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REVIEW ARTICLE

End of life care for people with alcohol and drug problems: Findings from a Rapid Evidence Assessment

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Abstract

People who use alcohol and other drugs (hereafter “substances”) and who are over the age of 40 are now more likely to die of a non-drug related cause than people who use substances under the age of 40. This population will therefore potentially need greater access to palliative and end of life care services. Initially, the purpose of this rapid evidence assessment (REA), conducted August 2016–August 2017, was to explore the peer-reviewed evidence base in relation to end of life care for people with *problematic* substance use. The following databases were searched using date parameters of 1 January 2004–1 August 2016: Amed, Psycharticles, Ovid, Ageinfo, Medline, Ebscohost, ASSIA, Social Care Online, Web of Knowledge, Web of Science, SSCI, Samsha, NIAAA. Data were extracted using a predefined protocol incorporating inclusion and exclusion criteria. Given the dearth of evidence emerging on interventions and practice responses to *problematic* substance use, the inclusion criteria were broadened to include any peer-reviewed literature focussing on substance use specifically and end of life care. There were 60 papers that met the inclusion criteria. These were quality assessed. Using a textual thematic approach to categorise findings, papers fell into three broad groups (a) pain management, (b) homeless and marginalised groups, and (c) alcohol-related papers. In general, this small and diverse literature lacked depth and quality. The papers suggest there are challenges for health and social care professionals in meeting the end of life needs of people who use substances. Addressing issues like safe prescribing for pain management becomes more challenging in the presence of substance use and requires flexible service provision from both alcohol/drug services and end of life care providers. Work is needed to develop models of good practice in working with co-existing substance use and end of life conditions as well as prevalence studies to provide a wider context for policy development.

KEYWORDS

addiction, alcohol, drugs, end of life care, palliative care, Rapid Evidence Assessment

1 | BACKGROUND

In the last 20 years there have been numerous changes evident among the population who use substances whether this be alcohol or other drugs. The most important changes appear to be an increase in the number of older drugs users, a subsequent rise in rates of death from non-drug related conditions (Beynon, 2010), an increase in alcohol-related morbidity among older users (Kaplan et al., 2012) and the burgeoning of New Psychoactive Substances (NPS) use. The increase in older drug users may be associated with changes to the treatment management for illicit opiate users in the 1990's (McKeganey, 2006) and, in particular, the expansion and greater availability of methadone prescription (Clausen, 2008; Clausen, Waal, Thoresen, & Gossop, 2009). This increased availability means that increasing numbers of people with current and previous substance use have better survival rates and are more likely to die from the same chronic conditions that affect the general population (Corkery, 2008; Beynon et al., 2010). It may be that some of this population are using substances for longer or commencing drug use later in life but, whatever the cause, there has been an increase in older drug users accessing drug treatment services in the UK (Beynon, 2010; Beynon et al., 2010).

Before methadone treatment programmes were introduced, people who used substances had a greater risk of dying from overdoses (deliberate or accidental), as well as accidents, violence and disease. These could be related to the substance itself or its route of administration, such as liver disease, HIV (Human Immunodeficiency Virus) and bacterial infections (Gibson et al., 2008). The adoption of evidence-based interventions like supervised injecting facilities, needle exchange programmes and outreach programmes for illicit drug users is considered to be an effective overarching policy approach for reducing harm (Ritter & Cameron, 2006). Harm reduction policies and related treatment approaches have led to older substance users (over the age of 40) now being more likely to die of a non-drug related cause than people using substances under the age of 40 (Beynon et al., 2010; Stenbacka et al., 2008). However, people using substances are still more likely to die at an earlier age than the general population and have patterns of disease and morbidity that reflect the impact of substance use or the traumatic life experiences more frequently encountered in this group (Beynon, Roe, Duffy, & Pickering, 2009; Beynon et al., 2010). In addition, there are higher rates of alcohol-related morbidity and mortality associated with chronic and acute alcohol problems (Chang, Kreis, Wong, Simpson, & Guymer, 2008; Shield, Parry, & Rehm, 2014; Taylor et al., 2010). This highlights a more nuanced picture of alcohol-related harm given that the highest consumption is among more affluent groups of the population (Office for National Statistics, 2017) but the highest rates of alcohol-related problems are among the least affluent (Erskine, Maheswaran, Pearson, & Gleeson, 2010).

The final set of changes is the increase in the use of NPS. Some of the more immediate consequences of NPS use are evident in the prisons system and in admissions to hospital accident and emergency departments for acute intoxication (Liakoni, Dolder, Rentsch,

What is known about this topic

- There is an increase in older substance users who will require end of life care.
- Meeting end of life needs for this group of people will require flexible service provision.
- Problematic substance users often present with complex social and medical problems that make accessing formalised end of life care services more difficult to navigate than other populations.

What this paper adds

- This paper identifies and documents the limited evidence base that exists on end of life care for people with substance problems.
- It identifies gaps in the evidence relating to focus and methodology.
- It identifies examples of good practice and highlights future directions for research

& Liechti, 2016; Ralphs, Williams, Ashew, & Norton, 2017). These harmful consequences are particularly associated with people who are homeless (Henshall et al., 2018). The impact of NPS use on mortality and morbidity, both medium and long-term has yet to be evaluated.

While there has been an improvement in life expectancy within the general population, it has been associated with more years living with poor health or disability at the end of life (Bell & Marmot, 2017). This has subsequently increased the anticipated number of deaths that are likely to need palliative and end of life care (Etkind et al., 2017). There appears to be only fragmented evidence relating to (a) the extent and nature of the care needs by people using substances and (b) the challenges services will face in supporting people with problematic substance use at the end of life. This Rapid Evidence Assessment (REA) aimed to explore what is already known about responses to end of life care need for people using substance and identify gaps in the evidence base. It forms one part of a wider programme of research on end of life care for people with problematic substance use (Galvani, Tetley, et al., 2016).

1.1 | Conceptual framework

Within the current literature, discrete definitions of palliative as opposed to end of life care are ambiguous and indistinct with authors often interchanging between the two terms. For this REA, we explored the existing theoretical literature and sought advice from experts in the field. We based the definition of *palliative care* on a combination of World Health Organisation (WHO) guidelines and part of a definition used by the European Association of Palliative Care (EAPC):

TABLE 1 Final search terms

Key search terms:	End of life, palliative, dying, death, life limiting, life threatening Drug misuse/abuse/use, substance use/misuse/abuse, medication use or abuse, alcohol
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Palliative care is an approach that improves the quality of life of patients and service users facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It also provides care to family members, friends and carers of patients and service users to recognise their need for support in their own right and as well as to support them to care for their relative or loved one. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

End of life care definitions can have limited clinical utility since recognising dying is difficult to assess or predict with many chronic conditions. For this REA, our end of life definition remains similar to the palliative care definition but the time scale is reduced to the last 12 months of life (General Medical Council, 2010). For this REA we excluded tobacco and caffeine. Drugs refers to illicit drugs and the misuse of prescription medication. Substance use we initially defined as current or previous problematic alcohol or other drug use (prescribed or illicit) while receiving palliative or end of life care. However, the dearth of literature resulted in the definition changing to include any alcohol or drug use, rather than problematic use, except we retained problematic prescription drug use to ensure manageability of the evidence.

2 | METHODS

2.1 | Aims

The question to be addressed was; what does the existing international research and wider literature tell us about current responses to end of life care for people with substance problems? The question focussed initially on care *responses* and was broken down further into the following aims:

1. To explore and document the evidence base that already exists on responses to end of life care for people with substance problems.
2. To identify gaps in the evidence relating to focus and methodology.
3. To identify examples of good practice and to highlight future directions for research.

2.2 | Design

A Rapid Evidence Assessment (REA) methodology was identified as the most appropriate research tool to use to enable a speedy identification of key pieces of evidence. This would inform our wider study and provide a reference document to underpin further work on this topic in policy or practice. REAs can be defined as providing.

‘... a more structured and rigorous search and quality assessment of the evidence than a literature review’ but one critique is that it has narrower parameters and is not “as exhaustive as a systematic review” (Department for International Development (DFID), 2017: online). REAs, therefore, stem from Systematic Review methodology that, historically, focus on interventions and their effectiveness using experimental or quasi-experimental research design. By contrast, REAs are used to gain an overview of the prevalence and quality of evidence focusing on topic areas to support commissioning or programming decisions and identifying evidence gaps requiring further research (DFID, 2017: online). An REA is conducted within a shorter timeframe than a Systematic Review but retains the key characteristics of systematic review; transparency, replicability and comprehensiveness (Government Social Research (GSR) and EPPI Centre, 2009; Galvani & Forrester, 2011; GSR, 2013).

Our initial goal was establishing if there were any interventions for this group. As the review proceeded, the lack of a cohesive body of evidence to answer the research questions indicated became clear. Therefore, a combination of a REA and systematic mapping methodology (Clapton, Rutter, & Sharif, 2009) was adopted. Systematic maps aim to describe the existing literature and gaps in the literature, in a broad topic area and the literature quality and content can be analysed in depth or more superficially as appropriate to individual projects (Clapton et al., 2009, p. 11). The review, therefore, was conducted with the rigour of planning and approach of an REA. However, as a result of our experience conducting the REA and the diversity of the literature found, it also encompassed systematic mapping of the review's findings.

2.3 | Search methods

This REA was an iterative review, the findings of which sought to support the wider programme of research of which it was part. To ensure it did so, five separate protocols were developed for the initial searches that spoke directly to the focus of the other strands of the research. The first protocol examined the *prevalence and incidence* of palliative/end of life care and co-existing substance use/problematic substance use. The second reviewed *interventions* for people using alcohol or other drugs with co-existing end of life conditions and their families, carers, friends. The third examined the *personal/family/social experiences*, challenges and opportunities, for people using alcohol or other drugs with co-existing end of life care conditions. The fourth and fifth searches focused on both *professional/clinical/practice challenges/concerns* for practitioners supporting those using alcohol or other drugs with co-existing end of life

TABLE 2 Coding table

A	Is not related to palliative or end of life care
B	Is not related to substance use
C	Is not related to palliative or end of life care or substance use
D	Not about: practice or pathways: professional practice concerns; family and social networks
E	Does not meet the above, but is of interest and relevance (set aside).

care conditions and *good practice models* and care pathways in relation to this population.

These original protocols for the review were adapted as the REA proceeded due to the very limited relevant data generated by them. This strategy allowed us to refine the questions and the focus of the research once the review was being conducted. Subsequently, the search terms were broadened to capture all the literature within this field within our search parameters (see Table 1 below).

This strategy is one of the features of an iterative, as opposed to an a priori, review. Two broad groups of evidence were relevant; existing research on palliative and end of life care and existing research on substance use. The search protocol needed to ensure these bodies of evidence were included. Common to all five searches, were the databases; Amed, Psycharticles, Ovid, Ageinfo, Medline, Ebscohost, ASSIA, Social Care Online, Web of Knowledge (including Social Science Citations Index), Web of Science, SSCI, Samsa, NIAAA.

Studies reviewed were published in peer-reviewed journals between 1 January 2004 and 1 August 2016. The rationale for the starting date parameter of 2004 was the publication of key reports concerning end of life and palliative care that year (Department of Health, 2004; National Institute for Clinical Excellence, 2004). An additional limiter was that the papers were written in English. We excluded tobacco-related studies. Excluded papers were coded A-E (see coding table below in Table 2).

2.4 | Data extraction and synthesis

Given the dearth of intervention studies and the limited literature found through the initial searching, a systematic mapping approach was adopted. This facilitates a visual map of the existing literature on the broad topic of substance use and end of life care. It also allowed categorisation of the existing evidence in a number of ways, including its methodology, focus and country of origin. Textual narrative synthesis (Barnett-Page & Thomas, 2009) was used to explore any similarities, differences and relationships between papers. The textual narrative approach involves a commentary describing study characteristics, context, quality and findings. This was facilitated by a three-step process (Lucas, Baird, Arai, Law, & Roberts, 2007) including, (a) study grouping; in which studies belonging to each of the sub-groups, for example pain management or alcohol were identified with two researchers independently categorising and theming the papers. (b) Themes produced by each researcher were compared and a consolidated list

produced. (c) sub-group synthesis were then developed. If there were any disagreement, a third researcher would review the paper. Study commentaries were produced in an excel file to summarise key aspects of the papers in relation to the sub-group within which they were included. This included both key findings and/or recommendations that speak to the aims of this REA. In terms of quality control, each commentary was reviewed by a second researcher independently to assess the summary in relation to the original paper.

2.5 | Quality appraisal

The quality of the individual studies was assessed based on six principles derived from DFID guidance, each of which have a number of quality related questions within the principles (DFID, 2014). The key principles are: (a) Conceptual framing, (b) Transparency, (c) Appropriateness, (d) Cultural sensitivity, (e) Validity and (f) Cogency.

The empirical studies in the evidence base were scored on all six criteria on a three-point scale reflecting the extent to which the studies followed good research practice: 3 = no concerns; 2 = some minor concerns; 1 = major concerns. This resulted in a score ranging from 6 to 18 for each study. Studies were then assigned a quality category of high, moderate or low, based on their score. It is important to note that a low or moderate "quality" rating does not imply that a study was poorly designed or executed and does not suggest that its conclusions are incorrect or unreliable. It can simply mean that the report of the study did not fully explain its design or methods.

3 | FINDINGS

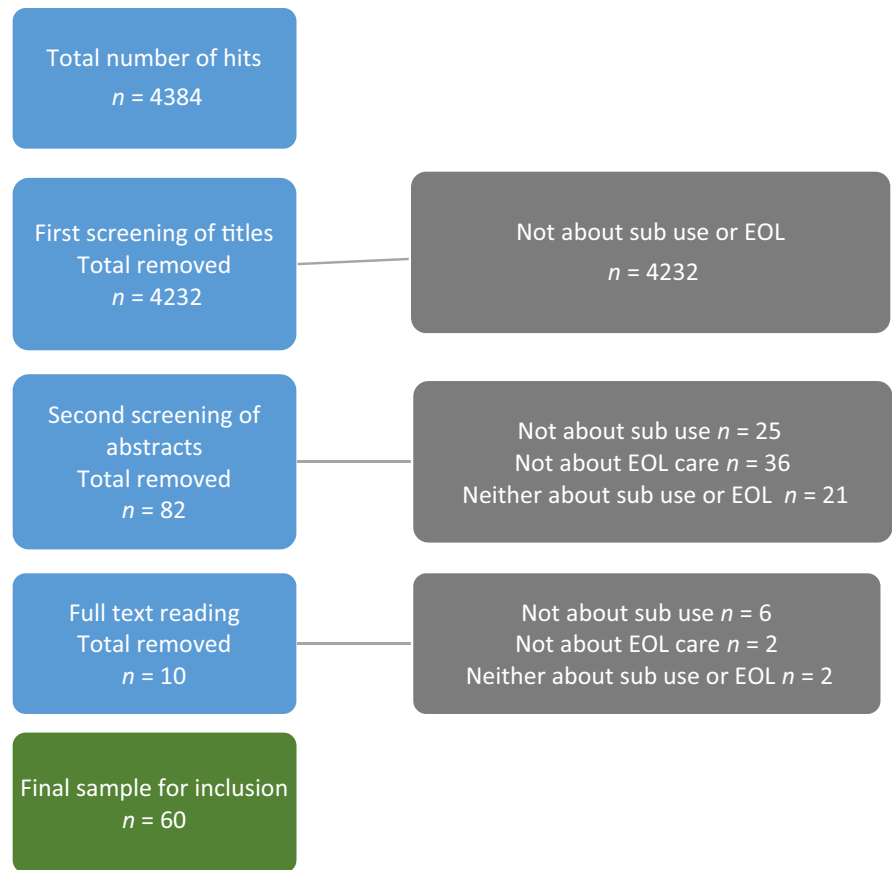
The initial search of peer-reviewed articles resulted in a large number of papers. The inclusion and exclusion criteria were applied at abstract and full text reading stages (see Figure 1 below).

There were 60 papers generated from our search after applying the inclusion and exclusion criteria. They were, however, extremely diverse in methodology, focus and audience. The systematic map (Figure 2) illustrates the range of evidence found among the 60 papers.

All empirical studies ($n = 32$) referred to in this REA were scored according to the DFID (2014) guidance (Table 3). Table 3 summarises the evidence base found for this REA in terms of types of study and quality.

The majority of papers found were published in the last decade and were North American (USA or Canadian) in origin. Just over half were based on empirical research of some kind with more quantitative data than qualitative data presented. The greater number of journal articles compared to other sources was a result of our search strategy which focussed on published research. As with other new areas of research, for example sight loss and substance use (Galvani, Livingston, & Morgan, 2016), there were a number of clinical case studies presented in the literature. The final list of papers is included at the end of this paper in Table 4.

FIGURE 1 Review process from initial search to final sample of papers



3.1 | Thematic groups

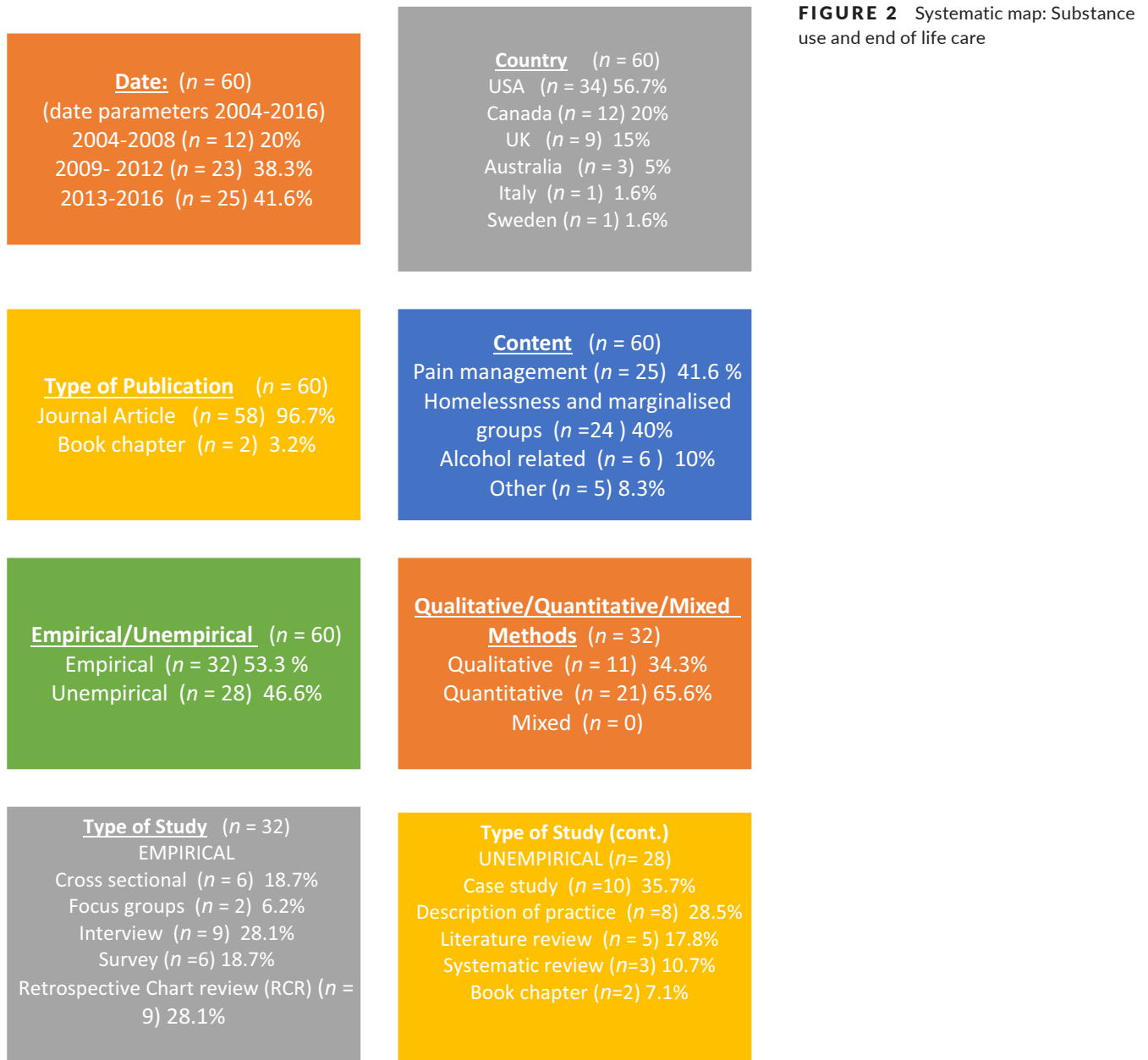
As the systematic map shows, the topic focus of the evidence could be grouped around three main themes: pain management ($n = 25$), homeless and miscellaneous populations ($n = 24$) and alcohol-related papers ($n = 6$). In addition, five remaining papers were diverse in focus and methodology.

3.2 | Pain management

Pain management was, marginally, the largest category to emerge from the peer-reviewed literature. The majority ($n = 23$) were from the USA with the other single papers from Canada and the UK. The studies ranged from clinical chart/note reviews (Barclays et al., 2014; Childers et al., 2015; Kwon et al., 2013, 2015; Rowley et al., 2011), to small scale case study reviews (Arthur et al., 2016; Burton-MacLeod et al., 2008; Farnham, 2012; Kirsh & Passik, 2006; Koyyalagunta et al., 2011; Kutzen, 2004; Walsh & Broglio, 2010). There was also one integrated literature review (Carmichael et al., 2016) examining assessment and risk in relation to opioid misuse within cancer care and two systematic reviews (Chou et al., 2009; Taveros & Chuang, 2016). Chou et al. (2009) examined opioid misuse in the context on non-cancer chronic pain and Taveros and Chuang (2016) examined pain management strategies for people on methadone maintenance therapy. Five studies used structured questionnaires as part of their approach (Blackhall et al., 2013; Childers & Arnold, 2012; Knowlton et al., 2015;

Williams et al., 2014; Tan et al., 2014). The remaining five papers were descriptions or discussions of practice (Krashin et al., 2012, 2015; Passik et al., 2009; Pancari & Baird, 2014; Riesfield et al., 2009).

In terms of the populations of interest, the majority of papers ($n = 13$) were within a context of pain in cancer care (Arthur et al., 2016; Barclay et al., 2014; Burton-MacLeod et al., 2008; Carmichael et al., 2016; Childers et al., 2015; Kirsh & Passik, 2006; Koyyalagunta et al., 2011; Kwon et al., 2013, 2015; Passik et al., 2009; Rowley et al., 2011; Taveros & Chuang, 2016; Walsh & Broglio, 2010). One study examined pain in prison populations (Williams et al., 2014) whilst Kutzen (2004) and Knowlton et al. (2015) focused on pain in the context of HIV disease with Koyyalagunta et al. (2011) also exploring a subset of HIV patients. The other studies examined problematic substance use from a general palliative care context (Childers & Arnold, 2012; Farnham, 2012; Krashin et al., 2015; Pancari & Baird, 2014; Riesfield et al., 2009; Tan et al., 2014) with two studies focussing on chronic non-cancer pain (Chou et al., 2009; Krashin et al., 2012). A number of papers acknowledged both the complexity of pain management and persistent issues of under-treatment of patients with substance misuse issues (Farnham, 2012; Koyyalagunta et al., 2011; Krashin et al., 2015; Kwon et al., 2015; Lum, 2003; Passik et al., 2009; Rowley et al., 2011; Walsh & Broglio, 2010; Williams et al., 2014). This led most papers to emphasise the need for comprehensive assessment as an essential step in managing pain in people using substances, requiring active engagement from the clinician.



3.3 | Homeless and marginalised groups

This group of papers focussed on people who are homeless or precariously housed, people with mental health difficulties and people with HIV in the context of multiple social problems. Three papers addressed marginalised populations more generally (Doukas, 2014; Dzul-Church et al., 2010; Sulistio & Jackson, 2013).

3.4 | Homeless populations

The majority of papers in this thematic group focussed on homeless and precariously housed persons (Collier, 2011; Dzul-Church et al., 2010; Hudson, 2016; Kusel & Miaskowski, 2006; MacWilliams et al., 2014; McNeil & Guirguis-Younger, 2012a, 2012b; McNeil et al., 2012a; McNeil et al., 2012b; Page et al., 2012; Podymow et al., 2006;

Song et al., 2007a, 2007b). Most were qualitative studies conducted in Canada ($n = 7$), with four from the USA and one from Australia and two from the UK. The four papers by McNeil and colleagues drew on a single primary piece of qualitative work to examine the particular needs of homeless people, including staff experiences. The research looked at gaps in services and proposed that some of these could be met by "shelter-based" palliative and end of life care. The work of Song et al. (2007a, 2007b) and Podymow et al. (2006) identified similar issues finding that end of life advanced directives were perceived very positively by homeless people including "do not attempt cardio-pulmonary resuscitation" orders. As Song et al (2007a) comment, participants expressed preferences to avoid "heroic interventions", with advance care planning being important because of their '... belief that EOL care is paternalistic and unresponsive, advance care planning was also seen as a way to maintain control' (p. 437).

TABLE 3 Quality ratings of empirical literature

Study quality	Symbol	Type of study	Number	% of all studies
High (14–18)	↑	Primary Secondary	9	28.1%
Moderate (10–13)	→	Primary Secondary	18	56.2%
Low (6–9)	↓	Primary Secondary	5	15.6%
Total			32	100%

MacWilliams et al.'s (2014) case study approach identified similar issues but focused on the consequent difficulties with compliance in treatment. In particular, they discussed what this then meant for pain control and reducing the risks of sudden crisis and deterioration where someone is homeless. Kushel and Miaskowski (2006) identified the usefulness of “patient contracts” as a means of addressing such difficulties. The remaining papers examining homelessness included one systematic review paper from the UK, (Hudson, 2016), Webb (2005) who examined seven UK hostel workers' experiences in relation to supporting homeless people at their end of life, and a paper by Page et al. (2012) which looked at causes of death among homeless people in Alberta. The findings from this study showed that most deaths were due to “natural causes”; that is, not the types of death often associated with drug use such as overdoses and suicides. Page et al. (2012) also proposed that this meant that the circumstances of death could be improved by more effective delivery of end of life care to homeless persons.

3.5 | Mental Health, HIV and miscellaneous groups

Mental ill health was highlighted in many of the papers identified in this review. Depression is known to be associated with chronic and terminal illness and with pain, both as a factor in causation and arising as a consequence of illness (Hotopf, Chidgey, Addington-Hall, & Lan Ly, 2002). This links with the pain literature, where a number of authors suggested screening and referral to secondary mental health services as an appropriate response (Barclay et al., 2014; Burton-MacLeod et al., 2008; Kirsh & Passik, 2006; Koyyalagunta et al., 2011; Krashin et al., 2015). Mental ill health was identified as a primary issue in a review paper by Miovic and Block (2007) looking at psychiatric disorders and substance “misuse” in advanced cancer. Antoni et al. (2012) examined substance “misuse” experienced by US army veterans. Halman et al. (2014) undertook a retrospective chart review (single institution) from 83 late-stage HIV patients from Canada highlighting substance use co-morbidities of a subset of people dying with HIV-related conditions. Two papers from the USA, Karus et al. (2004) and Morgan and Kochan (2008) explored HIV in relation to substance use and end of life and found issues of underlying poverty and a lack of sufficient health insurance. HIV disease per se was not seen as an issue for end of life care but rather HIV in a cluster of

mental health problems alongside substance use, the combination of which raises the sorts of issues previously highlighted around compliance and pain control. There were four papers addressing what we have termed marginalised populations including a discussion paper, proposing that training was needed to increase methadone counsellors' palliative and end of life care skills (Doukas, 2014). This was echoed by Mundt-Leach (2016) who suggests closer working relationships between palliative care and addiction services. Dzul-Church et al. (2010) and Sulistio and Jackson (2013) highlight complex issues related to poverty, multiple substance use and emotional and social difficulties. In particular, pain management strategies should be more effective with increased awareness of the challenges in prescribing for analgesia compared with opioid substitution therapy (Sulistio & Jackson, 2013) and healthcare providers should examine the complexity of needs in these populations and provide structured, person-centred approaches predicated on effective communication.

3.6 | Alcohol

There were six papers identified that had alcohol as a primary focus (Dev et al., 2011; Irwin et al., 2005; Kwon et al., 2013b; Mercadante et al., 2015; Poonja et al., 2014; Webber & Davies, 2012). Five of the papers examined alcohol use in relation to cancer and one related to liver cirrhosis. Men form the overwhelming majority of problematic alcohol users; usually by a factor of more than 2:1 and this continues into the palliative/advanced cancer population. This gender bias was reflected in the populations of the existing evidence on alcohol and end of life care. However, problematic alcohol use appears to be more common in younger palliative populations referred late to supportive palliative care services (Kwon et al., 2013b). The most frequently used alcohol screening instrument documented in the evidence to date appears to be the CAGE questionnaire (Dev et al., 2011; Kwon et al., 2013, 2015; Mercadante et al., 2015) although others are used in addition to or instead of, CAGE. The papers focussed on the importance of screening and concerns about “undocumented” alcohol difficulties and its impact on people's end of life experience. This focus on screening for alcohol problems among the end of life care population mirrors the concerns identified in the pain literature around “chemical coping”, where people use substances to compensate for the inadequate pain relief prescribed (Kwon et al., 2015).

TABLE 4 Final included papers

FINAL PAPERS (n = 60)	Quality indicator	Country of Origin
Antoni, C., Silverman, M. A., Nasr, S. Z., Mandi, D. & Golden, A. G. (2012). Providing support through life's final chapter for those who made it home. <i>Military Medicine</i> , 177(12), 1498–1501. https://doi.org/10.7205/MILMED-D-12-00315	Non-empirical	USA
Arthur, J. A., Haider, A., Edwards, T., Waletich-Flemming, J., Reddy, S., Bruera, E., & Hui, D. (2016). Aberrant opioid use and urine drug testing in outpatient palliative care. <i>Journal of Palliative Medicine</i> , 19(7), 778–782. https://doi.org/10.1089/jpm.2015.0335	Non-empirical	USA
Barclay, J. S., Owens, J. E., & Blackhall, L. J. (2014). Screening for substance abuse risk in cancer patients using the Opioid Risk Tool and urine drug screen. <i>Supportive Care In Cancer</i> , 22(7), 1883–1888. https://doi.org/10.1007/s00520-014-2167-6	15	USA
Beynon, C., McVeigh, J., Hurst, A., & Marr, A. (2010a). Older and sicker: Changing mortality of drug users in treatment in the North West of England. <i>International Journal of Drug Policy</i> , 21(5), 429–431. DOI: 10.1016/j.drugpo.2010.01.012	9	UK
Beynon, C., Stimson, G., & Lawson, E. (2010b). Illegal drug use in the age of ageing. <i>British Journal of General Practice</i> , 60 (576), 481–482. DOI: 10.3399/bjgp10X514710	Non-empirical	UK
Blackhall, L. J., Alfson, E. D., & Barclay, J. S. (2013). Screening for substance abuse and diversion in virginia hospices. <i>Journal of Palliative Medicine</i> , 16 (3), 237–242. https://doi.org/10.1089/jpm.2012.0263	8	USA
Burton-MacLeod, S., & Fainsinger, R., L. (2008). Cancer pain control in the setting of substance use: Establishing goals of care. <i>Journal of Palliative Care</i> , 24 (2), 122–125.	Non-empirical	Canada
Carmichael, A., N., Morgan, L., & Del Fabbro, E. (2016). Identifying and assessing the risk of opioid abuse in patients with cancer: an integrative review. <i>Substance Abuse And Rehabilitation</i> , 7, 71–79. https://doi.org/10.2147/SAR.S85409	Non-empirical	USA
Childers, J. W., & Arnold, R. M. (2012). "I feel uncomfortable 'calling a patient out": Educational needs of palliative medicine fellows in managing opioid misuse. <i>Journal of Pain and Symptom Management</i> , 43(2), 253–260. DOI: 10.1016/j.jpainsymman.2011.03.009	12	USA
Childers, J. W., King, L. A., & Arnold, R. M. (2015). Chronic pain and risk factors for opioid misuse in a palliative care clinic. <i>American Journal of Hospice & Palliative Medicine</i> , 32(6), 654–659. https://doi.org/10.1177/1049909114531445	14	USA
Chou, R., Fanciullo, G. J., Fine, P. G., Passik, S. D., & Portenoy, R. K. (2009). Opioids for chronic noncancer pain: prediction and identification of aberrant drug-related behaviors: A review of the evidence for an American Pain Society and American academy of pain medicine clinical practice guideline. <i>The Journal of Pain</i> , 10(2), 131–146. https://doi.org/10.1016/j.jpain.2008.10.009	Non-empirical	USA
Collier, R. (2011). Bringing palliative care to the homeless. <i>CMAJ: Canadian Medical Association Journal</i> , 183(6), E317–E318. https://doi.org/10.1503/cmaj.109-3756	Non-empirical	Canada
Corkery, J. (2008). UK drug-related mortality -- issues in definition and classification. <i>Drugs & Alcohol Today</i> , 8(2), 17–25. https://doi.org/10.1108/17459265200800014	Non-empirical	UK
Dev, R., Parsons, H. A., Palla, S., Palmer, J. L., Del Fabbro, E., & Bruera, E. (2011). Undocumented alcoholism and its correlation with tobacco and illegal drug use in advanced cancer patients. <i>Cancer</i> , 117(19), 4551–4556. DOI: 10.1002/cncr.26082	11	USA
Doukas, N. (2014). Are methadone counselors properly equipped to meet the palliative care needs of older adults in methadone maintenance treatment? Implications for Training. <i>Journal of Social Work in End-of-Life & Palliative Care</i> , 10(2), 186–204. https://doi.org/10.1080/15524256.2014.906370 .	Non-empirical	Canada
Dzul-Church, V., Cimino, J. W., Adler, S. R., Wong, P. & Anderson, W. G. (2010). "I'm sitting here by myself...": experiences of patients with serious illness at an Urban Public Hospital. <i>Journal of Palliative Medicine</i> , 13(6), 695–701. https://doi.org/10.1089/jpm.2009.0352	15	USA
Farnham, C. (2012). Palliative Care for Substance Misusers. In D. Olivere, B., Monroe, & S. Payne. (Eds.). <i>Death, Dying, and Social Differences</i> (2nd Edition) (pp. 173–182). Oxford, Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199599295.001.0001	Non-empirical	UK
Halman, M., Carusone, S. C., Stranks, S., Schaefer-McDaniel, N. & Stewart, A. (2013). Complex care needs of patients with late-stage HIV disease: A retrospective study. <i>AIDS Care</i> , 26(3), 320–325. https://doi.org/10.1080/09540121.2013.819404	11	Canada
Hudson, B. F. (2016). Challenges to access and provision of palliative care for people who are homeless: A systematic review of qualitative research. <i>BMC Palliative Care</i> , 15(1), 96. https://doi.org/10.1186/s12904-016-0168-6	Non-empirical	UK

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TABLE 4 (Continued)

FINAL PAPERS (n = 60)	Quality indicator	Country of Origin
Irwin, P., Murray, S., Bilinski A., Chern, B., & Stafford, B. (2005). Alcohol withdrawal as an underrated cause of agitated delirium and terminal restlessness in patients with advanced malignancy. <i>Journal of Pain & Symptom Management</i> , 29(1), 104–108. DOI: 10.1016/j.jpainsymman.2004.04.010	Non-empirical	Australia
Karus, D., Raveis, V., Marconi, K., Hanna, B., Selwyn, P., Alexander, C., Perrone, M., & Higginson, I. (2004). Service needs of patients with advanced HIV disease: a comparison of client and staff reports at three palliative care projects. <i>Aids Patient Care and STDs</i> , 18(3), 145–158. https://doi.org/10.1089/108729104322994838	14	USA
Kirsh, K., & Passik, S. (2006). Palliative care of the terminally ill drug addict. <i>Cancer Investigation</i> , 24(4), 425–431. doi.org/10.1080/07357900600705565	Non-empirical	USA
Knowlton, A., R., Nguyen, T., Q., Robinson, A., C., Harrell, P., T. & Mitchell, M., M. (2015). Pain symptoms associated with opioid use among vulnerable persons with HIV: An exploratory study with implications for palliative care and opioid abuse prevention. <i>Journal of Palliative Care</i> , 31(4), 228–233. https://doi.org/10.1177/082585971503100404	12	USA
Koyalagunta, D., Burton, A. W., Toro, M. P., Driver, L., Novy, D., M. (2011). Opioid abuse in cancer pain: Report of two cases and presentation of an algorithm of multidisciplinary care. <i>Pain Physician</i> , 14(4), E361–371	Non-empirical	USA
Krashin, D., Murinova, N., & Ballantyne, J. (2012). Management of pain with comorbid substance abuse. <i>Current Psychiatry Reports</i> , 14(5), 462–468. https://doi.org/10.1007/s11920-012-0298-3	Non-empirical	USA
Krashin, D., Murinova, N., Jumelle, P. & Ballantyne, J. (2015). Opioid risk assessment in palliative medicine. <i>Expert Opinion on Drug Safety</i> , 14(7), 1023–1033. https://doi.org/10.1517/14740338.2015.1041915 .	Non-empirical	USA
Kushel, M. B., & Miaskowski, C. (2006). End-of-life care for homeless patients: “she says she is there to help me in any situation”. <i>JAMA</i> , 296(24), 2959–2966. https://doi.org/10.1001/jama.296.24.2959	Non-empirical	USA
Kutzen, H. S. (2004). Integration of palliative care into primary care for human immunodeficiency virus-infected patients. <i>American Journal of the Medical Sciences</i> , 328(1), 37–47. DOI: https://doi.org/10.1097/00000441-200407000-00006	Non-empirical	USA
Kwon, J. H., Hui, D., Chisholm, G., & Bruera, E. (2013). Predictors of long-term opioid treatment among patients who receive chemoradiation for head and neck cancer. <i>The Oncologist</i> , 18(6), 768–774. https://doi.org/10.1634/theoncologist.2013-0001	14	USA
Kwon, J. H., Hui, D., Chisholm, G., Ha, C., Yennurajalingam, S., Kang, J. H., & Bruera, E. (2013). Clinical characteristics of cancer patients referred early to supportive and palliative care. <i>Journal of Palliative Medicine</i> , 16(2) 148–155. https://doi.org/10.1089/jpm.2012.0344 .	11	USA
Kwon, J. H., Tanco, K., Park, J. C., Wong, A., Seo, L., Liu, D., Chisholm, G., Williams, J., Hui, D. & Bruera, E. (2015). Frequency, predictors, and medical record documentation of chemical coping among advanced cancer patients. <i>The Oncologist</i> , 20(6), 692–697. https://doi.org/10.1634/theoncologist.2015-0012 .	14	USA
MacWilliams, J., Bramwell, M., Brown, S. & O'Connor, M. (2014). Reaching out to Ray: delivering palliative care services to a homeless person in Melbourne, Australia. <i>International Journal of Palliative Nursing</i> , 20(2) 83–88. https://doi.org/10.12968/ijpn.2014.20.2.83	6	Australia
McNeil, R., & Guirguis-Younger, M. (2012a). Harm reduction and palliative care: Is there a role for supervised drug consumption services? <i>Journal of Palliative Care</i> , 28(3) 175–177.	Non-empirical	Canada
McNeil, R., & Guirguis-Younger, M. (2012b). Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals. <i>Palliative Medicine</i> , 26(4), 350–359. https://doi.org/10.1177/0269216311402713	14	Canada
McNeil, R., Guirguis-Younger, M. & Dille, L. B. (2012). Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. <i>BMC Palliative Care</i> , 11, 14. https://doi.org/10.1186/1472-684X-11-14	15	Canada
McNeil, R., Guirguis-Younger, M., Dille, L. B., Aubry, T. D., Turnbull, J., & Hwang, S. W. (2012). Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs: a qualitative analysis. <i>BMC Public Health</i> , 12(1), 12:312. https://doi.org/10.1186/1471-2458-12-312	14	Canada
McNeil, R., Dille, L. B., Guirguis-Younger, M., Hwang, S. W., & Small, W. (2014). Impact of supervised drug consumption services on access to and engagement with care at a palliative and supportive care facility for people living with HIV/AIDS: A qualitative study. <i>Journal of the International AIDS Society</i> , 17(1) 18855. https://doi.org/10.7448/IAS.17.1.18855	12	Canada

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TABLE 4 (Continued)

FINAL PAPERS (n = 60)	Quality indicator	Country of Origin
Mercadante, S., Porzio, G., Caruselli, A., Aielli, F., Adile, C., Girelli, N., Casuccio, A., & Home Care-Italy, G. (2015) The frequency of alcoholism in patients with advanced cancer admitted to an acute palliative care unit and a home care program. <i>Journal of Pain & Symptom Management</i> , 49(2), 254-257. https://doi.org/10.1016/j.jpainsymman.2014.06.005	12	Italy
Miovic, M., & Block, S. (2007) Psychiatric disorders in advanced cancer. <i>Cancer</i> , 110(8) 1665-1676. https://doi.org/10.1002/cncr.22980	Non-empirical	USA
Morgan, B., & Kochan, K. A. (2008). I'll Always Want More: Complex Issues in HIV Palliative Care. <i>Journal of Hospice & Palliative Nursing</i> , 10(5) 265-271. https://doi.org/10.1097/01.NJH.0000319176.48165.44	Non-empirical	USA
Mundt-Leach, R. (2016). End of life and palliative care of patients with drug and alcohol addiction. <i>Mental Health Practice</i> , 20(3) 17-21. https://doi.org/10.7748/mhp.2016.e1148	Non-empirical	UK
Page, S. A., Thurston, W. E. & Mahoney, C. E. (2012). Causes of Death Among an Urban Homeless Population Considered by the Medical Examiner. <i>Journal of Social Work in End-of-Life & Palliative Care</i> , 8(3) 265-271. https://doi.org/10.1080/15524256.2012.708111	11	Canada
Pancari, J., & Baird, C. (2014) Managing Prescription Drug Diversion Risks. <i>Journal of Addictions Nursing</i> , 25(3), 114-121. https://doi.org/10.1097/JAN.0000000000000036	Non-empirical	USA
Passik, S. D., Dhingra, L. K., & Kirsh, K. L. (2009). Cancer pain management in the chemically dependent patient. In E.D. Bruera & R. K. Portenoy (Eds) <i>Cancer Pain: Assessment and Management</i> (Second Edition) (pp. 423-432), Cambridge, Cambridge University Press. https://doi.org/10.1017/CBO9780511642357	Non-empirical	USA
Perry, B. A., Westfall, A. O., Molony, E., Tucker, R., Ritchie, C., Saag, M. S., Mugavero, M. J., & Merlin, J. S. (2013). Characteristics of an ambulatory palliative care clinic for HIV-infected patients. <i>Journal of Palliative Medicine</i> , 16(8), 934-937. https://doi.org/10.1089/jpm.2012.0451	12	USA
Podymow, T., Turnbull, J. & Coyle, D. (2006). Shelter-based palliative care for the homeless terminally ill. <i>Palliative Medicine</i> , 20(2), 81-86. https://doi.org/10.1191/0269216306pm1103oa	12	Canada
Poonja, Z., Brisebois, A., van Zanten, S. V., Tandon, P., Meeberg, G., & Karvellas, C. J. (2014). Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. <i>Clinical Gastroenterology & Hepatology</i> , 12(4), 692-698. https://doi.org/10.1016/j.cgh.2013.08.027	13	Canada
Reisfield, G. M., Paulian, G. D., & Wilson, G. R. (2009). Fast Facts and Concepts #127 Substance use disorders in the palliative care patient. <i>Journal of Palliative Medicine</i> , 12 (5) 475-476. https://doi.org/10.1089/jpm.2009.9630	Non-empirical	USA
Roe, B., Beynon, C., Pickering, L., & Duffy, P. (2010). Experiences of drug use and ageing: health, quality of life, relationship and service implications. <i>Journal of Advanced Nursing</i> , 66(9) 1968-1979. https://doi.org/10.1111/j.1365-2648.2010.05378.x	12	UK
Rowley, D., McLean, S., O'Gorman, A., Ryan, K., & McQuillan, R. (2011). Review of cancer pain management in patients receiving maintenance Methadone therapy. <i>American Journal of Hospice and Palliative Medicine</i> , 28(3), 183-187. https://doi.org/10.1177/1049909110380897	8	USA
Song, J., Ratner, E. R., Bartels, D. M., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007b). Experiences with and attitudes toward death and dying among homeless persons. <i>Journal of General Internal Medicine</i> , 22(4), 427-434. DOI: 10.1007/s11606-006-0045-8	13	USA
Song, J., Bartels, D. M., & Ratner, E. R. (2007a). Dying on the streets: homeless persons' concerns and desires about end of life care. <i>Journal of General Internal Medicine</i> , 22(4), 435-441. https://doi.org/10.1007/s11606-006-0046-7	12	USA
Stenbacka, M., Leifman, A., & Romelsjo, A. (2010). Mortality and cause of death among 1705 illicit drug users: A 37 year follow up. <i>Drug and Alcohol Review</i> , 29(1), 21-27. https://doi.org/10.1111/j.1465-3362.2009.00075.x	12	Sweden
Sulistio, M., & Jackson, K. (2013). Three weeks from diagnosis to death: The chaotic journey of a long-term methadone maintenance patient with terminal cancer. <i>Journal of Pain and Symptom Management</i> , 46(4) 598-602. https://doi.org/10.1016/j.jpainsymman.2012.10.231	Non-empirical	Australia
Tan, P. D., Barclay, J. S., & Blackhall, L. J. (2015). Do Palliative Care Clinics Screen for Substance Abuse and Diversion? Results of a National Survey. <i>Journal of Palliative Medicine</i> , 18(9) 752-757. https://doi.org/10.1089/jpm.2015.0098	10	USA
Taveros, M. C., & Chuang, E. J. (2016). Pain management strategies for patients on methadone maintenance therapy: a systematic review of the literature. <i>BMJ Supportive & Palliative Care</i> , 7(4) 383-389. DOI: 10.1136/bmjspcare-2016-001126	Non-empirical	USA

(Continues)

TABLE 4 (Continued)

FINAL PAPERS (n = 60)	Quality indicator	Country of Origin
Walsh, A. F. & Broglio, K. (2010). Pain Management in Advanced Illness and Comorbid Substance Use Disorder. <i>Journal of Hospice and Palliative Care Nursing</i> , 12(1), 8–14. https://doi.org/10.1097/NJH.0b013e3181c72e19	Non-empirical	USA
Webb, W. A. (2015). When dying at home is not an option: Exploration of hostel staff views on palliative care for homeless people. <i>International Journal of Palliative Nursing</i> , 21(5) 236–244. https://doi.org/10.12968/ijpn.2015.21.5.236	9	UK
Webber, K. & Davies, A. N. (2012). An observational study to determine the prevalence of alcohol use disorders in advanced cancer patients. <i>Palliative Medicine</i> , 26(4), 360–367. https://doi.org/10.1177/0269216311409474	12	UK
Williams, B. A., Ahalt, C., Stijacic-Cenzer, I., Smith, A. K., Goldenson, J., & Ritchie, C. S. (2014). Pain behind bars: the epidemiology of pain in older jail inmates in a county jail. <i>Journal of Palliative Medicine</i> , 17(12), 1336–1343. https://doi.org/10.1089/jpm.2014.0160	12	USA

3.7 | Miscellaneous

There were five papers that fell outside of the thematic groups identified. Beynon, McVeigh, Hurst, and Marr (2010) examined the changing patterns of causes of death among substance users in the North West of England. They found that the median age of death rose from 36.46 in 2003–2004 to 41.38 in 2007–2008 and that causes of death were increasingly related to chronic conditions more associated with older age. Stenbacka et al. (2010) reviewed changes in substance-related mortality patterns in Sweden and found that the average age of death was 47 years; 25–30 years less than the general population. Women had lower mortality rates and accidents and suicides were the most common causes of death in younger substance users, with cardiovascular disease and tumours most common among older substance users. Corkery (2008) reviewed classification issues in drug related deaths (DRD) in the UK and found DRDs fall into two broad categories; those directly attributable to drug use (overdoses and poisoning) and indirectly attributable, that is, related to drug use such as infections and accidents. The author suggests that more attention is given to direct DRDs rather than the long-term consequences of drug use. Two papers looked at older drug users in particular. Roe et al. (2010) undertook qualitative interviews (n = 11) with older drugs users who used a voluntary drug treatment service and found drug use impacts negatively on health and family relationships and support. Many older users lived alone and had multiple experiences of loss. Beynon et al. (2010b) reviewed UK patterns of drug use with a focus on older users. They found older drug users presented with specific challenges, such as interactions between legal and illegal drugs, lack of social support, cognitive impairment and issues around managing pain, particularly at their end of life.

4 | DISCUSSION

There is a lack of diversity, quality, breadth and depth to the literature on palliative and end of life care for people with problematic substance use. The gaps in the existing evidence are multiple, both in terms of focus and methodology. However, this is not surprising in a newly recognised area of practice and research. What is evident

is the lack of research on responses to and interventions for, people with problematic substance use and palliative or end of life care needs. It appears policy and practice have yet to respond to the emerging needs of people with problematic substance use at or near, their end of life in a significant way. This is a concern given the trends around substance use among older age groups and the increasing longevity of the general population. This absence of practice response is reflected in the gaps in the evidence base and can reflect a lack of patient involvement in order to drive through relevant and effective health improvements that reflect the complexity and need of this population (Luxford & Sutton, 2014).

The implications from this REA would suggest that more empirical research needs to be conducted exploring all aspects of problematic substance use and palliative and end of life care. There is a lack of data from countries outside of North America. Comparative studies would be particularly beneficial to our understanding of the issues, as would health and social care responses within different cultural contexts. There may be different healthcare professional responses in relation to palliative and end of life care within East Asian countries (Morita et al., 2015), for example or even culturally diverse communities within western countries (Owen & Randhawa, 2004).

There were few prevalence studies identified. This is an area requiring more epidemiological research to provide a wider context for policy and practice development. In terms of methodological inquiry, more quantitative approaches are needed to provide larger scale data on the experiences of particular populations involved in service provision, e.g. palliative care social workers, community nurse provision.

Further research is needed on conditions other than cancer that co-exist with substance use, both in terms of their prevalence and incidence and also the health and social care responses available to people with experience of both substance use and life limiting illness. There are a wide range of co-morbidities associated with substance use, including COPD, diabetes, cardiovascular disease, mental health problems and liver disease (Cullen, O'Brien, O'Carroll, O'Kelly, & Bury, 2009; Shield et al., 2014).

There was no research identifying models of good practice for working with co-existing substance use and palliative or end of life conditions; they need developing, piloting and evaluating for their

effectiveness. Aldridge et al. (2017) and Luchenski et al. (2018) highlight the issues related to marginalised and excluded populations and recommends intervention development targeting modification of social determinants of health like housing and training. They also recommend examining models of care a primary, secondary and preventative levels to assess need at a population level.

Qualitative inquiry is required to establish the needs of family and friends of people with substance use problems at or near, their end of life. Such qualitative inquiry should extend to patients' voices that are currently under-researched and almost absent from the existing evidence. More dense description is required including social, demographic and health profiles of participants as well as setting and context to enhance transferability (Rolfe, Ramsden, Banner, & Graham, 2018). A clear representation of people with problematic substance use can give diverse perspectives to design relevant and appropriate studies and enhance sustainability (Wilson et al., 2015). Research should also include the experiences, views and attitudes of social and healthcare professionals in responding to the overlapping issues of substance use and palliative and end of life conditions. This could include concerns about potential safety risks for outreach or community-based practice in particular, as highlighted by Galvani, Dance, and Wright (2018) in their study of hospice and specialist substance use staff. Lastly, there was limited evidence found in relation to alcohol (for example, problematic alcohol consumption associated with liver cirrhosis specifically at the end of life). Further work needs to be done in this area given alcohol remains the most commonly used substance. The full REA report for this work can be accessed for further information (Witham, Galvani, & Peacock, 2018).

4.1 | Limitations

REAs have a number of limitations including the breadth and depth of the searching. The number and type of databases used for searching are often limited to allow for a more rapid result and usually do not include the comprehensive searching involved in systematic reviews (, undated). These limitations apply to this study too. The decision to set the cut-off date at 2004 and to access only English language literature meant that some studies may have been missed and it is not possible to know how many would have met our inclusion criteria. Nevertheless, agreeing and adhering to a date limiter is an accepted feature of REA's as is the need to set limits on the retrieval of full texts (Government Social Research & EPPI Centres, 2009). Thirteen databases across health and social care sources were accessed for this review. It is possible that more databases may have produced additional material. Similarly, expanding our search terms to include specific health conditions and specific types of licit and illicit drugs may have produced further hits. Data extraction and critique is often limited with REAs resulting in a focus on methodology and only key elements of data. While this review went slightly deeper in our reading and grouping of content within the evidence, a less rapid review could have included this greater depth.

5 | CONCLUSION

This REA set out to explore current responses to and models of practice for, people living with problematic substance use and palliative and end of life care conditions. There is a dearth of research available on this topic and thus the focus of this review was broadened to identify what evidence was available, its focus, quality and the gaps in the research evidence base. The resulting body of work comprised 60 papers, primarily from peer-reviewed journals. It was quite disparate in focus, with a diverse range of research populations, research questions and methodological choices. The available evidence resulted in two clear, but limited, groups of papers, those focussing on pain management and prescribing and those focussing on homelessness, substance use and end of life care. A third group included a small body of work on alcohol and palliative or end of life care and a small number of other papers including co-existing mental health or HIV-related conditions. This is clearly an area of work where far more research is needed. It is a new area of work and research focus and that has to be considered in considering our findings. However, the gaps identified are considerable and need to be filled in order to provide an evidence base on which to build future good policy and practice, both in the UK and internationally. Ultimately, this work is needed to ensure that this growing group of people have good quality care and equal access to service provision.

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