CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

Title	Patient reported outcome measures of quality of end-of-life care: a systematic review
Authors	Kearns, Tara;Cornally, Nicola;Molloy, D. William
Publication date	2017
Original Citation	Kearns, T., Cornally, N. and Molloy, W. (2017) 'Patient reported outcome measures of quality of end-of-life care: a systematic review', Maturitas, 96, pp. 16-25 doi: 10.1016/j.maturitas.2016.11.004
Type of publication	Review
Link to publisher's version	http://www.sciencedirect.com/science/article/pii/S0378512216302900 - 10.1016/j.maturitas.2016.11.004
Rights	© 2016, the Authors. Published by Elsevier Ireland Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/). - http://creativecommons.org/licenses/by-nc-nd/4.0/
Download date	2026-10-26 00:07:37
Item downloaded from	https://hdl.handle.net/10468/5384

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Maturitas 96 (2017) 16–25

Contents lists available at ScienceDirect

Maturitas

journal homepage: www.elsevier.com/locate/maturitas

Review

Patient reported outcome measures of quality of end-of-life care: A systematic review

Tara Kearns[a,*], Nicola Cornally[a,b], William Molloy[a]

[a] Centre for Gerontology and Rehabilitation, University College Cork, Western Road, Cork, Ireland
[b] School of Nursing and Midwifery, University College Cork, Western Road, Cork, Ireland

ARTICLE INFO

Article history:
Received 18 October 2016
Accepted 4 November 2016

Keywords:
End-of-life care
Long-term care
Chronic disease
Patient-reported outcome measures
Patient-reported outcomes
Cognitive impairment

ABSTRACT

End-of-life (EoL) care[1] is increasingly used as a generic term in preference to palliative care or terminal care, particularly with reference to individuals with chronic disease, who are resident in community and long-term care (LTC) settings. This review evaluates studies based on patient reported outcome measures (PROMS) of quality of EoL care across all health-care settings. From 1041 citations, 12 studies were extracted by searches conducted in EBSCO, Scopus, Web of Science, PubMed, Cochrane, Open Grey and Google Scholar databases.

At present, the evidence base for EoL care is founded on cancer care. This review highlights the paucity of studies that evaluate quality of EoL care for patients with chronic disease outside the established cancer-acute care paradigm, particularly in LTC. This review highlights the absence of any PROMs for the estimated 60% of patients in LTC with cognitive impairment. Patient-reported outcomes (PROs) are critical to understanding how EoL care services and practices affect patients' health and EoL experience. PROMs describe the quality of care from the patient's perspective and add balance to existing clinical or proxy-derived knowledge on the quality of care and services provided.

© 2016 The Authors. Published by Elsevier Ireland Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Contents

1. Introduction 17
   1.1. Rationale 17
   1.2. Objectives 17
2. Methods 17
   2.1. Eligibility criteria 17
   2.2. Information sources and searches 17
3. Results 18
   3.1. Study selection 18
   3.2. Study characteristics 18
   3.3. Synthesis of results 18
4. Discussion 19
   4.1. Summary of evidence 19
5. Conclusion 24
   Funding 24
   Ethics 24

* Corresponding author.
E-mail address: tarakearns@gmail.com (T. Kearns).

[1] The term EoL care has evolved as an umbrella term that encompasses all aspects of care related to death and dying provided towards the end of life [2]. There is no consensus in the literature regarding the time-frame it is applied to; definitions range from care in the last year of life, to care from time of terminal diagnosis until death. However, it is generally accepted as representing a broad continuum of care for people who are living with, or dying from terminal illness [1]. This wide focus lends itself to the description of care for patients with non-malignant chronic diseases where disease trajectories are more protracted, and prognostication less certain than for patients with cancer.

http://dx.doi.org/10.1016/j.maturitas.2016.11.004
0378-5122/© 2016 The Authors. Published by Elsevier Ireland Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Contributors 24
Conflicts of interest 24
References 24

1. Introduction

1.1. Rationale

By 2050, there will be 392 million people worldwide aged 80 years and over; more than three times the current number [3]. In developed countries, this demographic transition is underpinned by an epidemiological transition from high infant and maternal mortality, and high infectious disease rates, to low premature mortality and a predominance of chronic, non-communicable disease [4]. In congruence with population ageing, societies are ageing, and social environments are changing. Traditional, family-based options for EoL care are becoming less common [5]. Family size is decreasing and perspectives on intergenerational care of older people are shifting [6]. People are dying later in life, increasingly from chronic disease, and more frequently in LTC than at home [7].

Chronic diseases include cardiovascular disease, hypertension, stroke, cancer, diabetes, arthritis, chronic obstructive pulmonary disease (COPD), dementia, and depression. Cardiovascular diseases account for the majority (46%) of chronic disease deaths globally, followed by cancers (22%), respiratory diseases (10.5%) and diabetes (4%) [8].The prevalence of these diseases typically increases with age, and multi-morbidity is a common feature. Approximately 80% of older adults have at least one chronic disease, and 68% have at least two [9]. Chronic diseases are the leading cause of mortality worldwide, representing 60% of all deaths globally [10].

The proportion of U.S. deaths in LTC was 23% in 2008, this figure is projected to rise to 40% by 2040 [11]. This trend is mirrored elsewhere, in New Zealand [12], Australia [13], Canada [14], Ireland [7], and the U.K. [6]. A study of prevalence of chronic medical conditions in older residents in LTC in the U.S. found that the leading three chronic diseases were; hypertension (men 53%, women 56%), dementia (men 45%, women 52%), and depression (men 31%, women 37%) [15]. A study of patterns of chronic co-morbid medical conditions in older residents in LTC in the U.S. found that the most frequent two co-morbid disease combination in both men and women was hypertension and dementia [16]. It is estimated that as many as 60% of patients in LTC have cognitive impairment or dementia, many of whom do not have a formal diagnosis [17–20].

Evaluating EoL care for patients with cancer presents fewer methodological challenges than for other chronic disease populations. In comparison to other leading chronic diseases, cancer has a more predictable trajectory towards death, and more certainty in prognostication [21–23]. Consequently, much of the research to-date in evaluating EoL care has focused on patients with cancer in its associated care settings. Originally, PROMs of EoL care focused on the evaluation of physical symptoms, recently, their scope has broadened to include psycho-social factors, well-being, spirituality, mental health, communication and quality of life [24]. There are several condition-specific PROMs for patients with different types of cancer; typically these measures focus on symptoms such as pain, dyspnea, and nausea, in addition to subjective aspects of the patients' experience of EoL care.

While many of the physical symptoms experienced by cancer patients are common to other chronic disease populations, the patient experience at EoL is often different. Patients with non-malignant disease experience more burdensome symptoms in the last year of life than those suffering from cancer, not only because of the greater number of symptoms, but also because of the more protracted trajectory of decline in chronic conditions [25,26]. A gradual deterioration in functioning, punctuated by intermittent acute episodes is typical in conditions such as COPD and heart failure. Frail elderly patients and those with dementia typically experience a prolonged and progressive functional decline from an already low baseline of physical and cognitive function [27]. As a result, many of these patients use multiple healthcare settings for EoL care.

1.2. Objectives

Currently, the evidence base for EoL care is founded on the cancer-acute care paradigm [28]. Development of the evidence base necessitates measurement of the patient experience beyond these confines. The objectives of this review were to identify, describe and critically evaluate existing PROMs of quality of EoL care, for patients with chronic disease, in various healthcare settings.

2. Methods

2.1. Eligibility criteria

Papers were identified based on the following inclusion criteria:

1. Primary research studies based wholly or partially on PROs of EoL care, or that validate PROMs of EoL care
2. Sample of adults (18 years of age and over) with any chronic disease or condition
3. Conducted in any type of health-care setting
4. Using assessment measure(s) with described psychometric properties
5. Reported in English and published between January 2006 and July 2016 (inclusive)

The following exclusion criteria were used:

1. Studies based on samples where cancer is the sole diagnosis
2. Clinical trials and studies addressing technical interventions, physiological, laboratory-based, or radiological outcomes
3. Descriptive, non-clinical articles (e.g., reviews, discussion pieces, reports, expert statements)

2.2. Information sources and searches

A systematic review of the literature was conducted during July 2016. Searches were conducted in Academic Search Complete, CINAHL Plus with full text, PsycINFO, Scopus, Web of Science, PubMed, and Cochrane databases. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines were used in this systematic review [29]. The search strategy included a combination of free text and controlled vocabulary (MeSH) terms. The search strategy used three groups of terms combined with AND: "end of life care", "patient reported outcomes", and "scale". Details of the electronic search strategy, including search terms used are shown in Table 1. The grey literature was searched using Open Grey and Google Scholar databases.

Studies were examined for inclusion in a two-step process, with an initial screening of titles and abstracts, followed by screening of full-text articles against the inclusion criteria to identify relevant studies.

Table 1
Electronic search strategy and search terms used.

Search #	Academic search complete[a]	CINAHL plus with full text[a]	PsycINFO[a]	PubMed[b]	Scopus[c]	Web of science[d]	Cochrane databases[e]
#1 "end of life care"	10,000	5530	3819	7147	8548	20,812	40
#2 "end of life care" **	5602	91	788	1970	6343	12,032	39
#3 "end of life care" OR "terminal care" OR "hospice care" OR "palliative care" OR "end stage care" **	19,394	711	2734	13,423	35,388	12,354	61
#4 "patient reported outcome" OR "patient reported outcome measure" OR "patient self report" OR "patient outcome assessment" OR "patient outcome measure" **	77,094	24	205	2931	10,270	2837	537
#5 scale OR measure OR instrument OR survey OR questionnaire **	1,409,119	17,217	65,517	504,296	3,128,448	2,698,016	7819
#6 (#3 AND #4 AND #5) **	721	0	11	47	122	34	38

** Limiters applied.
[a] EBSCO (Academic Search Complete, CINAHL Plus, PsycINFO) Limiters: Publication date 2006–2016; English language.
[b] PubMed Limiters: Publication date 2006–2016; English language and Humans.
[c] Scopus Limiters: Publication date 2006–2016; English language.
[d] Web of Science Limiters: Publication date 2006–2016, English language.
[e] Cochrane Limiters: Publication date 2006–2016.

Searches in EBSCO and PubMed were saved and updated with weekly alerts and RSS feeds from July to September 2016 to ensure that any eligible studies published subsequent to the final search date were not missed. No further studies were identified for inclusion via alerts or feeds. Data was extracted from the identified articles and tabulated according to author and date, characteristics of the studies and key features of the measures used.

The measures used in the identified studies were reviewed and psychometrically evaluated according to quality criteria adapted from Terwee et al., [30] and Selman et al., [31]. Specific adaptations made were as follows: due to the lack of an agreed 'gold standard' for PROs of quality of care, criterion validity was not assessed; as the instruments reviewed were patient-reported, inter-rater agreement was deemed not to be relevant and test-retest reliability was used as a more appropriate test of reliability; as no scoring system was used, the quality criterion for 'no information found' was given a not reported (NR) rating instead of 0; the term 'doubtful' in the criteria for indeterminate rating was changed to 'inadequate'; due to the complexity of defining minimally important change (MIC) for quality of care, the requirement that the MIC be defined to satisfy the interpretability criterion was omitted. The adapted criteria used are shown in Table 2.

3. Results

3.1. Study selection

The database searches yielded 966 articles, searches of the grey literature, journals, reviews, and the Internet resulted in an additional 75 articles, yielding a total of 1041 articles. Eliminating duplicates gave a total of 940 articles for screening. The total number of articles retained post-screening was 24, the full text of these articles was retrieved and reviewed for final eligibility. Twelve articles were excluded for the following reasons: not based on PROs ($n = 1$), not EOL care ($n = 3$), based exclusively on sample of patients with cancer ($n = 4$), did not report or describe psychometric properties of assessment used ($n = 3$), was a descriptive/non clinical article ($n = 1$). A total of 12 studies were included in the final review. A flowchart of the stages of the review process according to the PRISMA guidelines is shown in Fig. 1.

3.2. Study characteristics

Of the 12 studies included in the review, six were primary research studies and six were validation studies. The studies were based in a range of settings, three in hospitals; three in community settings; four in multiple settings; and two in hospice settings. The patients sampled had a variety of diagnoses, two studies were based on patients with Multiple Sclerosis (MS); two on patients with HIV/AIDS; three on patients with unspecified chronic disease; and five on palliative care patients, predominantly, but not exclusively with a cancer diagnosis.

A total of 15 PROMs of quality of EoL care in patients with chronic disease were identified across the 12 studies included. Study characteristics, PROMs used, and their key features are shown in Tables 3 and 4. The majority of measures used five or eleven–point Likert rating scales and reported administration times of 10 min or less. The exception was the MCOHPQ, with a reported administration time of 25–30 min. Administration time for the Quality Measure for Palliative Nursing was not reported.

3.3. Synthesis of results

The psychometric properties of the included measures, evaluated according to criteria adapted from Terwee et al. [30] and Selman et al. [31] are presented in Table 5. Of the 15 measures evaluated, ten demonstrated adequate content validity. No information on target population involvement was found for the MCOHPQ, and the remaining four measures had an indeterminate rating as they lacked a clear description of the development process.

Six measures demonstrated adequate internal consistency. Three of the measures, the PHQ-9, the SKIPP and the MVQOLI, had an indeterminate rating for internal consistency, predominantly due to a lack of factor analysis. Five measures showed poor internal consistency: the MCOHPQ, the QOC, the SEC-P and the African POS. No information on internal consistency was found for the Quality Measure for Palliative Nursing.

Nine of the measures demonstrated adequate construct validity. Testing of three measures used an inadequate design or method. The SEC-P demonstrated poor construct validity, and no information on construct validity was found for the MCOHPQ and the Quality Measure for Palliative Nursing.

Seven measures, the POS, the MSIS, the SAS, the PHQ, the HADS-D, the BHI, and the African POS, demonstrated adequate test-retest reliability. Test-retest reliability was indeterminate for the SKIPP due to doubtful design in testing. No information on test-retest reliability was found for the remaining seven of the fifteen measures.

No information on responsiveness was available for eight measures. The PHQ and the HADS-D both demonstrated adequate responsiveness. Of the remaining five measures four had

Table 2
Quality criteria for psychometric evaluation of measures.

Property	Definition	Quality criteria [a, b]
1. Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire	+ A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection; ? A clear description of above-mentioned aspects is lacking OR only target population involved OR inadequate design or method; − No target population involvement; NR No information found on target population involvement.
2. Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct	+ Factor analyses performed on adequate sample size (7 * # items and ≥100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95; ? No factor analysis OR inadequate design or method; − Cronbach's alpha(s) $\alpha < 0.70$ or $\alpha > 0.95$, despite adequate design and method; NR No information found on internal consistency.
3. Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured	+ Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses; ? Inadequate design or method (e.g., no hypotheses); − Less than 75% of hypotheses were confirmed, despite adequate design and methods; NR No information found on construct validity.
4. Reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)	+ ICC or weighted Kappa ≥0.70; ? Inadequate design or method (e.g., time interval not mentioned); − ICC or weighted Kappa <0.70, despite adequate design and method; NR No information found on reliability.
5. Responsiveness	The ability of a questionnaire to detect clinically important changes over time	+ SDC or SDC<MIC OR MIC outside the LOA OR RR >1.96 OR AUC≥0.70; ? Inadequate design or method; − SDC or SDC≥MIC OR MIC equals or inside LOA OR RR≤1.96 OR AUC<0.70, despite adequate design and methods; NR No information found on responsiveness.
6. Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	+ ≤15% of the respondents achieved the highest or lowest possible scores; ? Inadequate design or method; − >15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods; NR No information found on interpretation.
7. Interpretability	The degree to which one can assign qualitative meaning to quantitative scores	+ Mean and SD scores presented of at least four relevant subgroups of patients ? Inadequate design or method OR less than four subgroups; NR No information found on interpretation.

Table adapted from Terwee et al. [30].
MIC = minimal important change; SDC = smallest detectable change; LOA = limits of agreement; ICC = Intraclass correlation; SD, standard deviation.
[a] + = positive rating; ? = indeterminate rating; − = negative rating; NR = not reported.
[b] Inadequate design or method = lacking of a clear description of the design or methods of the study, sample size smaller than 50 subjects (should be at least 50 in every (subgroup) analysis), or any important methodological weakness in the design or execution of the study.

an indeterminate rating and one, the SEC-P, demonstrated poor responsiveness.

No information on floor and ceiling effects was found for eight of the measures reviewed. Five measures demonstrated floor/ceiling effects despite adequate design and methods. Two measures, the POS-MSS and the MVQoLI demonstrated low floor/ceiling effects.

One measure, the SAS demonstrated adequate interpretability. No information on interpretability was found for eleven of the measures and three had an indeterminate rating.

4. Discussion

The aim of this review was to identify, describe and critically evaluate existing PROMs of quality of EoL care for patients with chronic disease, in various healthcare settings. A total of 15 PROMs of quality of EoL care in patients with chronic disease were identified across 12 studies.

4.1. Summary of evidence

The measures identified were heterogeneous in terms of their constituent domains. Physical symptoms and perceptions of quality of care or experiences of care were the most frequently occurring domains, with both occurring in nine of the 15 measures identified. Quality of life (QoL) or well-being featured as a domain in five measures, emotional/psychosocial symptoms featured in five measures, spiritual status featured in three measures, anxiety/depression featured in three measures and healthcare professionals' communication skills featured in three measures. These findings highlight that there is broad agreement across the PROMs identified, in that the evaluation of quality of EoL care requires multidimensional PROMs, encompassing both subjective and objective indicators. However, these findings also demonstrate the absence of consensus on what the essential, core domains for measurement should be.

The majority of studies were conducted in a single setting, with mixed, cancer–predominant populations. None of the studies identified were based in LTC settings. However, a small number ($n = 3$) of the patients sampled in Higginson's study [38] were nursing home residents.

None of the measures identified included patients with cognitive impairment in their validation study samples. The BHI, POS, SEC-P, QEOLC and QOC, all specify exclusion of patients with cognitive impairment in their validation study samples. Cognitive impairment was not specified as an exclusion criterion for the remaining measures; however various inclusion criteria used, such as the ability to remember and report [35], and to be mentally well-enough [42] act as de facto barriers to participation from patients with cognitive impairment. No cognitive impairment/dementia-specific PROMs were identified, and no adaptations of the PROMs

Table 3
Study characteristics and measures used.

1st author &Year	Instrument	Country	Sample	Setting	Constructs measured	Domains	No. of items	Scoring	Admin. time	Period of reference	Study type
Addington-Hall 2014 [32]	St. Christopher's Index of Patient Priorities (SKIPP)	U.K.	*n* = 35 Palliative care patients, predominantly with a cancer diagnosis (71%)	Hospice service with inpatient unit (60%), and day care services (40%)	Patients' perceptions of the impact of the service on their well-being while providing a broad indication of patients' own perceived quality of life (QoL)	QoL, Concerns, change in concerns, impact of service on concerns	8	7 point numerical scale for QoL items, 2 open questions for concerns, 5 point rating scales for changes and impacts items	7 min	Current perception and 'before starting hospice care'	Validation study
Cameron 2015 [33]	Quality Measure for Palliative Nursing	U.K.	*n* = 11 Palliative care patients, diagnosis not reported	Community palliative care service	Quality of care provided by palliative care specialist nurses from the patients' perspective	Personal characteristics, communication skills, knowledge, relationship with patient and providing comfort	15	Not reported	Not reported	Not reported	Validation study
Currow 2015 [34]	Symptom Assessment Scale (SAS)	Australia	*n* = 19, 747 Palliative care patients (85% cancer)	Hospital and community	Symptom distress: pain, insomnia, nausea, bowel problems, appetite problems, breathing problems, and fatigue	Insomnia, appetite, nausea, bowels, breathing, fatigue and pain	7	11 point Likert-type verbal rating scale	<10 min	In the last 24 h	Primary research study
Curtis 2013 [35]	Quality of Communication (QOC)*; Quality of End of Life Care (QEOLC)**; Patient Health Questionnaire (PHQ-8)***	U.S.	*n* = 1717 Patients with chronic disease and palliative needs, cancer, COPD, heart failure &liver disease	Hospital	*Overall quality of communication and specific aspects of communication **Patient-reported quality of EoL care ***Depressive Symptoms	*General communication skills, communication about EoL care **Patient-centred systems, communication skills, symptom skills, affective skills, patient-centred values ***Threshold disorders, subthreshold disorders	*18 **26 ***8	*11 point Likert scale **11 point Likert scale ***Score 0–24	*Not reported **Described as 'short' but time not specified ***<3 min	*In the last 6 months, and if patient remembered the encounter with the clinician **In the last 2 weeks ***In the last 2 weeks	Primary research study
Gade 2008 [36]	Modified City of Hope Patient Questionnaire (MCOHPQ)	U.S.	*n* = 517 Hospitalized patients with life limiting illness, predominantly cancer, COPD &organ failure	Hospital	Physical symptoms, psychosocial, emotional, and spiritual status and health care experiences	Physical area, emo-tional/relationship area, spiritual area, place of care/environment, care providers communication	95	11 point Likert scales	25–30 min	Current perception	Primary research study
Harding 2012 [37]	African Palliative Outcome Scale (African POS)	Southern &Eastern Africa	*n* = 1337 Patients with HIV	Public Health Clinics, Hospice, and palliative care services (home-based and in-patient units)	Respondent's perceptions regarding a different dimension of care or need in a palliative care setting	Physical &psychological well-being, inter-personal well-being, existential well-being	7 (+3 family oriented items)	Items scored from 0–5	10 min	In the last 3 days	Validation study

Table 4
Study characteristics and measures used (cont.).

1st author &year	Instrument	Country	Sample	Setting	Constructs measured	Domains	No. of items	Scoring	Admin. time	Period of reference	Study type
Higginson 2008 [38]	Palliative Care Outcome Scale (POS) *, Palliative Care Outcome Scale-MS symptoms (POS-MSS)** &MS Impact Scale (MSIS)***	U.K.	*n* = 52 Patients with advanced MS with palliative care needs	Various – home 87%, nursing home 6%, 2% each in hospital, rehab unit, day care and residential home	Patient outcomes following introduction of a new palliative care service	*Anxiety, patient &carer concerns, and practical needs **MS symptoms ***QoL and impact of MS	*8 **18 ***29	*5 point Likert scale ** 5 point Likert scale *** rated 1–5	*10 min **10 min ***5–8 min	* In the last 3 days **In the last 3 days *** In the last 2 weeks	Primary research study
Krevers 2014 [39]	Sense of Security in Care – Patients' Evaluation (SEC-P)	Sweden	*n* = 161 Patients in palliative stage of incurable disease, cancer or other non-malignant severe or lethal disease	Palliative home-care units	Patients' sense of security in palliatve care	Care Interaction, identity and mastery	15	6 point Likert scale	10 min	Current perception	Validation study
Krug 2010 [40]	Palliative Care Outcome Scale (POS)	U.S.	*n* = 67 Patients with advanced HIV/AIDS attending outpatient clinic at a teaching hospital	Hospital Outpatient Clinic	Respondent's perceptions regarding a different dimension of care or need in a palliative care setting	Physical, psychological, and spiritual	10	5 point Likert scale (8 items) 3 point Likert scale (2 items)	10 min	In the last 3 days	Primary research study
Mayahara 2015 [41]	*Hospital Anxiety and Depression Scale (HADS-D) **Brief Hospice Inventory (BHI)	U.S.	*n* = 46 Hospice program patients (60% cancer)	Hospice	* Depression **QoL	* Symptoms of anxiety and depression ** Physical &psychological symptoms, patients' perceptions of hospice care, and patients' ratings of QoL	*7 (Depression subscale) **9 (QoL subscale)	* Items scored on a scale of 0–3 **11 point Likert scale	*2–6 min **<10 min	* In the last week **In the last few days	Primary research study
Selman 2011 [42]	Missoula Vitas Quality of Life Index (MVQOLI)	South Africa and Uganda	*n* = 285 Palliative care patients with HIV (81%), cancer (18%) and MND	Hospices, home care, day care, outpatient and inpatient clinics	QOL in the context of advanced, progressive, incurable illness	Symptoms, function, interpersonal, well-being, transcendent	26	5 point scale	10–15 min	Current perception	Validation study
Sleeman 2013 [43]	*Palliative Care Outcome Scale (POS) **POS-MS-Symptoms (POS-MSS)	U.K.	*n* = 46 Patients with MS with palliative care needs	Setting not reported, interviews were mainly conducted in patients' homes	Psychological well-being and perceived quality of care	*Patient and family anxiety, patient and carer concerns and practical problems **Items specifically relating to MS symptoms	*8 **18	*5 point Likert scale **5 point Likert scale	* <10 min ** 10 min	In the last 3 days	Validation study

Table 5
Psychometric evaluation of identified measures.

Instrument	Content validity	Internal consistency	Construct validity	Test – retest reliability	Responsiveness	Floor/ceiling effects	Interpretability	Validation population
BHI [41,44]	?	+	?	+	?	NR	NR	U.S., Hospice patients, patients with dementia were excluded, $n = 145$
HADS-D [41,45,46]	?	–	+	+	+	NR	NR	U.K., Patients in a general medical hospital outpatient clinic, $n \geq 250$
MCOHPQ [36,47]	NR	–	NR	NR	NR	NR	NR	U.S., Sample size not reported
MSIS [38,48–50]	+	+	+	+	?	–	NR	U.K., MS patients, $n \geq 1000$
MVQOLI [51,42]	+	?	?	NR	NR	+	?	U.S., Hospice patients, $n = 257$
PHQ [35,52–54]	+	?	+	+	+	NR	NR	U.S., Primary care patients, $n = 357$
POS [38,55,40,43]	+	+	+	+	–	–	?	U.K., Palliative care patients without 'impaired mental status', $n = 148$
POS African version [56,37,57]	+	–	+	+	?	NR	NR	Africa, HIV/cancer patients, $n = 80$
POS-MSS [38,43,58,59]	+	+	+	NR	NR	+	NR	U.K., MS patients, $n = 50$
QEOLC [35,60]	+	+	+	NR	NR	–	?	U.S., Patients with life-limiting diseases (cancer, COPD, HF) without dementia or delirium, $n = 801$
QOC [61,62]	?	–	+	NR	NR	–	NR	U.S., Patients with AIDS, $n = 104$, without cognitive impairment or dementia
Qual measure for palliative nursing [33]	+	NR	NR	NR	NR	NR	NR	U.K., Palliative care patients, $n = 11$
SAS [63,34]	?	+	+	+	?	NR	+	Australia, Cancer &MI, $n = 572$
SEC-P [39]	+	–	–	NR	NR	–	NR	Sweden, Palliative care patients, $n = 161$, 'cognitive failure/confusion' used as an exclusion criterion
SKIPP [32,64]	+	?	?	?	NR	NR	NR	U.K., Palliative care patients, $n = 35$

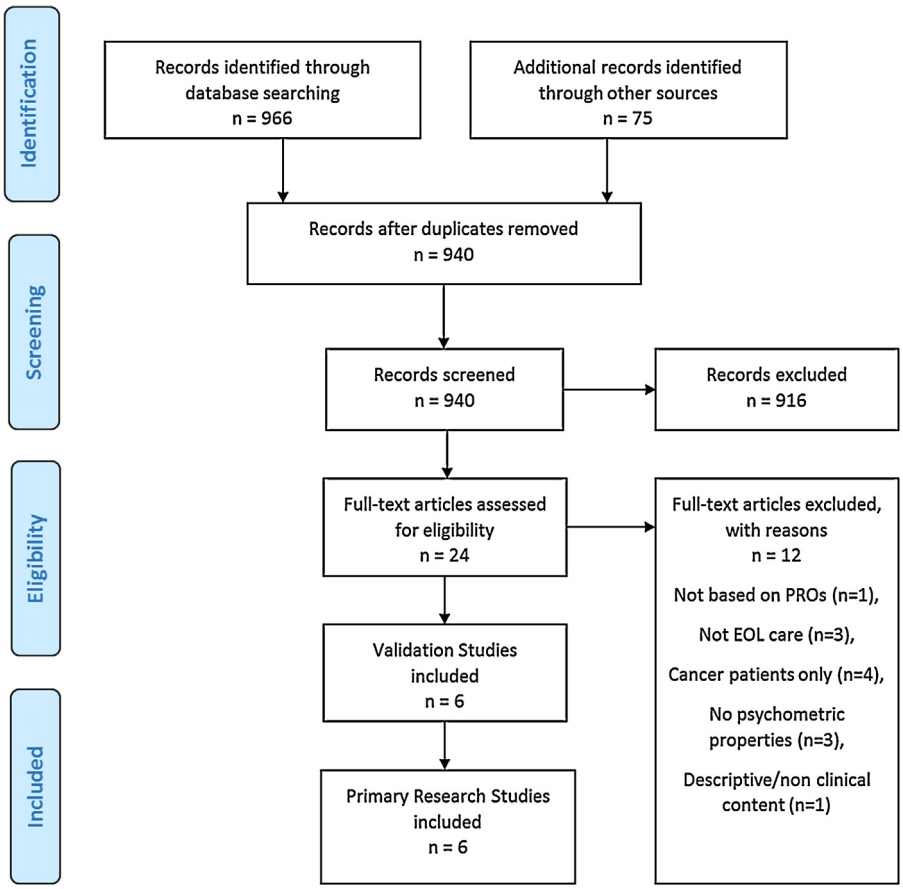

Fig. 1. PRISMA flowchart of stages of the review process.

identified for use with patients with cognitive impairment were reported.

The POS, a generic mutidimensional PROM was found to be one of the more robust measures identified, with good content validity, internal consistency, construct validity and test-retest reliability. The POS was the only measure reviewed that was used in a research study that included patients with cognitive impairment in the study sample, although the number of such participants was not reported [38]. The POS-MS, a version of the POS adapted for use with patients with MS, demonstrates good psychometric properties for validity criteria and floor and ceiling effects, however, the small sample size and lack of data for reliability and responsiveness indicate that further testing and validation is required.

Based on a large validation sample of over 1000 patients with Multiple Sclerosis (MS), the MSIS shows a strong psychometric profile with respect to validity and reliability. However, the measure's condition specificity may limit its adaptation and use in other chronic disease populations. The QEOLC also shows good psychometric properties for content and construct validity and internal consistency. However, further testing of its test-retest reliability and responsiveness are required.

The majority of the validation study samples of the included measures are small, with samples of less than 250 subjects [65]. The measures with the smallest validation study sample sizes, the SKIPP ($n = 35$), and the Quality Measure for Palliative Nursing ($n = 11$), both score poorly on the quality criteria used. This inevitably raises questions regarding design adequacy and methodological strength. However, as both measures are relatively new, further testing of validity and reliability is required.

Responsiveness is an important property in PROMs for evaluating quality of EoL care, yet only two measures, the PHQ and the HADS, demonstrated adequate responsiveness. Both are unidimensional measures of anxiety and depression symptoms, where significant change may be more easily quantified (using SDC, MIC, or GRR) than for multidimensional measures.

Overall, the measures evaluated were found to lack psychometric quality and methodological rigor. However, a number of considerations need to be made when evaluating PROMs of EoL care. The difficulty in defining what is minimal important change (MIC) for this population, impacts on the application of the responsiveness and interpretability criteria. Floor and ceiling effects are relevant only where the measure under consideration has a total score or subscale scores. Additionally, the methodological challenges inherent in carrying out research with patients at EoL with chronic disease, frequently preclude the recruitment and retention of the large study samples required for factor analyses.

Another consideration is the difference in the constructs measured across the various measures identified. The POS, African POS, MCOHPQ, QEOLC, BHI, MVQOLI and the SKIPP are generic, multidimensional PROMS that measure quality of care in relation to general health or well-being; the POS-MS and MSIS are condition-specific PROMS that measure quality of care in relation to MS symptoms; the SAS, PHQ-8 and HADS are symptom-specific, unidimensional measures; and the QOC, SEC and Quality Measure for Palliative Nursing measure communication, patients' sense of security and nursing skills, respectively. The time-frame across which quality of care was measured also varied, ranging from 'current perception' to 'in the last 6 months'. These disparities pose a challenge in drawing clear comparisons among the measures included in this review, and as such they were evaluated individually with respect to their psychometric properties.

A significant limitation of this review is that only articles written in English were included, and important studies in other languages may have been omitted as a result. Additionally, the limit on publication dates from 2006 to 2016 may have excluded additional relevant studies. Finally, a review of the qualitative literature would have enhanced the clarity of the theoretical bases for the concept of quality of care and its related constructs, but was beyond the scope of this review.

The findings of this review underline the lack of PROMS of EoL care for patients with chronic disease outside the cancer care model, and the absence of any PROMs of EoL care developed or validated for use with patients with cognitive impairment. Further research is required to develop of a core set of PROs for use with patients with non-malignant chronic disease, across multiple EoL care settings and disease trajectories.

5. Conclusion

Extension of the current evidence base requires further research to develop and adapt PROMs for the growing population of patients with chronic disease who reside in non-acute care settings, particularly in LTC.

The inherent methodological challenges in evaluating EoL care in this population necessitate the development of alternative methods of assessment and appraisal. Given the proportion of patients in LTC with cognitive impairment, the development of appropriate PROMs for this population will require the inclusion of these patients in study samples and the adaptation of measures to suit participants with varying levels of cognition.

This review highlights the need for a high quality PROM of quality of EoL care for patients with chronic disease beyond the established acute care-cancer paradigm, to include patients with varying levels of cognition. The development of a wider selection of context sensitive, methodologically sound and psychometrically robust PROMs is an essential step towards improving the quality of EoL care for our ageing populations and chronically ill.

Funding

This research was funded by a grant from the Health Research Board, Ireland.

Ethics

No ethics approval was required for this research.

Contributors

Professor William Molloy and Dr. Nicola Cornally for conceptual design and development.

Conflicts of interest

None.

References

[1] Irish Hospice Foundation, Irish Hospice Foundation, About Hospice Care: Definitions, 2016, http://hospicefoundation.ie/about-hospice-care/definitions/ (accessed 06-09-16).
[2] M. Ross, R. Fisher, M. MacLean, A Guide to End-of-Life Care for Seniors, Health Canada, Ottawa, 2000.
[3] United Nations, World Population Ageing 2013, Department of Economic and Social Affairs, Population Division, United Nations, 2013, http://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2013.pdf (accessed 06-09-16).
[4] R. Harwood, A. Sayer, World Health Organization, Current and Future Long Term Care Needs, 2002.
[5] E. Schulz, Use of health and nursing care by the elderly, AGIR WP2, ENEPRI Research Report 2, 2004.
[6] E. Grundy, M. Jitlal, Socio-demographic variations in moves to institutional care 1991–2001: a record linkage study from England and Wales, Age Ageing 36 (4) (2007) 424–430.
[7] J. Weafer, Irish Attitudes to Death, Dying and Bereavement 2004–2014, Irish Hospice Foundation, 2014.
[8] Global Health Observatory, NCD mortality and morbidity, Global Health Observatory (GHO) Data, 2016, http://www.who.int/gho/ncd/mortality_morbidity/en/ (accessed 06-09-16).
[9] National Council on Aging, Healthy Aging Facts, 2016, https://www.ncoa.org/news/resources-for-reporters/get-the-facts/healthy-aging-facts/ (accessed 06-09-16).
[10] World Health Organization, Global status report on Noncommunicable Diseases 2014, 2014, http://www.who.int/nmh/publications/ncd-status-report-2014/en/ (accessed 06-09-16).
[11] T. Mizrahi, L.E. Davis, Encyclopedia of Social Work, 20th ed., Oxford University Press, 2008.
[12] J.B. Broad, M. Gott, H. Kim, M. Boyd, H. Chen, M.J. Connolly, Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics, Int. J. Public Health 58 (2) (2013) 257–267.
[13] H. Ergas, F. Paolucci, Providing and financing aged care in Australia, Risk Manage. Healthcare Policy 4 (2011) 67.
[14] M.J. McGregor, R.B. Tate, K.M. McGrail, L.A. Ronald, A.M. Broemeling, M. Cohen, Care outcomes in long-term care facilities in British Columbia, Canada: does ownership matter? Med. Care 44 (10) (2006) 929–935.
[15] K.L. Moore, W.J. Boscardin, M.A. Steinman, J.B. Schwartz, Age and sex variation in prevalence of chronic medical conditions in older residents of U.S. nursing homes, J. Am. Geriatr. Soc. 60 (4) (2012) 756–764.
[16] K.L. Moore, W.J. Boscardin, M.A. Steinman, J.B. Schwartz, Patterns of chronic co-morbid medical conditions in older residents of U.S. nursing homes: differences between the sexes and across the agespan, J. Nutr. Health Aging 18 (4) (2014) 429–436.
[17] S. Cahill, E. O'Shea, M. Pierce, Future Dementia Care in Ireland, 2012, http://www.atlanticphilanthropies.org/app/uploads/2015/09/future-dementia-care-guide.pdf (accessed 06-09-16).
[18] H. Feldman, A.M. Clarfield, J. Brodsky, Y. King, T. Dwolatzky, An estimate of the prevalence of dementia among residents of long-term care geriatric institutions in the Jerusalem area, Int. Psychogeriatr. 18 (4) (2006) 643–652.
[19] J.G. Kosteniuk, D.G. Morgan, M.E. O'Connell, A. Kirk, M. Crossley, G.F. Teare, N.J. Stewart, V.D. Bello-Haas, D.A. Forbes, A. Innes, J.M. Quail, Incidence and prevalence of dementia in linked administrative health data in Saskatchewan, Canada: a retrospective cohort study, BMC Geriatr. 15 (1) (2015) 1–16.
[20] D. Seitz, N. Purandare, D. Conn, Prevalence of psychiatric disorders among older adults in long-term care homes: a systematic review, Int. Psychogeriatr. 22 (Special Issue 07) (2010) 1025–1039.
[21] M.J. Field, C.K. Cassel, Approaching Death: Improving Care at the End of Life, National Academies Press, 1997.
[22] J. Lynn, Learning to care for people with chronic illness facing the end of life, J. Am. Med. Assoc. (JAMA) 284 (19) (2000) 2508–2511.
[23] J.M. Teno, S. Weitzen, M.L. Fennell, V. Mor, Dying trajectory in the last year of life: does cancer trajectory fit other diseases? J. Palliat. Med. 4 (4) (2001) 457–464.
[24] D. Hui, M. De La Cruz, M. Mori, H.A. Parsons, J.H. Kwon, I. Torres-Vigil, S.H. Kim, R. Dev, R. Hutchins, C. Liem, Concepts and definitions for "supportive care", "best supportive care", "palliative care", and "hospice care" in the published literature, dictionaries, and textbooks, Support. Care Cancer 21 (3) (2013) 659–685.
[25] S.N. Etkind, B.A. Daveson, W. Kwok, J. Witt, C. Bausewein, I.J. Higginson, F.E. Murtagh, Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review, J. Pain Symptom Manage. 49 (3) (2015) 611–624.
[26] F. Murtagh, M. Preston, I. Higginson, Patterns of dying: palliative care for non-malignant disease, Clin. Med. 4 (1) (2004) 39–44.
[27] S.A. Murray, M. Kendall, K. Boyd, A. Sheikh, Illness trajectories and palliative care, Br. Med. J. 330 (7498) (2005) 1007–1011.
[28] R.A. Mularski, S.M. Dy, L.R. Shugarman, A.M. Wilkinson, J. Lynn, P.G. Shekelle, S.C. Morton, V.C. Sun, R.G. Hughes, L.K. Hilton, A systematic review of measures of end-of-life care and it's outcomes, Health Serv. Res. 42 (5) (2007) 1848–1870.
[29] D. Moher, A. Liberati, J. Tetzlaff, D.G. Altman, Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, Ann. Intern. Med. 151 (4) (2009) 264–269.
[30] C.B. Terwee, S.D.M. Bot, M.R. de Boer, D.A.W.M. van der Windt, D.L. Knol, J. Dekker, L.M. Bouter, H.C.W. de Vet, Quality criteria were proposed for measurement properties of health status questionnaires, J. Clin. Epidemiol. 60 (1) (2007) 34–42.
[31] L. Selman, R. Siegert, R. Harding, M. Gysels, P. Speck, I.J. Higginson, A psychometric evaluation of measures of spirituality validated in culturally diverse palliative care populations, J. Pain Symptom Manage. 42 (4) (2011) 604–622.
[32] J. Addington-Hall, K. Hunt, A. Rowsell, R. Heal, P. Hansford, B. Monroe, N. Sykes, Development and initial validation of a new outcome measure for hospice and palliative care: the St Christopher's Index of Patient Priorities (SKIPP), BMJ Support. Palliat. Care 4 (2) (2014) 175–181.

[33] D. Cameron, B. Johnston, Development of a questionnaire to measure the key attributes of the community palliative care specialist nurse role, Int. J. Palliat. Nurs. 21 (2) (2015) 87–95.
[34] D.C. Currow, S. Allingham, P. Yates, C. Johnson, K. Clark, K. Eagar, Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection, structured feedback and benchmarking, Support. Care Cancer 23 (2) (2015) 307–315.
[35] J.R. Curtis, A.L. Back, D.W. Ford, L. Downey, S.E. Shannon, A.Z. Doorenbos, E.K. Kross, L.F. Reinke, L.C. Feemster, B. Edlund, Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial, J. Am. Med. Assoc. (JAMA) 310 (21) (2013) 2271–2281.
[36] G. Gade, I. Venohr, D. Conner, K. McGrady, J. Beane, R.H. Richardson, M.P. Williams, M. Liberson, M. Blum, R.D. Penna, Impact of an inpatient palliative care team: a randomized controlled trial, J. Palliat. Med. 11 (2) (2008) 180–190.
[37] R. Harding, L. Selman, V.M. Simms, S. Penfold, G. Agupio, N. Dinat, J. Downing, L. Gwyther, B. Ikin, T. Mashao, 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. 45 (4) (2012) 746–752.
[38] I.J. Higginson, S. Hart, R. Burman, E. Silber, T. Saleem, P. Edmonds, Randomised controlled trial of a new palliative care service: compliance, recruitment and completeness of follow-up, BMC Palliat. Care 7 (1) (2008) 1.
[39] B. Krevers, A. Milberg, The instrument "sense of security in care-patients' evaluation": its development and presentation, Psycho-Oncology 23 (8) (2014) 914–920.
[40] R. Krug, D. Karus, P.A. Selwyn, V.H. Raveis, Late-stage HIV/AIDS patients' and their familial caregivers' agreement on the palliative care outcome scale, J. Pain Symptom Manage. 39 (1) (2010) 23–32.
[41] M. Mayahara, M.D. Foreman, J. Wilbur, J.A. Paice, L.F. Fogg, Effect of hospice nonprofessional caregiver barriers to pain management on adherence to analgesic administration recommendations and patient outcomes, Pain Manage. Nurs. 16 (3) (2015) 249–256.
[42] L. Selman, R.J. Siegert, I.J. Higginson, G. Agupio, N. Dinat, J. Downing, L. Gwyther, T. Mashao, K. Mmoledi, T. Moll, The MVQOLI successfully captured quality of life in African palliative care: a factor analysis, J. Clin. Epidemiol. 64 (8) (2011) 913–924.
[43] K.E. Sleeman, I.J. Higginson, A psychometric validation of two brief measures to assess palliative need in patients severely affected by Multiple Sclerosis, J. Pain Symptom Manage. 46 (3) (2013) 406–412.
[44] H. Guo, P.G. Fine, T.R. Mendoza, C.S. Cleeland, A preliminary study of the utility of the Brief Hospice Inventory, J. Pain Symptom Manage. 22 (2) (2001) 637–648.
[45] I. Bjelland, A.A. Dahl, T.T. Haug, D. Neckelmann, The validity of the Hospital Anxiety and Depression Scale: an updated literature review, J. Psychosom. Res. 52 (2) (2002) 69–77.
[46] C. Herrmann, International experiences with the Hospital Anxiety and Depression Scale – a review of validation data and clinical results, J. Psychosom. Res. 42 (1) (1997) 17–41.
[47] Providence Health System, Supportive Care of the Dying: Modified City of Hope Patient Questionnaire and CALL Care Cover Letters, 2004, http://www.promotingexcellence.org/tools/pe6020.html (accessed 02-09-16).
[48] J.C. Hobart, A. Riazi, D.L. Lamping, R. Fitzpatrick, A.J. Thompson, Improving the evaluation of therapeutic interventions in Multiple Sclerosis: development of a patient-based measure of outcome, Health Technol. Assess. 8 (9) (2004) 1–48.
[49] J.C. Hobart, A. Riazi, D.L. Lamping, R. Fitzpatrick, A.J. Thompson, How responsive is the Multiple Sclerosis Impact Scale (MSIS-29)? A comparison with some other self report scales, J. Neurol. Neurosurg. Psychiatry 76 (11) (2005) 1539–1543.
[50] A. Riazi, J.C. Hobart, D.L. Lamping, R. Fitzpatrick, A.J. Thompson, Multiple Sclerosis Impact Scale (MSIS-29): reliability and validity in hospital based samples, J. Neurol. Neurosurg. Psychiatry 73 (6) (2002) 701–704.
[51] I.R. Byock, M.P. Merriman, Measuring quality of life for patients with terminal illness: the Missoula VITAS Quality of Life Index, Palliat. Med. 12 (4) (1998) 231–244.
[52] K. Kroenke, R.L. Spitzer, J.B.W. Williams, The PHQ-9, J. Gener. Int. Med. 16 (9) (2001) 606–613.
[53] B. Löwe, K. Gräfe, K. Kroenke, S. Zipfel, A. Quenter, B. Wild, C. Fiehn, W. Herzog, Predictors of psychiatric comorbidity in medical outpatients, Psychosom. Med. 65 (5) (2003) 764–770.
[54] A. Martin, W. Rief, A. Klaiberg, E. Braehler, Validity of the Brief Patient Health Questionnaire mood scale (PHQ-9) in the general population, Gener. Hosp. Psychiatry 28 (1) (2006) 71–77.
[55] J. Hearn, I.J. Higginson, 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 8 (4) (1999) 219–227.
[56] R. Harding, L. Selman, G. Agupio, N. Dinat, J. Downing, L. Gwyther, T. Mashao, K. Mmoledi, T. Moll, L.M. Sebuyira, Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale, Health Qual. Life Outcomes 8 (1) (2010) 1.
[57] R.A. Powell, J. Downing, R. Harding, F. Mwangi-Powell, S. Connor, Development of the APCA African palliative outcome scale, J. Pain Symptom Manage. 33 (2) (2007) 229–232.
[58] I.J. Higginson, N. Donaldson, Relationship between three palliative care outcome scales, Health Qual. Life Outcomes 2 (1) (2004) 1.
[59] I.J. Higginson, S. Hart, E. Silber, R. Burman, P. Edmonds, Symptom prevalence and severity in people severely affected by Multiple Sclerosis, J. Palliat. Care 22 (3) (2006) 158.
[60] R.A. Engelberg, L. Downey, M.D. Wenrich, J.D. Carline, G.A. Silvestri, D. Dotolo, E.L. Nielsen, J.R. Curtis, Measuring the quality of end-of-life care, J. Pain Symptom Manage. 39 (6) (2010) 951–971.
[61] J.R. Curtis, D.L. Patrick, Barriers to communication about end-of-life care in aids patients, J. Gener. Int. Med. 12 (12) (1997) 736–741.
[62] R. Engelberg, L. Downey, J.R. Curtis, Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care, J. Palliat. Med. 9 (5) (2006) 1086–1098.
[63] S.M. Aoun, L. Monterosso, L.J. Kristjanson, R. McConigley, Measuring symptom distress in palliative care: psychometric properties of the Symptom Assessment Scale (SAS), J. Palliat. Med. 14 (3) (2011) 315–321.
[64] M. O'Reilly, Using the St Christopher's Index of Patient Priorities (SKIPP) Tool to Evaluate the Quality of Care Provided by a Specialist Palliative Care Service in Ireland, 2014.
[65] A.L. Comrey, H.B. Lee, A First Course in Factor Analysis, Psychology Press, 2013.