

Review Article

Palliative Care Assessment Tools for Older Adults

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Abstract

Background: The global population of people aged 60 years and older is expected to more than double. The prevalence of multiple chronic diseases among individuals is substantial among older adults. Therefore, palliative care remains a central part of healthcare services provision whether in the community or institutions. Assessing older adults' palliative care needs is the first step to delivering quality comprehensive care.

Objectives: This review aims to describe existing assessment tools used to measure palliative care needs of older adults, their scope of use, content, and psychometrics.

Methods: A systematic review search in electronic databases CINAHL, MedLine OVID, Psych Info, and Academic Search Complete, was conducted for the years 2000 to 2016. Older patients with palliative care needs regardless of their setting were included.

Results: The initial search yielded 942 articles. 17 articles met the inclusion criteria, describing 9 palliative care assessment tools used for older patients in various settings.

Conclusion: This review increases understanding of existing tools to assess older patients with palliative care needs. It can be concluded that no ideal tools are available to allow care providers to detect palliative care needs at an earlier stage in older adults. The POS and RAI tools demonstrated better comprehensiveness and sensitivity to change in comparison to others.

Keywords: Assessment Tool; Older Adult; Palliative Care; Systematic Review

Introduction

The global population of people aged 60 years and older is expected to more than double, rising from 900 million in 2015 to about 2 billion in 2050 [1]. In 2030, when the last baby boomer turns 65, more than 20% of the U.S. population will be an older adult [2]. Similarly, by 2050, estimates indicate that more than one quarter of the population of the European Region will be aged 65 years and older. Specifically, the greatest percentage increase will be among people aged 85+ years [3]. For older adults, good health ensures independence and security as they age. Unfortunately, millions battle everyday with the burden of chronic diseases [2]. A chronic disease refers to a "condition that lasts a year or more and requires ongoing medical attention and/or limits activities of daily living" [4]. In fact, the prevalence of multiple chronic diseases among

individuals is substantial among older adults [5]. For example, more than one in four Americans have multiple concurrent chronic conditions, including arthritis, asthma, chronic respiratory conditions, diabetes, heart disease, human immunodeficiency virus infection, and hypertension [6]. Older adults are disproportionately affected by other chronic conditions including malnourishment, confusion, functional decline, incontinence, anxiety and sleep deprivation [7].

Consequently, chronic diseases can limit a person's ability to perform daily functions and lead to dependence [2]. Therefore, palliative care remains a central part of healthcare services provision. Palliative care refers to the "approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [8]. The physical

and psychosocial needs are a major concern for people in the final stages of life that tend to significantly reduce their quality of life. Hence, the assessment and management of symptoms is one of the chief goals of palliative care [3]. Studies have shown that timely palliative care reduces the physical and emotional stress of a variety of serious life-threatening diseases for both patients and their family caregivers [9]. It may not only improve quality of life for patients, but also reduces unnecessary hospitalizations and use of healthcare services [10].

While more than 40 million people around the world are in need of palliative care, only 14% of whom are receiving it [10]. Studies have reported a number of significant barriers to palliative care provision including,

- 1) Lack of awareness among policy makers, health professionals, and the public about what palliative care is, and the benefits it can offer the patient;
- 2) Cultural and social barriers [10]; and
- 3) Lack of access to palliative care services for non-malignant diseased patients [11]. Consequently, national health systems need to incorporate palliative care in the continuum of care for people with chronic and life-threatening conditions, integrating it with early detection and treatment programs [10].

Nevertheless, appropriate provision of care can only be possible through diligent identification and impeccable assessment of palliative care needs using valid and robust tools for older adults and their caregivers. Identified tools should capture different domains of palliative care including, physical, psychosocial, spiritual, end of life care, and advance directives [12]. Despite the fact that palliative care assessment tools for older adults have been well established and widely used in palliative care research, several studies have focused on specific diseases [13] and targeted group of symptoms [14,15] or particular settings. Accordingly, to gain a comprehensive insight into the existing palliative care assessment tools, regardless of setting, disease condition, or symptoms, we conducted a systematic review of available data from the

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systematic review of available data from the literature. The current paper will describe existing assessment tools in palliative care for older adults, their scope of use, content and psychometrics.

Method

Literature Search Strategy

A systematic literature search in electronic databases was performed for the years 2000 to 2016. Two authors independently conducted a formal computer-assisted search of CINAHL (January 1, 2000 to December 31, 2016) MedLine OVID, Psych Info, and Academic Search Complete. The design of the search strategy was done in collaboration with a health librarian and in consultation of the PRISMA checklist [16]. Keywords used were palliative care, palliative, terminal care, end of life care, older adults, elderly, tool, instrument, appraisal tool, survey, questionnaire, assessment tool, assessment, scale, and index. Clinical studies published in peer reviewed journals in the English language were identified.

Study Selection

The study followed the integrative review methodology for systematic review studies [17]. Two authors independently screened all search results, initially on the basis of title and abstract, and then the full text of potentially eligible papers. Studies were included if they were written in English, full text articles, described tools which assessed palliative care in older adults with any type of chronic health condition, at any stage of their illness; and completed by patients under investigation or caregivers expressing patients' views and experiences. Exclusion criteria were disease specific instruments that assessed palliative care needs (e.g. Dementia); articles about non-palliative care populations; articles not specific to older adults; scales that measured solely the perception of family members and healthcare providers; and abstracts without full-text publications. Disagreements about inclusion were resolved in a consensus meeting with the PI.

Data Extraction

Two independent researchers reviewed the identified data on palliative care assessment tools for content and psychometric properties. The following data were extracted from studies that described palliative care assessment tools as perceived by older adults (Table 1):

1. Instrument
2. number of items
3. scale used
4. setting
5. Type of patients
6. Domains

7. Reliability
8. Construct validity
9. Content validity
10. Concurrent validity
11. Filled out by &
12. Completion time.

Instrument	Items	Scale	Reliability	Validity			Filled out by	Completion Time
				Construct	Content	Concurrent		
Palliative Care Outcome Scale (POS)	11	5-point Likert Scale & 3-point Likert scale (item 9) 1 open-ended question	Cronbach α .65-.70	N/A	N/A	Tested against EuroQoL & herth Hope Index	Staff & Patient versions	10 min
Resident Assessment Instrument for	74	Ordinal	The inter-rater reliability > .77 in all 20 min. Palliative Care (RAI-PC) domains (average Kappa = .83).	N/A	N/A	N/A	Multidisciplinary health care team	20 min.
McMaster Quality of Life Scale (MQLS)	32	7point numerical scale	internal consistency (α = .80), a high intra-rater reliability ($r \geq .83$) and a moderate inter-rater reliability	Verbally administered scores are lower than scores of self-completers $t = 1.83$ ($P = .04$).	N/A	The staff- MQLS is correlated with the Spitzer Quality of Life Index (SQLI) ($r = .70$) and the patient- MQLS correlated	Staff or patient	3-30 min.

Assessment Symptoms Palliative Elderly (ASPE)	40	5-point Likert scale to assess: (i) frequency & (ii) 4-point Likert scale to assess intensity. Binary answer (yes/no) was used for "weight loss".	Test-retest showed substantial agreement for 87.5% of the items	N/A	Face- and content validity assessed in a 3 round Delphi-procedure and Cognitive interview in g. (I-CVI 81.8%-100.0% and N/A Staff or patient 21 min S-CVI 92.9%).	N/A	Staff or patient	21 min
Needs Near the End-of-Life Screening Tool (NEST)	13	0 to 10 scale	Demonstrated reliability.	Demented content and validity	construct	N/A	Staff or patient	N/A
McGill Quality of Life Index (MQOL); McGill Quality of Life Index (MQOL) - Cardiff Short form	17 versus 9 items	0 to 10 scale	Original version: Cronbach's alpha .62 - .83 Short version: Cronbach's	The Existential domain of QOL McQuill is validated. Construct validity was demonstrated through N/A Correlations with the items from the Spitzer Quality of Life Index. Staff or patient 10-30 min. analysis of patterns of correlations with items from the Spitzer Quality of Life Index	N/A	Correlations with the items from the Spitzer Quality of Life Index.	Staff or patient	10-30 min.

Modified Quality-of-Life Concerns in the End of Life (mQOLC-E)	23	4-point Likert scale.	Internal consistency ($\alpha = .89$) Inter-rater reliability ($r = .83$) Cronbach's alpha 0.89 Cronbach's alpha of the 6 subscales: $r = .71-.86$.	N/A	Culturally validated for Chinese older people	Correlated with the Single-Item Quality of Life Scale (SIS) ($r = .60, p \leq 0.001$) and correlated in a negative way with the Cumulative Illness Rating Scale (CIRS) Multidisciplinary healthcare team 20-60 min. ($r = -.14, p = .013$)	Multidisciplinary healthcare team	20-60 min.
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Table 1: Summary of palliative care assessment tools.

No studies were found that discussed cultural validity except two studies by Chan et al. [18] and Lo [19] who reported on the cultural validation of the tool for the Chinese older adult population. Some studies did not include the measurement properties on the tools described thus the references were searched to complete information on origin of the instrument, number of items, scale, different versions, validity, reliability, and content.

Results

The initial search yielded 942 articles, identified in the original search (Figure 1) 67 duplicates were removed, resulting in 814 articles, which were screened for inclusion. Ten more articles were extracted via reference search. Subsequently, 86 full-text articles were assessed for eligibility, and 18 articles met the inclusion criteria describing nine different palliative care assessment tools in older adults: Palliative Care Outcome Scale (POS), Resident Assessment Instrument for Palliative Care (RAI-PC), McMaster Quality of Life (MQLS), Assessment Symptoms Palliative Elderly (ASPE), Needs Near the End-of-Life Screening Tool (NEST), McGill Quality of Life Index (MQOL), Edmonton Symptom Assessment Scale (ESAS), modified Quality-of-Life Concerns in the End of Life Questionnaire (MQOLC-E), and Integrated SAS and GWB tools.

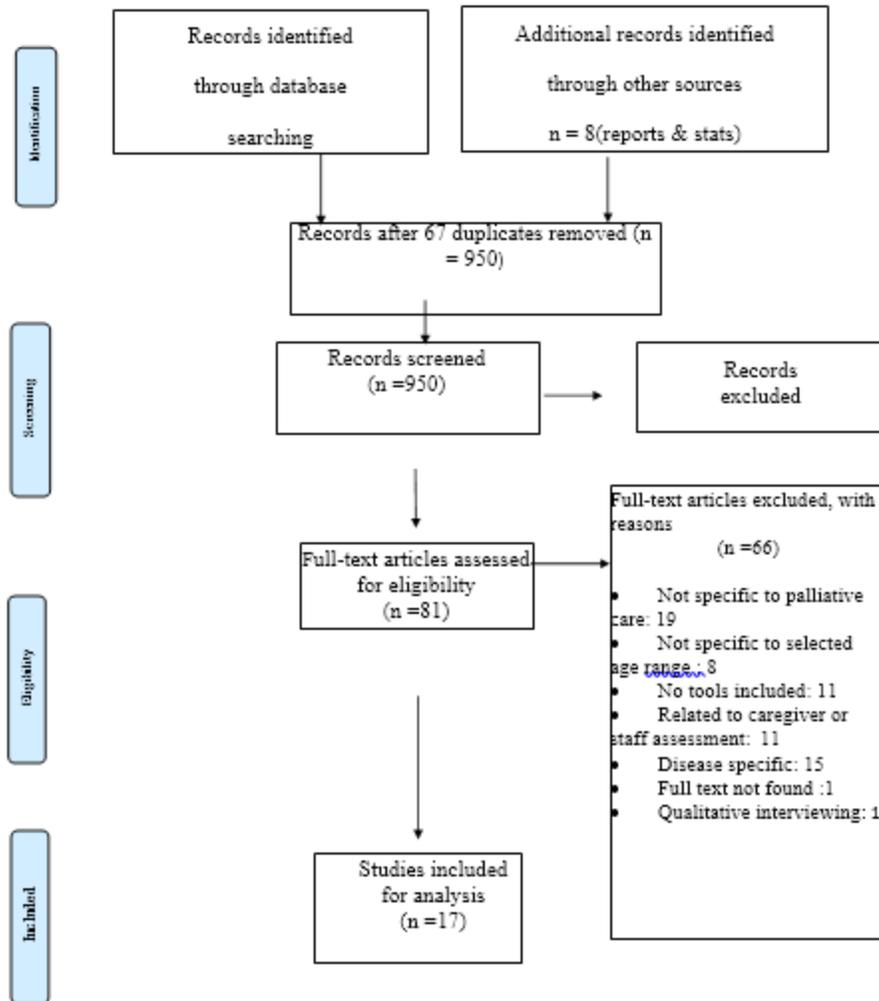


Figure 1: Prisma Flow Chart.

Overall, five palliative care instruments were used in long-term care settings; Palliative Care Outcome Scale (POS), the Resident Assessment Instrument for Palliative Care (RAI-PC), McMaster Quality of Life Scale (MQLS), the modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E), and the Integration of 2 instruments: a) Symptom Assessment Scale (SAS) and b) General Well-being Schedule (GWB); 1 tool was used in a community setting; the Assessment Symptoms Palliative Elderly (ASPE) instrument. The remaining 3 instruments were used in a hospital setting: Needs Near the End-of-Life Screening Tool (NEST), McGill Quality of Life Index (MQOL), and Edmonton Symptom Assessment Survey (ESAS). The content of each instrument was evaluated based on setting, types of patients, and covered domains (Table 2).

Instrument	Setting	Patients category	Covered domains
POS	Home, Hospital, Hospice and, nursing home	Cancer and non-cancer and (moderately) severely demented patients.	Physical, Psychological, Spiritual, Practical Psychosocial
RAI-PC	Inpatient or outpatient	N/A	Symptoms/conditions, Cognitive competency and communication, Mood, Functional status, Preferences, Social relations, Spirituality Services and treatments

MQLS	Nursing homes	Age 65 ± 15.5.	Physical symptoms, functional status, social functioning, emotional status, cognition, sleep and rest, energy and vitality, general life satisfaction, and meaning of life
ASPE	Hospitalized or hospitalized	Older palliative cancer patients	Physical, psychological, Functional Spiritual, social
NEST	Bedside setting	Terminally ill patients < 6 months prognosis; with a full range of diagnoses.	Needs, Existential matters, Symptoms, Therapeutic matters
MQOL	Hospice,	All phases of the disease	Existential, Physical wellbeing,
MQOL Cardiff short form	inpatient	trajectory for people with a life- threatening illness, mostly cancer	Physical symptoms, Psychological, & Support.
ESAS	Inpatient & home care	Advanced cancer patients.	Physical symptoms

Table 2: Palliative care assessment tool domains.

Palliative Care Outcome Scale (POS)

The POS was primarily developed by Hearn and Higginson in 1999 [20] in order to assess the quality of life, the quality of care provided and the PC service organization. It was utilized with patients suffering from advanced disease to improve outcome assessment by evaluating various key outcomes in palliative care. It is a suitable instrument to assess cancer and non-cancer as well as moderately to severely demented patients. There are two versions of POS: the POS-patient version and POS-staff version. It consists of a total of 11 items capturing the physical, psychosocial, spiritual, practical, and psychosocial domains. The POS includes one open-ended question on patients' concerns. It has established reliability and acceptability with both staff and patients, and is responsive to changes in patient condition over time. It can be used with patients who have palliative care needs irrespective of their clinical setting (e.g. hospital, hospice, or nursing home). Brandt et al. assessed the POS in 16 Dutch nursing homes [21]. Completion time is estimated to be 10 minutes. Concurrent validity was tested against Europol (EQ-5D) and the Hearth Hope Index. Cronbach Alpha is between .65 and .70. [21].

Resident Assessment Instrument for Palliative Care (Rai-Pc)- Former Minimum Data Set (MDS)

The RAI-PC was created by Multinational research collaboration (Inter-RAI) [22] in order to assess and manage residents in Long Term Care facilities. It has a core set of screening elements that assess clinical and functional status, that in turn enables health care professionals in coding categories, which forms the groundwork of the comprehensive assessment for all residents of long- term care facilities qualified to participate in Medicare or Medicaid. It is an all-inclusive questionnaire comprised of

74 items, measured using an ordinal scale. Multidisciplinary healthcare providers of in- and out- patients are eligible to fill it. The questionnaire covers several domains: Symptoms/conditions, cognitive competency and communication, mood, functional status preferences, social relations, spirituality, services and treatments. The inter-rater reliability is greater than .77 in all domains (average Kappa= .83). Completion time requires 20 minutes. The instrument improves the transfer of information between caregivers and health care settings and ensures continuity of care. The interRAI Palliative Care (inter RAI PC) instrument is a holistic and standardized assessment instrument to evaluate and manage the needs, strengths, and preferences of palliative care patients in all settings [23].

McMaster Quality of Life Scale (MQLS)

The MQLS took birth in McMaster University, Canada [24] by searching the palliative care literature for pertinent items and dimensions. It was developed to measure the quality of life in a palliative patient population. It is a 32-item instrument that uses a 7-point numerical scale for measurement. It is employed in nursing homes for residents older than 65 years, and covers physical symptoms, functional status, social functioning, emotional status, cognition, sleep and rest, energy and vitality, general life satisfaction, and meaning of life domains. Staff or patients can fill the questionnaire in 3 to 30 minutes depending on the domain content. The MQL shows good internal consistency ($\alpha = .80$), high intra-rater reliability ($r \geq .83$) and a moderate inter-rater reliability ($r = \geq .55$). Verbally administered scores are lower than scores of self-completers ($t = 1.83, P=0.04$). It has also evidence on concurrent validity where the staff-MQLS is correlated with the Spitzer Quality of Life Index (SQLI, $r = .70$) and the patient-MQLS is correlated with the SQLI ($r = .50$). [24,25].

Assessment Symptoms Palliative Elderly (ASPE)

The ASPE was developed in 2016 by Van Lancker [26] to assemble data on frequency and intensity of symptoms in the older palliative cancer patient population. It consists of 40 items covering the physical, psychological, functional, spiritual, and social domains of in- and out older cancer patients. Items were measured using a 5-point Likert Scale to assess frequency, and a 4-point Likert scale to assess intensity. A binary answer was used to assess weight loss items. Staff or patients require 21 minutes of completion time. Test-retest showed substantial agreement for 87.5% of the items [27]. Findings on face and content validity in a 3 round Delphi-procedure and Cognitive interviewing showed (I-CVI 81.8%- 100.0% and S-CVI 92.9%). Needs Near the End-of-Life Screening Tool (NEST). The NEST [28] was originally designed by a series of 15 focus groups and interviews that were conducted with patients, family caregivers, and professionals followed by a national survey of 988 patients with a terminal diagnosis. The tool is used primarily at the bedside for sequential evaluations to chart progress, for related team coordination, or for programmatic assessments. The questionnaire includes 13 items covering needs, symptoms, existential and therapeutic matters, measured on a 0 to 10 scale. NEST is relevant for hospitalized terminally ill patients, with all ranges of diagnosis, and with less than 6 months prognosis. Evidence demonstrated good reliability, content and construct validity.

McGill Quality of Life Index (MQLI)

Originally, it was developed by Cohen et al. in 1995 [29] to assess older patients with life threatening illnesses, mostly cancer, and consisted of 17 item questions. It was adapted to meet the needs of people with advanced diseases. MQOL-Cardiff Short form, consisting of 9 items, is relevant to all phases of the disease trajectory. All items were measured using a 0 to 10 scale. The instrument is used in hospice, outpatient and inpatient settings. Findings on the original version showed evidence of reliability: Cronbach's alpha 0.62 - 0.83. Similarly, the Short version: Cronbach's alpha = 0.46-0.85 and test-retest reliability $r = .51 - .86$. The Existential domain of QOL McGill was validated; construct validity was confirmed through analysis of patterns of correlations with items from the Spitzer Quality of Life Index. Patients or staff can complete the questionnaire in 10 to 30 minutes for the original version, as opposed to 3 minutes for the short version. Lo et al. [19] investigated the cross cultural validity of the tool in Hong Kong and it showed robust constructs.

Edmonton Symptom Assessment Scale (ESAS)

The Edmonton Symptom Assessment Scale is a short instrument intended to assess older patients with advanced cancer in hospitals or candidates for home care. It was devised by Chang (2000) [30] to assess 9 common symptoms experienced by advanced cancer patients. The tool investigates distress in palliative care

patients with advanced cancer, and contains detailed questions on the severity of physical and mental symptoms. Assessed symptoms are measured on a 0 to 10 scale. The ESAS consists of nine 100 mm visual analogue scales (VASs), which include pain, activity, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath.

Scores can range from 0 to 100 (higher scores reflect greater symptom severity). The ESAS is validated in 2 Italian palliative care settings. Reliability was established for daily administration by patients or staff, within 2 minutes of completion time [31].

Modified Quality-Of-Life Concerns in the End of Life Questionnaire (M-Qolc-E)

The Quality-of-Life Concerns in the End of Life Questionnaire (QOLC_E) [18] was originally designed to evaluate quality of life concerns of patients with terminal cancer. In 2008, the QOLC-E was modified to adapt to the needs of frail palliative care older people in nursing homes. The m-QOLC-E comprises 23 items, measured using 4-point Likert scale, in 6 subscales: value of life;

- 1) Care and support,
- 2) Food-related concerns,
- 3) Negative emotions,
- 4) Physical discomfort and
- 5) Existential distress.

Time completion requires between 20 to 60 minutes, and can be filled by patients or the multidisciplinary healthcare providers. The instrument demonstrated good reliability: Internal consistency ($\alpha = 0.89$) and inter-rater reliability ($r = 0.83$). Cronbach's alpha 0.89 Cronbach's alpha of the 6 subscales: $r = 0.71-0.86$. It was culturally validated for Chinese older people. It correlated with the Single-Item Quality of Life Scale (SIS) ($r = 0.60, p \leq 0.001$) and correlated in a negative way with the Cumulative Illness Rating Scale (CIRS) ($r = -0.14, p = 0.013$) [18].

Integration of two instruments SAS & GWB

The Symptom Assessment Scale (SAS) and the General Wellbeing Schedule (GWS) [32] are used in residential aged care settings and filled by patients. They assist in assessing frail elderly aging 69+ years. While the SAS tool contains 7 items, the GWB comprises 18 items, later shortened to 5-8 items. They both assess three domains:

- 1) Physical: nausea, pain, insomnia, fatigue, breathing, bowel, and appetite
- 2) Psychological and
- 3) Quality of life comprising six sub- scales: anxiety, depression, general health, positive wellbeing, self-control, and vitality. Items are measured on 10-point scale. In hospice setting, the

SAS internal consistency reliability coefficient was $>.60$. As for the GWB, internal consistency coefficients ranged from $.72$ to $.88$.

For the total original 18-item scale, internal consistency coefficients range from $.88$ to $.95$ [33].

Discussion

This review resulted in nine palliative care assessment tools used in older adults in various settings. Palliative Care Outcome Scale (POS), Resident Assessment Instrument for Palliative Care (RAI-PC), McMaster Quality of Life (MQLS), Assessment Symptoms Palliative Elderly (ASPE), Needs Near the End-of-Life Screening Tool (NEST), McGill Quality of Life Index (MQOL), Edmonton Symptom Assessment Scale (ESAS), modified Quality-of-Life Concerns in the End of Life Questionnaire (MQOLC-E), and Integrated SAS and GWB tools.

Psychometrically, some of the tools had more robust evidence of validity and reliability than others. For example, the MQLS, which was culturally validated in a Chinese population, covers nine domains of palliative care and shows high internal consistency ($\alpha = 0.80$) and sensitivity to change in QOL. However, it is only relevant for use in nursing home residents. Furthermore, the NEST instrument has a well-established validity and reliability (Cronbach alpha 0.90), but it lacks comprehensiveness of domains. The mQOLC-E is a psychometrically robust tool: Internal consistency $.89$, Cronbach alpha $.89$, and is culturally validated in Chinese older adults. It is however, only validated for use in outpatient settings & nursing homes. It is also time consuming given its required completion time (i.e. 20-60 min). In addition to validity and reliability properties, ability to detect change over time is a major element in assessing the psychometric properties of instruments. Our findings indicated that very few instruments were

able to show evidence for responsiveness to change, such as the MQLS instrument. Another key aspect is the clinical relevance of the tools, their length, and the time needed for completion.

Finally, no ideal tools are currently available to assess palliative care needs in older adults. Although the POS and the RAI are the most comprehensive tools, each of the other tools has specific strengths that should not be overlooked. The POS can be used in a wide range of settings, including home, hospital, hospice and nursing home, and has been used in the United States and in Europe. It is a suitable instrument to assess patients irrespective of diagnosis to improve their quality of life, quality of care, and palliative care services. It can also be used in the training of health professionals, in the early referral phases to palliative care. It is tested against different tools with acceptable reliability and validity in different settings.

The RAI is also a well-established assessment tool that is used extensively in various palliative care settings, community or facility based, and is the standard tool in long term care facilities in the United States. It is utilized to determine patient care needs and in case mix and outcome research. It is psychometrically tested and has been adopted for use in various countries in Europe and Canada. The time for completion is around twenty minutes.

(Tables 3) summarize the findings regarding the two selected tools and list the advantages and disadvantages of the remaining tools. In summary, this review demonstrates that further research is needed to provide robust tools for early detection of palliative care needs. The clinical relevance and cultural sensitivity of these tools need to be studied when used in different countries and cultures. Thus instrument validation is highly recommended in palliative care of older adults irrespective of diagnosis or disease trajectory.

Instrument	Domains	Setting	Responsiveness	Validity/reliability	Less burden
POS	6	Home, Hospital, Hospice, Nursing homes	Responsive to change but not validated	Reliability & internal consistency (0.7). Construct validity (Spearman rho = 0.43 to 0.80). Adapt and validated a number of cultural and linguistic settings.	10 min Has a Patient & staff version
RAI-PC	10	Hospital & Outpatient clinics	Sensitive to change but not validated	Kappa 0.83	20 min

Table 3: Recommended tools for Palliative Care older patients and Advantages and disadvantages of tools.

Conclusion

A regular evaluation of palliative care assessment is the foundation of good palliative care of older adults with chronic health conditions. This study makes a unique contribution to the palliative care assessment for older adults, as it examines palliative care tools in older adults irrespective of setting and disease. The use of a dedicated, standardized instrument that measures palliative care purely from the patients' perspective is an important development in palliative care in older adults. For a wholesome assessment of palliative

care, a better understanding of patients' attitudes towards the quality of palliative care they are receiving is needed. The current review has the potential to inform Evidence-Based practice on the assessment of palliative care in older adults regardless of chronic health condition and the stage of illness. Furthermore, this review can set the stage for policy development by recommending the inclusion of a standardized palliative care assessment instrument as an integral part to a quality care information system.

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