were quasi-experimental.^{34–36,39–42,44}

Of the eight STAS studies included, seven were observational^{45–51} and one was experimental.⁵² Of the observational studies, two were cross-sectional^{45,46} and five were longitudinal.^{47–51} The experimental study was longitudinal.⁵² A total of 8728 palliative care patients contributed data to the included POS and STAS studies.

Population

Both POS and STAS measures can be applied for a variety of diagnoses. As depicted in [Table 1](#), these tools have both been used predominantly with cancer patients, but also with populations with HIV/AIDS. Since the previous review, STAS has only been applied to cancer patients^{45–48,50–52} and those with unspecified palliative care needs.⁴⁹ In contrast, the POS has been applied not only for cancer,^{11,15,21,30,36,39,40,44} but also for a range of additional diagnoses; HIV/AIDS,^{16,17,25,31,32,34,38,43} dementia,^{13,27} MS,^{26,37} Parkinson disease,^{18,23} chronic kidney disease,^{6,33} chronic heart failure,^{29,38} and chronic obstructive pulmonary disease (COPD).^{11,30} Although the POS was used with some of these patient populations at the time of the previous review, it has now been used in a number of new populations, in subgroups, or at different stages of disease: renal transplant patients,⁶ end-stage renal disease,³³ Parkinson syndromes (idiopathic Parkinson disease, progressive supranuclear palsy, and multiple system atrophy),^{23,37} newly diagnosed HIV patients,²⁵ patients severely affected by MS,²⁶ and advanced COPD.³⁰

Whereas the STAS was developed to be used by health care professionals to assess patients, the POS was developed from the outset to have a patient and a staff version. One study using the STAS did involve informal carers; this was an audit of a telephone triage service used by patients, caregivers, and health professionals, which used a modified version of the STAS.⁴⁹ Two studies investigated the effect of a palliative care training intervention for health care professionals.^{36,41} The POS was completed by health care professionals and informal caregivers as a retrospective analysis of decedents with dementia,²⁷ whereas three other similar studies used only caregiver assessments.^{13,15,44} Four studies incorporated caregiver views on the experience of caring or of palliative care services, and on their views of patients' experiences.^{21,29,35,41}

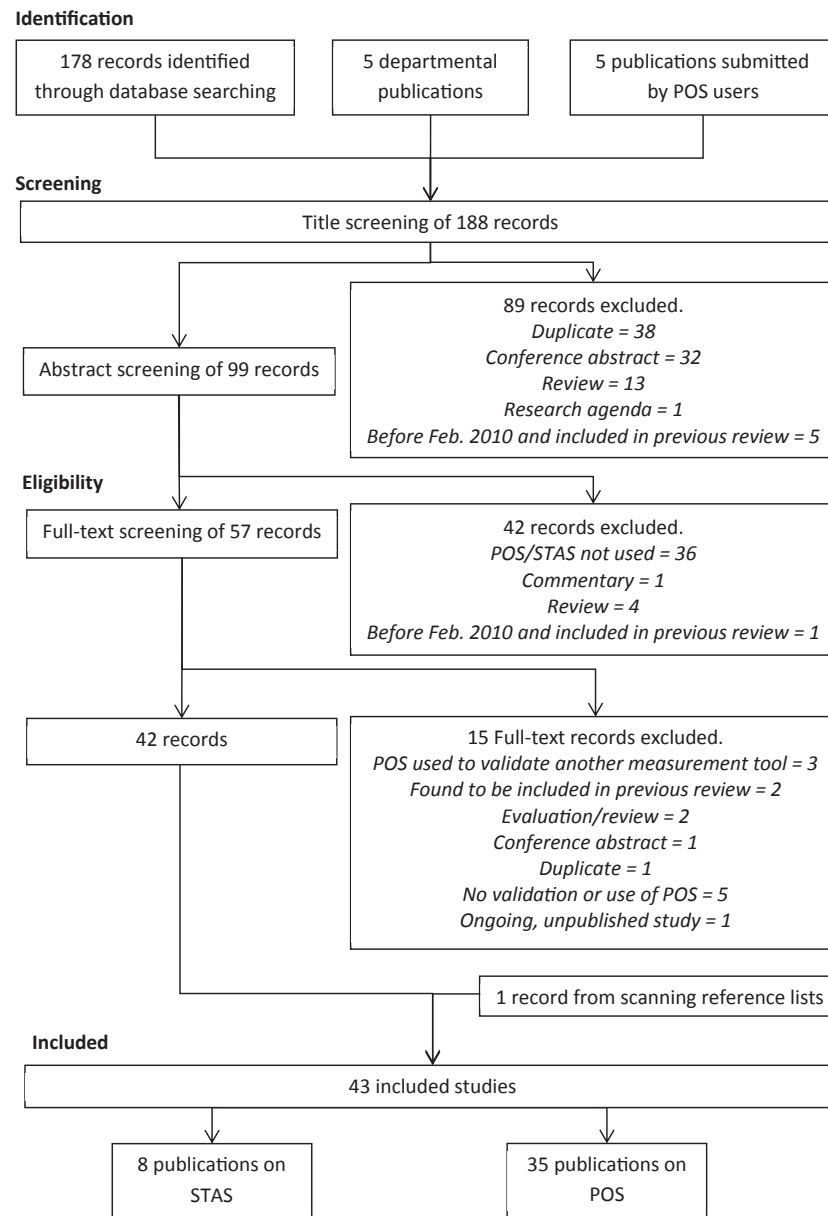


Fig. 1. PRISMA chart for identifying publications on POS and STAS. POS = Palliative care Outcome Scale; PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analysis; STAS = Support Team Assessment Schedule.

Versions of the POS and STAS

In addition to the original versions of the POS and STAS, several different versions and adaptations were used throughout studies. The POS-S has been used alongside the core POS to assess patients with breathlessness,²¹ although some studies used the extended versions of the POS-S; POS-S-PP,^{18,23} POS-S-MS,²⁶ and POS-S-renal.⁶ The study using POS-S-renal⁶ added nine items to the scale to capture additional symptoms in a renal transplant population, whereas a study assessing heart failure and lung cancer patients²¹ used the core POS with POS-S, with the addition of two items from POS-S-PP. There were 12

studies reporting use of the African Palliative Care Association (APCA) African POS,^{14,16,17,19,20,24,25,31,32,34,38,43} in comparison to just two in the previous review.

The STAS was originally developed as a 17-item score. A version that was adapted and validated for inpatient use⁵³ was used in Hong Kong.⁴⁵ The STAS was further adapted with additional symptom detail for use in a telephone triage service for palliative care patients in the UK.⁴⁹ Conversely, one study in Japan⁵¹ condensed the scale to use only the second item for assessing symptom control after radiation therapy.

Table 1
Classification of Studies by Sample Population

| Palliative Care Patients With | STAS (Total Studies n = 47) | POS (Total Studies n = 79) | STAS (New Studies n = 8) | POS (New Studies n = 35) |
|--|--------------------------------|-------------------------------|-----------------------------|-----------------------------|
| Cancer | 30 | 28 | 7 | 8 |
| Mixed diagnoses—palliative population (not specified) | 9 | 18 | 1 | 8 |
| HIV/AIDS | 4 | 12 | 0 | 8 |
| Neurological disease | 1 | 11 | 0 | 6 |
| Chronic kidney disease | 0 | 3 | 0 | 2 |
| Chronic heart failure | 1 | 3 | 0 | 2 |
| Chronic obstructive pulmonary disease | 0 | 3 | 0 | 2 |
| Studies that included formal/informal carers (with/without patients) | | | | |
| Health care professionals | 3 | 8 | 1 | 3 |
| Health care professionals (with patients) | 1 | 9 | 0 | 3 |
| Informal/family carers | 1 | 7 | 1 | 6 |
| Informal/family carers (with patients) | 0 | 6 | 0 | 3 |

STAS = Support Team Assessment Schedule; POS = Palliative care Outcome Scale.
Some studies had more than one population and were counted more than once.

Translations and Country of Data Collection

There have been numerous translations of the STAS and POS (Table 2), with several new POS translations becoming available since the last review. All new POS translations are versions of the APCA African POS,⁵⁴ which was formally translated and partially validated in various African languages: isiXhosa,^{16,24,38} isiZulu,^{16,24} Luganda,^{16,24,25} Runyankole,¹⁶ Runyoro,^{16,24} SeSotho,^{16,24} and SeTswana.^{16,24} Further

translated versions in Afrikaans,³⁸ KwaZulu Natal dialects,¹⁶ Luo,²⁵ Runyakitara,²⁵ Swahili,^{17,25,38} and Tumbuka⁴³ also are available and/or in use; however, these have not yet been validated. No new translations of the STAS were published, nor any validations of previous translations.

New studies using the STAS or POS have a broad geographical scope (Table 3), with the number of studies from Africa rivaling that of Europe. All

Table 2
Validation/Use of Translations of STAS and POS

| Language | STAS | | | POS | | |
|------------------------|-----------------------|-------------------------------------|------------------------------|-----------------------|-------------------------------------|------------------------------|
| | Translation Available | Articles on Validation ^a | Articles on Use ^a | Translation Available | Articles on Validation ^a | Articles on Use ^a |
| Afrikaans | | 0 | 0 | ✓ ^b | 0 | 1 |
| Dutch | ✓ | 0 | 0 | ✓ ^c | 2 | 1 |
| Chinese (Mandarin) | ✓ | 0 | 2 | ✓ | 0 | 0 |
| French | ✓ ^c | 0 | 1 | ✓ | 0 | 0 |
| German | | 0 | 0 | ✓ ^c | 0 | 4 |
| isiXhosa | | 0 | 0 | ✓ ^{b,c} | 1 | 2 |
| isiZulu | | 0 | 0 | ✓ ^{b,c} | 1 | 1 |
| Italian | ✓ ^c | 0 | 0 | ✓ | 0 | 1 |
| Japanese | ✓ | 0 | 4 | | 0 | 0 |
| Khmer | | 0 | 0 | ✓ | 0 | 0 |
| KwaZulu Natal dialects | | 0 | 0 | ✓ ^b | 0 | 1 |
| Luganda | | 0 | 0 | ✓ ^{b,c} | 1 | 2 |
| Luo | | 0 | 0 | ✓ ^b | 0 | 1 |
| Malayalam | | 0 | 0 | ✓ ^c | 0 | 0 |
| Polish | ✓ | 0 | 0 | | 0 | 0 |
| Portuguese | | 0 | 0 | ✓ ^c | 0 | 0 |
| Punjabi | | 0 | 0 | ✓ | 0 | 0 |
| Runyakitara | | 0 | 0 | ✓ ^b | 0 | 1 |
| Runyankole | | 0 | 0 | ✓ ^{b,c} | 0 | 1 |
| Runyoro | | 0 | 0 | ✓ ^{b,c} | 1 | 1 |
| SeSotho | | 0 | 0 | ✓ ^{b,c} | 1 | 1 |
| SeTswana | | 0 | 0 | ✓ ^{b,c} | 1 | 1 |
| Spanish | ✓ | 0 | 0 | ✓ ^c | 1 | 2 |
| Swahili | | 0 | 0 | ✓ ^b | 0 | 3 |
| Tumbuka | | 0 | 0 | ✓ ^b | 0 | 1 |
| Urdu | | 0 | 0 | ✓ ^c | 0 | 0 |

STAS = Support Team Assessment Schedule; POS = Palliative care Outcome Scale.

^aSince 2010 only; refer to Appendix II for a list of articles and translation used.

^bNew since last review.

^cFormally validated.

Table 3
Locations Where Data Using STAS and POS Have Been Collected

| Continent | Country | STAS (Total Studies n = 47) | POS (Total Studies n = 79) | STAS (New Studies n = 8) | POS (New Studies n = 35) | |
|-----------------------------|---------------------------|--------------------------------|-------------------------------|-----------------------------|--------------------------------|---|
| Europe | U.K. | 16 | 34 | 1 | 9 | |
| | Belgium | 1 | 0 | 0 | 0 | |
| | Denmark | 0 | 1 | 0 | 0 | |
| | France | 3 | 1 | 1 | 0 | |
| | Germany | 0 | 9 | 0 | 4 | |
| | Ireland | 2 | 0 | 0 | 0 | |
| | Italy | 3 | 1 | 0 | 1 | |
| | The Netherlands | 0 | 4 | 0 | 3 | |
| | Poland | 2 | 0 | 0 | 0 | |
| | Portugal | 0 | 1 | 0 | 0 | |
| | Spain | 1 | 4 | 0 | 3 | |
| | Asia | China | 5 | 0 | 2 | 0 |
| | | Japan | 13 | 0 | 4 | 0 |
| India | | 0 | 1 | 0 | 0 | |
| Singapore | | 0 | 1 | 0 | 0 | |
| Cambodia/Dominican Republic | | 0 | 1 | 0 | 0 | |
| North America | U.S. | 0 | 4 | 0 | 3 | |
| | Canada | 1 | 0 | 0 | 0 | |
| Latin America | Argentina | 0 | 1 | 0 | 0 | |
| | Cuba | 0 | 1 | 0 | 0 | |
| Africa | Africa | 0 | 3 | 0 | 0 | |
| | Kenya ^a | 0 | 4 | 0 | 4 | |
| | Malawi ^a | 0 | 1 | 0 | 1 | |
| | South Africa ^a | 0 | 6 | 0 | 6 | |
| | Tanzania ^a | 0 | 1 | 0 | 1 | |
| | Uganda ^a | 0 | 5 | 0 | 5 | |
| | Zimbabwe ^a | 0 | 1 | 0 | 1 | |

STAS = Support Team Assessment Schedule; POS = Palliative care Outcome Scale.

^aNew since last review.

together, STAS and POS articles have been published in many regions of the world, including Europe, Asia, North America, Latin America, and Africa, with the exception of Australia and New Zealand. STAS use remains popular in China and Japan, where it has been used to evaluate palliative interventions^{47,51,52} and to explore the relationship between family-related factors, awareness of prognosis, and patient outcomes.^{45,46,48} New countries in which POS use has been documented since the last review include Kenya,^{25,31,32,38} South Africa,^{16,19,24,32,34,38} Tanzania,¹⁷ Uganda,^{16,20,24,25,32} Zimbabwe,¹⁴ and Malawi.⁴³ There were no publications reporting on STAS use in a new country or culture.

Purpose of Administration of the POS or STAS

All articles were classified according to the study aim (Fig. 2). These data were combined with those of the previous review to present the overall categories of use for the POS and STAS (Fig. 3).

Five studies validated English or translated versions of the POS,^{24,26,27,40,44} whereas two reported factor analysis of the measure.^{28,32} Eight articles validated or used the POS in a new patient group,^{6,18,23,25,26,29,30,33} whereas the same number reported the validation or use of the POS in a new culture.^{14,16,17,20,29,31,34,43} Adaptations of the POS were

used in four studies.^{6,20,21,23} In five studies, the POS was compared with other clinical measurement tools.^{24,26–28,40} The POS helped to evaluate interventions in 11 studies.^{14,29,34–39,41–43} Seventeen studies reported use of the POS to assess symptom prevalence or palliative care needs.^{6,11,12,15,16,18–23,25,29–31,33,38} One article studied the implementation of the POS as an outcome measure,³⁴ whereas eight compared patient needs and outcomes in different palliative care settings.^{13,15,17,19,36,37,39,41} One study compared patients' and professionals' assessments.²⁹ Professionals' and informal caregivers' views on the POS were reported in one article.⁴⁴ In four studies, the POS was used by informal caregivers to assess patients.^{13,14,29,41}

Five studies used the STAS to evaluate an intervention.^{47–49,51,52} Seven (all but one) of the studies assessed the symptom prevalence among a patient population.^{45–48,50–52} One audited the implementation of the STAS as an outcome measure.⁴⁹ There were no validation studies or studies using the STAS in a new patient group, culture, or translation.

Methods of Data Collection

Most study data were collected in longitudinal studies with data collected at multiple times,

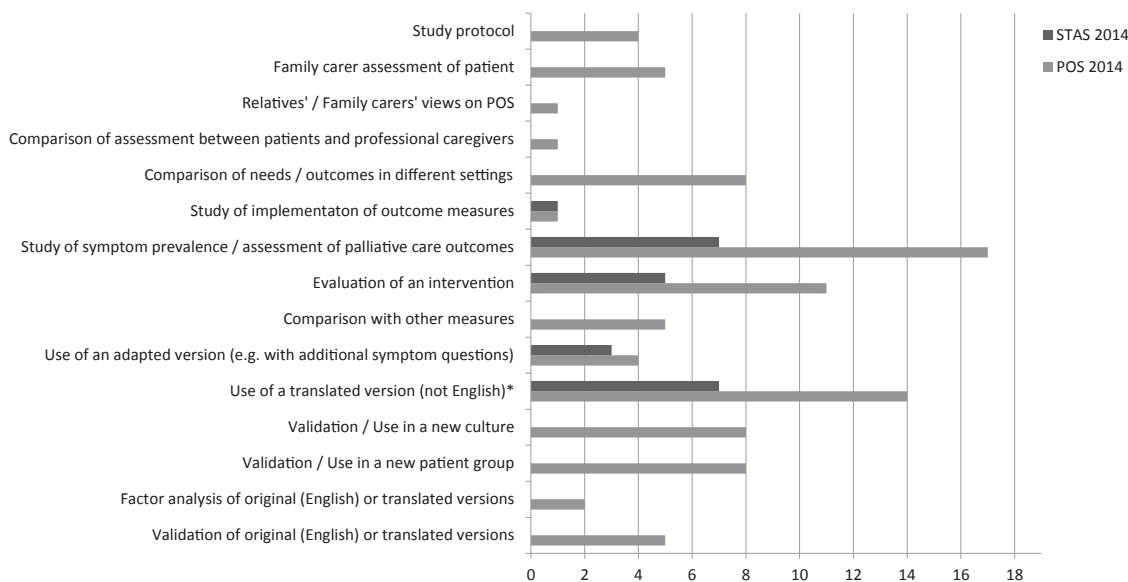


Fig. 2. Categories of use for POS and STAS publications 2010–2014. *Only those studies which clearly stated use of translated versions shown; Non-English translations may be validated or nonvalidated. POS = Palliative care Outcome Scale; STAS = Support Team Assessment Schedule.

both for the STAS ($n = 5$)^{47–51} and POS ($n = 22$).^{11,12,17–19,22,26,27,29–31,33–43} Cross-sectional studies also were used; two for the STAS (both of which used data mining methods)^{45,46} and 13 for the POS.^{6,13,15,16,20,21,23,25,28,31,32,37,44} One POS study used qualitative methods to determine the content and construct validity of two items in the POS for African palliative care populations.²⁴ Two studies, which used the measures as part of a project evaluation, were classified as audits; one using the POS¹⁴ and the other using the STAS.⁴⁹

Discussion

Following the initial, considerable contribution made by the POS and STAS to palliative care, as reported in the previous review,⁷ use and translation of these tools has steadily increased. This is indicated by a further eight articles using the STAS and 35 articles using the POS that were published since 2010. During this time, the global reach of these outcome measures has broadened, particularly in Africa, where POS use has now been documented in six additional

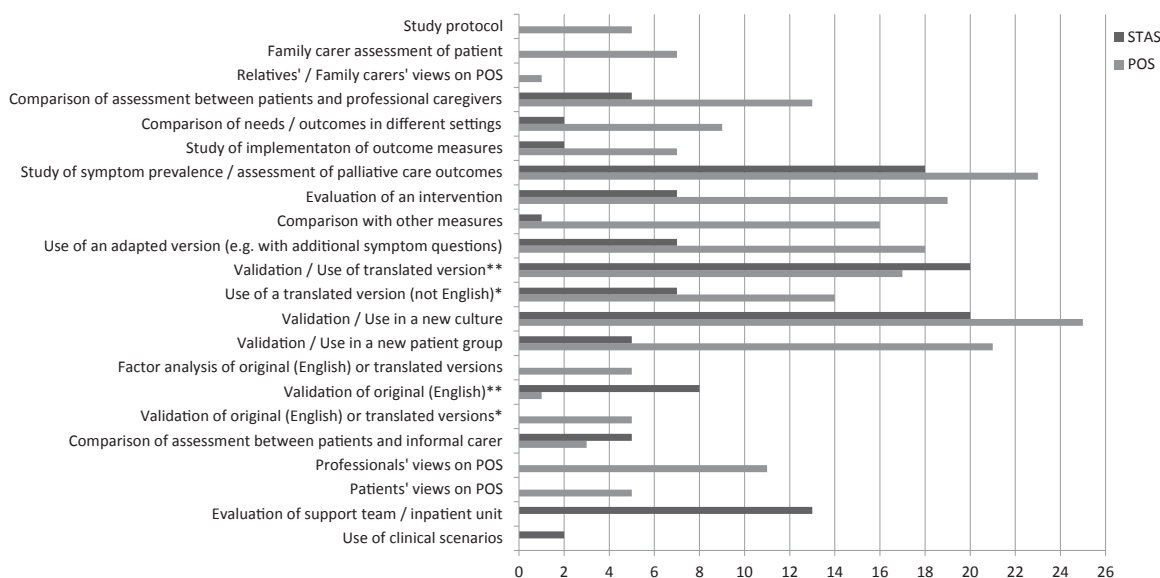


Fig. 3. Total categories of use for POS and STAS publications up to 2014. *New categorization in 2010–2014 review (only articles since 2010 shown). **Old categorization from Bausewein et al. (2011) review (only articles before February 2010 shown). POS = Palliative care Outcome Scale; STAS = Support Team Assessment Schedule.

countries. Similarly, in Europe, several new publications using the POS have come from the U.K., Germany, The Netherlands, and Spain. These findings are in line with a study by Harding et al.⁵⁵ which found that the POS was among the top five outcome measures used in research as well as clinical care and audit in Europe. Similarly, Higginson et al.⁵⁶ reported that across Europe and Africa, the POS was among the most common measures used by researchers and clinicians alike.

Patterns of use appear to have changed since the last review. Although in the previous review most published studies focused on validation of measures and their translations, or use in new cultures, publications since then have focused more on using the POS, and to a lesser degree the STAS, particularly to study symptom prevalence and evaluate interventions. This may indicate that earlier validation work, as captured by publications included in the previous review, has now resulted in these measures being used as validated and reliable tools to capture symptoms and needs. These findings are in line with a survey by Higginson et al.,⁵⁶ which found that 88% of POS users and 85% of STAS users used these measures to assess patients' symptoms and needs.

Despite this increase in use of the POS and STAS to assess symptom burden, as evidenced by our results, a recent systematic review found that several barriers still exist that might limit the implementation of outcome measures into routine clinical practice.⁵⁷ Among these barriers are a lack of time, resources, and training, as well as measure- and patient-specific issues. Therefore, although the results of this study indicate an increase in the use of these measures, more could be done to support clinicians who wish to implement outcome measures, such as the POS (or STAS), in their clinical practice.

Studies investigating the validity of the POS increased evidence for the validity of this measure. Two studies reported the reliability and concurrent validity of the measure, specifically of the core POS and POS-S-MS.^{26,41} The importance of the "at peace" item to patients and bereaved relatives is confirmed by two studies, as is the acceptability of the measure.^{24,44} However, one study reported that, among 10 measures of perceived quality of dying and quality of care, the POS had the least correlation with the other measures.²⁷ It is unclear, however, whether this indicates that the other measures were more or less reliable than the POS. In combination with the POS validation studies included in the previous review, there is a growing body of evidence for the validity of the POS and its acceptability among patients, caregivers, and health professionals. We also were made aware of ongoing work to develop and validate an IPOS, which

combines items from the POS, POS-S, and the APCA African POS (Appendix IV). However, no publications were available about the IPOS at the time of this review. Unfortunately, no further validation studies were identified for the STAS.

In general, there appears to be greater popularity for the POS than for the STAS, with more than four times as many publications for the POS being published over the last four years. This continues the trend identified in the previous review, which also identified more publications for the POS than the STAS.⁷ In Africa, the extensive use of the POS is likely linked to the endorsement of this measure by the APCA, as well as the availability of several translated versions.^{24,38,54,58} The reason for more frequent use of the POS in other parts of the world might be linked to the increasing popularity of PROMs over the years, as the POS is predominantly a patient-completed measure. Particularly in Europe and the U.S., there has been a push for increased use of PROMs in recent years, which may have impacted the choice of measures, both for research and clinical use.^{59,60} However, it is important to note that the POS also exists as a staff-completed measure, as well as a carer-completed measure. Although most studies included in this review used the patient version, some only used the carer version,^{13,15} or used several different versions.^{12,41}

Included studies did not report on comparisons between patient and proxy versions. Having completed patient and proxy ratings available is valuable, as it enables direct comparison of perceived severity of symptoms from patient and proxy perspectives. Future psychometric studies should include testing of interrater reliability, particularly between patient- and staff-completed versions. Data on patient versus proxy ratings support the validity of measures and ensure the whole of the palliative care population can be included.

Interestingly, the STAS appears to be more popular in China and Japan, with 18 STAS publications overall (including six new publications) from these countries, compared to none for the POS. This may be explained by the lack of fully validated translations of the POS in Chinese or Japanese, although it is worth noting that translation and validation of a Japanese POS is underway. It also may be a result of cultural differences and/or different health care systems in these countries, which may prefer a more paternalistic approach, with health professionals taking the lead.⁶¹

The STAS and POS were both developed and validated originally in patients with advanced cancer. This is still evident from the STAS publications, but the growing use of the POS among other palliative care populations was noted in the previous review,

and this has continued to be the case. There are now numerous publications reporting the use of the POS for patients with nononcological conditions; particularly in patients with HIV/AIDS and neurological conditions. This suggests that palliative needs are beginning to be recognized among a variety of populations beyond those with cancer. In addition, new subsets of previously explored patient populations are now being included in studies, suggesting a growing understanding of palliative needs along disease trajectories and spectrums. Although most of these studies focused on the use of the POS in noncancer populations, two studies reported the validation of the POS; one in MS patients²⁶ and another in dementia patients.²⁷

Multiple versions of the POS have been used in studies, including the core POS, POS-S-MS, POS-S-renal, POS-S-PP, and APCA African POS. In particular, there has been wide use of the APCA African POS, mostly for patient populations living with HIV/AIDS. In the previous review, one validation study reported a need for the POS to be better adapted to the needs of patients with motor neuron disease,⁶² but use of the POS-S-PP with this population of patients in two studies^{18,23} suggests that improvements have been made here.

Many new and older translations of the POS have been used successfully for data collection in several included studies.^{14,16,17,19,20,24,25,31,32,34,38} There have been no new translations of the STAS, although the Japanese,^{47,48,51,52} French,⁵⁰ and Chinese^{45,46} translations have been in use. There are still several translations of both the POS and the STAS that have not yet been formally validated, and future publications may report on the validation and use of these translations. Therefore, periodic review of the literature on the POS and the STAS in the future is recommended.

Strengths and Limitations

This systematic review incorporated an extensive search for relevant publications, including contacting of subscribers to the POS website and scanning of reference lists to complement the literature search. The findings presented build on an established body of evidence for the use of the POS and the STAS as collated by Bausewein et al.⁷ Similarities in the findings of these two reviews in terms of POS and STAS use promote the reliability of our findings. In this review, we counted number of studies rather than publications, to account for multiple reporting and increase the accuracy of the reported results.

A limitation of this review is that it did not pick up use of the POS and the STAS that was not reported in the literature. As both tools are available for use in clinical practice, the present review may somewhat

underestimate actual use by clinical teams, which may use these measures to assess and monitor patients' symptoms and needs to inform care.^{55,56} Other limitations of this review include the fact that data extraction was mainly performed by one researcher (E. S. C.) and that only published studies were included, although ongoing research that the authors were aware of is outlined in [Appendix IV](#). Finally, several of the authors were involved in the initial development and validation of the STAS and the POS (C. B., I. J. H., F. E. M. M.), which may somewhat bias them toward a more positive assessment of these measures. However, the range of identified publications from teams not associated with the authors supports the findings that these tools are acceptable and useful.

Conclusion

Overall, the present review shows that the POS, and to a lesser extent the STAS, has continued to be used in a variety of settings and countries since the last review was published. POS use has particularly increased in Europe and Africa, with 12 new African translations. In Asia, use of the STAS is more common. Both measures are now more frequently used in studies that assess symptoms and needs, rather than validation studies, which may be an indication that they are now perceived as reliable and valid tools that can be used for these purposes without the need for further validation. Owing to this widespread use, particularly the POS and to a lesser degree the STAS may be used in the future to compare data internationally and/or to compare symptoms and needs in different disease groups, especially diverse palliative care populations with a range of malignant and nonmalignant diagnoses.

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Several of the authors were involved in the initial development and validation of the STAS and POS (C.B., I.J.H., F.E.M.M.). There are no other conflicts of interest.

References

1. Donabedian A. The definition of quality and approaches to its assessment. Chicago, IL: Health Administration Press, 1980.
2. Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ. Outcome measurement in palliative care: The essentials 2010. Available at: <http://www.eapcnet.eu/LinkClick.aspx?fileticket=-T62WTgTHtU%3D&tabid=1577>. Accessed June 23, 2015.
3. Higginson I. The development, validity, reliability and practicality of a new measure of palliative care: The Support Team Assessment Schedule. Doctoral thesis. London: University College London, 1992. Available at: <http://discovery.ucl.ac.uk/1317889/1/296225.pdf>. Accessed June 23, 2015.
4. Higginson I, McCarthy M. Validity of the Support Team Assessment Schedule: do staffs' ratings reflect those made by patients or their families? *Palliat Med* 1993;7:219–228.
5. Hearn J, Higginson I. Development and validation of a core outcome measure for palliative care: the Palliative care Outcome Scale. *Palliative Care Core Audit Project Advisory Group. Qual Health Care* 1999;8:219–227.
6. Afshar M, Rebollo-Mesa I, Murphy E, Murtagh FEM, Mamode N. Symptom burden and associated factors in renal transplant patients in the U.K. *J Pain Symptom Manage* 2012;44:229–238.
7. Bausewein C, Le Grice C, Simon S, Higginson I. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. *Palliat Med* 2011;25:304–313.
8. Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient centred outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage* 2015;49:611–624.
9. Liberati A, Altman D, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ* 2009;339:b2700.
10. Moher D, Liberati A, Tetzlaff J, Altman D, for the PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 2009;339:b2535.
11. Bausewein C, Booth S, Gysels M, et al. Individual breathlessness trajectories do not match summary trajectories in advanced cancer and chronic obstructive pulmonary disease: results from a longitudinal study. *Palliat Med* 2010;24:777–786.
12. Bookbinder M, Glajchen M, McHugh M, et al. Nurse practitioner-based models of specialist palliative care at home: sustainability and evaluation of feasibility. *J Pain Symptom Manage* 2011;41:35–48.
13. Cohen LW, van der Steen JT, Reed D, et al. Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and the Netherlands. *J Am Geriatr Soc* 2012;60:316–322.
14. Di Sorbo PG, Chifamba DD, Mastrojohn J 3rd, Sisimayi CN, Williams SH. The Zimbabwe rural palliative care initiative: PCI-Z. *J Pain Symptom Manage* 2010;40:19–22.
15. Gomes B, McCrone P, Hall S, Koffman J, Higginson IJ. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer* 2010;10:400.
16. Harding R, Selman L, Agupio G, et al. Intensity and correlates of multidimensional problems in HIV patients receiving integrated palliative care in sub-Saharan Africa. *Sex Transm Infect* 2012;88:607–611.
17. Harding R, Simms V, Alexander C, et al. Can palliative care integrated within HIV outpatient settings improve pain and symptom control in a low-income country? A prospective, longitudinal, controlled intervention evaluation. *AIDS Care* 2013;25:795–804.
18. Higginson IJ, Gao W, Saleem TZ, et al. Symptoms and quality of life in late stage Parkinson syndromes: a longitudinal community study of predictive factors. *PLoS One* 2012;7:e46327.
19. Hongoro C, Dinat N. A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. *J Pain Symptom Manage* 2011;41:1015–1024.
20. Lewington J, Namukwaya E, Limoges J, Leng M, Harding R. Provision of palliative care for life-limiting disease in a low income country national hospital setting: how much is needed? *BMJ Support Palliat Care* 2012;2:140–144.
21. Malik FA, Gysels M, Higginson IJ. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med* 2013;27:647–656.
22. Saini A, Tucci M, Tampellini M, et al. Circadian variation of breakthrough pain in cancer patients. *Eur J Pain* 2013;17:264–270.
23. Saleem TZ, Higginson IJ, Chaudhuri KR, et al. Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: a cross-sectional study of patients with Parkinson's disease and related neurological conditions. *Palliat Med* 2013;27:722–731.
24. Selman L, Speck P, Gysels M, et al. 'Peace' and 'life worthwhile' as measures of spiritual well-being in African palliative care: a mixed-methods study. *Health Qual Life Outcomes* 2013;11:94.
25. Simms V, Gikaara N, Munene G, et al. Multidimensional patient-reported problems within two weeks of HIV diagnosis in East Africa: a multicentre observational study. *PLoS One* 2013;8:e57203.
26. Sleeman KE, Higginson IJ. A psychometric validation of two brief measures to assess palliative need in patients severely affected by multiple sclerosis. *J Pain Symptom Manage* 2013;46:406–412.
27. Van Soest-Poortvliet MC, Van der Steen JT, Zimmerman S, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-

- term care residents with dementia. *Qual Life Res* 2012;21:671–684.
28. Van Soest-Poortvliet MC, Van der Steen JT, Zimmerman S, et al. Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manage* 2011;42:852–863.
29. Vincent SE. Exploration of self-care following distribution of acute management tool for elder heart failure patients in clinic setting. [Dissertation]. Hattiesburg, MS: University of Southern Mississippi, 2012.
30. Weingaertner V, Scheve C, Gerdes V, et al. Breathlessness, functional status, distress, and palliative care needs over time in patients with advanced chronic obstructive pulmonary disease or lung cancer: a cohort study. *J Pain Symptom Manage* 2014;48:569–581.
31. Harding R, Simms V, Penfold S, et al. The presence of CD4 counts for the management of HIV patients in East Africa: a multicentred study. *AIDS Care* 2014;26:613–618.
32. Harding R, Selman L, Simms VM, et al. How to analyze palliative care outcome data for patients in sub-Saharan Africa: an international, multicenter, factor analytic examination of the APCA African POS. *J Pain Symptom Manage* 2013;45:746–752.
33. Murtagh FEM, Sheerin NS, Addington-Hall J, Higginson IJ. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clin J Am Soc Nephrol* 2011;6:1580–1590.
34. Defilippi KM, Cameron S. Expanding the reach of palliative care to community-based home care programs. *J Pain Symptom Manage* 2010;40:3–5.
35. Groh G, Vyhnalek B, Feddersen B, Führer M, Borasio GD. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *J Palliat Med* 2013;16:848–856.
36. Hermann K, Engeser P, Szecsenyi J, Miksch A. Palliative patients cared for at home by PAMINO-trained and other GPs—health-related quality of life as measured by QLQ-C15-PAL and POS. *BMC Palliat Care* 2012;11:13.
37. Higginson IJ, Costantini M, Silber E, Burman R, Edmonds P. Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained. *Postgrad Med J* 2011;87:769–775.
38. Lowther K, Simms V, Selman L, et al. Treatment outcomes in palliative care: the TOPCare study. A mixed methods phase III randomised controlled trial to assess the effectiveness of a nurse-led palliative care intervention for HIV positive patients on antiretroviral therapy. *BMC Infect Dis* 2012;12:288.
39. Molina EH, Nuno-Solinis R, Idioaga GE, et al. Impact of a home-based social welfare program on care for palliative patients in the Basque Country (SAIATU Program). *BMC Palliat Care* 2013;12:3.
40. Pelayo-Alvarez M, Perez-Hoyos S, Agra-Varela Y. Reliability and concurrent validity of the palliative outcome scale, the Rotterdam symptom Checklist, and the brief pain Inventory. *J Palliat Med* 2013;16:867–874.
41. Pelayo-Alvarez M, Perez-Hoyos S, Agra-Varela Y. Clinical effectiveness of online training in palliative care of primary care physicians. *J Palliat Med* 2013;16:1188–1196.
42. Slort W, Blankenstein AH, Schweitzer BP, et al. Effectiveness of the palliative care ‘Availability, Current issues and Anticipation’ (ACA) communication training programme for general practitioners on patient outcomes: a controlled trial. *Palliat Med* 2014;28:1036–1045.
43. Nkhoma K, Seymour J, Arthur A. An educational intervention to reduce pain and improve pain management for Malawian people living with HIV/AIDS and their family carers: study protocol for a randomised controlled trial. *Trials* 2013;14:216.
44. Gomes B, McCrone P, Hall S, et al. Cognitive interviewing of bereaved relatives to improve the measurement of health outcomes and care utilisation at the end of life in a mortality followback survey. *Support Care Cancer* 2013;21:2835–2844.
45. Chan WCH. Being aware of the prognosis: how does it relate to palliative care patients’ anxiety and communication difficulty with family members in the Hong Kong Chinese context? *J Palliat Med* 2011;14:997–1003.
46. Chan WCH, Epstein I. Researching “good death” in a Hong Kong palliative care program: a clinical data-mining study. *Omega (Westport)* 2012;64:203–222.
47. Hashimoto T, Usuba O, Toyono M, et al. Evaluation of salvage surgery for type 4 gastric cancer. *World J Gastrointest Surg* 2012;4:301.
48. Nakajima N, Hata Y, Onishi H, Ishida M. The evaluation of the relationship between the level of disclosure of cancer in terminally ill patients with cancer and the quality of terminal care in these patients and their families using the Support Team Assessment Schedule. *Am J Hosp Palliat Med* 2013;30:370–376.
49. Sutherland J, Stananought N. Improving access to specialist palliative care through a telephone triage service. *Eur J Palliat Care* 2011;18:122–125.
50. Vassal P, Le Coz P, Herve C, Matillon Y, Chapuis F. Return home at the end of life: patients’ vulnerability and risk factors. *Palliat Med* 2011;25:139–147.
51. Yamaguchi S, Ohguri T, Matsuki Y, et al. Palliative radiotherapy in patients with a poor performance status: the palliative effect is correlated with prolongation of the survival time. *Radiat Oncol* 2013;8:166.
52. Murakami H, Matsumoto H, Nakamura M, Hirai T, Yamaguchi Y. Octreotide acetate-steroid combination therapy for malignant gastrointestinal obstruction. *Anticancer Res* 2013;33:5557–5560.
53. Higginson I. Audit methods: validation and in-patient use. In: Higginson I, ed. *Clinical Audit in Palliative Care*. Oxford: Radcliffe Medical Press, 1993:48–54.
54. Harding R, Selman L, Agupio G, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health Qual Life Outcomes* 2010;8:1477–7525.
55. Harding R, Simon ST, Benalia H, et al. The PRISMA Symposium 1: outcome tool use. Disharmony in European outcomes research for palliative and advanced disease care: too many tools in practice. *J Pain Symptom Manage* 2011;42:493–500.

56. Higginson IJ, Simon ST, Benalia H, et al. Republished: which questions of two commonly used multidimensional palliative care patient reported outcome measures are most useful? Results from the European and African PRISMA survey. *Postgrad Med J* 2012;88:451–457.
57. Antunes B, Harding R, Higginson IJ. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med* 2013;28:158–175.
58. Defilippi K, Downing J. Feedback from African palliative care practitioners on the use of the APCA POS. *Int J Palliat Nurs* 2013;19:577–581.
59. Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167.
60. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr A. The routine use of patient reported outcome measures in healthcare settings. *BMJ* 2010;340:c186.
61. Claramita M, Nugraheni M, van Dalen J, van der Vleuten C. Doctor-patient communication in Southeast Asia: a different culture? *Adv Health Sci Educ Theory Pract* 2013;18:15–31.
62. Hughes RA, Aspinall F, Higginson IJ, et al. Assessing palliative care outcomes for people with motor neurone disease living at home. *Int J Palliat Nurs* 2004;10:449–453.

Appendix I

Search Strategy

Search Terms

“Support team assessment schedule”

“STAS and palliative”

“Palliative care outcome scale”

“Palliative outcome scale”

“Patient outcome scale”

“POS and palliative”

CINAHL

Abstract search. January 2010–June 2014. Each phrase/term searched for separately and then combined with OR.

47 records identified.

British Nursing Index

Abstract search. After January 1, 2010. Each phrase/term searched for separately and then combined with OR.

13 records identified.

Ovid (MEDLINE, Embase, and PsycInfo)

Keyword search.

- 1) Support team assessment schedule
- 2) STAS AND palliative
- 3) Palliative care outcome scale
- 4) Palliative outcome scale
- 5) Patient outcome scale
- 6) POS AND palliative
- 7) 1 OR 2 OR 3 OR 4 OR 5 OR 6
- 8) Limit (7) to yr = “2010-current”
- 9) Remove duplicates from (8)

118 records identified.

Appendix II
Data Extraction

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|------------------------------|------|----------------------------------|---------|---|---------|---|---|--|---|
| Overview of POS publications | | | | | | | | | |
| 1 | 2012 | Afshar M. and Mamode N. | U.K. | 110 renal transplant patients who received transplant at least one yr before study. | Use | Cross-sectional | To identify symptom prevalence, severity, and total symptom burden in renal transplant patients, whether symptom clusters existed, and the relationship of symptoms to comorbidity and renal function. | Symptom burden was high among patients and included weakness, difficulty sleeping, dyspnea, feeling anxious, and drowsiness. Significant inverse relationship between renal function and number of symptoms, and between time since transplant and number of symptoms emerged. | Used modified version of POS-S-renal, which had not been validated in patient population. |
| 2 | 2010 | Bausewein C. and Higginson I. | Germany | 49 patients with lung cancer, 60 patients with COPD. | Use | Prospective longitudinal (baseline, monthly over 6 months or until death) | To describe and compare the summary and individual trajectories of breathlessness and overall symptom burden over time and toward the end of life following patients with advanced cancer or COPD in inpatient and outpatient healthcare settings. POS used to assess patient-reported palliative care needs. | Breathlessness increased over time for COPD patients, whereas breathlessness increased toward death for cancer patients. Four patterns of individual breathlessness trajectories: fluctuation, increasing, stable, and decreasing. | German POS used. |
| 3 | 2011 | Bookbinder M. and Portenoy R. K. | U.S. | 114 patients living at home with varying diagnoses receiving palliative care from one of two nurse practitioner-based services. | Use | Longitudinal | To evaluate the financial sustainability and feasibility of two nurse practitioner-based models in an urban setting. POS used to assess | High burden of medical and instrumental need documented by POS. Hospice-based nurse practitioner model was shown to be sustainable in an | |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|-----------------------------------|----------------------|---|---------|---|--|---|---|
| 4 | 2012 | Cohen L. W. and Zimmerman S. | U.S./The Netherlands | Family caregivers of 196 residents with dementia who had died (U.S. = 126, The Netherlands = 70). | Use | Interviews and self-administered questionnaires | patient-reported palliative care needs in one of the two programs. To examine cross-national care and outcomes related to end-of-life experiences. | urban environment. U.S. caregivers reported better care and outcomes, and better quality of care in the last 3 days of life; caregivers in The Netherlands reported better quality of life in the last month and 3 days of life. | Unclear whether Dutch translation was used in The Netherlands or not. |
| 5 | 2010 | Defilippi K. M. and Cameron S. | South Africa | Four community-based organizations which run HIV/AIDS-related programs: 30 caregivers and 24 patients with advanced disease completed the African Palliative Care Association POS (APCA POS). | Use | Assessment of pilot project | To assess the impact of a model of introducing a palliative care component and professional supervision of community caregivers on the quality of care given to people living with HIV/AIDS and their families. African Palliative Care Association POS (APCA POS) was used to assess the level of care provided by the organization through impact on patients and families. | African Palliative Care Association POS (APCA POS) was relevant assessment score. Average improvement of caregivers scores by 28.5%. The reach of professional palliative care supervision can be expanded beyond hospice boundaries. | African Palliative Care Association POS (APCA POS). Scores summarized into graph. |
| 6 | 2010 | Di Sorbo P. G. and Williams S. H. | Zimbabwe | Project targets 1013 patient households. | Use | Project report | To assess the implementation of the Zimbabwe Rural Palliative Care Initiative, which aimed to add palliative care to | Palliative care model appears well suited for Zimbabwean context. Follow-up needed on baseline POS figures. | APCA POS. Report of project set up with no evaluation. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|--------------------------------|-------------------------|---|------------|--|--|---|--|
| 7 | 2010 | Gomes B. and Higginson I. J. | U.K. | Bereaved relatives of adults who died from cancer in a 1 yr period. | Use | Mortality follow-back postal survey with nested case-control study of home vs. hospital deaths | existing home-based care teams comprising indigenous rural volunteers. To examine variations in the quality and costs of end-of-life care, preferences, and palliative outcomes associated with home vs. institutional death in cancer. | [Protocol] | |
| 8 | 2013 | Gomes B. and Higginson I. J. | U.K. | 20 bereaved relatives of cancer patients. | Validation | Cross-sectional | To improve the measurement of health outcomes and care utilization at the end of life for bereaved relatives. | Bereaved relatives able to understand most of the questions despite finding them demanding and intense. Adaptation of POS to foster participant understanding and include peace item. | Preparation for QUALYCARE study. |
| 9 | 2013 | Groh G. and Borasio G. D. | Germany | 60 patients treated by Specialized Outpatient Palliative Care service and their primary caregivers. | Use | Prospective | To evaluate the acceptance and effectiveness of an SOPC team as perceived by patients and caregivers. | POS and QoL scores of patients and caregivers improved significantly over time through involvement with SOPC team; reduced burden of home care for caregivers. | Not primary outcome. German POS used. |
| 10 | 2012 | Harding R. and Higginson I. J. | South Africa/ Uganda | 230 patients with HIV across five palliative care sites. | Use | Cross-sectional | To determine the intensity of multidimensional problems in a three day period among HIV patients receiving integrated palliative care in sub-Saharan Africa and to identify associations with problem severity. | Most burdensome problems were pain, worry, symptoms, and adequate information to plan for the future. Patients receiving home care may require additional support to enhance wellbeing. | APCA POS and versions in African languages used. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|-------|-------------------------------|-----------------------------------|---|-----------------|---|---|---|--|
| 11 | 2013a | Harding R. and Powell R. A. | Kenya/ South Africa/ Uganda | 1337 patients with HIV across 12 PEPFAR sites. | Factor analysis | Secondary analysis of cross-sectional data | To determine which specific factors underpin the APCA African POS to assist the analysis of data in routine clinical care and audit. | Confirmatory factor analysis: three-factor solution of 1) physical and psychological wellbeing, 2) interpersonal wellbeing, and 3) existential wellbeing. Factors map well to palliative care goals and enable audit. | APCA POS and versions in African languages used. |
| 12 | 2013b | Harding R. and Loy G. | Tanzania | 120 patients at an HIV Use outpatient center | | Prospective longitudinal (baseline, then fortnightly until Week 10) | To evaluate, in terms of patient outcomes, palliative care delivered by the existing HIV outpatient clinical personnel in Tanzania, compared to standard HIV outpatient care. | Significantly lower reported pain and improved POS scores in palliative care site when delivered alongside ART, regardless of prognosis. | APCA POS. |
| 13 | 2014 | Harding R. and Higginson I.J. | Kenya | 548 HIV patients across five sites | Use | Cross-sectional | To identify what proportion of HIV outpatients has a CD4 result present in their clinical records, and to examine which characteristics are associated with the presence of a CD4 result. | Lack of CD4 result associated with antiretroviral use, facility, poverty, prevalence of multidimensional problems, and education level. Inconsistencies in results. | APCA POS. |
| 14 | 2012 | Hermann K. and Miksch A. | Germany | 100 cancer patients receiving palliative care and 45 General Practitioners (GPs); 27 trained in palliative care by a regional training initiative, 18 controls. | Use | Longitudinal (baseline, monthly over 6 months or until death) | To evaluate if palliative patients of GPs trained in palliative care have a better health-related Quality of Life (QoL). | Patients cared for by palliative-trained GPs did not report better QoL and care outcomes than patients cared for by other GPs. | German POS used. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|--------------------------------|--------------|--|---------|--|---|--|--|
| 15 | 2011 | Higginson I. J. and Edmonds P. | U.K. | 52 patients severely affected by multiple sclerosis. | Use | RCT fast-track Phase II longitudinal. | To determine (1) whether the timing of referral to the short-term palliative care team (three months earlier) had an impact on longer term outcomes, and (2) the potential staff-modifying effect of the short-term palliative care intervention. | Receiving palliative care earlier has a similar effect on reducing symptoms but greater effects on reducing caregiver burden, compared to later referral. The palliative care intervention has an effect after withdrawal for six weeks before waning. | |
| 16 | 2012 | Higginson I. J. and Leigh N. | U.K. | 82 patients with idiopathic Parkinson disease, progressive supranuclear palsy, or multiple system atrophy. | Use | Longitudinal (baseline, then three times over one yr) | To determine how symptoms and quality of life of late stage Parkinson syndrome patients change over time; and what demographic and clinical factors predicted changes. | Profound and complex mix of nonmotor and motor symptoms in patients. Symptoms are not resolved and half of patients deteriorate. Early palliative assessment is predictive of future symptoms. | POS-PP (for Parkinson) and core POS. Same data set as Saleem et al. (2013) |
| 17 | 2011 | Hongoro C. and Dinat N. | South Africa | 72 patients to palliative care service completed POS. Cost analysis of N'Doro Palliative Care pilot at Chris Hani Baragwanath Hospital | Use | Cost accounting procedure—APCA POS applied at five intervals in two months | To establish the costs and cost drivers for a hospital outreach palliative care service in a low-resource setting, and to elucidate possible consequential cost savings. | Some of the POS of a subsample showed statistically significant improvements. Outreach visits cost 50% less than the average cost of a patient day equivalent for district hospitals. | APCA POS. Unclear which translation(s) used. |
| 18 | 2012 | Lewington J. and Harding R. | Uganda | 78 hospital inpatients with active life-limiting disease. | Use | Cross-sectional (census and interviews) | To measure the magnitude of palliative care needs among hospital inpatients. | Prevalence of active life-limiting disease here (46%) is greater than in comparable European studies | APCA POS and versions in African languages used. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|--------------------------------------|------------------------|--|---------|---|---|---|--|
| 19 | 2012 | Lowther K. and Harding R. | Kenya/ South Africa | 240 patients with HIV who have been receiving ART for one month. | Use | RCT | To assess the effectiveness of palliative care for HIV outpatients on antiretroviral treatment. | (5%–23%). POS revealed multidimensional need in 96% of patients. [Protocol] | APCA POS and versions in African languages used. |
| 20 | 2013 | Malik F.A. and Higginson I. J. | U.K. | 51 heart failure and 50 lung cancer patients experiencing breathlessness on day-to-day basis, plus 101 caregivers. | Use | Cross-sectional, descriptive, comparative | To compare experiences of caring for a breathless patient with lung cancer versus those with heart failure and to examine factors associated with caregiver burden and positive caring experiences. | Severity of patient breathlessness and caregiver concerns similar across both groups. | POS-S and core POS. |
| 21 | 2013 | Molina E. H. and Media J. F. O. | Spain | 1478 oncology patients with a malignant neoplasm. | Use | Longitudinal prospective | To analyze whether a programme of social intervention in palliative care results in a reduction in the consumption of healthcare resources and cost by end-of-life patients and promotes a shift toward a more community-based model of care. | [Protocol] | Spanish POS used. |
| 22 | 2011 | Murtagh F. E. M. and Higginson I. J. | U.K. | 74 patients with Stage 5 chronic kidney disease managed without dialysis. | Use | Longitudinal | To describe, for patients with Stage 5 chronic kidney disease managed conservatively (without dialysis), the trajectory of symptoms and | Moderate symptom distress and health-related concerns, with marked increase in the last two months of life. | Related to article by Murphy et al. (2009), included in previous review. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|-------|--------------------------------------|---------|--|------------|-------------------------------------|---|--|--|
| 23 | 2013 | Nkhoma K. and Arthur A. | Malawi | People living with HIV/AIDS and their carers. | Use | Longitudinal | patient health-related concerns over the last year of life. To evaluate the effect of an educational intervention for patients with HIV/AIDS and their family carers. | | Study protocol. APCA POS in Tumbuka translation used. |
| 24 | 2013a | Pelayo-Alvarez M. and Agra-Varela Y. | Spain | 145 palliative care professionals; 124 corresponding patients; 48 caregivers. | Use | Longitudinal (case control) | To test the clinical effectiveness of online palliative care education of physicians through impact on symptom control, quality of life, caregiver satisfaction, and knowledge-attitude of physicians at 18 months of the intervention. | Participation in educational program improved patient scores for some symptoms and family anxiety on POS. | Spanish POS used. Related to Pelayo-Alvarez M. et al., 2013b. |
| 25 | 2013b | Pelayo-Alvarez M. and Agra-Varela Y. | Spain | 117 outpatients with advanced cancer. | Validation | Longitudinal (baseline + 7/10 days) | To investigate the reliability and concurrent validity of POS, the Rotterdam Symptom Checklist (RSCL), and the Brief Pain Inventory (BPI). | Significant correlations and agreement between the three measures. Adequate reliability and moderate concurrent validity among POS, RSCL, and BPI. | Spanish POS used. Related to Pelayo-Alvarez M. et al., 2013a. |
| 26 | 2012 | Saini A. and Berruti A. | Italy | 123 advanced cancer patients being treated with major opioids for severe chronic pain. | Use | Longitudinal prospective (7 days) | To determine whether breakthrough cancer pain (BTP) has a circadian rhythm and to correlate patterns of BTP occurrence with diminished QoL. | BTP episodes showed a circadian pattern, and were negatively correlated with QoL. | Italian POS used. |
| 27 | 2013 | Saleem T. Z. and Leigh N. | U.K. | 82 patients with idiopathic Parkinson disease, progressive supranuclear palsy, | Use | Cross-sectional | To assess symptom prevalence, severity, and palliative care needs in advanced stages of | Burden of symptoms high in advanced stages of disease. Symptoms causing severe problems | Core POS and POS-PD used as an adapted version of POS-S. Same data set as Higginson I. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|-----------------------------------|-------------------------|--|------------|---|---|--|---|
| | | | | or multiple system atrophy | | | Parkinsonism. | were pain, fatigue, constipation, and drooling. Moderate palliative care needs. | J., Gao W., Saleem T. Z. et al., 2012 |
| 28 | 2013 | Selman L. and Harding R. | South Africa/ Uganda | Palliative care patients; 72 for interviews, 285 for quantitative data collection. | Validation | Validation (mixed methods) | To determine the content and construct validity of POS items relating to “peace” and “life worthwhile” as measures of spiritual wellbeing in African palliative care populations. | “Peace” and “life worthwhile” are useful POS items as distinct but related measures of spiritual wellbeing. Correlations with Spirit 8 items were weak to moderate. | APCA POS and versions in African languages made and partially validated (isiXhosa, isiZulu, SeSotho, SeTswana, Luganda, Runyoro). |
| 29 | 2013 | Simms V. and Harding R. | Kenya/Uganda | 438 patients recently diagnosed with HIV. | Use | Cross-sectional | To determine for the first time the prevalence and severity of multidimensional problems in a population newly diagnosed with HIV at outpatient clinics in Africa. | Most prevalent problems were lack of help and advice and difficulty sharing feelings. Limited physical function associated with more physical/psychological and existential problems but fewer interpersonal problems. | APCA POS and versions in African languages used. |
| 30 | 2013 | Sleeman K. E. and Higginson I. J. | U.K. | 46 patients with multiple sclerosis and palliative care needs. | Validation | Secondary analysis of longitudinal data | To assess the psychometric properties of core POS and POS-MS-S (for symptoms in multiple sclerosis) in patients severely affected by MS. | Missing data were low, and floor and ceiling effects were absent. Good internal consistency. Construct validity was consistent. Core POS and POS-MS-S are acceptable, reliable, and valid. | Core POS and POS-MS-S |
| 31 | 2014 | Slort W. and Deliens L. | The Netherlands | 126 GPs and 157 patients with advanced illness. | Use | Longitudinal | To report outcomes reported by patients who received | No significant effects of training programme on | Dutch POS used. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|--|-----------------|---|------------|--|---|--|--|
| 32 | 2012 | van Soest-Poortvliet M. C. and de Vet H. C. W. | The Netherlands | 70 family members and 103 healthcare professionals of 119 long-term care decedents with dementia. | Validation | Longitudinal (prospective and retrospective) | palliative care of GPs who participated in the Availability, Current issues and Anticipation training programme. To assess and compare the validity and reliability of 10 measures of perceived quality of care and quality of dying for residents dying with dementia in nursing homes and residential care homes. | patient-reported outcomes (including POS). Instruments within the constructs of quality of care and quality of dying were highly correlated. POS performed worst in this population. | Dutch POS used. |
| 33 | 2011 | van Soest-Poortvliet M. C. and de Vet H. C. W. | The Netherlands | Instruments assessing quality of care/dying for dementia population in long-term care settings. | Validation | Qualitative content analysis | To evaluate the content of available measurement instruments to assess the quality of dying and care when dying. | Instruments differed and most do not measure a single construct. POS measured quality of dying (70%), process of care (20%), and satisfaction with health care (10%). | Dutch POS used. |
| 34 | 2012 | Vincent S. | U.S. | 10 heart failure patients, seven caregivers, and health professionals. | Use | Longitudinal | To determine factors influencing worsening symptoms of heart failure (HF) in elder HF patients and to examine POS functional scores following distribution of an HF management tool. | Significant differences in reporting of pain and symptoms between health professionals and patients, suggesting that worsening symptoms were not being recognized by HPs. | PhD thesis. |
| 35 | 2014 | Weingaertner V. and Simon S. T. | Germany | 82 patients with Chronic Obstructive | Use | Longitudinal | To describe and compare the courses of | The palliative care needs of patients with advanced | German POS used. |

(Continued)

Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|-------------------------------|------|------------------------------|-------------------|---|---------|-------------------------------------|--|---|---|
| | | | | Pulmonary Disease (COPD) Stage III or IV, or primary lung cancer. | | | refractory breathlessness, functional status, distress, and palliative care needs in patients with advanced COPD or lung cancer over time. | COPD are comparable with lung cancer patients, and breathlessness severity and distress are even higher. | |
| Overview of STAS publications | | | | | | | | | |
| 1 | 2011 | Chan W. C. H. ¹ | China (Hong Kong) | Clinical records of 935 deceased cancer patients in a hospital palliative care unit between 2003 and 2005. | Use | Data mining | To explore the relationships among patients' awareness of prognosis, family members' awareness of prognosis, and two psychosocial outcomes of patients: patients' anxiety and communication with family members. | Patients who did not have a clear idea of their prognosis were more likely to experience anxiety and difficulty communicating with family members. | Not primary outcome measure. Chinese version of STAS. |
| 2 | 2012 | Hashimoto T. and Endou T. | Japan | Four esophageal cancer patients who underwent salvage surgery to reduce gastric stenosis/obstruction following unsuccessful chemotherapy. | Use | Case series | To examine the impact of salvage surgery on QoL in patients who were unsuccessfully treated with chemotherapy. | STAS-J scores improved for three of four patients who received salvage surgery. | Japanese version of STAS. |
| 3 | 2013 | Murakami H. and Yamaguchi Y. | Japan | 27 patients hospitalized with malignant gastrointestinal obstruction. | Use | Longitudinal (retrospective cohort) | To investigate improvements in symptoms caused by gastrointestinal obstruction following administration of octreotide acetate injection in combination with steroid and opioid administration. | Response rate of 77.8%. Intravenous administration of octreotide acetate with steroid can effectively improve gastrointestinal symptoms without adverse events. | Japanese version of STAS. Scores not reported directly but included in regression analyses. |

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Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|----------------------------------|---------|---|---------|-------------------------------------|---|---|--|
| 4 | 2012 | Nakajima N. and Ishida M. | Japan | 87 terminally ill cancer patients who died during a 27 month period. | Use | Longitudinal (retrospective cohort) | To examine the relationship between informing patients of cancer and the quality of terminal care. | Informing patients of more specific information will increase the quality of terminal care regarding patient anxiety, recognition of disease conditions, and level of communication. | Japanese version of STAS. |
| 5 | 2011 | Sutherland J. and Stananought N. | U.K. | 50 patients/ healthcare professionals/ caregivers who had previously contacted the telephone triage team. | Use | Audit (retrospective) | To determine the ability of a telephone triage team to either reduce patients' STAS scores that were rated three or more on a telephone assessment, or to refer them to the appropriate service. | 60% of STAS scores of over three had improved by second telephone contact. Telephone triage team has same impact as community palliative care team; can provide high-quality palliative care. | |
| 6 | 2011 | Vassal P. and Chapuis F. | France | 146 hospitalized patients at the end of life who wanted to return home. | Use | Longitudinal | To clarify the influence of the overall vulnerability of patients, family, and caregivers on the return home. | Patients' overall vulnerability had a significant influence on the return home; applied in 40% of clinical cases and made possibility of return home 50% less likely. | French version of STAS. |
| 7 | 2013 | Yamaguchi S. and Korogi Y. | Japan | 133 patients treated with palliative radiotherapy with a poor performance status at the beginning of treatment. | Use | Longitudinal | To evaluate the palliative effect, assessed by the second item of STAS, and tolerability of palliative radiation therapy in patients with a poor performance status and to analyze the relationship between the | Improvement in STAS scores for 61% patients, significant improvement in mean. Most statistically significant prognostic factor for overall survival time after radiotherapy. Low rates of acute toxicities. | Only second item of the STAS used. Japanese version of STAS. |

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Appendix II
Continued

| Number | Year | Authors (First and Last) | Country | Population, Sample Size | Purpose | Study Design | Study Focus | Result | Additional Comments or Notes (e.g., Versions Used) |
|--------|------|---|-------------------|-------------------------------|---------|--------------|---|---|--|
| 8 | 2012 | Chan W. C. H. and Epstein I. ² | China (Hong Kong) | 638 deceased cancer patients. | Use | Data mining | palliative effect and the survival time. To operationalize and assess the percentage of “good deaths” achieved among Chinese cancer patients in a palliative care programme, and the relationship of a good death with other factors. | 21.5% of patients had a good death—these patients were significantly older, in palliative care longer, indicated fullness of life and had caregiver acceptance and support. | Chinese version of STAS. |

POS = Palliative care Outcome Scale; RCT = randomized controlled trial; ART = antiretroviral therapy; SOPC = specialized outpatient palliative care.

Appendix III
Categories of Use

| POS | Afshar M. 2012 | Bausewein C. 2010 | Bookbinder M. 2011 | Cohen L. W. 2012 | Defilippi K. 2010 | Di Sorbo P. 2010 | Gomes B. 2010 | Gomes B. 2013 | Groh G. 2013 | Harding R. 2012 | Harding R. 2013a |
|--|--------------------------------------|----------------------|-----------------------|---------------------|----------------------|---------------------|------------------|------------------|-----------------|--|---------------------|
| Validation of original (English) or translated versions | | | | | | | | X | | | |
| Factor analysis of original (English) or translated versions | | | | | | | | | | | X |
| Validation/use in a new patient group | Kidney disease (transplant patients) | | | | | | | | | | |
| Validation/use in a new culture | | | | | South Africa | Zimbabwe | | | | | |
| Use of a translated version (not English; only those studies which clearly stated use of translated versions included) | | German | | | | | | | German | Kenya, South Africa, Uganda, Luganda, Runyankole, SeSotho, Runyoro, SeTswana, isiXhosa, isiZulu, Gauteng, KwaZulu Natal dialects | |
| Use of an adapted version of original (English) measure | POS-S-renal + 9 items | | | | | | | | | | |
| Comparison with other tools | | | | | | | | | | | |
| Evaluation of an intervention | | | | | X | X | | | X | | |
| Study of symptom prevalence/assessment | X | X | X | | | | | X | | X | |
| Study of implementation of outcome measures | | | | | X | | | | | | |
| Comparison of needs/outcomes in different palliative care settings | | | | X | | | X | | | | |
| Comparison of assessment between patients/professional caregivers | | | | | | | | | | | |
| Professionals' views on POS | | | | | | | | | | | |
| Relatives'/carers' views on POS | | | | | | | | X | | | |
| Carer assessment of patient | | | | X | | X | | | | | |
| Patients' views on POS | | | | | | | | | | | |

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Appendix III
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| POS | Afshar M. 2012 | Bausewein C. 2010 | Bookbinder M. 2011 | Cohen L. W. 2012 | Defilippi K. 2010 | Di Sorbo P. 2010 | Gomes B. 2010 | Gomes B. 2013 | Groh G. 2013 | Harding R. 2012 | Harding R. 2013a |
|--|------------------|-------------------|--------------------|-------------------|---------------------|------------------|---|--------------------------------|---|-------------------|---|
| Study protocol | | | | | | | X | | | | |
| Longitudinal | | X | X | | X | | | | X | | |
| Cross-sectional | X | | | X | | | X | X | | X | X |
| Qualitative | | | | | | | | | | | |
| Quality assurance (audit) | | | | | | X | | | | | |
| POS | Harding R. 2013b | Harding R. 2014 | Hermann K. 2012 | Higginson I. 2011 | Higginson I. 2012 | Hongoro C. 2011 | Lewington J. 2012 | Lowther K. 2012 | Malik F. A. 2013 | Molina E. H. 2013 | Murtagh F. E. M. 2011 |
| Validation of original (English) or translated versions | | | | | | | | | | | |
| Factor analysis of original (English) or translated versions | | | | | | | | | | | |
| Validation/use in a new patient group | | | | | Parkinson syndromes | | | | | | Kidney disease (Stage 5 chronic kidney disease) |
| Validation/use in a new culture | Tanzania | Kenya | | | | | Uganda | | | | |
| Use of a translated version (not English; only those studies which clearly stated use of translated versions included) | Swahili | | German | | | | Seven local languages in Uganda (unspecified) | Kiswahili, isiXhosa, Afrikaans | | Spanish | |
| Use of an adapted version of original (English) measure | | | | | | | African Palliative care Association POS (APCA POS) plus seven items | | Core POS and POS-S plus two items from POS-S-neurological | | |
| Comparison with other tools | | | | | | | | | | | |
| Evaluation of an intervention | | | X | X | | | | X | | X | |
| Study of symptom prevalence/assessment | | X | | | X | X | X | X | X | | X |
| Study of implementation of outcome measures | | | | | | | | | | | |
| Comparison of | X | | X | X | | X | | | | X | |

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Appendix III
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| POS | Harding R. 2013b | Harding R. 2014 | Hermann K. 2012 | Higginson I. 2011 | Higginson I. 2012 | Hongoro C. 2011 | Lewington J. 2012 | Lowther K. 2012 | Malik F. A. 2013 | Molina E. H. 2013 | Murtagh F. E. M. 2011 | | |
|--|------------------|-------------------------|-------------------------|-------------------|---------------------|-----------------|------------------------------------|------------------------|------------------|-------------------|-----------------------|-----------------|----------------------|
| needs/outcomes in different palliative care settings | | | | | | | | | | | | | |
| Comparison of assessment between patients/professional caregivers | | | | | | | | | | | | | |
| Professionals' views on POS | | | | | | | | | | | | | |
| Relatives'/carers' views on POS | | | | | | | | | | | | | |
| Carer assessment of patient | | | | | | | | | | | | | |
| Patients' views on POS | | | | | | | | | | | | | |
| Study protocol | | | | | | | | X | | X | | | |
| Longitudinal | X | | X | X | X | X | | X | | X | X | | |
| Cross-sectional | | X | | | | | X | | X | | | | |
| Qualitative | | | | | | | | | | | | | |
| Quality assurance (audit) | | | | | | | | | | | | | |
| POS | Nkhoma M. 2013 | Pelayo-Alvarez M. 2013a | Pelayo-Alvarez M. 2013b | Saini A. 2012 | Saleem T. Z. 2013 | Selman L. 2013 | Simms V. 2013 | Sleeman K. E. 2013 | Slort W. 2014 | van Soest-P. 2012 | van Soest-P. 2011 | Vincent S. 2012 | Weingaertner V. 2014 |
| Validation of original (English) or translated versions | | | X (Spanish) | | | | X (African dialects) | X | | X (Dutch) | | | |
| Factor analysis of original (English) or translated versions | | | | | | | | | | X (Dutch) | | | |
| Validation/use in a new patient group | | | | | Parkinson disease | | HIV (newly diagnosed) | MS (severely affected) | | | Heart failure | COPD (advanced) | |
| Validation/use in a new culture | Malawi | | | | | | | | | | U.S. | | |
| Use of a translated version (not English; only those studies which clearly stated use of translated versions included) | Tumbuka | Spanish | | Italian | | | Swahili, Luo, Luganda, Runyakitara | | Dutch | | | | German |
| Use of an adapted version of original (English) | | | | | POS-PD—adapted from | | | | | | | | |

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Appendix III
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| POS | Nkhoma M. 2013 | Pelayo-Alvarez M. 2013a | Pelayo-Alvarez M. 2013b | Saini A. 2012 | Saleem T. Z. 2013 | Selman L. 2013 | Simms V. 2013 | Sleeman K. E. 2013 | Slort W. 2014 | van Soest-P. 2012 | van Soest-P. 2011 | Vincent S. 2012 | Weingaertner V. 2014 |
|--|-------------------|----------------------------|----------------------------|------------------|----------------------|-------------------|---------------------|-----------------------|-----------------------|----------------------|----------------------|----------------------|-------------------------|
| measure | | | | | | | | | | | | | |
| Comparison with other tools | | | X | | | X | | X | | X | X | | |
| Evaluation of an intervention | X | X | | | | | | | X | | | X | |
| Study of symptom prevalence/assessment | | | | X | X | | X | | | | | X | X |
| Study of implementation of outcome measures | | | | | | | | | | | | | |
| Comparison of needs/outcomes in different palliative care settings | | X | | | | | | | | | | | |
| Comparison of assessment between patients/professional caregivers | | | | | | | | | | | | X | |
| Professionals' views on POS | | | | | | | | | | | | | |
| Relatives'/carers' views on POS | | | | | | | | | | | | | |
| Carer assessment of patient | | X | | | | | | | | | | X | |
| Patients' views on POS | | | | | | | | | | | | | |
| Study protocol | X | | | | | | | | | | | | |
| Longitudinal | X | X | X | X | | | | X | X | X | | X | X |
| Cross-sectional | | | | | X | | X | | | | | | |
| Qualitative | | | | | | X | | | | | X | | |
| Quality assurance (audit) | | | | | | | | | | | | | |
| STAS | | Chan W. C. H. 2011 | Hashimoto 2012 | | Murakami H. 2013 | | Nakajima N. 2013 | | Sutherland J. 2011 | | Vassal P. 2011 | Yamaguchi S. 2013 | Chan W. C. H. 2012 |
| Validation of original (English) or translated versions | | | | | | | | | | | | | |
| Validation/use in a new patient group | | | | | | | | | | | | | |
| Validation/use in a new culture | | | | | | | | | | | | | |
| Use of a translated version (not English; only those studies which clearly | | Chinese | Japanese | | Japanese | | Japanese | | | French | Japanese | | Chinese |

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Appendix III
Continued

| STAS | Chan W. C. H. 2011 | Hashimoto 2012 | Murakami H. 2013 | Nakajima N. 2013 | Sutherland J. 2011 | Vassal P. 2011 | Yamaguchi S. 2013 | Chan W. C. H. 2012 |
|---|---------------------------------|-------------------|---------------------|---------------------|--|-------------------|-------------------------------|-----------------------|
| stated use of translated versions included) | | | | | | | | |
| Use of an adapted version of original (English) or translated measure | Modified for inpatient care use | | | | “Adapted version” with additional symptom detail | | Only second item of STAS used | |
| Comparison with other tools | | | | | | | | |
| Evaluation of an intervention | | X | X | X | X | | X | |
| Evaluation of support team/ inpatient unit | | | | | | | | |
| Study of symptom prevalence/symptom assessment | X | X | X | X | | X | X | X |
| Study of implementation of outcome measures | | | | | X | | | |
| Comparison of needs/ outcomes in different palliative care settings | | | | | | | | |
| Comparison of assessment between patients/ professional caregivers | | | | | | | | |
| Use of clinical scenarios | | | | | | | | |
| Longitudinal | | | X | X | | X | X | |
| Cross-sectional | X | | | | | | | X |
| Qualitative | | | | | | | | |
| Quality assurance (medical records and audit) | | | | | X | | | |

POS = Palliative care Outcome Scale; STAS = Support Team Assessment Schedule.

Appendix IV
Ongoing Studies

| Author(s) | Type of Study | Purpose of POS | Population/ Sample Size | Focus | Country | Comment |
|--|---|---|--|--|------------------------|--|
| Murtagh F. E. M., Higginson I. J. H., Bausewein C. | Cognitive interviewing | Development | 10 U.K. patients, 15 German patients | To develop and test items in a new outcome measure called the Integrated Palliative care Outcome Scale (IPOS) | U.K. and Germany | The IPOS is a new outcome measure that combines items from the POS, POS-S, and APCA African POS |
| Murtagh F. E. M., Higginson I. J. H., Bausewein C. | Psychometric testing | Validation | Approximately 400 patients in total from U.K. and Germany | To fully validate the IPOS measure | U.K. and Germany | The IPOS is a new outcome measure that combines items from the POS, POS-S, and APCA African POS |
| Dobrina R. | Action research project | Validation (choosing an assessment tool for future use) | 20 members of the hospice team | To develop and to evaluate the impact of an advanced and personalized caring model in an Italian hospice to improve patient centered care | Italy | Two yr study. Italian translation of POS |
| Raj R. | Longitudinal (two POS measurements) | Use | 50–100 outpatients on dialysis | Correlations of renal dialysis with QoL | Tasmania, Australia | POS-renal. POS administered by nurses and self-completed by patients |
| Secchi M. and Villa G. | Longitudinal (baseline + 2 measurements) | Use | 324 cancer patients and 13 nurses | To investigate quality of life perception by patients and nurses working and living in Milan San Raffaele Hospital day hospital environment | Italy | Italian translation of POS |

POS = Palliative care Outcome Scale; APCA = African Palliative Care Association; QoL = Quality of Life.