

Toward a systematic approach to assessment and care planning in palliative care: A practical review of clinical tools

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ABSTRACT

Objective: Ensuring a consistent and systematic approach to the delivery of care for people with advanced disease is a priority for palliative care services worldwide. Many clinical tools are available to aid in this process; however, they are often used sporadically, and implementation of a routine set of clinical tools to guide care planning in the specialist palliative care sector in Australia has not been achieved. This study sought to recommend key clinical tools that may assist with the assessment and care planning of specialist palliative care provision for patients and family caregivers admitted to specialist palliative care settings (home, hospital, and hospice).

Method: A mixed-methods sequential approach over four phases was employed, involving: (1) a palliative care sector survey, (2) a systematic literature review, (3) an appraisal of identified clinical tools, and (4) a focus group with an expert panel who critiqued and endorsed a final suite of clinical tools recommended for specialist palliative care.

Results: Twelve tools with practical relevance were recommended for use across settings of care.

Significance of Results: Palliative services should review current practices and seek to implement this recommended suite of tools to enhance assessment and guide care delivery across care settings. Subsequent evaluation should also occur.

KEYWORDS: Palliative care, Assessment, Tools, Care planning

INTRODUCTION

Ensuring a consistent, standard approach to the delivery of “best” care for people with life-limiting illnesses is a priority for palliative care services worldwide (Ferris et al., 2002; Ferris et al., 2007; Hardy et al., 2007). To achieve this, palliative care service provision must be founded on a quality management approach (Palliative Care Australia, 2003)

that strives to provide patients and their families with seamless care, involving timely, coordinated, and appropriate needs-based support (Palliative Care Australia, 2005). The needs of palliative care patients and their families are typically complex, however, and interdisciplinary management is required to ensure that care is responsive and well coordinated (Ferris et al., 2002).

Specialist palliative care services provide care to those patients with life-threatening illness whose needs exceed the capacity and resources of primary healthcare providers. In Australia, patients can move freely between community, acute hospital,

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and hospice services dependent on needs, but most will have intermittent involvement with a specialist palliative care service (Palliative Care Australia, 2003). Given the diversity of care settings available, a systematic approach to care planning and delivery is needed so as to ensure that patients receive the best palliative care support available and in the place of their choosing.

Implementing a prescribed suite of clinical tools can enhance assessment and guide care delivery across disciplines and settings and may improve patient and family outcomes (Ferris et al., 2002; Weissman & Meier, 2011; Antunes et al., 2013). Clinical tools encompass brief screening instruments, needs assessments, and patient-reported outcome measures, which can be used by health professionals to inform clinical decision making. When used consistently, clinical tools may assist in promoting best patient care through: identifying areas of unmet need; facilitating communication around patients' goals and preferences for treatment; ensuring regular monitoring of patient outcomes; and providing an equitable, systematic approach to ensure all patients have equal opportunity to accessing support (Antunes et al., 2013). Strategic use of clinical tools may also assist with judicious use of human resources.

Despite this, the use and implementation of a routine set of clinical tools in the specialist palliative care sector has not been achieved (Antunes et al., 2013). Many tools are available for use, but they are often used sporadically at the individual service level. Uncertainty exists surrounding the most appropriate and useful tools for health professionals to utilize in specialist palliative care services.

Given this background, our study sought to recommend a suite of key clinical tools that may assist with the assessment and care planning of specialist palliative care provision for patients and family caregivers admitted to specialist palliative care settings (home, hospital, and hospice). Our study was undertaken in the state of Victoria, Australia, with the following objectives: (1) to develop a broad understanding of current practices of palliative care providers associated with assessment and care planning strategies and to identify tools currently in use; (2) to identify clinical tools from the palliative care literature; (3) to critically appraise these clinical tools; and (4) to endorse a suite of clinical tools considered appropriate and practical for specialist palliative care practice.

METHODS

This study employed a mixed-methods sequential design over four phases. Ethical approval was provided

for by the institutional human research and ethics committee. A study advisory committee was assembled based on relevant expertise including clinical, research, and government policy disciplines. The advisory committee provided study oversight, ensured clinical relevance to specialist palliative care settings throughout Victoria, and facilitated dissemination of study findings.

Phase 1: Palliative Care Sector Survey

A survey of the palliative care sector in Victoria was undertaken with the objective of identifying clinical tools that are currently employed, their purpose (clinical assessment or data collection), and providers' perceptions of their usefulness in aiding practice. A pilot of the survey was first undertaken by members of the project advisory committee to assess face validity, and minor alterations were made.

The survey was administered online to specialist palliative care providers funded by the Victorian Department of Health across community, inpatient, and consult services. The manager of each Victorian specialist palliative care service ($n = 60$) was asked to nominate a representative with broad awareness of palliative care service delivery to complete the survey. Descriptive and summary statistics were undertaken to provide an overview of results across services.

Phase 2: Systematic Literature Review

Search Strategy

A systematic literature review was undertaken with the objective of identifying clinical tools specific to adult palliative care, and relevant to the following *domains*: symptoms, pain, psychological/emotional, quality of life, spirituality, family, prognosis, performance/functional status, multidomain assessment/needs assessment, and care of the imminently dying patient. These were selected based on the World Health Organization's definition of palliative care (WHO, 2006), as well as national standards of palliative care practice (National Consensus Project for Quality Palliative Care, 2009).

Electronic databases (Medline, CINAHL, PsychInfo, EMBASE, PubMed, Cochrane Database of Systematic Reviews, DARE) were systematically searched to identify clinical tools utilized in the palliative care setting. Core concepts searched included: (1) clinical assessment/needs assessment tools, and (2) adult palliative care populations. All search terms were chosen individually for each database to ensure that the terminology corresponded to the database's system of indexing. Searches were restricted to

literature on adult populations, published in English between January of 1998 to December of 2012.

Given the limitations previously recognized with systematic “bottom-up” searches (O’Leary et al., 2007; Richardson et al., 2007), supplementary data gathering strategies were also conducted to identify clinical tools not detected by systematic searches. Grey literature was searched using resources such as CareSearch (CareSearch, 2013), SIGLE (System for Information on Grey Literature in Europe) (Open Grey, 2011), and key palliative care organizations including the statewide (Palliative Care Victoria, 2015) and national (Palliative Care Australia, 2012) peak bodies. Prior reviews of clinical tools as well as “needs assessments” relevant to domains of palliative care (Hølen et al., 2006; Kirkova et al., 2006; Lau et al., 2007; Richardson, Medina et al., 2007; Thekkumpurath et al., 2008; Vodermaier et al., 2009; Albers et al., 2010; Hudson et al., 2010; Selman et al., 2011) were consulted. Finally, professional and academic contacts of the advisory committee were contacted to identify additional published tools in use throughout the palliative care sector.

Selection of the Literature

The above search strategy resulted in 2738 studies that were screened by two reviewers by their titles. From these studies, 424 were selected for abstract review based on their relevance to adult palliative care. Finally, 98 articles were reviewed in full, and 86 met the following inclusion criteria:

- The publication described a specific *clinical* tool relevant to at least one or more of the domains of palliative care (not including research tools).
- The publication measured/reported the impact of the tool on patient or caregiver outcomes, including physical, psychological, and social.
- The publication referred to a tool that involved an adult palliative care population.

- The tool referred to in the publication focused on the clinical assessment and/or care planning of patients already admitted to a palliative service.

Data Extraction and Synthesis

Data extraction was carried out to gather important information about each clinical tool identified, including: study setting, name of tool, description of tool, primary purpose of tool (screening/assessment), intended users, number of items, translations, breadth of use, administration methods, validity and reliability tested (yes/no), and domains covered. All clinical tools identified were then sorted according to the domain of palliative care in preparation for the appraisal process. In instances where the same tool covered several domains of interest, it was categorized as a multidimensional tool.

Phase 3: Appraisal of Clinical Tools

An appraisal process was conducted to evaluate the clinical tools identified in phase 2. In line with the pragmatic aims of this review, tools were assessed according to their clinical and practical utility for specialist palliative care services defined according to the variables listed in Table 1, which were developed by the project team. Each tool was independently appraised by two reviewers according to predetermined criteria, which were established in partnership with the project advisory group, to assess their utility (scored on a 1–10 scale). In the case of discrepancies, the tool was discussed and agreement reached.

For particular domains of palliative care that had already been subject to a recent and comprehensive systematic review, we assessed only the clinical tools recommended by previous authors in line with our criteria (Table 1). These domains included: family/caregiver needs assessment (Hudson et al., 2010), psychological/emotional needs (Thekkumpurath et al., 2008; Vodermaier et al., 2009), quality of life (Albers et al., 2010), and prognostic tools (Lau et al., 2007).

Table 1. Clinical tools appraisal criteria

| Criterion | Score | Justification |
|--|-------|--|
| Administered by healthcare professional? | 0–1 | Clinical tools should be administered by a healthcare professional (yes = 1). |
| Brief? | 0–1 | Brevity is important (yes = 1). |
| Could be used across settings? | 0–3 | Aim to identify clinical tools that are suitable for use in different palliative care settings (best score = 3). |
| Practicality and clinical use? | 0–4 | Aim to identify clinical tools that are practical and suited to clinical use (best score = 4). |
| In widespread use? | 0–1 | Answered to the best of the knowledge of the reviewers and/or as reported by the literature examined (Yes = 1). |

Phase 4: Expert Palliative Care Focus Group

A multidisciplinary expert focus group ($n = 7$) was assembled to review the clinical utility of the tools that were appraised in phase 3, with a view to providing recommendations regarding particular tools with relevance to practice in the Victorian palliative care setting. Purposive sampling was undertaken to identify members of the Palliative Care Clinical Network (a statewide initiative to foster improvement in palliative care) and to ensure a variety of disciplines and sites (home, hospital, hospice) of care provision were represented.

The focus group was facilitated by one investigator (JP) and structured according to the domains of palliative care. Perceptions of tools within each domain were sought. Copies of the included tools and their appraisal scores were made available to focus group participants, who considered these alongside the tools' appropriateness and practicality for palliative care practice.

The preferred clinical tool in each domain was recorded, along with observations about the tools and recommendations of how the preferred tools were to be used to ensure both the functions of screening and assessment or ongoing monitoring.

RESULTS

In addition to the results outlined below, a summary of our results is illustrated in [Figure 1](#).

Palliative Care Provider's Perceptions of Clinical Tools (Phase 1)

Phase 1 participants included 38 healthcare professionals from 60 invited palliative care providers (response rate 63.3%). The participants worked across settings, including community (68%), inpatient (18%), and consultancy (13%) services, from metropolitan (32%), regional (45%), and rural (55%) areas. Participants identified several clinical tools that were currently being utilized through the palliative care sector in Victoria. The most widely used tools included: the Karnofsky Performance Status (KPS) scale (Karnofsky et al., 1948) (79%), the RUG-Activities of Daily Living scale (Williams et al., 1994) (66%), the Australian Palliative Care Outcomes Collaboration (PCOC) tools (Eagar et al., 2010) (47%), the Edmonton Symptom Assessment System (ESAS) (Nekolaichuk et al., 2008) (47%), the Liverpool Care Pathway for the Dying Patient (24%), and the Eastern Cooperative Oncology Group (ECOG) scale (Oken et al., 1982) (24%).

Participants recognized and indicated their support for the use of clinical tools in specialized palliative care settings. Common benefits cited included:

“enables prioritizing care,” “improves quality of care,” and “enables benchmarking.” Completion of clinical tools was generally reported to be undertaken by senior staff within the organization. The main barrier to the use of clinical tools reported by participants was the perceived resources needed to enter patient data into information systems following completion. Nonetheless, benefits were reported to outweigh the effort involved for all common clinical tools identified in the survey.

Systematic Literature Review and Critical Appraisal (Phases 2 And 3)

The search strategy undertaken resulted in the identification of 90 clinical tools that were appraised for their applicability for use in specialist palliative care ([Table 2](#)). These tools represented several domains of palliative care, including assessment of: symptoms (17 tools); performance/functional status (11 tools); pain (22 tools); needs/multidimensional assessments (18 tools); spirituality (10 tools); and care of the imminently dying patient (2 tools). Additionally, appraisal was also undertaken on recommended tools by recent systematic reviews of the following domains: family/caregiver needs assessment (two tools) (Hudson et al., 2010); psychological/emotional needs (three tools) (Thekkumpurath et al., 2008; Vodermaier et al., 2009), quality of life (five tools) (Albers et al., 2010); and prognostic tools (two tools) (Lau et al., 2007).

Overall, there were a number of tools available with relevance to the specialist palliative care setting. The quality of tools across domains, however, was variable, as evidenced in the wide variation of appraisal scores (1–10). Some tools identified within a particular domain were very specific to a particular patient subgroup or problem, such as the dementia pain scoring system. While some of these particular tools were identified as robust and scored highly on the parameters, their specificity meant that generalization to a broader patient group and set of problems was limited.

Clinical Tools Recommended for Widespread Use in Specialist Palliative Care Services (Phase 4)

The focus group participants reviewed the tools identified within each of the domains, noted the results of the appraisal of each tool, and discussed the applicability of each to clinical care in light of these factors. In each domain, a preferred tool was identified through consensus. The practicality of application was a key factor in each case ([Table 3](#)). For this reason, the highest-scoring tool during the appraisal process was not always chosen by the focus group

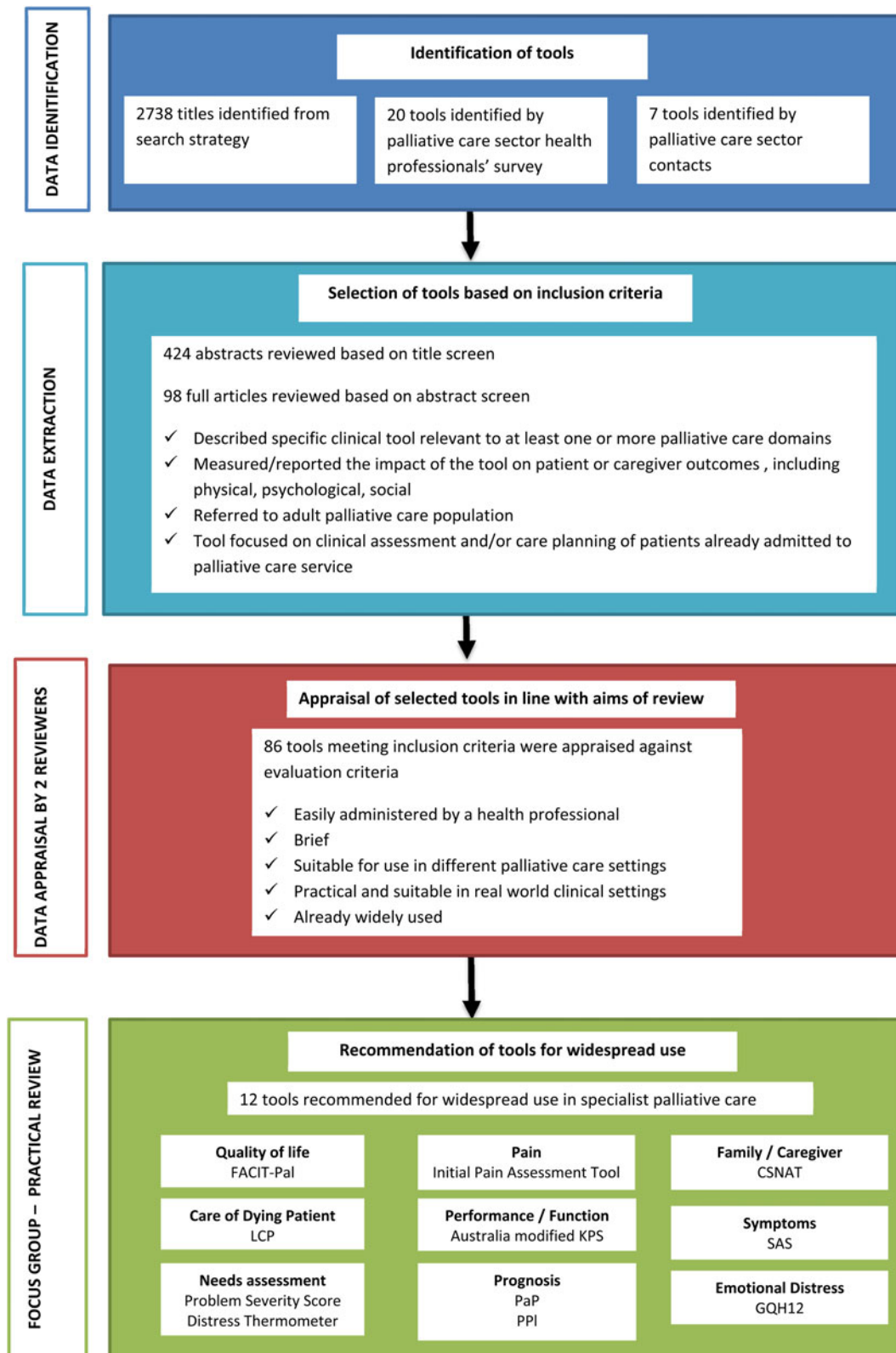


Fig. 1. Summary of results.

Table 2. *Clinical tools identified and appraised by reviewers*

| Phase 2: Identification of Tool | | Phase 3: Appraisal of Tool | | | | | |
|---|--|----------------------------|--------------|----------------------------|----------------------------------|-----------------------|-------------|
| Reference | Name of Tool | Administered by HCP (0/1) | Brief? (0/1) | Use Across Settings? (0–3) | Practical in Clinical Use? (0–4) | Widespread Use? (0–1) | Total (–10) |
| Symptom Assessment Tools | | | | | | | |
| Morita et al. (2001) | Agitation Distress Scale (ADS) | 1 | 1 | 3 | 3 | 0 | 8 |
| Stillman & Rybicki (2000) | Bedside Confusion Scale (BCS) | 1 | 1 | 3 | 1 | 0 | 6 |
| Ewing et al. (2004) | Cambridge Palliative Assessment Schedule (CAMPAS–R) | 0 | 0 | 3 | 1 | 0 | 4 |
| Morita et al. (2001) | Communication Capacity Scale | 1 | 1 | 3 | 3 | 0 | 8 |
| Ryan et al. (2009) | Confusion Assessment Method (CAM) | 1 | 1 | 3 | 3 | 1 | 9 |
| Nekolaichuk et al. (2008) | Edmonton Symptom Assessment System (ESAS) | 1 | 1 | 3 | 4 | 1 | 10 |
| Munch et al. (2006) | Multidimensional Fatigue Inventory | 1 | 0 | 3 | 0 | 0 | 4 |
| Emanuel et al. (2001) | Needs at the End of Life Screening Tool (NEST) | 1 | 0 | 0 | 0 | 0 | 1 |
| Chochinov et al. (2008) | Patient Dignity Inventory | 0 | 0 | 2 | 0 | 0 | 2 |
| Sands et al. (2010) | Single Question in Delirium (SQiD) | 1 | 1 | 1 | 1 | 0 | 4 |
| Aoun et al. (2011) | Symptom Assessment Scale (SAS) | 1 | 1 | 3 | 4 | 1 | 10 |
| Zloklikovits et al. (2005) | Symptom List for Quality Assurance in Palliative Care | 0 | 0 | 1 | 2 | 0 | 3 |
| Identified in Kirkova et al. (2006) | Memorial Symptom Assessment Scale (MSAS–SF) | 1 | 1 | 3 | 2 | 1 | 8 |
| Identified in Kirkova et al. (2006) | Symptom Distress Scale (SDS) | 1 | 1 | 3 | 2 | 0 | 7 |
| Identified in Edmonds et al. (1998) and Kirkova et al. (2006) | Reduced E-STAS | 1 | 1 | 2 | 4 | 0 | 8 |
| Identified in Kirkova et al. (2006) | Symptom Monitor | 0 | 0 | 0 | 1 | 0 | 1 |
| Identified in Kirkova et al. (2006) | Canberra Symptom Scorecard | 1 | 1 | 3 | 2 | 0 | 7 |
| Performance/Functional Status | | | | | | | |
| Abernethy et al. (2005) | Australian-modified Karnofsky Performance Scale (AKPS) | 1 | 1 | 3 | 4 | 1 | 10 |
| Morita et al. (2001) | Communication Capacity Scale | 1 | 1 | 3 | 3 | 0 | 8 |
| Fyllingen et al. (2009) | A Computer-Based Assessment Tool | 0 | 0 | 0 | 0 | 0 | 0 |
| Gonçalves et al. (2008) | Consciousness Level Scale | 1 | 1 | 3 | 1 | 1 | 7 |
| Oken et al. (1982) | Eastern Cooperative Oncology Group Performance Status (ECOG) | 1 | 1 | 3 | 4 | 1 | 10 |
| Campos et al. (2009) | Palliative Performance Scale (PPS) | 1 | 1 | 3 | 2 | 0 | 7 |
| Chuang et al. (2004) | A prognostic scale | 1 | 1 | 3 | 2 | 0 | 7 |

Continued

Table 2. Continued

| Phase 2: Identification of Tool | | Phase 3: Appraisal of Tool | | | | | Total (-- 10) |
|------------------------------------|--|------------------------------|-----------------|----------------------------------|--|--------------------------|------------------|
| Reference | Name of Tool | Administered by HCP (0/1) | Brief? (0/1) | Use Across Settings? (0-3) | Practical in Clinical Use? (0-4) | Widespread Use? (0-1) | |
| Kaasa & Wessel (2001) | Revised version of Edmonton Functional Assessment Tool (EFAT-2) | 1 | 1 | 3 | 2 | 0 | 7 |
| Nikoletti et al. (2000) | Thorne KPS | 1 | 1 | 1 | 3 | 0 | 6 |
| Quality of Life Tools | | | | | | | |
| Identified in Albers et al. (2010) | McGill Quality of Life (MQoL) | 0 | 0 | 2 | 1 | 0 | 3 |
| Identified in Albers et al. (2010) | Measuring the Quality of Life of Seriously Ill Patients (QUAL-E) | 1 | 0 | 1 | 0 | 0 | 2 |
| Identified in Albers et al. (2010) | FACIT-PAL | 0 | 0 | 3 | 1 | 0 | 4 |
| Identified in Albers et al. (2010) | MVQoLI-R | 0 | 1 | 2 | 1 | 0 | 4 |
| Petersen et al. (2006) | EORTC QLQ-C30 | 1 | 0 | 3 | 1 | 1 | 6 |
| Pain Assessment Tools | | | | | | | |
| Van Iersel et al. (2006) | Abbey Pain Scale | 1 | 1 | 2 | 2 | 0 | 6 |
| Van Iersel et al. (2006) | Belgian Pain Scale | 1 | 1 | 3 | 2 | 0 | 7 |
| Groen (2007) | Verbal Rating Scale | 1 | 1 | 3 | 4 | 1 | 10 |
| Groen (2007) | Visual Analogue Scale | 1 | 1 | 3 | 3 | 1 | 9 |
| Costello et al. (2001) | Numerical Rating Scale | 1 | 1 | 3 | 4 | 1 | 10 |
| Groen (2007) | Faces Scale | 0 | 1 | 3 | 3 | 0 | 7 |
| Groen (2007) | Descriptive Differential Scale of Pain Intensity (DDS-I) | 0 | ? | 2 | 2 | 0 | 5 |
| Groen (2007) | Pain Behavior Observation | 1 | 1 | 2 | 1 | 0 | 5 |
| Groen (2007) | McGill Pain Questionnaire | 0 | 0 | 0 | 0 | 1 | 1 |
| Van Iersel et al. (2006) | Pain Assessment in Advanced Dementia (PAINAID) | 1 | 1 | 3 | 3 | 1 | 8 |
| Philip et al. (1998)* | Brief Pain Inventory | 0 | 0 | 3 | 2 | 1 | 6 |
| Identified in Holen et al. (2006) | Borg Category Ratio | 1 | 1 | 1 | 0 | 1 | 4 |
| Identified in Holen et al. (2006) | Initial Pain Assessment Tool | 1 | 0 | 3 | 2 | 1 | 7 |
| Identified in Holen et al. (2006) | Integrated Pain Score | 0 | 1 | 1 | 2 | 0 | 4 |
| Identified in Holen et al. (2006) | McGill Pain Questionnaire-SF | 1 | 0 | 3 | 2 | 0 | 6 |
| Identified in Holen et al. (2006) | Memorial Pain Assessment Card | 0 | 1 | 3 | 2 | 0 | 6 |
| Identified in Holen et al. (2006) | Pain Assessment Questionnaire | 1 | 0 | 3 | 3 | 0 | 7 |
| Identified in Holen et al. (2006) | Pain Disability Index | 0 | 1 | 1 | 1 | 1 | 3 |
| Identified in Holen et al. (2006) | WHO-QoL Pain | 0 | 0 | 2 | 1 | 0 | 3 |
| Nekolaichuk et al. (2008) | Edmonton Symptom Assessment System (ESAS) | 1 | 1 | 3 | 3 | 1 | 9 |
| Identified in Holen et al. (2006) | Aberdeen Low Back Pain | 0 | 0 | 1 | 0 | 0 | 1 |
| Identified in Holen et al. (2006) | Brief Pain Diary | 0 | 1 | 1 | 1 | 0 | 3 |

Continued

Table 2. Continued

| Phase 2: Identification of Tool | | Phase 3: Appraisal of Tool | | | | | |
|--|--|------------------------------|-----------------|----------------------------------|--|--------------------------|-------------------|
| Reference | Name of Tool | Administered by HCP (0/1) | Brief? (0/1) | Use Across Settings? (0–3) | Practical in Clinical Use? (0–4) | Widespread Use? (0–1) | Total (– – 10) |
| Multidimensional Tools/Needs Assessments | | | | | | | |
| Palliative Care Outcome Collaboration (2010) Emanuel et al. (2001) | Problem Severity Score (PSS) | 1 | 1 | 3 | 4 | 1 | 10 |
| Hearn & Higginson (1999); Bausewein et al. (2011) | Needs at the End of Life Screening Tool (NEST) | 1 | 0 | 3 | 1 | 0 | 5 |
| Bausewein et al. (2011) | The Palliative Care Outcome Scale (POS) | 1 | 1 | 3 | 3 | 1 | 9 |
| Richards et al. (2011) | Support Team Assessment Schedule (STAS) | 1 | 1 | 3 | 4 | 1 | 10 |
| Waller et al. (2008) | Screen for Palliative and End-of-Life Care Needs in the Emergency Department (SPEED) | 0 | 1 | 1 | 2 | 0 | 4 |
| Identified in Richardson et al. (2007) | Needs Assessment Tool Progressive disease Cancer (NAT: PD–C) | 1 | 1 | 3 | 4 | ? | 9 |
| Identified in Richardson et al. (2007) | CNAT | 1 | 0 | 2 | 0 | 0 | 3 |
| Identified in Richardson et al. (2007) | SCNA–SF34 | 0 | 0 | 1 | 1 | 0 | 2 |
| Identified in Richardson et al. (2007) | Symptom and Concern Checklist | 1 | 0 | 3 | 3 | 0 | 7 |
| Identified in Richardson et al. (2007) | CARES Short Form | 0 | 0 | 1 | 1 | 0 | 2 |
| Identified in Richardson et al. (2007) | Cancer Care Monitor | 0 | 0 | 1 | 0 | 0 | 1 |
| Identified in Richardson et al. (2007) | Concerns Checklist | 0 | 1 | 1 | 1 | 0 | 3 |
| Identified in Richardson et al. (2007) | Needs Evaluation Questionnaire | 1 | 1 | 1 | 2 | 0 | 5 |
| Identified in Richardson et al. (2007) | PNAT | 1 | 1 | 1 | 2 | 1 | 6 |
| Ewing et al. (2004) | CAMPAS–R | 1 | 1 | 2 | 3 | 0 | 7 |
| Identified in Richardson et al. (2007) | Social Difficulties Inventory | 0 | 0 | 1 | 1 | 0 | 2 |
| Identified in Richardson et al. (2007) | Problems Checklist | 0 | 1 | 1 | 2 | 0 | 4 |
| Family/Caregiver Needs Assessment Tools | | | | | | | |
| Identified in Kristjanson et al. (1995) and Hudson et al. (2010) | Family Inventory of Needs (FIN) | 1 | 1 | 3 | 3 | 0 | 8 |

Continued

Table 2. Continued

| Phase 2: Identification of Tool | | Phase 3: Appraisal of Tool | | | | | Total (--10) |
|--|--|------------------------------|-----------------|----------------------------------|--|--------------------------|-----------------|
| Reference | Name of Tool | Administered by HCP (0/1) | Brief? (0/1) | Use Across Settings? (0-3) | Practical in Clinical Use? (0-4) | Widespread Use? (0-1) | |
| Identified in Hudson et al. (2010) and Ewing et al. (2012) | Carer Support Needs Assessment (CSNAT) | 1 | 1 | 3 | 4 | 0 | 9 |
| Psychological/Emotional Assessment Tools | | | | | | | |
| Identified in Thekkumpurath et al. (2008) and Vodermaier et al. (2009) | Distress Management Tool (Distress Thermometer) | 1 | 1 | 3 | 4 | 1 | 10 |
| Identified in Thekkumpurath et al. (2008) and Vodermaier et al. (2009) | General Health Questionnaire (GHQ-12) | 1 | 0 | 3 | 3 | 0 | 9 |
| Identified in Thekkumpurath et al. (2008) and Vodermaier et al. (2009) | Hospital Anxiety Depression Scale (HADS) | 1 | 0 | 2 | 3 | 0 | 6 |
| Prognostic Tools | | | | | | | |
| Identified in Glare et al. (2003) and Lau et al. (2007) | Palliative Prognostic Score (PaP) | 1 | 1 | 2 | 4 | 0 | 8 |
| Identified in Lau et al. (2007) and Stone et al. (2008) | Palliative Prognostic Index (PPI) | 1 | 1 | 3 | 4 | 0 | 9 |
| Care of the Dying Patient | | | | | | | |
| Ellershaw & Murphy (2005) | Liverpool Care Pathway | 1 | 1 | 1 | 4 | 1 | 8 |
| Spirituality Tools | | | | | | | |
| Dobratz (2004) | Life Closure Scale | 1 | 0 | 3 | 1 | 0 | 5 |
| Emanuel et al. (2001) | Needs at the End of Life Screening Tool (NEST) | 1 | 1 | 3 | 2 | 0 | 6 |
| Hearn & Higginson (1999) and Bausewein et al. (2011) | The Palliative Care Outcome Scale (POS) | 1 | 1 | 3 | 1 | 0 | 6 |
| Mack et al. (2008) | PEACE Scale | 1 | 1 | 2 | 2 | 0 | 6 |
| Richards et al. (2011) | Screen for Palliative and End-of-Life Care Needs in the Emergency Department (SPEED) | 1 | 1 | 3 | 2 | 0 | 8 |
| Hermann (2006) | Spiritual Needs Inventory (SNI) | 0 | 0 | 3 | 3 | 0 | 6 |
| Bausewein (2011) | STAS | 1 | 1 | 2 | 2 | 0 | 6 |
| Ambuel (2005) | Taking a Spiritual History Tool | 1 | 0 | 3 | 4 | 0 | 8 |
| Identified in Lunder et al. (2011) | FACIT-Sp | 1 | 1 | 3 | 4 | 0 | 9 |
| Identified in Lunder et al. (2011) | FICA | 1 | 1 | 3 | 4 | 1 | 10 |

Table 3. Overview of the clinical tools recommended for widespread use

| Domain of Palliative Care | Clinical Tool | Initial / Screening Assessment | Comprehensive Assessment | Follow-Up | Special Situation | Reference |
|---|-------------------------------------|--------------------------------|--------------------------|-----------|-------------------|--|
| Multidomain assessment/needs assessment | Problem Severity Score | ✓ | | ✓ | | Palliative Care Outcome Collaboration (2011) (www.pcoc.org.au) |
| | Distress Thermometer | ✓ | | ✓ | | National Comprehensive Cancer Network (2015) (www.nccn.org) |
| Pain | Initial Pain Assessment Tool | | ✓ | | | McCaffery & Pasero (1999) |
| Family/caregiver | Carer Support Needs Assessment Tool | | ✓ | | | Ewing & Grande (2012) |
| Emotional distress | GHQ12 | | ✓ | | | Goldberg (1978) |
| Spirituality | FICA Spiritual History Tool | | ✓ | | | George Washington Institute for Spirituality and Health (2015) |
| Symptoms | Symptom Assessment Scale | ✓ | | ✓ | | Palliative Care Outcomes Collaboration (2010) (www.pcoc.org.au) |
| Performance/function | Australian-modified KPS | ✓ | | | | Abernethy (2005) |
| Quality of life | FACIT-PAL | | ✓ | | | FACIT.org (2015) (www.facit.org) |
| Prognosis | PaP PPI | | | | ✓ ✓ | Glare et al. (2003) Stone et al. (2008) |
| Care of dying patient | Liverpool Care Pathway | | | | ✓ | Marie Curie Palliative Care Institute (2015) |

participants as the preferred tool. Of note, the focus group agreed upon an approach that involved screening broadly for problems at key points, and then application of specific tools to regularly monitor those problems identified in order to foster effective care planning.

DISCUSSION

Multiple tools are available to assist healthcare professionals to assess and record patient care; however, discerning which ones are most pertinent for routine systematic use across services and sites of care can be challenging. Our study provided recommendations for a suite of clinical tools to assist specialist palliative care services in Victoria to assess and plan care for patients and their family caregivers.

While we have recommended tools across several domains of palliative care provision and advocate for routine assessment to include these aspects of care, we recognize the challenges associated with im-

plementation. For services that do not currently use tools in practice, we suggest to focus attention on one domain in the first instance, and to systematically implement a single tool to gradually orientate staff to the assessment system. For services that utilize a few tools sporadically, our recommendations may be used to review current practice and tighten assessment accordingly, moving toward a consistent approach to care. Finally, services with an established practice of clinical assessment measurement may wish to implement the whole suite of tools into clinical care, and monitor outcomes and resourcing issues of this change to practice.

The process of developing the list of recommended tools in this study was comprehensive, yet we took a pragmatic approach to ensure that recommended tools were relevant to “real-world” practice. There were, however, several limitations. Importantly, while we noted if there had been psychometric data published for each tool, we did not explicitly examine validity and reliability data. Although we have

evaluated the clinical utility of relevant tools, others have pointed to a lack of testing of such tools in practical care, and we know little about the responsiveness, feasibility, appropriateness, and acceptability of many needs assessments.

CONCLUSIONS

We have recommended a suite of practical clinical tools that cover the most important domains of palliative care. We suggest that subsequent work be undertaken to explore the pragmatic implications of systematically implementing these clinical tools into standard specialist palliative care practice. This will need to involve consideration of cost, policy, and resource issues. In addition, training for staff would also be required. Finally, evaluation of the implementation would need to be undertaken.

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