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Transitional palliative care interventions for older adults with advanced non-malignant diseases and frailty: a systematic review

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Received 13 February 2020 Revised 21 April 2020 Accepted 5 May 2020



Journal of Integrated Care Vol. 28 No. 4, 2020 pp. 387-403 © Emerald Publishing Limited 1476-9018 DOI 10.1108/JICA-02-2020-0012

This work is part of Joint Action '724099 / ADVANTAGE' which has received funding from the European Union's Health Programme (2014-2020).

IICA Abstract

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Purpose – To identify transitional palliative care (TPC) interventions for older adults with non-malignant chronic diseases and complex conditions.

Design/methodology/approach – A systematic review of the literature was conducted. CINAHL, Cochrane Library, Embase and Pubmed databases were searched for studies reporting TPC interventions for older adults, published between 2002 and 2019. The Crowe Critical Appraisal Tool was used for quality appraisal. **Findings** – A total of six studies were included. Outcomes related to TPC interventions were grouped into three categories: healthcare system-related outcomes (rehospitalisation, length of stay [LOS] and emergency department [ED] visits), patient-related outcomes and family/carer important outcomes. Overall, TPC interventions were associated with lower readmission rates and LOS, improved quality of life and better decision-making concerning hospice care among families. Outcomes for ED visits were unclear.

Research limitations/implications – Positive outcomes related to healthcare services (including readmissions and LOS), patients (quality of life) and families (decision-making) were reported. However, the number of studies supporting the evidence were limited.

Originality/value – Studies examining the effectiveness of existing care models to support transitions for those in need of palliative care are limited. This systematic literature review identified and appraised interventions aimed at improving transitions to palliative care in older adults with advanced non-malignant diseases or frailty.

Keywords Palliative care, End-of-life care, Transitional care, Older adults, Advanced disease, Non-malignant, Chronic disease, Frailty, Care models

Paper type Literature review

Introduction

According to the World Health Organisation (WHO) (Sepúlveda *et al.*, 2002) and the Worldwide Palliative Care Alliance (Connor and Sepulveda Bermedo, 2018), palliative care is a holistic approach that involves patients and families who are living with life threatening illnesses, with the aim of improving quality of life, preventing and/or identifying pain and other problems at the earliest possible stage and providing effective management and support to relieve suffering. Despite its important role in the care of end-stage illnesses, both malignant and non-malignant diseases, many countries have been reluctant to invest in palliative care, favouring more curative interventions (Sepúlveda *et al.*, 2002). While the term "palliative care" is "embedded in emotions" (Broom *et al.*, 2013) and often perceived with an initial sense of shock and fear as well as a herald of imminent death (Ronaldson and Devery, 2001), many patients express their satisfaction with this approach to care, reporting a sense of comfort, peace and hope (Ronaldson and Devery, 2001). The literature supports this, showing that palliative care improves quality of life and quality of care while reducing healthcare costs (Carpenter, 2017). There is also evidence that multi-disciplinary palliative care support can reduce unnecessary admissions to hospital including those with non-malignant disease (Lorenz *et al.*, 2008).

Recognition of the need for palliation and end-of-life care can be challenging, particularly among older adults and those with advanced (non-malignant) chronic diseases and syndromes such as frailty (Gott *et al.*, 2011; Peel *et al.*, 2013; Loeffler, 2016; Allen *et al.*, 2014). Frailty has strong psychological impacts including a significant overlap with depression (Mezuk *et al.*, 2013) as well as a significant risk of reduced quality of life (Kojima *et al.*, 2016). Palliative care can be highly appropriate to alleviate discomfort and to improve quality of life for frail older adults (Boockvar and Meier, 2006).

Despite the benefits of palliative care, the smooth transition between curative and symptomatic care is challenged by medical factors, patient and family factors and system factors (Thompson *et al.*, 2006). The boundaries between curative, palliative and terminal phases of disease can be blurred (Jeffrey, 1995). Trajectories may be an important factor with very different survival trajectories between cancer, organ failure and the less predictable decline associated with frailty or dementia (Murray *et al.*, 2005). Notably, the majority of care transitions are unplanned due to sudden changes and decompensation in both acute and chronic diseases (Coleman *et al.*, 2005). Advanced care planning, good communication and

easy access to information are essential to provide a robust palliative approach during care transitions (Gott *et al.*, 2011; Healthcare Improvement Scotland, 2019). Thus, the effectiveness of a palliative approach is largely dependent on quality of care and also on the quality of transitions in care (National Consensus Project for Quality Palliative Care, 2004). Hence, any palliative approach to health needs to be operationalised through a meaningful integration with other systems and models of care (Sawatzky *et al.*, 2016).

Transitional care includes a wide range of services that are time-limited but play an important role in supporting patients as they facilitate the smooth transition of care from one healthcare setting to another (Sezgin *et al.*, 2020; Wong *et al.*, 2016). These services are delivered by interdisciplinary teams and aim to provide proactive support, integration and continuity of care between different settings and levels of care (Wong *et al.*, 2016). There is evidence that transitional care services improve quality of life (Wee *et al.*, 2014) and satisfaction with care (Hernandez *et al.*, 2018) as well as reducing hospitalisation rates (Wee *et al.*, 2014; Lowthian, 2017; Naylor, 2006) and healthcare costs (Naylor *et al.*, 2013). Examples of transitional care models include, but are not limited to, pre-discharge assessments and post-discharge follow-up, guidance and counselling programmes delivered via telephone calls or home visits (Harbor Light Hospice, 2017; Wee *et al.*, 2014; Allen *et al.*, 2014)

Transitional palliative care (TPC) models specifically support the transition from treatmentfocused "curative" activities to palliative services (Butcon and Chan, 2017). Individualised care is central to good TPC (Butcon and Chan, 2017; Doug *et al.*, 2011) with most models focusing on providing support to patients and their families considering their individual needs and priorities (Boyd and Murray, 2010). As with transitional care, there is evidence that TPC improves quality of life and the level of satisfaction with care (Levine, 2015; Butcon and Chan, 2017; Gott *et al.*, 2011). While several approaches are recognised (Schofield *et al.*, 2006), no specific models of TPC are recommended. A previous scoping literature review found that the main problems with transitions to palliative care are the nature of the transition itself, the timing of the transition and a lack of information or understanding around this (Marsella, 2009). Furthermore, disruptions to palliative care during hospital discharge may negatively impact communication, and coordination of care, with worsening of symptoms (Carpenter, 2017).

To date, few studies have examined whether models exist to support transitions for those in need of palliative care and it is unclear if these are effective in improving outcomes for patients or their families. Therefore, there is need to identify which individualised TPC models are most effective in managing symptoms and alleviating suffering in this particular population, those with advanced non-malignant chronic diseases, including those who are frail. In order to investigate this, we conducted a systematic literature review aimed at identifying and appraising interventions that improve transitions to palliative care in older adults with advanced non-malignant diseases or frailty.

Methods

Data sources and search strategy

The search was conducted in Pubmed, CINAHL, Embase and Cochrane Library using the search string: (("palliative care") AND ("intermediate care" OR "transitional care") AND (frailty OR frail OR "older person*" OR "older adult*" OR "hospital at home" OR "reablement" OR "independ*" OR "readmission" OR "prolonged stay" OR "community hospital")).

Eligibility

To be included in this systematic review, all studies had to fulfil all of the following criteria: (1) studies which employed TPC as an intervention, (2) inclusion of adults aged 65 years and over, as a widely used chronological definition of older people in many countries (World Health Organisation, n.d.), (3) inclusion of adults with advanced non-malignant chronic

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diseases including frailty, (4) published between 01.01.2002 and 01.12.2019, (5) published in English and (6) had full text available. Studies that did not meet the inclusion criteria were excluded.

Screening and data extraction

The screening and data extraction were performed by two reviewers (DS and MOD). Any conflicts occurring between the reviewers were resolved by involvement of a third independent reviewer (ROC). A standard template was used for data extraction. The template included author name, title, year, aim, setting, summary of intervention, characteristics of sample and organisational structure for delivering the intervention, use of technology, outcomes, transferrable lessons, and limitations. Quality appraisal of included studies were performed using the Crowe Critical Appraisal Tool (CCAT), a scale with appraisal scores ranging between 0 and 40 (Crowe, 2013).

Results

The search yielded 144 records. After removal of duplications, title and abstract screening was performed for 127 studies. Thirty studies were eligible for full-text screening. However, six of them met the inclusion criteria. Results of the critical appraisal are presented in Table A1. Additional details of the screening process with the reasons why papers were excluded are summarised in Figure 1 (flow diagram). The quality appraisal scores of the included studies ranged between 20 and 39 (50–98%).

Most included studies were conducted in the USA (n = 4), with one in the UK and one conducted in Hong Kong. Overall, the total sample size from the included studies was 41,353 with the mean age of participants ranging between 69 and 83.9 (available for three studies). All transitional care interventions were delivered by interdisciplinary teams. Five studies employed technology-assisted interventions, including electronic health records (n = 3) and telephone calls (n = 3). Four studies implemented pre and post discharge transitional care, while two studies delivered post-discharge follow-up with home visits. Characteristics of the included studies are summarised in Table 1. The studies were categorised according to whether they targeted outcomes related to healthcare systems, patients or families.

Healthcare system related outcomes

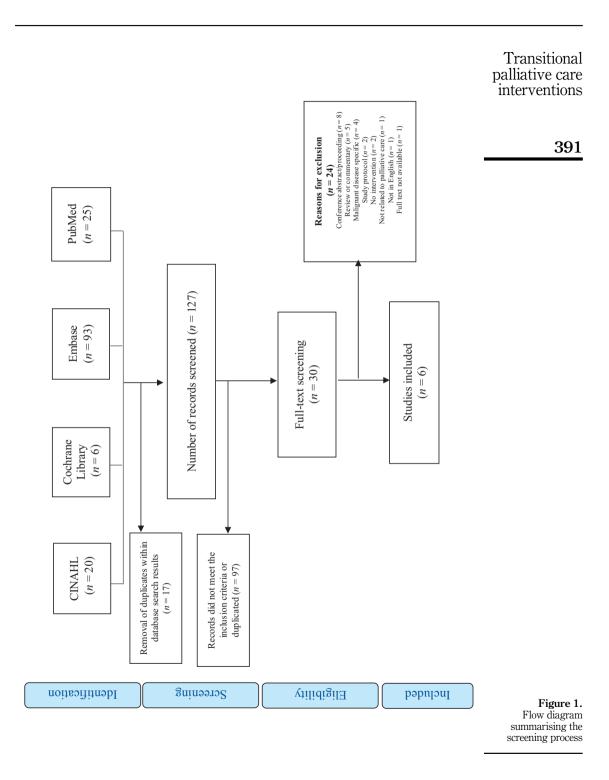
All included studies investigated outcomes related to readmissions, hospitalisations and emergency department (ED) attendances.

Readmissions (n = 4)

Most of the studies reported significant decreases in readmissions. A transitional care program to enhance communication between care settings for nursing home residents with complex care needs (including frail older adults), decreased rehospitalisation rates from 15.2% to 13.9% and increased rates of residents receiving in-house palliative care from 18 to 27% (Giuffrida, 2015). Similarly, Baxter *et al.* (2018) delivered TPC to improve communication between service providers and reduced readmission rates from 22% to 16% for all palliative care patients and from 26% to 10% for patients discharged to partner facilities. Tuso *et al.* (2013) provided palliative care in their additional care bundles for Medicare general high-risk patients and decreased 30-day readmission rates from 12.8% to 11%. A randomised controlled trial (RCT) by Wong *et al.* (2016) implemented a TPC programme for end-stage heart failure patients including multidisciplinary case management, case discussions and follow-up. While their intervention reduced rehospitalisation rates at 12 weeks (33.6% in intervention group vs 61% in control group), this outcome was insignificant at 4 weeks post-discharge.

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JICA 28,4	Limitations to interventions	The absence of control groups The PPC program patients with complex conditions may have been declining more rapidly	(continued)
392	Key healthcare outcomes	CNS led interventions: reduced ED visits and hospitalizations in the four months post-intervention PPC (physicians specializing in palliative care) intervention: non- significant reduction in ED visits and a significant reduction in hospitalizations post-intervention	
	Use of technology	Electronic health records	
	Main components of the intervention	CNS led and physician led assessment and interventions including post- home visits	
	Setting	Rural community hospital- Emergency department (ED)	
	Population (mean age, and condition)	Condition: General Mean age: 69 for the CNS-led intervention 81 for the PPC intervention	
	Sample size	Clinical nurse specialist (CNS) led intervention included 98 patients The PPC intervention included 40 patients	
	Aim	To compare the number of ED visits and hospitalizations in the 120 days before and after the intervention for patients emolled two different transitional care programs	
Table 1. Summarycharacteristics ofincluded studies $(n = 6)$	Author, title, year, country, design	Morrison et al, Reducing Preventable Hospitalizations with Two Models of Transitional Care (2016), USA Retrospective cohort (pre-post single-patient design without controls)	

Limitations to interventions	One hospital, small number of patients. Other skilled nursing facilities could not adopt the intervention due to funding issues during transitions from a skilled services facility to a hospice	(continued)	Transitional palliative care interventions
Key healthcare outcomes	Reduced readmission rates for all palliative care patients		393
Use of technology	Electronic health records		
Main components of the intervention	A transition team for enhancing communication between skilled nursing facilities and community providers		
Setting	Hospital and nursing home		
Population (mean age, and condition)	Condition: General Mean age: NA		
Sample size	896 patients		
Aim	To improve transitions of care and reducing hospital readmissions for patients receiving inpatient palliative care consult at one hospital		
Author, title, year, country, design	Baxter et al., Providing palliative care across the continuum to reduce readmissions from community settings, 2018, UK, Prospective patient tracking		Table 1.

JICA 28,4	Limitations to interventions	AN	(continued)
394	Key healthcare outcomes	Reduced all-cause 30-day readmission rates	
	Use of technology	Telephone calls	
	Main components of the intervention	Bundle elements for risk stratification, standardised discharge summary, medication reconcliation, follow-up, discharge instructions One of the additional two bundles was related to pundles was	
	Setting	Hospital - first quarter of 2012 at 13 medical centres	
	Population (mean age, and condition)	Condition: General (Médicare risk patients) Mean age: NA	
	Sample size	Approximately 40,000 Medicare risk hospital discharges	
	Aim	To describe the award-winning Readmission Program of Kaiser Pernanente Southern California	
Table 1.	Author, title, year, country, design	Theso et al., The Readmission Reduction Program of Kaiser Permanente Southern California – Knowledge Transfer and Performance Improvement (2013), USA, Retrospective study	

Limitations to interventions		(continued)	Transitional palliative care interventions
Limitations to interventions	NA	(con	interventions
Key healthcare outcomes	Reduced re- hospitalization rate Increased in-house residents on the palliative care programme		395
Use of technology	AA		
Main components of the intervention	The Transition Coach and receiving clinical team meeting prior to arrival in order to enhance communication Follow-up by transition coach with the resident and/or family within one-week post-admission Staff training for patients' and wishes, and family involvement, and emotional support Family		
Setting	Skilled nursing and rehabilitation facility		
Population (mean age, and condition)	Condition: Individuals with chronic and complex care needs who are who are vulnerable to experiencing poor quality of care during transitions between settings (including frail older adults) Mean age: NA		
Sample size	173 patients		
Aim	To implement a facility-uide polliative care transitions programme to improve communication communication imterdisciplinary team regarding each patient's uvishes and values, especially with regard to hospitalization		
Author, title, year, country, design	<i>Giuffrida et al.</i> Palliative Care in Your Nursing Home: Program Development and Innovation in Transitional Care (2015), USA, Pre-post intervention study		Table 1.

JICA 28,4	Limitations to interventions	Limited enrolment of dementia patients due to short hospital stays and caregiver stress. Need for extending the duration of specialty palliative beyond discharge	(continued)
396	Key healthcare outcomes	No difference in hospital and ED visits Increase in addressing of palliative care domains and likelihood of receiving hospice Increased families to discuss prognosis and goals of care as well as to make decisions to avoid rehospitalisation, and to have a MOST (Medical Orders for Scope of Treatment) at 0-day follow-up	
	Use of technology	Electronic health records and telephone calls	
	Main components of the intervention	Dementia-specific pre-discharge specialty palliative care consultation and post-discharge two-week transitional telephone support by a palliative care nurse practitioner	
	Setting	Hospital	
	Population (mean age, and condition)	Condition: Late stage dementia Mean age 83.9 (83 for the intervention group and 84.7 for the control group)	
	Sample size	62 patients (30 in the intervention group and 32 in group)	
	Aim	To test dementia- specific specialty palliative care triggered by hospitalization	
fable 1.	Author, title, year, country, design	Hanson et al., Triggered Palliative Care for Late-Stage Dementia: A Pilot Randomized Randomised- controlled trial (RCT)	

Author, title, year, country, design	Aim	Sample size	Population (mean age, and condition)	Setting	Main components of the intervention	Use of technology	Key healthcare outcomes	Limitations to interventions
<i>Wong et al.</i> , Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial, 2016, Hong Kong, RCT	To examine the effects of home-based transitional palliative care for stage heart stage heart discharge discharge	84 patients (41 in the intervention group and 43 in the control group)	Condition: Patients with end stage heart failure who had been discharged home from hospitals and referred for palliative service Mean age 78.3 (78.4 for the intervention group and 78.3 for the control group)	Hospital	Case management with periodic review (follow-up by weekly home visits/telephone calls in the first four weeks) Discussion of end- of-life issues Multidisciplinary approach (monthly follow- up provided by a nurse case manager supported by a multidisciplinary team) Staff development for communication, cardiovascular and PC Discussion of treatment preferences and Integrated model of care	Telephone calls	Reduced readmission rate at 12 weeks post- intervention Significant difference in the mean number of readmissions (between groups) No significant difference in readmissions (between groups) at four weeks Innprovement in depression, dyspnoea and total Edmonton Symptom Assessment Score (ESAS) at four weeks Significant changes in quality of life	The loss of follow-up was high The sample size was relatively small The results may not be generalisable since study was only carried out in Hong Kong

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Table 1.

IICA Length of stay (n = 1)

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Only one study reported outcomes related to length of hospital stay. Morrison *et al.* (2016) compared two interventions delivered by clinical nurse specialists (CNS) and physicians specialising in palliative care (PPC). Both interventions consisted of post-hospital discharge assessments and follow-up home visits. Although they had a slightly different focus (chronic disease and palliative care), both reduced inpatient stays from 1.03 to 0.21 and 0.72 to 0.34 days, respectively.

ED visits (n = 2)

The evidence for reductions in ED visits was unclear. As described above, Morrison *et al.* (2016) compared interventions administered by CNS and physicians. While the CNS-led intervention decreased the mean ED visits from 0.93 to 0.22, the PPC did not result in a significant reduction. Similarly, a recent pilot RCT implementing a pre and post-discharge specialist palliative care and follow-up intervention to hospitalised patients with late stage dementia did not find a significant difference in mean ED visits per 60 days (0.68 vs 0.53) (Hanson *et al.*, 2019).

Patient outcomes

Only one study (a RCT) reported outcomes directly for patients. A TPC programme delivered by Wong *et al.* (2016) in Hong Kong provided monthly follow-ups by nurse case managers and overall adopted a multidisciplinary approach. The programme also implemented staff training for improving communication and supported discussions about treatment preferences and integrated care models. It demonstrated improvements in depression (45.9% vs 16.1%), dyspnoea (62.2% vs 29%), and Edmonton Symptom Assessment Score (73.0% vs 41.4%) in patients with end-stage heart failure at four weeks post-discharge. The programme also resulted in improvements in quality of life.

Family outcomes

A pilot RCT of pre-discharge dementia-specific palliative care delivered by specialists plus two-week post-discharge telephone support had positive family outcomes (Hanson *et al.*, 2019). The programme increased their participation in discussions about prognosis and goals of care. Moreover, it supported them in making decisions to avoid hospitalisation and/or receive hospice care. This resulted in higher rates of hospice care received by the intervention group compared to the control group (25% vs 3%).

Discussion

Transitions are one of the key considerations in relation to palliative care and should not be understated (Marsella, 2009; Sawatzky *et al.*, 2016; Thompson *et al.*, 2006). Moreover, early and phased but structured transitions are essential for success implementing timely and appropriate palliative care (Gardiner *et al.*, 2011), especially in older adults with chronic diseases and complex conditions. Transitional care is a key element of integrated care to prevent and manage frailty (Hendry *et al.*, 2018).

This systematic review identified a diverse but limited number of TPC interventions for older adults with advanced non-malignant disease or frailty. These specifically targeted symptoms and investigated the impact on avoidable hospital admissions. The results suggest that TPC can reduce readmission rates to hospital, lower inpatient LOS, improve quality of life for patients and support healthcare providers and families with decision-making around the need and timing of palliative care. Despite the potential benefits, few studies were identified, highlighting the need for further studies of TPC.

Although studies reported an impact on healthcare utilisation including reduced LOS and readmission, there was insufficient evidence that TPC decreased ED attendances. Specifically, specialist-delivered pre and post-discharge assessments and follow-up interventions did not reduce the mean number of ED attendances (Morrison *et al.*, 2016; Hanson *et al.*, 2019). This may relate to the inability of TPC to address unexpected crisis, where urgent assessment in ED is appropriate. However, as only two studies assessed this outcome, there is a need for further research in this area. Similar to our findings, a recent systematic review by Saunders *et al.* (2019), examining adults with malignant or mixed malignant-non-malignant diseases and reporting outcomes of palliative care transitions from acute to community-based care including LOS, discharge support and hospital readmissions, concluded that the evidence for their effectiveness were limited due to heterogeneity of study designs.

Pre and post discharge TPC interventions implementing strategies to improve communication between care providers reduced hospital readmission rates (Giuffrida, 2015; Baxter *et al.*, 2018). Relevant and accessible information has been highlighted as a key factor in patient's transition to palliative care (Ronaldson and Devery, 2001). Other important factors include agreement, timing, and decision making amongst staff members (Agren Bolmsjö *et al.*, 2007). According to a systematic review (Ahmed *et al.*, 2004), the main problems with access to palliative care are lack of knowledge and education amongst health and social care professionals, and a lack of standardised referral criteria.

Patient outcomes identified in this review included improved quality of life, and reduced depression and dyspnoea in patients with heart failure in one study (Wong *et al.*, 2016).

The views of families and care givers should be considered when planning the transition from hospital to home or other settings (Carrillo *et al.*, 2018). The systematic review found limited research evidence for family related outcomes. Only one study reported on benefits for families in decision making around referrals to hospice care (Hanson *et al.*, 2019).

This systematic review has some limitations. Firstly, the inclusion criteria did not focus on all types of available evidence in the literature; therefore, reference tracking of previously published systematic reviews on the topic could not be conducted. This may mean that important studies may not have been included. However, we are encouraged that the systematic review by Saunders *et al.* (2019) similarly found few papers on the topic. Secondly, methodological and overall reporting quality of the included studies ranged between 50 and 98% according to the CCAT assessment, suggesting considerable variability in their quality. Moreover, there was heterogeneity among the design of the included studies (only one RCT was available), which limited the interpretability, comparability and ultimately the generalisability of the findings. Finally, there were only a limited number of studies reporting evidence for the effectiveness of TPC interventions in older adults with advanced non-malignant disease or frailty.

Conclusions

Enabling smooth transitions to palliative care, described as "paramount" (Larkin *et al.*, 2007) and "essential" (National Consensus Project for Quality Palliative Care, 2004) to the provision of good care, has the potential to improve quality of life for patients, enhance shared decision making by families and deliver benefits for the healthcare system. This systematic review identified important outcomes related to healthcare services (readmissions and LOS), patients (quality of life) and families (decision-making) following TPC interventions in older adults with advanced non-malignant disease or frailty. However, the results may not be generalisable due to the heterogeneity and wide range of methodological and reporting quality of the included studies.

Prior to reaching any conclusions about the implications of TPC interventions on clinical practice and society, there is a need for high-quality studies that apply standardised study designs and outcome measures to address their effectiveness in this growing population. In Transitional palliative care interventions

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addition, there is a need to standardise the definition of TPC used and examine more homogenous samples. These actions should reduce heterogeneity between studies and improve the understanding of whether, and how, these interventions are effective or not. This evidence will be vital to inform how we extend access to integrated palliative care across the continuum of care for this population with complex needs and an often-unpredictable disease trajectory.

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Appendix 1

Percentage 68% 50% 68% %86 %8% Total (0-40) $^{27}_{27}$ 33 g 8. Discussion 4000 വന 7. Results 4000 2 10 6. Ethics ຕາມຕາ 04 5. Data collection 4 0 4 n 2 10 4. Sampling 0040 ററ 3. Design 00 10 00 വന 2. Intro ი 4 ი ი വവ 1. Prelim 4 0 0 4 വ വ Braxter et al. (2018) Giuffrida (2015) Hanson et al. (2019) Wong et al. (2016) Author and year Tuso et al., 2013 Morrison et al. (2016)

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Table A1. Crowe critical appraisal tool (CCAT) – quality appraisal of included studies