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Palliative Care for People who are Homeless and Vulnerably Housed: A Scoping Review and Thematic Synthesis

Richard James *Leeds Teaching Hospitals Trust*
(Corresponding Author) *Leeds*
LS97TF
UK
0113 2433144
Richard.james14@nhs.net

Kate Flemming *Department of Health Sciences*
University of York
York
UK

Melanie Hodson *Hospice UK*
London
UK

Tammy Oxley *Leeds Teaching Hospitals Trust*
Leeds
UK

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ABSTRACT

Introduction

People who are homeless or vulnerably housed are subject to disproportionately high risks of physical and mental illness and are further disadvantaged by difficulties in access to services. Research has been conducted examining a wide range of issues in relation to end of life care for homeless and vulnerably housed people, however, a contemporary scoping review of this literature is lacking.

Objectives

To understand the provision of palliative care for people who are homeless or vulnerably housed from the perspective of, and for the benefit of, all those who should be involved in its provision.

Design

Scoping review with thematic synthesis of qualitative and quantitative literature.

Data Sources

MEDLINE, Embase, PsychINFO, Social Policy and Practice, and CINAHL databases were searched, from inception to May 2020. Citation chasing and manual searching of grey literature were also employed.

Results

Sixty-four studies, involving 2117 homeless and vulnerably housed people were included, with wide variation in methodology, population, and perspective. The thematic synthesis identified three themes around: experiences, beliefs and wishes; relationships; and end of life care.

Conclusion

Discussion highlighted gaps in the evidence base, especially around people experiencing different types of homelessness. Existing evidence advocates for service providers to offer needs-based and non-judgemental care, for organisations to utilise existing assets in co-producing services, and for researchers to address gaps in the evidence base, and to work with providers in transforming existing knowledge into evaluable action.

KEY MESSAGE BOX

What was already known?

- Homeless and vulnerably housed people are disadvantaged in accessing palliative care.

What are the new findings?

- The evidence around this topic is summarised and synthesised into themes around experiences, relationships, and end of life care.

What is their significance?

Clinical:

- Evidence of how services may better meet this population's needs.

Research:

- Gaps in the existing research are identified.

INTRODUCTION

Background

It is estimated that globally one in every fourteen people are homeless, and even more are vulnerably housed or at risk of homelessness.[1] Despite global and national ambitions to end or reduce homelessness, overall rates continue to increase.[1,2] Although the greatest burden of homelessness is in the developing world, developed countries such as the UK also experience high prevalence, with around one in 200 people homeless.[1,2] While research and policy are needed to address the root causes of homelessness, in the interim, parallel work is required to reduce its impact.

People who are homeless or vulnerably housed are subject to extreme health inequities and premature mortality.[3,4] They experience a disproportionately high prevalence of physical and mental illness, both from the contribution co-morbidities can have to becoming homeless, and the risks homelessness has on deteriorating physical and mental health.[3,4] When homeless and vulnerably people do become ill, they are further disadvantaged by difficulties in access to services, including palliative care.[4–6]

There have been concerted efforts by governments, charities, hospices, and research institutions to understand these inequalities, and to consider how they can be levelled.[6,7] However, inequalities for homeless and vulnerably housed people remain and further action is required to ensure this group are able to receive the palliative care they require.[6,8,9]

Rationale and Statement of the Problem.

Efforts are underway to strengthen the evidence base underpinning palliative care; the specialty has been moving forward rapidly, with evidence published in a diverse range of forms.[10] The field of palliative care for people who are homeless or vulnerably housed has been no different, and there is potentially a large volume of research that service planners and providers could benefit from understanding and assimilating.[6,11–13] Researchers in the area could also benefit from a full understanding of what is already known, and where future efforts may be best focussed.

Whilst existing systematic and scoping reviews have been undertaken in the field, most address specific aspects such as social care,[13] access to care,[6] or advance care planning.[12] Even those with broader inclusion focus on specific questions about preferences and delivery of palliative care to homeless and vulnerably housed people.[11] Further to this, the research body has moved forward since earlier reviews were conducted.

The sources of literature remain disparate and are not well mapped. Therefore, there is a need for a broad and exploratory scoping review to be conducted that addresses these gaps.

Objectives

The objectives of the review are:

1. To map the current evidence-base around palliative care provision for homeless and vulnerably housed individuals and populations from the perspective of both homeless and vulnerably housed people and those providing, commissioning, and designing services.
2. To describe the key findings and recommendations of the existing literature body to aid those providing and designing services to better address the palliative care needs of homeless and vulnerably housed individuals.
3. To establish what further research is needed to better understand how to improve palliative care outcomes for homeless and vulnerably housed individuals.

METHODS

This scoping review aims to map, describe, and reflect on the current diaspora of research in the field. It is based around Arksey and O'Malley's (2005) framework,[14] and reported in accordance with PRISMA-Scoping guidance.[15]

Stage 1: Identifying the research questions

The "PerSPE(C)TiF" framework was used to develop this question (Table 1), forming the question:[16,17]

"What do we know about the delivery of palliative care for people who are homeless or vulnerably housed in the UK from the perspective of, and for the benefit of, all those who should be involved in its provision?"

TABLE 1: CLARIFYING QUESTION FORMULATION, PERSPE(C)TiF TABLE BASED ON BOOTH ET AL. (2019).[16]

PerSPE(C)TiF Term	Scoping Review Definition
Perspective	From the perspective of those who are homeless or vulnerably housed, or who help provide palliative care for those who are homeless or vulnerably housed.
Setting	UK homeless and vulnerably housed population requiring specialist palliative care input.
Phenomenon/ Problem	What do we know about palliative care provision?
Environment	Both inside and outside of existing services.
(Optional Comparison)	(Nil fixed comparator)
Time/timing	In the time period when palliative care and support could be beneficial.
Findings	With relevance to researchers, policy makers, and clinicians.

Stage 2: Identifying Relevant Studies

The following databases were searched from inception to May 1st 2020: APA PsycInfo, Embase, Medline, Social Policy and Practice and CINAHL. Titles and abstracts were searched in English with the terms "(Homeless* OR vulnerably housed) AND (palliat* OR terminal* OR end-of-life OR supportive care OR end of life)". The search terms were developed through the "PerSPE(C)TiF" question formulation framework with iterative development calibrated through index papers.[6,11,12,18,19]

Database searching was complemented with retrospective citation chasing of articles included in eligible systematic and scoping reviews, and ineligible literature reviews, dissertations, and reports. "Grey" resources from Hospice UK and St. Mungo's were also searched.

Stage 3: Study Selection

Included papers:

1. Focussed on adults who are homeless or vulnerably housed (in accordance with the research-focussed European Typology on Homelessness and Housing Exclusion (ETHOS) light definitions, Table 1),[20] or groups directly involved in the provision or design of palliative care services to homeless people.
2. Related directly to palliative care interventions, services, access, or experiences of these.
3. Were published in the English language.

Excluded papers:

1. Literature reviews, dissertations, or reports lacking structured synthesis or systematic primary or secondary research characteristics
2. Studies focusing on fields that may include homelessness or palliative care, but not specific to either

Eligibility was established through title screening and abstract screening by a lead (XX) and second reviewer (XX) independently; and where there was ambiguity in initial screening, by full article review, then third reviewer consultation (XX).

TABLE 2: *ETHOS LIGHT HARMONISED DEFINITION OF HOMELESSNESS FOR STATISTICAL PURPOSES.*[20]

ETHOS Light Operational Categories	
1	People living rough
2	People in emergency accommodation
3	People living in accommodation for the homeless
4	People living in institutions
5	People living in non-conventional dwellings due to lack of housing
6	Homeless people living temporarily in conventional housing with family and friends (due to lack of housing).

Stage 4: Charting the Data

A charting table was developed with reference to the “PerSPE(C)TiF” framework and calibrated by trialling it with ten articles until no further modification was required.[16] Information was recorded around date and authors, participants and perspectives, study design, location, aims, themes, and

conclusions. The lead reviewer charted included articles chronologically in order to iteratively understand how the body of literature has developed.

Stage 5: Collating, Summarising and Reporting Results

Firstly, evidence was mapped through description of the spread of studies and the “characteristics of evidence” (time, place, methods, participants) in the data charting.[15] This is not an attempt to quantify the qualitative, nor a proxy for relevant narrative discussion, but to help convey the complexities of multi-domain descriptions from a potentially large body of evidence.

Secondly, an integrative mixed methods approach was used to collate and summarise findings, directed through Booth *et al.*'s (2016) qualitative review methodologies matrix.[17] A thematic synthesis appeared the best *a priori* fit.

The approach to the thematic synthesis was adapted from Thomas and Harden's (2008) methods.[21] There was pragmatic deviation from the first of Thomas and Harden's (2008) stages,[21] with the articles not coded “line by line” from the included papers, but with coding applied to the data already charted in Stage 4 around “key themes, headings and/or outcomes” and “conclusions/recommendations”. From this charting, initial free codes were produced for each study, and grouped into descriptive themes which represented the first level of the synthesis. In order to go beyond a descriptive content of the original studies [21], these descriptive themes were iteratively developed into analytical themes until they reflected the full scope of the included literature. At each stage, coding, descriptive themes and analytical themes were discussed amongst the authors and any disagreements resolved by consensus.

Funding, Ethics and Protocol

There was no specific funding for the scoping review. No ethical approval or specific ethical issues were raised, as it is a review of existing published research, but all consideration of evidence, reporting of findings, and subsequent communication were carried out in accordance with relevant ethical principles.

A research protocol was developed using the PRISMA-ScR guidance,[15,22] but not intended for publication within PROSPERO.

RESULTS

Collating, Summarising, and Reporting Results: Distribution of the Research

1877 articles were identified, after the removal of duplicates 1132 were screened, with 1003 excluded by title or abstract, and 65 excluded on full-text review, resulting in the inclusion of 64 articles (Figure 1). Full details of charted articles are summarised in Table 3 (supplementary table).

There was almost perfect agreement between reviewers during screening (Cohen's k 0.99), with no disagreement after full article review. Although efforts were made (interlibrary loans and contact with authors and/or journals) it was not possible to obtain full copies of four articles that could potentially have met inclusion criteria.[23–26]

Time and Place

Articles were from peer reviewed journals ($n=48$, 75%), conference abstracts ($n=10$, 16%), and non-peer reviewed sources ($n=6$, 9%). Most articles were from the USA ($n=27$, 42%), Canada ($n=15$, 23%), or the UK ($n=11$, 17%), with fewer from the Netherlands, Republic of Ireland (ROI), Australia, Sweden, and Germany. The bulk of the research body has been published in the five years preceding this scoping review (2016-2020: $n=39$, 61%), with nearly all studies ($n=62$, 97%) having been published after 2005.

Methods

Forty-seven studies used primary qualitative research, seven were predominantly quantitative observational studies, six were interventional, and four were systematically conducted reviews.

Participants and Perspectives

Most studies ($n=40$, 63%) included homeless and vulnerably housed people; in total 2117 homeless and vulnerably housed people have contributed to this review. Where ETHOS light domain was reported most people were within category 2; people in emergency accommodation ($n=215$, 10%), or category 3; people living in accommodation for the homeless ($n=689$, 33%), usually residing in hostels. Very few people ($n=75$, 4%), and relatively few studies ($n=15$, 38%) concerned those who were “living rough”, “living in institutions”, “living in non-conventional dwellings”, or “living temporarily in conventional housing”. [20]

A fifth ($n=551$, 20%) of all included participants worked with homeless or vulnerably housed people, and their perspectives were included in around half of the studies ($n=34$, 53%). Looking at the composition of this group, health and social care workers were represented in 30% ($n=19$) of included

studies, hostel workers in 6% (n=4), and outreach workers in 5% (n=3). The other seven categories identified were only represented in a single study.

The four review article populations were not included in these figures to avoid duplication, as is highlighted by Table 4.

TABLE 4: COVERAGE OF INCLUDED SYSTEMATIC AND SCOPING REVIEWS

Citations within Systematic and Scoping Reviews		Petruik, 2018 [13]	Klop et al., 2018 [11]	Sumalinog et al., 2017 [12]	Hudson et al., 2016 [6]	Inclusion/Exclusion status within this current Scoping Review <i>Novel inclusions and excluded citations in italics</i>
KEY TO COLOUR-CODING						
EXCLUDED FROM THIS REVIEW	-					
INCLUDED IN ONE OTHER REVIEW	1					
INCLUDED IN TWO OTHER REVIEWS	2					
INCLUDED IN THREE OTHER REVIEWS	3					
INCLUDED IN FOUR OTHER REVIEWS	4					
(McGrath, 1986)	[55]		Y			Database Search
(Ratner, Bartels and Song, 2004)	[85]		Y			<i>Not Specific</i>
(O’Connell et al., 2004)	[86]		Y			<i>Not Specific</i>
(Hwang et al., 2001)	[87]		Y			<i>Not Specific</i>
(Ahmed et al., 2004)	[88]	Y				<i>Not Specific</i>
(Norris et al., 2005)	[89]		Y			<i>Not Specific</i>
(Song et al., 2005)	[28]		Y			Database Search
(Tarzian, Neal and O’neil, 2005)	[33]		Y		Y	Database Search
(Kushel and Miaskowski, 2006)	[68]	Y				Database Search
(Podymow, Turnbull and Coyle, 2006)	[64]		Y	Y		Database Search
(Song et al., 2007b)	[29]	Y	Y		Y	Database Search
(Song et al., 2007a)	[32]	Y	Y		Y	Database Search
(Bartels et al., 2008)	[90]		Y			Citation Chaining
(Song et al., 2008)	[52]	Y	Y	Y		Database Search
(Bywaters, 2009)	[91]	Y				<i>Not Specific</i>
(Cagle, 2009)	[92]	Y				<i>Literature Review</i>
(Song, 2010)	[51]		Y	Y		Database Search
(Davis et al., 2011)	[40]		Y			Citation Chaining
(McNeil et al., 2012)	[58]	Y	Y		Y	Database Search
(McNeil and Guirguis-Younger, 2012)	[78]		Y		Y	Database Search
(McNeil, Guirguis-Younger and Dilley, 2012)	[77]	Y	Y	Y	Y	Database Search
(Page, Thurston and Mahoney, 2012)	[93]	Y				<i>Not Specific</i>
(Davis-Berman, 2013)	[94]	Y				<i>Not Specific</i>
(Krakowsky et al., 2013)	[43]		Y		Y	Database Search
(Walsh, 2013)	[74]		Y			Citation Chaining
(Ko and Nelson-Becker, 2014)	[34]		Y		Y	Database Search
(MacWilliams et al., 2014)	[72]		Y		Y	Citation Chaining
(Ko, Kwak and Nelson-Becker, 2015)	[35]		Y		Y	Database Search
(Leung et al., 2015)	[53]		Y	Y		Database Search
(W. Webb, 2015)	[42]	Y			Y	Database Search
(Courtwright and Rubin, 2016)	[96]	Y				<i>Not Specific</i>
(Davis-Berman, 2016)	[65]	Y			Y	Database Search
(Håkanson et al., 2016)	[45]		Y	Y	Y	Database Search
(Hudson et al., 2016)	[6]	Y			-	Database Search
(Webb, 2016)	[95]		Y			<i>Same Data [42]</i>
(Dubbert et al., 2017)	[48]	Y				Database Search
(Hubbell, 2017)	[97]	Y				<i>Literature Review</i>
(Nikouline and Dosani, 2017)	[59]		Y			<i>Novel Inclusion</i>
(Sumalinog et al., 2017)	[12]	Y		-		Database Search
(Tobey et al., 2017)	[30]	Y				Database Search
(Hutt et al., 2018)	[76]		Y			Database Search
(Klop et al., 2018)	[11]	Y	-			Database Search
(Shulman et al., 2018)	[69]	Y				Database Search
Totals		21	27	6	13	43 (31 included)

Collating, Summarising, and Reporting Results: Thematic Synthesis

Following coding of charted “themes” and “recommendations” 76 initial codes were developed. From these, and following Thomas & Harden’s approach to thematic synthesis, eleven descriptive themes were developed, and synthesised into “analytical themes” which in turn were tested for fit against the initial data charting. Ultimately, three core analytical themes were identified: “Experiences, beliefs, and wishes”, “relationships”, and “EOLC”.

Theme 1: Experiences, Beliefs, and Wishes

Death

Homeless and vulnerably housed people are exposed to “ubiquitous” death, often this has been premature, violent, traumatic, and experienced early on in life.[6,27–31] Unique experiences with death, lead to unique beliefs around death and dying, potentially neglected in the wider EOL literature.[32] Whilst some people develop a fatalistic acceptance of death, others live in constant fear of an unpredictable and unpleasant death.[28,29,33,34] This leads to paradoxical approaches to risk; strong acceptance or aversion.[29]

Pervasive contact with death may increase the importance of religion, spirituality, and an afterlife.[9,28,32,33] Fears around what will happen to the body after death exist independently from religious beliefs,[9] but are especially concerning where beliefs give importance to the body and what happens to it after death.[28,32]

Experiences and perceptions around death lead to beliefs about what makes a “good” or “bad” death. Amongst homeless and vulnerably housed people, a “bad death” may be defined by violence, dependence, becoming burdensome, or loneliness.[28,31,35,36] Contrastingly a “good death” is peaceful, without suffering, with access to substances of addiction, and involves resolution of relationship and spiritual issues.[31,35,37] Common fears around death build on these beliefs, with fears described around dying alone, leaving nothing behind, and not being remembered.[9,28,38]

Freedom, Autonomy, and Dignity

Homeless and vulnerably housed people have commonly stated their prioritisation of freedom,[28,38] wishes for dignity and respect,[31,32,39] and desire to maintain autonomy and self-determination.[9,40,41] Both homeless and vulnerably housed people and hostel staff perceive that EOLC services often fail to provide sufficient choice and dignity around death.[42]

Prior experiences with EOLC have been described as “frequently poor and frightening”, [32] and “shaped by discrimination, disrespect and disempowerment”. [6] Previous negative experiences with

EOLC and the wider health and social care system lead to negative associations with these services.[6,29,30] For example, there is an association with EOLC services and life prolonging treatment, itself linked to loss of freedom, autonomy and dignity.[9,28,38] Further concerns exist around how service providers may treat homeless and vulnerably housed people; with stigmatisation and non-personalised care.[6,13,30,43] Service rigidity and bias may not be limited to the views and behaviours of individual health and social care professionals, but can exist at policy level too.[44] All of these factors contribute to the belief that engagement with EOLC services may compromise the values individuals prize the most, all at a vulnerable stage in life when things like freedom, autonomy, and dignity already feel under threat.[28,32,38]

Rigid organisations reduce independence and autonomy, at a time when these values may already be under threat, leading to care avoidance, regardless of clinical need.[9,39] Independent of whether homeless and vulnerably housed people have experienced indignities, restrictions on autonomy and freedom, or disrespect through life, through a patient centred needs based approach it is possible to “re-dignify the person” in death.[45]

Advance Care Planning and Advanced Directives

Homeless and vulnerably housed people are disproportionately less likely to have completed an Advanced Directive (AD) or participated in Advance Care Planning (ACP).[19,37] However, given the potential for surrogate decision makers to be lacking, and even where present to be mistrusted,[37] ACP and AD may offer real benefit.[46]

Some literature suggests that the “chaotic lives” of homeless and vulnerably housed people were incompatible with ACP,[47] however, as more work has been carried out, it appears AD and ACP uptake has been lower in this population because it has been discussed in an incompatible manner.[34,37] This view is supported by the fact that many homeless and vulnerably housed people have thought about AD,[48] and show willingness to discuss ACP in the right setting, with the right support.[36,37,49]

A number of attempts have been made to adapt ACP and AD to suit homeless and vulnerably housed people. Simple interventions such as very brief advice have not been effective.[50] However, trials have demonstrated that if AD are made accessible, homeless and vulnerably housed people will complete them with and without assistance, and may have some of their pre-discussed concerns around death addressed.[37,51–53]

Discussions around ACP may be especially difficult because of beliefs around death, the “recovery” focus of many homeless and vulnerably housed people services, uncertainty in prognosis, as well as

more practical concerns around place of care and addiction.[18,19] Discussions therefore need to incorporate the uncertainty homeless and vulnerably housed people may have around EOL, and respect people's experiences, beliefs and wishes.[19] They may take place over a number of sessions, with someone they have a pre-existing relationship with,[36] or with someone who they can build a trusted relationship with;[34] such as primary care providers.[49] Even when ACP discussions are carried out effectively, given the potential for multi-agency working in EOLC for homeless and vulnerably housed people, it is important that documentation and communication are clear.[48] It is only then that discussion of ACP can lead to the realisation of an individual's preferences.[54] Although ACP requires good documentation in any group, homeless and vulnerably housed people may lack the social network and organisational literacy required to correct and mitigate failures in documentation and communication within and between organisations.[55]

There are limits to the current understanding of how AD and ACP can adapt to better fit homeless and vulnerably housed people; and there may now be a need to shift to more patient-focussed outcomes, although given the nature of EOLC, there can be pragmatic challenges in obtaining these.[56] Further to this, it should be remembered that homeless and vulnerably housed people are not a homogenous group, and although ETHOS domain has been considered specifically in this review, AD is less frequently documented in other sub-sections of the homeless and vulnerably housed population, such as black and minority ethnic (BAME) and rural homeless groups.[48]

Theme 2: Relationships

Historically, services may have under-utilised existing relationships when providing EOLC,[33] despite its potential utility.[41] Often homeless and vulnerably housed people have poor or absent familial relationships and a lack of trusted friends.[28,34,45,57] However, small social networks still exist, and they can provide support at EOL,[55] in some cases to such an extent that where inflexible systems force a choice, individuals chose peer support over palliative support at EOL.[58] The dense networks homeless and vulnerably housed people have,[55] may reflect the fact that many have traumatic and abusive histories.[6,27–29] Trust is slow to build, mistrust develops quickly, and news of both can spread fast.[58] Accordingly, trusted institutions such as hostels,[42] and harm-reduction services,[58] can better engage homeless and vulnerably housed people than traditional healthcare services.[6]

Hostels can be an excellent setting to provide EOLC to homeless and vulnerably housed people, and hostel workers may be the best people to provide support at EOL.[42] Within hostels, staff act as advocates, friends, and family,[27,45] and go above and beyond to meet the emotional needs of the people they work with.[6,42] Despite the ability of hostels to facilitate choice and enable homeless and vulnerably housed people to feel connected, supported, and safe; hostels were not designed to

provide healthcare,[6,59] and staff have questioned how well resourced they are to meet the needs of residents at EOL.[42,60] Specifically, hostel workers may not be able to provide personal care or store and administer medications.[42,57,60] These limitations can necessitate transfer to inpatient settings, potentially restricting choice and contradicting an individual's preferences around EOL.[6] Beyond this, EOLC places a burden on hostel staff, especially given their emotional investment.[6,18,42,59,61]

Communication

Those frequently providing support around EOL may benefit from training around communication and common issues,[40,62] toolkits have been developed to aid in this process,[63] and a pilot looking at training hostel staff involved with palliative clients found staff stress was reduced, and self-perceived openness, confidence, and knowledge improved.[18] Homeless communities and hostel staff also have need of good bereavement support.[27] Efforts have been made to establish entire hostel/shelter based palliative care programmes,[45] which have provided needs-based care to homeless and vulnerably housed people at EOL.[64] Beyond the benefits to homeless and vulnerably housed people and hostel workers, shelter-based care models may also be cost-effective,[64] however, the evidence of how this effectiveness may translate is uncertain.[12] Similar evaluation is required for all interventions in this area.[62]

Clear, accessible, and multi-modality communication may enable improved relationships.[59] However, relationships are dynamic, and authority and knowledge do not sit solely with palliative care professionals. Those providing palliative care to homeless and vulnerably housed people could learn from the approaches used by services specialising in supporting homeless and vulnerably housed people which commonly offer diverse and judgement-free person-centred care.[43] Involvement of the homeless community, as well as those that serve them, may also aid in establishing shelter-based care, especially as a tool to overcome issues with trust in healthcare systems.[59,62]

Partnership Working

Other institutions may also have a role to play. Internationally, healthcare outside of the acute setting may be lacking for homeless and vulnerably housed people,[65] although the predominance of health insurance systems may contribute to this, it seems systemic exclusion in accessing care at EOL is prevalent in the UK as well.[6,58,66] There may not be awareness of available services, both amongst homeless and vulnerably housed people, and amongst those working closest to them.[65]

The importance of gateways into palliative care for homeless and vulnerably housed people should not be underestimated, given the potential for death to occur outside of palliative care services.[67]

Although hostels can provide one such gateway, the more doors that exist, the easier it is to find one. Social workers, key to multi-disciplinary working,[68] may have developed similarly trusted relationships with clients, and may also be well positioned to advocate for both homeless people, and palliative care.[13,58,65] Harm-reduction services may offer a further path into existing EOL services.[58] Existing relationships are potential assets in providing EOLC, however, those working with hostel, social, harm-reduction, and other services require adequate education and support to do this effectively.[6,13,41,69] Unfortunately it seems specialist knowledge and specialist access are not always linking up well; in the Republic of Ireland (ROI) interviews with shelter staff suggested communication between homeless services and healthcare services were poor.[60]

A house is a building, but a home is much more, in this sense many “homeless” people are not homeless, they are imbedded in social networks, and taking that away may be more harmful than if an individual simply had no engagement in EOLC.[55,58] It is possible to adapt the philosophy of “hospice at home” to those wishing to die in non-permanent and non-traditional dwellings, and to involve similarly “non-traditional” social networks in their support.[55,70] Despite this, many homeless and vulnerably housed people die in an unsupported environment,[69] or as an ROI case-audit revealed, die in hospitals and hospices,[57] potentially outside of their social networks.

Theme 3: End of Life Care

The literature describes an overall picture of inadequacy of current models for homeless and vulnerably housed people.[9,19,31,41] However, a lot has been done to suggest why this might be, and how this can be resolved.

Clinical Complexity

The underlying pathologies of homeless and vulnerably housed people with palliative care needs are often complex, even in isolation of other factors. Diseases such as liver failure and acquired immune deficiency syndrome (AIDS), more common amongst homeless and vulnerably housed people, follow unpredictable courses, often require frequent hospital admissions, and present high symptomatic burden.[19,30,40,57,60,64,71]

These factors are often compounded by late presentation due to care-avoidance,[39,72] often based around negative previous experiences, fears of stigma, the assumption that needs-based care will not be offered, and competing priorities.[39] The complexity of these cases is increased by the frequent concurrence of other physical illness (e.g. human immunodeficiency virus (HIV), AIDS, hepatitis, tuberculosis, sexually transmitted infections), psychiatric conditions,[30] and addiction.[11,64,66]

Hostel, social, addiction, and harm-reduction workers may be well placed to pick up on deteriorating condition, even when palliative care services have not specifically been sought; but they can only do so if they know what to look out for, and how to act upon it.[40,58,68] Even with training, it can be difficult to identify deterioration in homeless and vulnerably housed people, because of the nature of underlying pathology, physical, psychiatric, and substance related co-morbidities, and irregular or incongruous interactions with services.[8,39,40]

There are further practicalities to consider around difficulties with medications.[67] Some may not have access to food and water to take with oral medication, the ability to keep skin clean enough for topical administration, or a secure place or refrigerator to store medication safely.[68] Frequent dispensing of small quantities of long-acting medication may help alleviate these difficulties.[73]

Mental health conditions, concomitant illicit drug use, and language barriers may make communication difficult; open, honest, clear, precise, and structured communication is key to addressing this.[45,58]

Non-Clinical Complexity

Palliative care may have to be provided amid apparent “social dis-organisation”, [68] and those addressing the palliative care needs of homeless and vulnerably housed people are not always aware of what the competing needs that create this picture may be.[8,11,39] Competing needs can lead to “non-compliance”; however, “compliance” with non-holistic decisions may be unpreferable, or even impossible. “Selling” the benefits of patient centred EOLC may help overcome minor conflicts of preference,[72] but will not overcome competing priorities around basic needs; housing, food, hygiene and security; if these remain unaddressed then engagement with services is unlikely to succeed.[34,74] Occasionally, service providers have excluded people from services until they have met these needs themselves;[39,75,76] leaving homeless and vulnerably housed people locked out of services, until they have overcome any addiction, functional limitations, or forensic history, all whilst dealing with the complications that potentially unmanaged symptoms present.

Harm-reduction outreach workers have been used in Canada to address basic needs at EOL.[58] Even where it is not possible to address these needs, a flexible, pragmatic, and goal-orientated approach to care is required, considerate of the broad scope of an individual’s specific needs, and open to harm-reduction approaches.[41,45,58,77] Health and social care professionals are not always familiar with the specific needs of homeless and vulnerably housed people; open communication can help address these knowledge gaps.[42,43,65]

Multi-agency working, essential in addressing knowledge gaps,[44] is made difficult through fragmented services,[18] and the more agencies involved, the greater the chances for discontinuities between care,[75,76] an issue not limited to USA studies, but also highlighted within the UK.[8] Further, more practical problems may be presented by multi-agency working, for example community resources may not be able to meet regulations required for collaborative care.[76] All of this can be compounded by the fact that homeless and vulnerably housed people may lack the health and institutional literacy to translate information about their own situation between disconnected organisations.[13] Joined-up partnership care is required,[71] within this, there is need for discharge services to improve co-ordination of care,[6,13] and there is need for in-reach,[19] or outreach,[71] of services.

Harm-reduction

Illicit drug use may act as a competing priority to engagement with EOLC, experiences of systematic and individual prejudice may reduce trust in health and social-care, and “internalised discrimination” may affect self-worth to such an extent that help is not sought.[78] There may be professional mistrust of those with a history of substance abuse, especially around the prescription of sedatives and opioids.[68] Healthcare professionals have treated illicit drug users with “blame and even hostility”, withholding analgesia in contraindication to patient need.[65,76] Some of this behaviour may be founded on concerns that prescription drugs may be sold to support competing priorities such as addiction;[68,72,76] this should not be viewed as evidence to withhold treatment, but as evidence to support a holistic harm-reduction approach to care. Those receiving care may have high tolerance for analgesics, which can lead to hesitancy in prescribing doses adequate to control pain.[78] An open and honest history of previous opioid use could address these concerns.

Those directly under the influence of drugs and alcohol may be especially difficult to engage.[61] However, even if homeless and vulnerably housed people do engage in EOLC services, addiction may act as a direct contraindication to EOLC, with institutions having inflexible rules around drug use,[78] and failing to comply with harm-reduction methods.[43] This may apply to palliative care institutions,[43,58] as well as supporting institutions such as housing initiatives that insist on sobriety.[75,76] Strict legislation can lead to non-disclosure, increasing the risk of adverse drug reactions, the risk of sub-optimal opioid dosing, and making it harder to understand changes in behaviour and health status.[78] Beyond this, it can reinforce institutional mistrust, and prevent the honest relationship between patient and carer desired by both parties.[9] Non-disclosure may be managed through open discussion of thorough substance and pain histories, and subsequent

multidisciplinary management,[68] an approach homeless and vulnerably housed people have expressed a preference for.[9]

Substance abuse, a common issue for homeless and vulnerably housed people,[11,64,66] highlights how individual and organisational stigma and lack of a harm-reduction approach make it very difficult for some homeless and vulnerably housed people to receive palliative care.[31,39,58,78] The harm-reduction approach required to manage substance abuse at EOL could offer wider benefits. The non-clinical complexity of EOLC for homeless and vulnerably housed people may seem insurmountable, and palliative care services cannot solve all these competing problems. However, even where people may continue to abuse substances, live in unsuitable environments, or make choices that might seem hard to comprehend without an understanding of an individual's life up to that point, palliative care services need to find a way to provide holistic palliative care.

DISCUSSION

Research Coverage

This review synthesises information from 2117 homeless and vulnerably housed people, much of it qualitative, in combination with the perspectives of those involved in the provision of EOLC, whether palliative care professionals or not.

The body of research contains a wide array of qualitative and observational methods, which has led to good understanding of what the challenges around providing palliative care for homeless and vulnerably housed people are, and why they might exist. Although focussed primarily on ACP and AD, interventional work has taken this knowledge further, to design and evaluate specific interventions. Further qualitative and quantitative (including economic evaluations) research around what works in co-producing services is now required. Given the value of both granular information, and insight from those directly involved in palliative care for homeless and vulnerably housed people it is important that academic and more “practical” spheres are not tangential. The work of third-sector organisations such as Hospice UK and St. Mungo’s are vital in transforming both research into practice, and practice into research.

The ETHOS light categories used highlight the breadth of the homeless and vulnerably housed population. However, the research focusses most on those living in hostels and shelters, which may not match the distribution of homelessness seen in the wider population. For example, in the UK those in category 2 and 3 are overrepresented, whilst those in categories 4, 5, and 6 are underrepresented compared to available national estimates.[79–82] The definition of homelessness used for this review is not universal, groups considered homeless and vulnerably housed under ETHOS criteria such as Travellers have been considered both in research,[83] and in guidelines outside of the “homelessness” umbrella.[7] However, other groups such as “squatters” and “sofa surfers” appear more absent in the body of evidence. Even within ETHOS categories 2 and 3, the literature focussed on models of care using hostels and shelters,[27,42,45] which does not necessarily reflect the nature of all temporary accommodation.

Globally, all of the research comes from developed nations such as the USA, Canada, and the UK. However, homeless and vulnerably housed populations are largest in developing nations, where palliative care services may also be less developed.[1] The language restrictions used in searching the literature may have led to potential exclusion of literature from some parts of the developing world, but cannot explain the lack of work identified from English speaking developing nations.

Limitations

Conclusions and recommendations made are generated from the evidence considered, although included articles have not been systematically appraised.

Methodological frameworks have been applied largely as intended,[16,17,84] although a degree of synthesis has occurred beyond the remit of a scoping review as described by Arksey and O'Malley. This has been justified by both the choice of exploratory qualitative methods employed, and in the cautious interpretation of the thematic synthesis as a well described map of knowledge. Similarly, a pragmatic interpretation of Thomas and Hardy's thematic synthesis framework was used to accommodate the resources available for the review. This may increase the potential for reflexivity and subjective biases to influence thematic synthesis.

The ETHOS categories were often not possible to apply, this was rarely a fault of the framework, and more often from inadequate reporting. Wider application of the ETHOS framework elsewhere in the literature may help draw attention to often neglected groups such as Travellers and sofa-surfers, however this review's reliance on others to describe these groups as "homeless", may in this case have contributed to their exclusion.

The analytical thematic construction used for the thematic synthesis has led to the deliberate omission of themes seen elsewhere in the literature. For example, the descriptive theme often seen around "barriers" has been explored across all themes as a product of the way experience, beliefs and wishes, relationships, and the complexities of EOLC interact to shape behaviours and the realities of care.

Recommendations

At service provision level there is a need for consistent, flexible, multi-disciplinary, open, respectful, and non-judgemental care. Although these values are held in high regard by clinical professionals, it seems that when it comes to the palliative care needs of homeless and vulnerably housed people they have at times been neglected. Care should be provided in a needs-based and personalised manner, avoiding paternalistic restrictions on freedom, autonomy, and dignity that have long been associated with health and social care systems.

At an organisational level there is a need for co-production, combining expertise in palliative care, expertise in the care of homeless and vulnerably housed people, and expertise from homeless and vulnerably housed people and their social networks. These are not novel ideas within palliative care, but again they seem to have been underutilised. Similarly, interventions need to use existing relationships, support networks, and safe environments. This approach must be considerate and consistent; the bridges that hostels, social, harm-reduction and primary care services have built with

homeless and vulnerably housed people have been slow to construct but can be quick to fall if misused.

For researchers, the unified messages contained in the review may validate the emphasis on qualitative literature, although this is well complemented by observational, interventional, and review-literature. Whatever shape research takes, the perspectives of those directly involved in care are essential. Coverage of the literature is far from universal, with the most noticeable gap being around research in the developing world; to aid future models of palliative care for the entire homeless and vulnerably housed population, attempts are needed to address this.

CONCLUSION

A rich, but not yet fully complete, evidence base is developing to understand why the needs of homeless and vulnerably housed people may not be met by the way palliative care services are currently configured.

The beliefs, wishes, and experiences of homeless and vulnerably housed people may not be addressed by existing services, re-enforcing feelings of disenfranchisement and discrimination. Where positive relationships do exist between services users and providers, they may be undervalued, or under-supported. Finally, those providing EOLC may be unfamiliar and uncomfortable in managing the additional complications homelessness creates.

There are implications at a service provision, organisational, and research level, although the overarching message is a need for these strands to unite with the voices behind the included research to transform available knowledge into practical and evaluable action.

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FIGURE LEGENDS

Figure 1: PRISMA flowchart [22]

FIGURE 2: PRISMA FLOWCHART .[22]

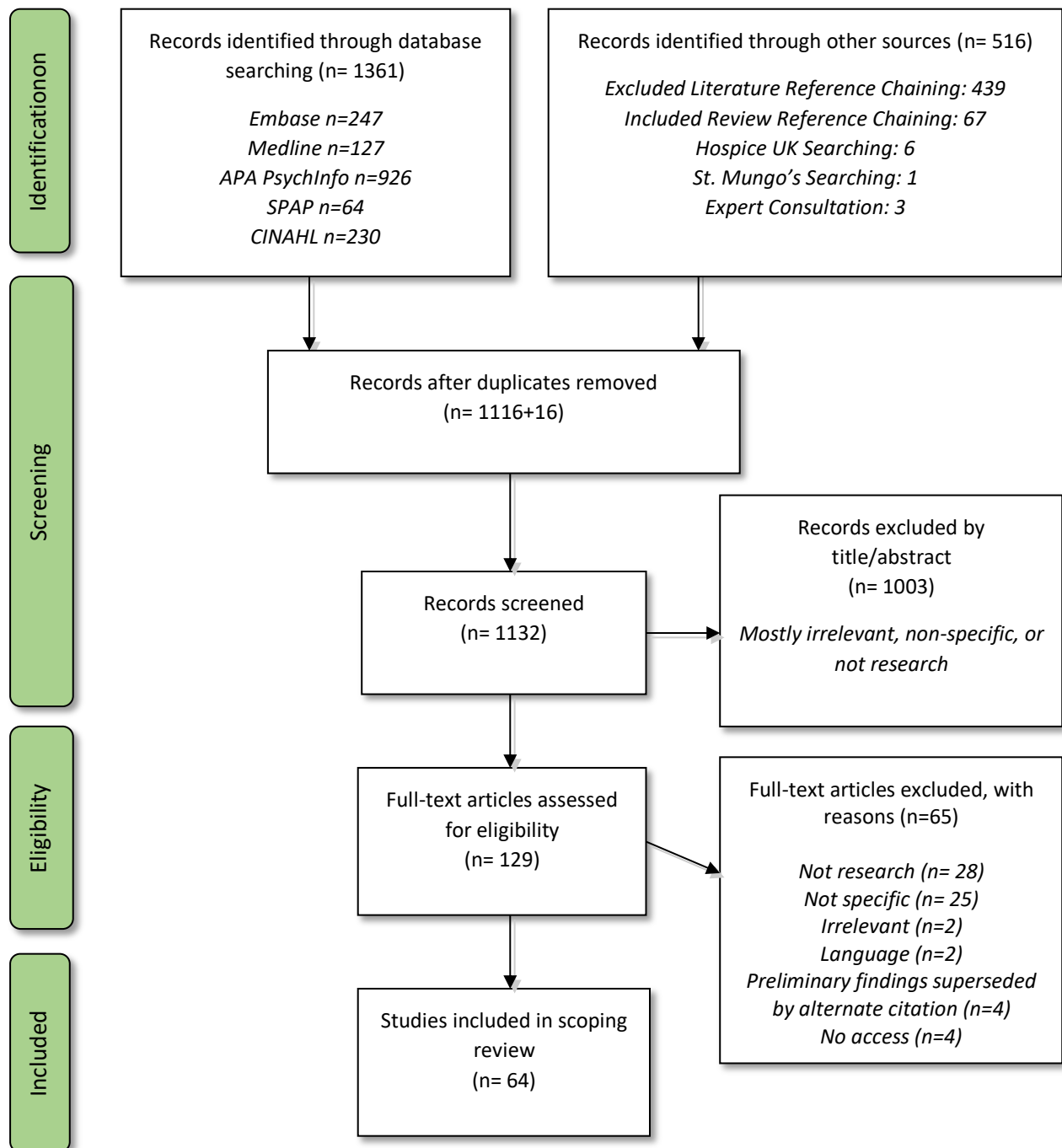


TABLE 3: DATA CHARTING

ETHOS Light category of any homeless and vulnerably housed people was extrapolated and listed on nested tables as 1-6, or unknown.[20] The upper row is ETHOS category (1-6) and the second row provides the count for each category. Participants from other sources were then also described. If perspectives other than those of the participants were also involved, this too was noted. Given the mixed methods employed, “design” covered both the methods of gathering primary and secondary data, as well as any subsequent descriptive or analytical processes this data was taken through. The location of the study was recorded, this was the location of the primary author’s institution; it has been stated if component data was from an additional or alternate country, aside from the multi-national review articles described in Table 4. Aims and objectives were, where possible, copied directly from the literature. Where this was not possible aims and objectives were extracted from available narrative. In some cases, it was not possible to establish the aims and objectives of research, in these cases this fact is stated. Key themes, headings, and outcomes, as well as conclusions and recommendations were compiled in a similar manner.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
McGrath, 1986 [55] <i>Peer Reviewed Journal Article</i>	1 8	2	3	4	5	6	Interviews with social network analysis	USA	Understand the social networks of those living on “Skid Row” and their potential for EOL support.	The men in this study shared many similarities in lifestyle and had small, highly dense networks.	Although it was of a limited nature, social support did exist within the networks analysed.
Wright, Wright and Jones, 1999 [27] <i>Peer Reviewed Journal Article</i>	1	2 or 3 6		4	5	6	Case Series with unstructured interviews	USA	To provide “an integrated examination of the process of death among the homeless and the integral role that shelter staff and residents play in this process”.	<ul style="list-style-type: none">• The role of shelter staff as advocates, legal guardians, and friends where other friends and family cannot be found• Stigma around homelessness, and conditions associated with homelessness such as HIV• The role that premature and often violent death plays in the lives of homeless people and shelter workers• The need for bereavement support for homeless people and shelter workers	<ul style="list-style-type: none">• Shelter staff need to be trained to deal with EOL illnesses and death• Shelter staff need to be trained to counsel bereaved residents, and potentially their friends and families• Need for community support around EOL for homeless people
Derema, 2005 [70] <i>Peer Reviewed Journal Article</i>	1 1	2	3	4	5	6	Case Study with written response statements	USA	Explore case study to learn lessons for EOLC.	<ul style="list-style-type: none">• Potential to adapt “hospice at home” care to those who chose to remain living on the streets• Holistic approach taken once patient admitted to hospice to include the homeless community they saw as “family”.	Requirement for holistic care at EOL and education of hospice workers around homelessness.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Song et al., 2005 [28] <i>Peer Reviewed Journal Article</i>	1	2, 3 and 5			1	6	Focus groups, semi-structured interviews and framework analysis	USA	<ul style="list-style-type: none">• To understand whether homeless people want to discuss death and EOLC, whether concerns align with the wider literature• To “inform the development of a larger investigation into the issue	<ul style="list-style-type: none">• Context of death• Concerns and fears about dying• Barriers to care and EOLC• Interpersonal relationships, models, and communication• The meaning of life and death	<ul style="list-style-type: none">• Homeless people want to talk about “EOLC, dying, and death”• Concerns are not always described in the literature• Further research is required with a “larger and broader sample”
Tarzian, Neal and O’neil 2005 [33] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Focus groups and thematic analysis	USA	To increase Health Care Professionals' awareness and understanding of homeless or similarly marginalized individuals' EOL experiences and treatment preferences.	<ul style="list-style-type: none">• Valuing an individual’s wishes• Acknowledging emotions• The primacy of religious beliefs and spiritual experience• Seeking relationship—centred care• Reframing ACP	<ul style="list-style-type: none">• Relationship-centred care, characterized by compassion and respectful, two-way communication, was obvious by its described absence• Recommendations for reframing ACP include ways for HCPs to transform ACP from that of a legal document to a process of goal setting that is grounded in human connection, respect, and understanding
Kushel and Miaskowski, 2006 [68] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Case Study with unstructured interviews	USA	To discuss the challenges faced providing palliative care to those experiencing homelessness.	<ul style="list-style-type: none">• The chronically homeless at the EOL• Homeless patients in the health care system• Delivering palliative care amid social disorganisation• Shelter and housing options• Medication adherence• Pain management• Ongoing monitoring for effective pain management• Legal issues• Goals for care• Where to die• Palliative care services in public hospitals• Surrogate family: decision making in the absence of family and friends	Clinicians can develop good relationships with individuals experiencing homelessness.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Podymow, Turnbull and Coyle, 2006 [64] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Retrospective cross-sectional analysis with cost comparison	Canada	Test the hypothesis that effective shelter-based palliative care could be provided to terminally ill homeless individuals at substantial cost savings.	<ul style="list-style-type: none"> • Average length of stay 120 days, most frequent diagnoses liver disease, HIV/AIDS and malignancy. • Addiction to drugs/alcohol in 82% of patients. • Continuous opiates required for pain in 71% of patients. • The hospice projected \$1.39 million savings for the patients described 	<ul style="list-style-type: none"> • The homeless terminally ill have a heavy burden of disease including physical illness, psychiatric conditions, and addictions • Shelter-based palliative care can provide effective EOLC to terminally ill homeless individuals at potentially substantial cost savings
Song et al., 2007[29] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Focus groups, semi-structured interviews, and thematic analysis	USA	To explore the experiences and attitudes toward death and dying among homeless persons.	Personal: <ul style="list-style-type: none"> • Early Loss • Experiences with death • Life threatening experiences • Fear and uncertainty • Coping mechanisms • Risk perception Relationship: <ul style="list-style-type: none"> • Distrust in health-care professionals 	<ul style="list-style-type: none"> • Importance of previous experiences of death on perceptions and behaviours around EOLC • Homeless populations may feel disenfranchised with services/healthcare
Song et al., 2007 [32] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Focus groups and thematic analysis	USA	Explore the concerns and desires for EOLC among homeless persons.	Personal: <ul style="list-style-type: none"> • Experience with EOLC • Fears and uncertainties • Preference, wishes, and hopes • ACP • Spirituality/religion • Veteran status Relational themes: <ul style="list-style-type: none"> • Relationships with known people/burden to others • Relationships with strangers • Communication tools/strategies Environmental: <ul style="list-style-type: none"> • Barriers/facilitators to good EOLC • Participant-suggested interventions 	Homeless persons have significant personal experience and feelings about death, dying, and EOLC, much of which is different from those previously described in the EOL literature about other populations.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Bartels et al., 2008 [90] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Qualitative analysis of participants' responses to individual items in an AD	USA	To know more about the content of ADs completed by homeless people who participated in a guided AD intervention of a pilot adding "dignity therapy" to ADs in Minnesota.	Intervention developed around existing framework: <ul style="list-style-type: none"> • Generativity: the sense that one's life has stood for something • Continuity of self: a sense that one's essence is intact despite advancing illness • Role preservation: a sense of identification with previously held roles • Hopefulness: ability to maintain a sense of meaning and purpose • Concerns regarding the aftermath of death • Tenor of care: the attitude and manner with which others interact 	<ul style="list-style-type: none"> • Homeless and vulnerably housed people were interested and compliant in completing AD • Homeless and vulnerably housed people had concerns about physical and psychological distress, in line with hospice patient's concerns • Enhanced ADs may help both homeless and vulnerably housed people and clinicians
Song et al., 2008 [52] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Prospective non-blinded randomised trial	USA	<ul style="list-style-type: none"> • Will homeless people complete AD if given the opportunity? • Does completion of AD change knowledge and beliefs? 	<ul style="list-style-type: none"> • There was insignificant increased AD completion in counsellor guided groups compared to self-guided groups • AD completion was associated with an insignificant increase in knowledge around EOLC • Those completing AD were significantly more likely to write down and discuss EOL wishes 	Homeless people are interesting in and worried about EOL and can be engaged in completion of AD whether counsellor or self-guided.
Song, 2010 [51] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Prospective single-blinded randomised trial	USA	To determine whether homeless persons will complete a counselling session on ACP and fill out a legal AD designed to assess care preferences and preserve the dignity of marginalised persons.	<ul style="list-style-type: none"> • Significantly higher rate of AD completion in counsellor led groups compared to self-guided groups. • Preference for surrogate decision making. 	Homeless persons can respond to an intervention to plan for EOLC and can express specific preferences for care or a surrogate decision maker, but additional studies are needed to assess the effect of these directives on subsequent care.
Suen, 2010 [47] <i>Conference Proceedings</i>	1	2 or 3	4	5	6	Case Study		USA	"Discuss how to increase awareness and understanding of homeless patients' decision-making preferences in EOLC" and "identify medical and social barriers that may affect AD discussions in homeless patients.	The case discusses the difficulties in AD throughout the care of a man with terminal rectal cancer.	The homeless may want to make their EOLC decisions similar to how they live their lives: in the moment.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)	Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Davis et al., 2011 [40] <i>Third Sector Report</i>	1 2 3 4 5 6 24 2 1 ETHOS UNKNOWN Homeless service workers (n=13)	Case note audit, focus group with structured interviews	UK	To identify the observed changes in physical condition or behaviour of homeless people with liver disease who may be in deteriorating health and approaching the EOL.	<ul style="list-style-type: none"> • Liver disease is a common cause of death for homeless people, leads to a high rate of admissions, significant morbidity, and distress in the last six months of life • Complex needs, including physical, psychological, social, and substance misuse issues, hamper care • The course of liver failure can be unpredictable, especially towards EOL, and deaths can occur suddenly • Often poor symptomatic control 	<ul style="list-style-type: none"> • Training for staff working with homeless people to provide support as health deteriorates and death approaches. • An EOLC resource pack was produced • Access to tailored bereavement services • Maintenance of the role of the Palliative Care Co-ordinator • Further qualitative and economic research • New innovative services and service configurations
Jaspers et al., 2012 [38] <i>Conference Proceedings</i>	1 2 3 4 5 6 • 15 ETHOS UNKNOWN	Semi-structured interviews and thematic analysis	Germany	To explore wishes in order to identify themes which could be important for a needs-based provision of EOLC.	<ul style="list-style-type: none"> • Life prolonging treatment • Suicide • Dying alone • Romantic freedom • Dignified death • Being remembered • Pain • Trust in professionals/welfare state • Awareness of death • Emotional coldness 	<ul style="list-style-type: none"> • Common themes underpinned by autonomy, dignity, trust, and fatalism • Both similarities and differences in wishes and beliefs of German homeless people when compared to those seen in US studies [29]
McNeil, Guirguis-Younger and Dilley, 2012 [77] <i>Peer Reviewed Journal Article</i>	Health and social care professionals (n=54)	Semi-structured interviews with thematic analysis	Canada	To identify barriers to the EOLC system for homeless populations and generate recommendations to improve their access to end-of-life care.	<p>Barriers:</p> <ul style="list-style-type: none"> • Insufficient availability of EOL services • Exclusionary operating procedures • Poor continuity of care <p>Participant recommendations:</p> <ul style="list-style-type: none"> • Adopting low-threshold strategies • Linking with population-specific health and social care providers • Strengthening population-specific training 	<ul style="list-style-type: none"> • Homeless persons may be underserved by the EOLC system because of barriers that they face to accessing end-of-life care services. • Changes in the rules and regulations that reflect the health needs and circumstances of homeless persons and measures to improve continuity of care have the potential to address this.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)	Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
McNeil and Guirguis-Younger, 2012 [78] <i>Peer Reviewed Journal Article</i>	Health and social care professionals (n=50)	Semi-structured interviews with thematic analysis	Canada	To explore the challenges of end-of-life care services to homeless illicit drug users based on data collected during a national study on end-of-life care services delivery to homeless persons in Canada.	Barriers to access <ul style="list-style-type: none"> • Competing priorities • Lack of trust in healthcare providers • Discrimination Challenges to EOLC services delivery <ul style="list-style-type: none"> • Non-disclosure of illicit drug use • Pain and symptom management • Interruptions in care • Lack of experience with addictions 	There is a need for increased research on the role of harm-reduction in end-of-life care settings to address these challenges.
McNeil et al., 2012 [58] <i>Peer Reviewed Journal Article</i>	Health and social care professionals (n=54)	Semi-structured interviews with thematic analysis	Canada	To explore the role of harm reduction services in end-of-life care services delivery to homeless and marginally housed persons who use alcohol and/or illicit drugs.	<ul style="list-style-type: none"> • Harm reduction services are a critical point of entry to EOLC • Harm reduction services provided EOLC and support, increased autonomy, and improved quality-of-life 	While partnerships between harm reduction programs and end-of-life care services are identified as one way to improve access, it is noted that more comprehensive harm reduction services might be needed in end-of-life care settings.
Krakowsky et al., 2013 [43] <i>Peer Reviewed Journal Article</i>	Nurses (n=3) Outreach providers (n=4)	Semi-structured interviews with thematic analysis	Canada	To examine how a major urban city's palliative care resources can be improved to increase access and better serve the homeless.	<ul style="list-style-type: none"> • Access to palliative care compromised by non-adherence to harm reduction strategies and homeless individuals not trusting care providers • Access to palliative care restricted, with available staff unable to discuss EOL or issues around homelessness • Palliative services must respect patient's wishes • Diverse offering of care: hospital based; shelter based; and street based. 	<ul style="list-style-type: none"> • Increasing positive interaction between the health care system and the homeless • Training staff to deal with the unique issues confronting the homeless • Providing patient-centred care • Diversifying the methods of delivery
Walsh, 2013 [74] <i>Third Sector Report</i>	1 2 3 4 5 6 3 People with homeless experience (n=13) Policy makes (n=3) • Palliative care (n=5) • Researchers (n=5)	Expert consultation and unstructured interviews	ROI [Data also from UK]	To influence policy and practice responses to the needs of older people who are homeless as they age and are faced with the issues of serious ill health, dying and death.	Key needs identified included: <ul style="list-style-type: none"> • Access to appropriate health care. • Services which contribute to good health and well-being. • EOLC. • Suitable and stable accommodation and accommodation support. • Information and research. 	Recommendations specific to EOLC included the need to raise awareness of homeless needs, enhance access to palliative care, and ensure palliative care beds are made accessible to people who are homeless.
Ko and Nelson-Becker, 2014 [34] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 21	Structured interviews with grounded theory analysis	USA	To understand the perspectives, needs, and concerns relating to ACP among older homeless Adults.	<ul style="list-style-type: none"> • The EOL topic is uncomfortable • God plans EOLC • Physicians are preferred as decision makers • The EOLC is not a priority • Approach homeless people with sensitivity 	Efforts to promote ACP need to include exploring a potential health care proxy, providing resources, and planning in accordance with needs, and developing rapport.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Leung et al., 2014 [98] <i>Peer Reviewed Journal Article</i>	1	2 or 3	4	5	6	205	Single group intervention study	Canada	To determine the acceptability of a counsellor-guided intervention for the completion of ADs among chronically homeless individuals.	<ul style="list-style-type: none"> • 50.2% Completed an AD when offered the chance to do so with a counsellor • Routinely used predictors of AD completion were not linked to likelihood of completion • Completion more likely in participants who regularly thought about death, valued friends and family, or had pre-existing wishes about E-o-L care 	A single-encounter, one-on-one counsellor-guided intervention can achieve a high rate of AD completion among chronically homeless individuals.
MacWilliams et al., 2014 [72] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Case study with semi-structured interviews	Australia	<ul style="list-style-type: none"> • To identify best practice for managing the palliative care needs of clients experiencing homelessness in a community setting • To guide the development of policies for a community-based palliative care service working with these clients 	<ul style="list-style-type: none"> • Late stage presentation and multiple admissions • Safe use of drugs • Non-compliance • Staff stress 	A flexible, compassionate, and coordinated response is required, and more work is needed to explore how the needs of this group can be met.
Ko, Kwak and Nelson-Becker, 2015 [35] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Structured interviews with grounded theory analysis	USA	To explore perspectives of older homeless people around what constitutes a good and bad death.	<p>What constitutes a good death:</p> <ul style="list-style-type: none"> • Dying peacefully • Not suffering • Experiencing spiritual connection • Making amends with significant others <p>What constitutes a bad death:</p> <ul style="list-style-type: none"> • Experiencing death by accident or violence • Prolonging life with life supports • Becoming dependent while entering a dying trajectory • Dying alone 	It is important for healthcare, case management, and other professionals to support the dignity and learn the desires of elderly homeless people.
Leung et al., 2015 [53] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Cross-sectional survey	Canada	To determine the rate of AD completion using a counsellor-guided intervention, identify characteristics associated with AD completion and describe EOLC preferences in a group of chronically homeless individuals.	<ul style="list-style-type: none"> • 50% chose to complete an AD, with no association with socio-demographic characteristics, health status, or health care use. • More likely to complete an AD if thinking about death, or already knew wishes around EOL 	<ul style="list-style-type: none"> • A counsellor-guided intervention can achieve a high rate of AD completion among chronically homeless persons. • Most participants expressed a preference to receive cardiopulmonary resuscitation in the event of a cardiorespiratory arrest.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)	Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Webb, 2015 [42] <i>Peer Reviewed Journal Article</i>	Hostel workers (n=7)	Semi-structured interviews with phenomenology	UK	Understand the views of hostel workers around hostel based palliative care.	<ul style="list-style-type: none"> • Understanding palliative care • Working with limited medical information • Taking responsibility • Building rapport • Upholding residents' dignity • Recognising physical deterioration • Managing environmental challenges • Role limitations and support needs of hostel staff 	<ul style="list-style-type: none"> • Hostel workers are the most appropriate people to support a dying homeless person, however enhanced collaborative working with health professionals is needed.
Care Quality Commission, 2016 [66] <i>Public Sector Report</i>	1 2 3 4 5 6 2	Case series	UK	To support organisational goals around reducing inequalities in EOLC for people who are homeless.	<ul style="list-style-type: none"> • Lack of awareness • Poor physical healthcare • Unequal access to care 	Commissioners and providers to: <ul style="list-style-type: none"> • Recognise and address the EOL needs of homeless people. • Support early identification of EOL in people who are homeless
Binkley, Davila and Sanchez-Reilly, 2016 [50] <i>Conference Proceedings</i>	Before/After: Homeless/Domiciled Veterans (ETHOS UNKNOWN n=19) Non-Veteran Homeless (ETHOS UNKNOWN n=16) Cohort: Homeless Veterans (ETHOS UNKNOWN n=106)	Before/after intervention study with included retrospective cohort study Cohort comparator: Domiciled Veterans (n=99)	USA	To assess effects of a short in-person educational intervention around ACP.	<p>Increased completion of ADs amongst homeless and domiciled veterans but not non-veteran homeless following brief intervention.</p> <p><i>No discussion of cohort component of study beyond results – has therefore been “coded” as a before/after interventional study.</i></p>	Very brief educational intervention not sufficient at addressing ACP needs of homeless populations.
Davis-Berman, 2016 [65] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 4 Healthcare professionals (n=2) Social workers (n=4) Funeral director (n=1) Administrators and managers (n=3)	Semi-structured interviews with key informant needs analysis	USA	To examine EOL services and barriers to EOL services for homeless and vulnerably housed people in a Midwestern US city.	<ul style="list-style-type: none"> • Lack of services for serious, chronic, and life-threatening illnesses • Barriers to access to services • Stigma • EOLC 	<ul style="list-style-type: none"> • Education and support for social workers • Better partnership working • Improved hospice involvement • Alternative creative models to deliver care
Håkanson et al., 2016 [45] <i>Peer Reviewed Journal Article</i>	Healthcare/social care workers (n=12)	Case study with reflective conversations	Sweden	To explore the staff members' experiences of and reasoning about the palliative care they provided in a medical and social support home.	<p>Conditional Factors Framing Palliative Care:</p> <ul style="list-style-type: none"> • Building Trustful and Family-Like Relationships • Re-Dignifying the Person • Re-Considering Communication About Illness and Dying • Re-Defining Flexible and Pragmatic Care Solutions 	Recommend intervention based around the conditional framing approach outlined and encourage investigations of experiential outcomes of this approach.

Authors and Year	Participants/Perspective (ETHOS categories 1-6)						Design	Location	Aims/Objectives	Key Themes, Headings, and/or Outcomes	Conclusions/Recommendations
Hudson and McQuillan, 2016 [57] <i>Conference Proceedings</i>	1	2	3	4	5	6	Case series	ROI	To review the deaths of hostel dwellers receiving specialist palliative care (SPC) from a Dublin service.	<ul style="list-style-type: none"> • 50% patients died in hospital, 35% died in hospice, 15% died in hostel • Average of 8 symptoms, pain, constipation, and anxiety most common • 75% misused substances, 70% had poor compliance, 50% estranged from family. • Hostel staff concerned about symptoms and drug safety • SPC staff concerned about symptoms, compliance, and estrangement 	<ul style="list-style-type: none"> • Low rates of referral to SPC • Complex needs • Hostel staff, primary care and SPC providers need additional support
Hudson et al., 2016 [6] <i>Peer Reviewed Journal Article</i>	13 articles, reporting 9 studies <i>See Table 4 for further information</i>						Systematic review of qualitative research with thematic synthesis	UK <i>[Articles from USA, UK, Canada, Sweden, Australia]</i>	To provide a deeper understanding of the challenges to and suggestions for palliative care access and delivery for homeless people.	<p>Challenges related to the chaotic lifestyles associated with being homeless:</p> <ul style="list-style-type: none"> • Death in the day to day context of homelessness • Attitudes to health care; substance misuse & competing priorities <p>Challenges to the delivery of EOLC and specialized palliative care within a hostel The</p> <ul style="list-style-type: none"> • The hostel environment • Practical and emotional burdens for staff <p>Challenges to the provision of palliative care to homeless persons relating to mainstream health care systems</p> <ul style="list-style-type: none"> • Inflexibility of health care service and limited planning • Health care professional's attitudes and inexperience in supporting homeless people 	Greater needs of homeless populations because of a varied range of individual and systemic factors.

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Hutt et al., 2016 [75] <i>Conference Proceedings</i>	1 2 3 4 5 6 n=? ETHOS UNCLEAR Multidisciplinary providers (n=?) Community and veteran administration leaders (n=?)	Interviews and focus groups	USA	<ul style="list-style-type: none"> Describe current services and perceived challenges of caring for HV at EOL by surveying existing Veterans Administration (VA), homeless Veterans, and EOL programs Develop a deep and broad understanding of the issues, barriers and facilitators to excellent EOLC for HV Define the key structural, clinical and policy elements required to deliver excellent care to HV at EOL 	<ul style="list-style-type: none"> While declining health of HV prevents independent living or realistic plans to abstain, housing options are too often limited to places that insist on functional independence and sobriety Pain management within the context of addiction, unstable housing, and behavioural health problems are challenging Discontinuities within and between systems restricts care delivery Veteran administration regulations pose significant challenges to collaboration with community providers Care providers for HV at EOL must compete for attention and resources with other pressing challenges within VA 	Lack of housing suited to HV with rapidly declining health and isolation of homeless and EOL providers from each other are among the most pressing challenges.
Nash et al., 2016 [99] <i>Peer Reviewed Journal Article</i>	Nursing Students (n=15)	Survey with naturalistic narrative synthesis	USA	Do baccalaureate nursing students require moral courage to help homeless persons complete advance directives?	Nursing students were afraid of: <ul style="list-style-type: none"> Their behaviour been perceived as inappropriate Discussing a homeless person's death The challenge of discussing and recording ADs 	<ul style="list-style-type: none"> Nursing students do require moral courage. Homeless and vulnerably housed people are misunderstood and marginalised, training nurses may help address this problem
Vivat et al., 2016 [46] <i>Conference Proceedings</i>	People with experience of homelessness (n=8)	Semi-structured interviews and focus groups	UK	Explore the thoughts and personal experiences of homeless people regarding EOLC and ACP	Priority around professionals providing compassionate and hopeful care to build trust prior to discussing ACP	Homeless people need compassionate care, not ACP, unless EOL is imminent.

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Care Quality Commission, 2017 [8] <i>Public Sector Report (Underlying discussion is based around the findings of [19] however, there are novel cases/analysis warranting inclusion)</i>	1	2	3	4	5	6	Case series with expert consultation	UK	To support organisational goals: to improve the quality of health care for these groups of people by setting standards and supporting services so that generosity, kindness, and compassion combine with a passionate commitment to professional quality to become the defining characteristics of health services for homeless and multiply disadvantaged people.	Reducing inequalities for homeless people: <ul style="list-style-type: none"> • Lack of awareness of the extent of the problem • Poor continuity of care • Promoting access and continuity of care Knowledge, skills, and support: <ul style="list-style-type: none"> • Lack of recognition or action on deteriorating health • Lack of understanding of a person's individual context and needs • Challenges of exploring EOL wishes with homeless people The role of hospices in championing equality.	<ul style="list-style-type: none"> • Homeless people may die in hostels because of a lack of alternatives, cared for by hostel staff ill equipped to manage. • Conversations about preferences around EOL need to begin earlier and become more holistic. • There is a need for greater multi-disciplinary working, extended in-reach into hostels, and training for different professional groups.
Cole, 2017 [61] <i>News article interview</i>	1	2	3	4	5	6	Case study	UK	Unstated.	<ul style="list-style-type: none"> • Difficulties in having conversations with people often under the influence of drugs and alcohol • Hostel staff difficulties in caring for people at EOL • Bereavement following the death of a homeless person 	The possibility of positive outcomes in respecting wishes around death for homeless people.
Dubbert et al., 2017[48] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Cross-sectional study with sub-group comparisons, and comparisons to comparator studies.	USA	To learn about previous experience of homeless people with different steps of advance health care planning and personal goals for future steps.	<ul style="list-style-type: none"> • 70% had thought about AD, but on 26% had a documented AD on record • Older veterans and those in urban environments more likely to have AD documented than younger veterans and those living in rural environments • BAME groups were less likely to have AD than white groups 	Need for improved communication and documentation of veteran preferences about emergency and EOLC.
Henry et al., 2017 [44] <i>Peer Reviewed Journal Article</i>	Policies (n=2)						Policy analysis	Canada	To look at the current data concerning known disparities in access to good palliative care services experienced by the homeless population.	Barriers, gaps, and challenges: <ul style="list-style-type: none"> • Impaired trust and respect • Justice: when the palliative care system is the problem • Palliative care as a public health issues: necessity, proportionality, and least infringement 	<ul style="list-style-type: none"> • System-wide structural changes to effectively remove barriers and to add the necessary services in the right places are needed • A public health approach is required to improve palliative care delivery • Care integration and partnerships with homeless shelters and various service providers are crucial in bringing palliative care services to the places where homeless people feel most comfortable—in their home communities, as defined by them

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Hudson et al, 2017 [19] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 28 ETHOS UNCLEAR People with homeless experience (n=10) Health and social-care providers (n=48) Hostel staff (n=30) Outreach staff (n=10)	Focus groups, interviews, and thematic analysis	UK	To explore the views and experiences of people who are homeless and those supporting them regarding conversations and approaches to palliative care.	<ul style="list-style-type: none"> • Attitudes to health • Focus on recovery • Fear of impact on homeless person and staff • Uncertainty 	<ul style="list-style-type: none"> • Need for novel approaches to support homeless people with advanced ill health • Promote well-being, dignity, and choice • Incorporate uncertainty with the use of parallel planning/mapping
Leung et al., 2017 [54] <i>Peer Reviewed Journal Article</i>	1 2 or 3 4 5 6 103 <i>Cohort formed from patients included in Leung et al. (2014)</i>	Prospective cohort study, comparator Homeless people without and AD (n=102, ETHOS 2&3)	Canada	To determine of homeless individuals who had completed an AD as part of Leung et al.'s 2014 intervention were likely to have an AD documented or used during hospitalisation, when compared to homeless individuals without an AD.	<ul style="list-style-type: none"> • 36.6% of total participants were admitted to hospital over 1-year follow up across five hospitals • Those who had completed an AD as part of the intervention were significantly more likely to have one documented/used than those who had not (9.7% vs 2.9%, p=0.047) 	A shelter-based AD intervention for homeless individuals can increase the likelihood that health care providers have access to specific information on patient preferences to guide health care decisions during subsequent hospitalisations.
Nikouline and Dosani, 2017 [59] <i>Non-peer-reviewed research article</i>	Social service providers (n=unclear for structured interviews, n=5 for semi-structured interviews)	Structured interviews, semi-structured interviews, and thematic analysis	Canada	To determine the benefits and barriers of in-shelter palliative care and possible enablers to future implementation in Toronto.	Benefits of In-Shelter Palliative Care Programs <ul style="list-style-type: none"> • Choice • Staying in shelter Barriers to In-Shelter Palliative Care <ul style="list-style-type: none"> • Resources • Trust Enablers to In-Shelter Palliative Care <ul style="list-style-type: none"> • Communication • Community Involvement 	<ul style="list-style-type: none"> • Palliative care for homeless people needs improvement • Shelter staff were receptive to in-shelter care • In-shelter care may be under-resourced and mistrusted. • Strong communication and community support can act as enablers.
Sumalinog et al., 2017 [12] <i>Peer Reviewed Journal Article</i>	6 articles <i>See Table 4 for further breakdown</i>	Systematic Review	Canada	To summarize and evaluate the evidence surrounding ACP, palliative care, and EOLC interventions for homeless persons.	<ul style="list-style-type: none"> • AD Completion • Shelter-based and supportive housing-based palliative care • Harm reduction services 	The effectiveness of ACP, palliative care, and EOLC interventions for homeless individuals is uncertain. High-quality studies of interventions that reflect the unique and complex circumstances of homeless populations and investigate patient-related outcomes, caregiver burden, and cost-effectiveness are needed.
Tobey et al., 2017 [30] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 12 8 ETHOS UNKNOWN	Cross-sectional survey with comparisons to comparator studies.	USA	To examine the symptoms experienced by homeless individuals nearing the EOL and explore social background, attitudes, and experiences.	<ul style="list-style-type: none"> • High rates of substance use and psychiatric disorders • High burden and frequency of physical and psychiatric symptoms • Universal previous experience with death • Mistrust around decisions at EOL 	Homeless individuals may experience a high frequency of pain and other symptoms as they approach the EOL. Care for such individuals may require a tailored approach.

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Chau, Norris and Heyworth, 2018 [36] <i>Conference Proceedings</i>	1	2	3	4	5	6	Semi-structured interviews with grounded theory analysis	USA	To better understand what is known about the POLST (Physician Orders for Life Sustaining Treatment) amongst this patient population, and to explore the barriers to broader utilization of the form for end-of-life planning.	<ul style="list-style-type: none"> Homeless and vulnerably housed people in favour of using POLST Values found around quality of life, desire to maintain independence, and not become a burden Several visits preferred for discussions rather than a single visit Comfort discussing EOL decisions with primary care providers 	<ul style="list-style-type: none"> ACP appears a welcome topic amongst homeless and vulnerably housed people POLST may improve documentation, healthcare resource allocation, and EOL experiences for high-risk populations such as homeless and vulnerably housed people
Conneely et al., 2018 [60] <i>Conference Proceedings</i>	Shelter staff (n=11)						Semi-structured interviews	ROI	To explore the experience of homelessness staff working with homeless people with a life-limiting illness in homeless accommodation in Dublin and identify areas for education and collaboration between palliative care and homeless services.	<ul style="list-style-type: none"> Poor communication between hospitals and homeless services Concerns about medication handling Uncertainty about prognosis (especially non-malignant conditions) <p>Concerns about meeting care needs for homeless people at the EOL.</p>	The requirement for a needs-based approach in care considering co-morbidities with physical health, mental health, and substance misuse problems.
de Veer et al., 2018 [71] <i>Peer Reviewed Journal Article</i>	1	2 or 3	4	5	6	19	Semi-structured interviews with inductive analysis	Netherlands	To give insight into the extent people experiencing homelessness have access to good palliative care.	<p>Late access</p> <ul style="list-style-type: none"> Difficulty in recognising palliative care needs Ambivalence towards accepting care No palliative care facilities <p>Capricious trajectory</p> <ul style="list-style-type: none"> Behaviour that is challenging for professionals Unpredictable disease progression <p>Complex care</p> <ul style="list-style-type: none"> Pain and symptom control Psychosocial and spiritual care Social network 	<ul style="list-style-type: none"> There are bottlenecks regarding timely identification, the social network, and the assessment and management of physical symptoms and psychosocial and spiritual care needs Education in palliative care of outreach professionals, training staff in shelters in the provision of palliative care and building a network of palliative care specialists for people experiencing homelessness
Gruenewald et al., 2018 [100] <i>Peer Reviewed Journal Article</i>	People with homeless experience (n=unclear) Healthcare professionals (n=unclear)						Semi-structured interviews and focus groups with thematic analysis	USA	To describe the barriers and facilitators of end-of-life (EOL) care for Veterans without stable housing (VWSH) as perceived by Veterans at 1 VA medical centre and EOL care staff.	<ul style="list-style-type: none"> Relationship and trust building Flexibility and co-ordination Key people Key services Navigating change Stigma and self-depreciation 	These findings suggest that to improve health care for VWSH, interventions must be multifaceted, including a suite of support services, flexibility and creative problem-solving, and adaptations in communication approaches.

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Hutt et al., 2018 [76] <i>Peer Reviewed Journal Article</i>	Healthcare professionals (n=10) Peer supporters (n=2) Relatives (n=1)	Focus groups with nominal group process analysis	USA	Understand the challenges of providing EOLC to veterans in unstable housing with unmet need from current homeless and palliative care programs.	Barriers: <ul style="list-style-type: none"> Declining health often makes independent living or plans to abstain impossible, but housing programs usually require functional independence and sobriety. Managing symptoms within the homelessness context is challenging. Discontinuities within and between systems restrict care. Veterans Affairs regulations challenge collaboration with community providers. Veterans with unstable housing who are at EOL and those who care for them must compete nationally for prioritization of their care. 	Care of veterans at EOL without homes may be substantially improved through policy changes to facilitate access to appropriate housing and care; better dissemination of existing policy; cross-discipline and cross-system education; facilitated communication among VA, community, homeless and EOL providers; and pilot testing of VA group homes or palliative care facilities that employ harm reduction strategies.
Klop et al., 2018 [11] <i>Peer Reviewed Journal Article</i>	27 Studies <i>See Table 4 for further breakdown</i>	Mixed-methods systematic literature review	Netherlands <i>[Articles from UK, USA, Sweden, Canada, Australia, ROI]</i>	<ul style="list-style-type: none"> What is known about concerns, care needs, preferences of homeless people regarding palliative care? What is known about what barriers and facilitators exist in the delivery of palliative care for homeless people? What is known about recommendations for practice regarding palliative care to homeless people? 	<p>Concerns, care needs, and future preferences:</p> <ul style="list-style-type: none"> Concerns around physical, psychological, social, spiritual, and care domains Care needs around attitudes and behaviours, involvement of the family, treatment/care options, and after death Preferences relating to treatment preferences, wishes for the dying process, and proxy-decision makers. <p>Barriers to care:</p> <ul style="list-style-type: none"> Barriers relating to homeless people in relation to receiving healthcare, social relationships, and health behaviours Relating to interactions between homeless people and healthcare professionals Relating to healthcare professional's knowledge, skills, and organisation <p>Facilitators to care:</p> <ul style="list-style-type: none"> Relating to homeless people Relating to interactions between homeless people and healthcare professionals through attitudes, treatments, and activities/therapies Relating to healthcare professionals' knowledge, skills, and organisations 	Recommendations for practice made around training, education, knowledge, delivering care, and overall organisation.

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Klop et al., 2018 [41] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 15 ETHOS UNKNOWN Healthcare professionals (n=19)	Focus groups with thematic analysis	Netherlands	To provide insights into the palliative care experiences of professionals and homeless people, including barriers and facilitators to care, and to investigate whether a consultative function can help improve palliative care for homeless people.	<ul style="list-style-type: none"> • Complexity of palliative care for the homeless <ul style="list-style-type: none"> ◦ Behaviour of homeless people ◦ Lack of expertise among professionals ◦ Sharing of knowledge • Variety of palliative care • Self-determination • Different perceptions on care • Trusting relationship • Less barriers • Flexible care 	Consultation can play an important role in improving palliative care by linking disciplines, providing support to professionals and appropriate palliative care to homeless people.
Petruik, 2018 [13] <i>Peer Reviewed Journal Article</i>	21 Articles <i>See Table 4 for further breakdown</i>	Scoping Review	Canada <i>[articles from Canada, UK, and USA]</i>	What role(s) should/do social workers play in palliative care and EOLC for persons experiencing homelessness?	Key themes identified around: <ul style="list-style-type: none"> • Trusting relationships • Collaboration and partnership • Education training and knowledge 	The themes of trusting relationships and need for education, training, and knowledge are often overlooked in the literature.
Recoche, O'Connor and Clerehan, 2018 [62] <i>Peer Reviewed Journal Article</i>	NA <i>Perspective of institutions and organisations</i>	Critical discourse-historical analysis	Australia	To report on the analysis of discourse used in palliative care and homelessness talk and text.	Government, palliative care and other organisational documents lacked voices of people with homeless experience and palliative care needs.	Importance of stakeholder involvement, education of care providers, and funding models to support share care.
Shulman et al., 2018 [18] <i>Peer Reviewed Journal Article</i>	Hostel workers (n=24)	Mixed-methods pre-/post-intervention study	UK	To pilot and evaluate the impact of a training course for hostel staff supporting clients with palliative care needs, and increasing multiagency working.	<ul style="list-style-type: none"> • Training resulting in self-perceived reduced hostel staff stress, and increased knowledge, confidence, and openness. • Longer term changes were seen in how palliative care was visualised, with further increase in confidence and knowledge around palliative care. Anxieties around palliative care in hostel environments, a focus on recovery, and fragmented services presented challenges	Recommendations for effective training: <ul style="list-style-type: none"> • Embedding training into routine practice • Promoting multidisciplinary working • Incorporating flexibility within the recovery focused approach of services Recognising the need for emotional support for staff

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Shulman et al., 2018 [69] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Focus groups, interviews, and thematic analysis	UK	To explore the views and experiences of current and formerly homeless people, frontline homelessness staff and health- and social-care providers, regarding challenges to supporting homeless people with advanced ill health, and to make suggestions for improving care.	<ul style="list-style-type: none"> Many homeless people are dying in an unacceptable and unsupported situation. Identifying those with palliative requirements is challenging Lack of appropriate places to deliver palliative care needs Substance misuse issues can complicate palliative care provision 	Greater multidisciplinary working, extended in-reach into hostels from health and social services and training for all professional groups along with more access to appropriate supported accommodation are required.
Sudore et al., 2018 [101] <i>Peer Reviewed Journal Article</i>	1	2	3	4	5	6	Cross sectional cohort analysis and multivariate logistic regression analysis	USA	To examine the prevalence of ACP engagement and factors associated with discussion and documentation.	<ul style="list-style-type: none"> 36% contemplated ACP, 21.5% discussed ACP, often with family, 19% had formal ACP documentation, and 8% had an AD Those with a lower duration of homeless experience, recent primary care contact or multiple confidants were more likely to have discussed ACP Participants who were black, health literate, not using drugs “moderate to severely”, or had multiple confidants were more likely to have ACP documentation 	Interventions need to acknowledge factors related to homelessness such as “cultural diversity, limited health literacy, lack of access to healthcare, mistrust in the healthcare system, and constraints of safety-net healthcare settings”.
Tedesco, Dosani and Shanks, 2018 [102] <i>Conference Proceedings</i>	Healthcare professionals (n=7) <i>Data from 27 homeless people, ETHOS unclear</i>						Semi-structured interviews and cross-sectional analysis of service user data with thematic analysis.	Canada	To understand “provider perspectives” around the “Good Wishes Project”, a partnership project between palliative care and homeless services.	<p>24 of 40 made “wishes” granted around:</p> <ul style="list-style-type: none"> Basic necessities EOL preparations Personal connections Paying it forward Leisure <p>Providers highlighted benefits around:</p> <ul style="list-style-type: none"> Establishing and enhancing connection Satisfying basic needs Promoting person-centred care 	The “Good Wishes” project demonstrates promise as a “psychosocial intervention” providing palliative care.
van Dongen et al., 2018 [67] <i>Conference Proceedings</i>	1	2 or 3	4	5	6		Mixed-methods retrospective record review	Netherlands	To describe the characteristics of people who deceased after having been homeless, the care they received at the EOL, and difficulties in care provision at medical respite shelters.	<ul style="list-style-type: none"> Majority had somatic (98%), psychiatric (85%), and addiction (93%) issues Imminent death was recorded in 75% of cases, a median of 67 days before death Palliative care was consulted in 26% of cases Most patients died in their shelter (64%), with 26% in hospital and 4% in a hospice Barriers present from fragmented expertise, communication breakdown, and pharmacological issues 	Homeless people have need of expert palliative care, but are often admitted elsewhere.

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Kaplan-Weisman et al., 2019 [49] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 2 91 People with homeless experience (n=45)	Single group intervention study with cross sectional cohort analysis	USA	To discuss and document advance care plans with all patients aged 45 and older" in homeless clinics. • Assess burden of unbefriendedness in homeless population attending clinics • Identify barriers to ACP in primary care with relation to homelessness	<ul style="list-style-type: none"> • ACP was discussed with 48% of the population over 14 months as part of the program, with health care proxy appointments taking place for 91% of these patients • 38% of homeless people seeking a healthcare proxy were "surrogateless" (this included those nominating a surrogate from their medical or social care team), there were no demographic predictors of surrogacy 	Conclusions highlight the importance of documenting ACP whilst patients have capacity, especially where patients are surrogate-less, advising incorporation into routine care.
Kaplan-Weisman, Tam and Crump, 2019 [56] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 4 People with experience of homelessness (n=2)	Case series	USA	To examine the feasibility and outcomes of ACP in primary care for patients who have experienced homelessness.	Completion of ACP impacted on patient's hospital care and meant that their wishes could be honoured, even when they lost capacity towards the EOL..	Outpatient ACP for adults who have experienced homelessness is a valuable use of limited clinical time and should be integrated into routine primary care.
MacKenzie and Purkey, 2019 [39] <i>Peer Reviewed Journal Article</i>	Health and social service providers (n=136)	Surveys with phenomenology	Canada	To examine health and social service providers' experiences providing EOLC to people experiencing homelessness, seeking recommendations to improve both patient and provider experience.	<ul style="list-style-type: none"> • Barriers to EOLC internal to the health-care-system • Care avoidance • The experience of stigma for this population when accessing EOLC • Lack of provider information and awareness on how to provide care for marginalized groups • How to provide care in the context of substance misuse • How to assist clients in accessing the formal palliative care system • The need for harm reduction approaches to EOLC for persons experiencing homelessness 	Focusing on harm reduction and using the framework of Equity-Oriented Health Care to make systemic, cultural, and policy changes to develop a palliative-care system for persons experiencing homelessness may improve care experience for both patients and providers.
Purkey and MacKenzie, 2019 [31] <i>Peer Reviewed Journal Article</i>	1 2 or 3 4 5 6 3 4 3 ETHOS UNKNOWN People with homeless experience (n=16)	Focus groups, interviews, and phenomenology	Canada	To explore the experience, goals, fears, and hopes surrounding death in the setting of homelessness or vulnerable housing.	<ul style="list-style-type: none"> • Experience with death and dying • Relationship with mortality • Ideas for a good death • Desires for EOL 	<ul style="list-style-type: none"> • Participants were articulate in EOL views and wishes • Current palliative care system not meeting participants needs • Recommendation for harm reduction, equity orientated care, and a combination of outreach and inpatient services
Stone, Mixer and Mendola, 2019 [37] <i>Peer Reviewed Journal Article</i>	1 2 3 4 5 6 ETHOS UNKNOWN n=30) Student Nurses (n=8)	Interviews with thematic analysis	USA	To understand how to provide culturally congruent ACP through AD completion.	<ul style="list-style-type: none"> • It needs to be done • The presence or absence of trusted family support • ACP for PEHs is facilitated by an AD workshop 	Nursing interventions based on study findings can be used to help promote a dignified, meaningful ACP experience for vulnerable populations.

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Webb et al., 2020 [9] <i>Peer Reviewed Journal Article</i>	1	2 or 3 9	4	5	6	Interpretive phenomenolog y	UK	To explore the EOL concerns, fears, preferences and priorities of a sample of people experiencing homelessness in the UK.	<ul style="list-style-type: none"> • Spiritual concerns • Practical concerns • Fear of needing care • Fear of being forgotten • Preference for dying suddenly • Preference for being somewhere comfortable where people know me • Prioritising autonomy and self-determination • Prioritising authenticity 	A strengths-based, trauma-informed, person-centred, collaborative 'compassionate community' approach to care is recommended for people experiencing homelessness at EOL.