Institution: King’s College London

Unit of Assessment: 3. Nursing & Midwifery, and Palliative Care

Title of case study: Improved palliative care locally and globally due to development of the Palliative care Outcome Scale (POS)

1. Summary of the impact

King’s College London (KCL) researchers have created, refined and validated the Palliative care Outcome Scale (POS), a tool that measures the physical, psychological, spiritual and information needs of patients at the end of their lives and their families. The POS has had an outstanding impact on clinical competencies and knowledge, and has underpinned an international collaboration to develop standards for palliative care outcomes. The POS is embedded increasingly in everyday clinical practice, improving the care of patients affected by advanced conditions and providing support for their families. The POS, widely used regionally and nationally in the UK to evaluate and improve the quality of care, has been culturally adapted for use in 20 European Union countries, and in Africa and other countries around the globe.

2. Underpinning research

In clinical practice, traditional ways of assessing patients, by measuring their pulse rate and blood pressure and by scans and examining their physical functions, fail to capture aspects of health and wellbeing most important to patients with advanced diseases or approaching the end of life. Historically, screening, clinical practice, auditing and monitoring progress were restricted because clinical assessment was highly variable. The Palliative care Outcome Scale (POS) has transformed clinical assessment and improved the measurement of outcomes in palliative care. Professor Higginson (Professor, Palliative Care and Policy from 1997), Dr Harding (PhD student/ researcher/lecturer/senior lecturer/reader, from 1997), Dr Murtagh (senior lecturer, from 2009) and Dr Gao (research associate/research fellow/lecturer, from 2007) created, refined, psychometrically validated and disseminated POS as a tool for clinical practitioners and researchers.

The initial version of the POS was a 10-item form that captured physical, emotional, social and spiritual concerns in palliative care that affect patients and their families. Specifically designed to integrate clinical assessment and care, the POS was made available in two formats: a self-report version for patients and an observational report for staff to use when patients are too ill to self-report.

To refine, scientifically evaluate and maximise the usefulness of the POS in clinical practice and research, the KCL team undertook empirical studies of patients with advanced diseases, their informal carers and health-care staff across eight UK hospice, hospital and homecare facilities. The team collected data from 337 staff and from 148 patients with advanced cancer. The study was one of the largest of its time involving profoundly ill people. The findings showed that the POS was acceptably valid – it measured what it intended to measure – and reliable – it measured consistently across time, individuals and situations.(1) As the team found that patients were often too ill to complete the POS self-reports, researchers developed an additional version for patients’ families or their unpaid caregivers to complete. Interestingly, this study found that caregivers’ positivity and burden affected their assessments. Awareness of the influence of carers’ positivity and burden can help clinicians and researchers better interpret caregiver assessments.(2) An additional module, the POS-S, was also developed to assess symptoms. The validation of this module included neglected populations, such as patients with multiple sclerosis.(3)

This research has been unique in developing clinical tools that are globally relevant and locally valid. Subsequent KCL collaborative research refined and validated the POS through clinimetric tests and comparison with two other palliative care outcome measures. The research involved 140 palliative day-care patients. The patients identified positivity, self-sufficiency and symptoms as aspects that should be measured to assess the quality of life in advanced cancer. The aspects identified by patients are incorporated in the POS and confirm its relevance.(4) Further collaborative research, with colleagues in Germany (5) and Argentina,(6) among many others, led to validating the POS for other diseases, and in other settings, languages and cultures. Harding led further validation that spanned eight eastern and southern African countries and involved 682 patients and 437 family carers.(7) KCL also recently led confirmatory and exploratory factor analyses involving 231 British patients, which confirmed that the POS measures holistic care across cultures and that the POS is clinicians’ preferred measure of outcomes in palliative and end-of-life care.(8)

3. References to the research

1. Hearn J, **Higginson IJ**. 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(4):219-27. http://qualitysafety.bmj.com/content/8/4/219.long (173 Scopus citations)
2. **Higginson IJ, Gao W**. Caregiver assessment of patients with advanced cancer: concordance with patients, effect of burden and positivity. Health and Quality of Life Outcomes 2008;6:42. http://www.hqlo.com/content/6/1/42 (26 Scopus citations)
3. **Higginson IJ,** Hart S, Silber E, Burman R, Edmonds P. Symptom prevalence and severity in people severely affected by Multiple Sclerosis. J Pall Care 2006;22:158-65. PMID: 17058754 (pdf available on request) (29 Scopus citations)
4. **Higginson IJ**, Donaldson N. Relationship between three palliative care outcome scales. Health Qual Life Outcomes 2004;2:68. http://www.hqlo.com/content/2/1/68 (37 Scopus citations)
5. Bausewein C, Fegg M, Radbruch L, Nauck F, von Mackensen S, Borasio GD, **Higginson IJ**. Validation and clinical application of the German version of the palliative care outcome scale. J Pain Symptom Manage 2005;30(1):51-62. http://www.sciencedirect.com/science/article/pii/S0885392405002368 (33 Scopus citations)
6. Eisenchlas JH, **Harding R**, Daud ML, Perez M, De Simone GG, **Higginson IJ**. Use of the palliative outcome scale in Argentina: a cross-cultural adaptation and validation study. J Pain Symptom Manage 2008 Feb;35(2):188-202. http://www.sciencedirect.com/science/article/pii/S0885392407005970 (14 Scopus citations)
7. **Harding R,** Selman L, Agupio G, Dinat N, Downing J, Gwyther L, Mashao T, Mmoledi K, Moll T, Sebuyira LM, Panjatovic B, **Higginson IJ**. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. Health and Quality of Life Outcomes 2010;8:10. http://www.hqlo.com/content/8/1/10 (35 Scopus citations)
8. Siegert R, **Gao W**, Walkey FH, **Higginson IJ**. Psychological well-being and quality of care: a factor-analytic examination of the palliative care outcome scale. J Pain Symptom Manage 2010;41(1):67-74. http://www.sciencedirect.com/science/article/pii/S0885392410002770 (17 Scopus citations)

Selected competitive grant support: POS development and validation was part of the following awards from national and international peer review funders, totalling £1.07 million.

- 1996-1998. NHS Executive (Central Office, Leeds). Developing a core clinical audit for palliative care. Principal Investigators (PIs): **Higginson** and Dunlop. £46,400
- 1999-2002. National Lottery Charities Board. Project to Improve the Management of Terminal Illness (PROMOTE). PIs: Dunlop, **Higginson**, Addington-Hall, Edmonds. £555,542
- 1999-2002. NHS Executive (South and East) Research and Development. Evaluation of a New Palliative Day Care Service in Chichester. PIs: **Higginson**, Normand, Amesbury. £126,907
- 2000. Help the Hospices. Palliative care Outcome Scale Action Partnership Publication. PIs: **Higginson, Harding**. £7,500
- 2005-2008. The Big Lottery UK International Grants/The Cicely Saunders Foundation. Improving HIV care through the prevention of suffering: palliative care for patients and families in sub-Saharan Africa. PIs: **Harding**, **Higginson**, Easterbrook. £336,568

4. Details of the impact

Improvement in the quality of palliative care in the UK

The Palliative care Outcome Scale (POS) has led to substantial improvements in the quality of care for patients with advanced diseases and has helped patients and their families to access holistic palliative care. The POS is a straightforward, easy-to-use tool that clinicians, educators and those developing palliative care services can use to measure aspects of health and wellbeing most important to patients. An independent assessment of the POS in 2012 showed that it helps patients and families receive the best care available and enables care teams to quickly tailor care to needs. The POS data were also used to advocate for palliative care.(9a)

In 2011 the Cicely Saunders Institute at KCL launched the POS website which provides downloadable versions of the POS, guidance on its use and links to publications related to the POS. In its first year the website had over 251,000 hits and 10,102 visitors. Also 1,274 individuals, groups or organisations from 74 different countries registered as POS users.(9b) An analysis supported by the European Commission and the European Association for Palliative Care (EAPC) identified the POS as one of the four most commonly used measures for clinical care, audit, training and research in Europe and Africa.(9c) The POS is used for many diseases, including HIV/AIDS, neurological conditions, cancer and chronic obstructive pulmonary disease. The renal version (POS-S renal) is recommended by NHS Kidney Care as a Gold Standard tool.(9d,e)

In the UK, the government, NHS and independent sources have recommended use of the POS. In 2008, the Department of Health (DoH) produced an ‘End of Life Care Strategy’ that drew on KCL-led studies (Section 3 references 5, 1 and 4) to help compile key elements of end of life care.(9f) In 2011, the DoH Palliative Care Funding Review recommended that development of outcome measures for palliative care should be based on Australian work on patient outcome measures and the POS.(9g) The End-of-Life Care Horizon Scanning Service also endorses the POS.(9h) This website targets commissioners and primary and secondary care service-managers in order to ensure best practice and innovation. The NHS website recommending best practice for collecting data on outcomes (9i) provides a link to the POS resources, indicating the use of the POS at a national level. Electronic platforms that collect national outcome data, such as the Welsh CANISC platform for Welsh patients’ clinical records,(9j) also use the POS. At the local level, several NHS services including Leeds teaching hospitals, St Gemma's and Sue Ryder Wheatfields hospices, Leeds Adult Social Services and the Yorkshire Ambulance Service NHS Trust (9k) use the POS.

Across Europe

The PRISMA (Positive diveRsities of European prIorities for reSearch and Measurement in end of life cAre) project 2008-2010, funded by the European Commission, coordinated the use of the POS across Europe to optimise the quality of palliative care and access to palliative care services. PRISMA was led by KCL researchers and drew widely on their expertise. The project coordinated action, and helped compare and exchange experiences and best practices, and optimise research through a strategic cross-national approach.(10a,b) The 2011 PRISMA symposium focused on cross-national measurement and research as a means to progress policy and collaboration. During the symposium, the President of the European Cancer Patient Coalition cited the POS as a preferred tool in palliative care.(10b) The Recommendation Rec (2003) 24 of the Committee of Ministers of the Council of Europe to member states on the organisation of palliative care (10c) also names the POS as a tool for strengthening palliative care throughout Europe.

Worldwide

The POS is used by clinical practitioners in at least 44 countries. It has been translated into 28 languages spanning Europe, Asia, South America and Africa.(11a-b) The Thai version of the POS is being used across the public health sector (11c); the Vietnamese version in a project to determine the most prevalent and severe symptoms among patients with cancer and HIV/AIDS.(11d) Disease-specific POS versions are also used worldwide. For example, the report of an Australian renal unit for end stage kidney disease states that the POS-S (renal) “has worked successfully in the context of this clinic as patients and family are not forgetting to mention specific problems, and the clinician can systematically go through the form with the patients, thus not missing troubling symptoms”.(11e)

KCL collaboration in many African countries has led to wide use of the POS. The African Palliative Care Association (APCA) recommends the Palliative care Outcome Scale (APCA POS) (11f) as a tool for ensuring holistic assessment and access to care for all African palliative care patients (11g) and improving the quality of care.(11h) Guidelines for the APCA POS (11g) cite several KCL-led studies (Section 3 references 7 and 1). Following validation of the APCA POS (Section 3 reference 7) it has become the most commonly used patient-level outcome measure in Africa. English, French and Arabic versions are used where appropriate. It has been translated into 15 African languages for use in Kenya, Mauritania, Namibia, Rwanda, South Africa, The Gambia and Uganda.(11b) The Handbook of Palliative Care in Africa endorses the POS method of scoring pain, and provides guidance in English, French and Portuguese.(11h) The Hospice Palliative Care Association of South Africa uses the APCA POS to accredit and grade the performance of hospice and palliative care services. These standards for care are endorsed by the Council for Health Service Accreditations of South Africa, a body responsible for quality improvement and accreditation.(11i)

5. Sources to corroborate the impact

9. Improvement in the quality of palliative care

a) Dix O. Impact of the APCA Palliative care Outcome Scale (POS) on care and practice. November 2012. http://www.csi.kcl.ac.uk/files/Impact_of_APCA_POS.pdf
b) The POS website: http://pos-pal.org/maix/about-us.php
c) European Association for Palliative Care (EAPC): Outcome measurements White Paper 2013 (Cites Section 3: Ref 1, pp. 6, 8, 11; Ref 2, p. 7; Ref 6, p. 25; Ref 7, pp. 10, 11, 23, 28)
d) NHS Kidney Care, 2012. Getting it right: End of life care in advanced kidney disease. http://webarchive.nationalarchives.gov.uk/20130504185629/http://kidneycare.nhs.uk/document.php?o=470
e) NHS screening tool to identify patients for the GOLD register: http://www.endoflifecare.nhs.uk/assets/downloads/Appendix2ScreeningtooltoidentifypatientsfortheGOLDregister.pdf
f) End of Life Care Strategy 2008
    - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf
    - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136441/EOLC_bibliography.pdf (Cites Section 3: Ref 1, p. 9; Ref 3, p. 10; Ref 4, p. 10; Ref 5, p. 1.)
g) Palliative Care Funding Review (p47): https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf
h) End-of-Life Care Horizon Scanning Service: http://palliativecarenwpctl.wordpress.com/2011/06/14/
i) End of Life Care NHS: http://www.endoflifecare.nhs.uk/research-evaluation/how-to-evaluate/think-about-outcomes.aspx (Nb: link leads to PRISMA document discussed in 10a)
j) Palliative Care in Wales: http://wales.pallcare.info/
k) Leeds: http://www.leedspalliativecare.co.uk/staff/resources/ (“service improvement” tab)

10. Europe

a) PRISMA:
    - http://www.csi.kcl.ac.uk/files/PRISMA_Final%20Report_290611.pdf (p3)
    - http://www.eapcnet.eu/LinkClick.aspx?fileticket=-T62WTgTHtU%3d&tabid=1577
b) Daveson BA, et al. J Pain Symptom Manage 2011;42(4):511-6. See reference to patient involvement presentation at p.513.
c) Recommendation Rec (2003) 24 of the Council of Europe Committee of Ministers to member states on the organisation of palliative care: http://tinyurl.com/pdaqseg
See the POS recommendation 125 on page 53, and the POS reference on p.77.

11. Worldwide

a) Bausewein C, et al. Palliat Med 2011;25(4):304-13. Doi: 10.1177/0269216310395984
b) APCA weblink: http://tinyurl.com/pfjonga
c) Suandok Palliative Care, Thailand: http://www.med.cmu.ac.th/dept/family/2012/index.php/en/2012-05-05-09-40-01
d) Vietnamese use of the POS: http://connects.catalyst.harvard.edu/Profiles/display/Person/40300 http://www.med.cmu.ac.th/dept/family/2012/index.php/en/2012-05-05-09-40-01
e) Josland E, et al. Renal Society Australasia Journal 2012; 8(1):12-18: http://www.renalsociety.org/RSAJ/journal/mar12/josland.pdf (p. 15)
f) APCA Standards for Providing Quality Palliative Care Across Africa: http://www.africanpalliativecare.org/images/stories/pdf/APCA_Standards.pdf (p34-35,138-139)
g) APCA Guidelines for use of the POS: http://www.africanpalliativecare.org/images/stories/pdf/POS_Guidelines.pdf
h) Handbook of Palliative Care in Africa: http://africanpalliativecare.org/images/stories/pdf/Handbook.pdf (p41)
i) Impact of the APCA POS: http://pos-pal.org/doca/Impact_of_APCA_POS.pdf (p9)