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RESEARCH BRIEFING NO. 1

Rapid Evidence Assessment:

End of Life Care for People with Alcohol and Drug Problems

“There is a dearth of evidence overall and no body of evidence that identifies effective interventions, responses, or models of practice.”

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Key findings

1. The aim of this Rapid Evidence Assessment (REA) was to determine the nature and extent of the international research evidence on *current responses* to end of life care for people with substance problems published between 2004-2016.
2. There is a dearth of evidence overall and no body of evidence that identifies effective interventions, responses, or models of practice.
3. This REA, therefore, refocussed on a broader scoping of the evidence and producing a systematic map of the evidence available, the themes and implications for practice, and future research. The same date parameters were set.
4. A final sample of 60 papers was included in the review, 32 of which reported empirical research.
5. Of the 32 empirical papers, quality assessment indicated that only nine were of high quality, 18 were of moderate quality and five were of low quality.
6. Most of the papers reported on studies in North America and to a lesser extent, Europe and Australia. Only nine were UK based.
7. Methodologically, quantitative studies dominated the available evidence. Only 11 papers (34.3%) were qualitative.
8. The majority of papers focussed on some aspect of pain management and prescribing practice where there are, or have been, substance problems. Most of these focussed on people with cancer diagnoses.
9. A small body of work focussed on particular groups of people, primarily homeless people, people with mental ill health and people with HIV.
10. Six papers focussed on alcohol use among people with cancer diagnoses.
11. There were some common recommendations relating to safe and effective pain management strategies, harm reduction strategies and the acknowledgement of complex comorbidities among this group of people.
12. The literature highlighted the under-utilisation of preventative or primary care services by this group of people, the need for empathetic communication by professionals, and a flexible service response.

This Briefing is drawn from a more detailed report (Witham et al., 2018) that sets out the findings of the REA including a listing of the final papers reviewed. The full report provides a narrative on some of the recommendations and practice challenges that were embedded in the papers. These data can help to extend the debate on how best to ensure that the health inequalities faced by people with substance problems needing end of life care are addressed.

Background

In the last two decades there has been a number of changes evident among the population whose use of substances¹ is problematic. The most notable is the increase in the number of older drug users and a resultant rise in rates of death from non-drug related conditions (Beynon, 2010). This means that current and previous substance users now survive long enough to die of health conditions more commonly found in deprived cohorts of the wider population (Corkery 2008; Beynon et al. 2010). Further, changes in life expectancy in the general population leading to a pattern of population ageing is likely to be mirrored in the smaller population of substance users. The shifts in harm reduction and treatment policies means that older substance users (over the age of 40) are now more likely to die of a non-drug related cause than users under the age of 40 (Stenbacka et al. 2008, Benyon et al. 2010).

There has also been an increase in alcohol-related morbidity and mortality among older drinkers (Kaplan et al. 2012). This increase runs parallel to the increasingly clear evidence that alcohol causes cancers of the oropharynx, larynx, oesophagus, liver, colon, rectum and breast (Connor 2016). Excessive alcohol consumption is linked to a number of other chronic and potentially end of life conditions, including cardiovascular disease and liver cirrhosis (Rehm et al 2009).

Finally, the emergence and increasing use of New Psychoactive Substances (NPS - previously known as Legal Highs) is also part of the changing landscape of drug use. The impact of this increase on mortality and morbidity is not yet known. Some of the more immediate consequences of NPS use are apparent in the prisons system and in admissions to hospital accident and emergency departments for acute intoxication (Ralphs et al. 2017, Liakoni et al. 2016).

For the general population, while life expectancy has been increasing, so too has the number of years spent at the end of life living with disability and ill-health (Bell and Marmot 2017). This has led to a growth in the numbers of deaths which can be anticipated and which are likely to require palliative and end of life care (Etkind et al. 2017). However, little is known about the nature and extent of need for end of life care by substance using populations or how well services are equipped to work with the people with problematic substance use. The wider programme of research, of which this REA is part, set out to fill this gap in knowledge. Specifically, this REA focusses on determining what is already known as well as identifying gaps in the evidence base.

¹ We use 'substances' to mean alcohol and other drugs.

Methodology

This strand of the research programme exploring end of life care for people with substance problems set out to answer the following research question:

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 objectives:

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

The review was conducted with the rigour of planning and approach of an REA. However, as a result of the dearth of evidence and the diversity of the literature found in its early stages, it also encompassed a systematic mapping of the review's findings.

The following databases and search terms comprised the final search protocol (see tables 1 and 2 below). The search focussed on English language literature between the years 2004 to 2016².

Table 1 – Search fields, databases and other sources

| Search within fields | Keywords/ subject terms/abstract |
|----------------------|---|
| Databases | Amed, Psycarticles, Ovid, Ageinfo, MedLine, Ebscohost, ASSIA, Social Care Online, Web of Knowledge (including Social Science Citations Index), Web of Science, SSCI, Samsha, NIAAA, |

Table 2 - Final search terms

| | |
|--------------------------|--|
| Key search terms: | <ol style="list-style-type: none">1. end of life, palliative, dying, death, life limiting, life threatening2. drug misuse/abuse/use, substance use/misuse/abuse, medication use or abuse, alcohol |
|--------------------------|--|

² 2016 was the start date of the REA.

Inclusion and exclusion criteria were drawn up for each search and applied throughout the screening process; title, abstract, and full text. We also excluded tobacco-related studies. Excluded papers were coded A-E (see coding table below in table 3).

Table 3 – 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 nor substance use. |
| D | Not about pathways; not about professional practice concerns; not about family and social networks; not about impact or considerations. |
| E | Does not meet the above, but is of interest. |

For 'borderline' papers, further discussion took place between two reviewers as to whether the paper should be included in the review. If any disagreement remained, the papers were reviewed by a third member of the research team who had the casting vote.

Assessing quality and relevance

The quality of the individual studies was assessed based on six principles derived from DFID (2014) guidance; conceptual framing, transparency, appropriateness, cultural sensitivity, validity and cogency. The papers were scored on these six criteria using a three-point scale:

- 3 = no concerns;
- 2 = some minor concerns;
- 1 = major concerns.

This resulted in a score ranging from 6 to 18 for each study. Nine studies were judged to be high quality, 18 moderate and 5 low. It is important to note that a low or moderate 'quality' rating does not imply that a study was poorly designed or executed, it can simply mean that the report of the study did not fully explain its design or methods.

Findings

The final search of peer reviewed articles resulted in 4384 hits. Application of the inclusion and exclusion criteria were applied at abstract and full text reading stages resulting in a final sample of 60 papers. The papers were extremely diverse in methodology, focus and audience. The systematic map below (figure 1) illustrates the range of evidence found.

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 the systematic map shows (see figure 1 below), the evidence could be grouped around three main themes: pain management (n=25), homeless and marginalised populations (n=24) and alcohol-related papers (n=6). In addition, there were five remaining papers which were diverse in focus and methodology. There were some overlap of categories within the papers.

The findings of this REA demonstrated a largely heterogeneous literature, with limited empirical work in any specific area of end of life care for people with substance problems. In the thematic analysis of these studies, pain management was, marginally, the largest category (n=25), followed by homeless and marginalised groups (n=24) and finally, alcohol-related papers (n=6). The majority of studies focused exclusively or predominantly on cancer populations, including 14 studies within the thematic category of pain management and all six of the papers related to the alcohol literature.

Within the pain literature, six studies were from more general palliative care populations with three related to HIV and two to non-cancer chronic pain. There were a small number of miscellaneous papers (n=5). In terms of geographical distribution of the published literature, the majority of the studies were from North America, (n=46; 76.7%) with the second largest sample from Europe (n=11; 18.2%). Only nine papers were from the UK. Therefore, the majority of the published literature from this REA is from a narrow geographical area. Within the thematic category of homeless and marginalised populations, the studies focused on mental health needs, HIV and homelessness and often related to service provider response. This category was often represented by studies using qualitative approaches (n=9) and therefore exploratory in nature, examining both service user and service provider perspectives.

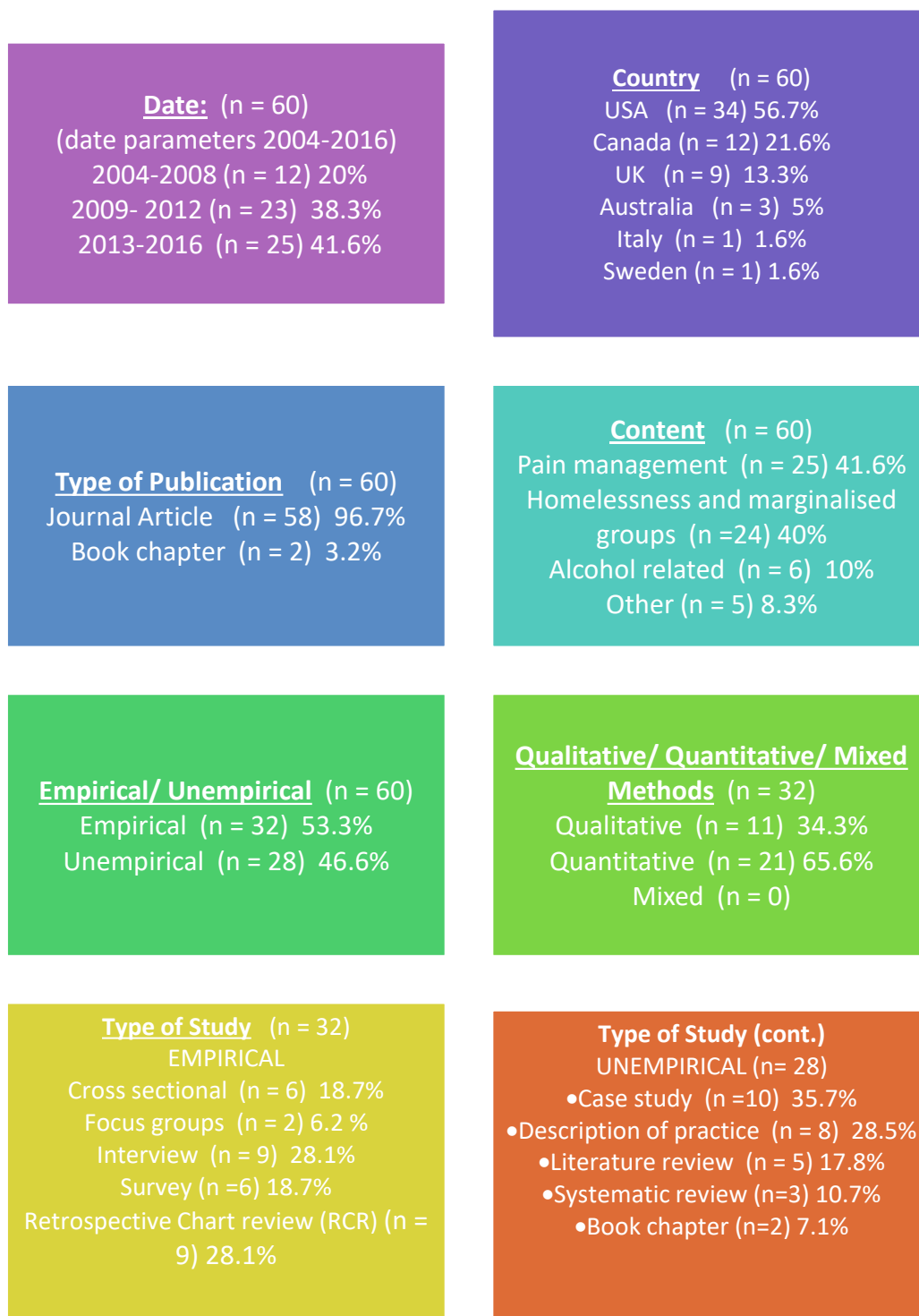


Figure 1 - Systematic Map: Substance Use and End of Life Care

Gaps in the evidence

Key gaps in the evidence include:

- Very little research has been done in the UK. Most published research in this area has been generated in North America.
- Less than two thirds of the literature identified was empirical work with the remainder descriptive papers, book chapters, single case studies, or reviews of literature.
- The existing evidence is also dominated by quantitative research with approximately one third of it using qualitative methods.
- There were no identified papers related specifically to family or carers/supporters of people with substance problems at the end of life.
- There were only eight papers that documented professionals' perspectives, three that mentioned service user perspectives of family members and carers' involvement, and seven that documented service users' perspective or those with experience of receiving services previously.
- Finally, the map shows a narrow and limited topic focus of the evidence to date³.
- There were no intervention or evaluation studies and no practice models that were underpinned by a robust evidence base relating to substance use and end of life care.
- There was no consensus about what constitutes good practice.
- There were no studies relating to New Psychoactive Substance (NPS) use and its impact on end of life care.
- There were only four papers examining older drug users (Beynon et al. 2010a, 2010b, Roe et al. 2010 and Williams et al. 2014).

Good practice recommendations

A number of recommendations⁴ for practice emerged from the literature.

Managing pain

In terms of good practice in relation to pain management, most of the papers were based on anecdotal evidence rather than strong empirical data. There were, however, some common recommendations from the diverse papers focusing on risk management and risk assessment:

³ We offer a note of caution, however, in that the thematic groupings are our own and others may group them differently.

⁴ These are recommendations highlighted in the research literature.

Not under prescribing for pain

There was an acknowledgement in a number of papers that the most significant prescribing problem in relation to substance misuse is the persistent under treatment of pain in this population, driven by the inappropriate fear that opioids will be misused.

Screening for substance use

Identifying substance use was important for most authors with Arthur et al. (2016) suggesting that drug screening (within palliative care clinics) can be used to initiate an effective conversation about the potential dangers of drug behaviours. Most papers suggested universal screening using validated screening tools.

Screening for risk factors for substance use

Krashin et al. (2015) also suggested assessing for validated risk factors for developing problems with opioid use, for example, assessing for a history of substance use, including smoking, family history of substance misuse, history of childhood abuse including post-traumatic stress disorder, and psychiatric comorbidities (anxiety, depression, personality disorder).

Talking about substance use

Underpinning most papers was the prerequisite requirement of effective and often direct communication. Whether this happened, how to achieve it, and what sort of strategies would be helpful in managing direct conversations about substance misuse, was not a feature of the current literature. This literature also suggests that clinicians need to distinguish between pseudo-addictive behaviour(s), such as chemical coping and misuse of prescribed medication.

Awareness of harm reduction approaches to substance use

Underlying approaches to substance misuse were articulated by some authors, with harm reduction rather than abstinence seen as a more helpful approach and liaison with local substance misuse teams to reach realistic goals.

Homelessness and marginalised groups

The literature identified in this REA did not contain any papers which specifically identified recommendations. Some empirical papers proposed models which fell into the following four categories (see table 4 below):

Table 4: Guidelines for practice with homeless and marginalised people

| Category | Practice guidelines |
|--|---|
| Environment(s) of care | Deliver services in settings familiar to service users (e.g. "shelter based care", services in needle exchanges). |
| Philosophy of care | Use of a harm reduction rather than abstinence only model. Services should aim for low threshold strategies, i.e. those with minimum restrictions on service users' normal patterns of behaviour. |
| Service delivery | Need for services to be flexible and responsive. Need for coordinated care with a case manager/case worker to prevent service users slipping through the gaps. Partnering of agencies to promote joint working. |
| Safety plans for identified high risk patients | Piloting of supervised consumption (of both alcohol and illicit drugs). |

Alcohol literature

The alcohol literature was sparse with only six papers included in this REA. The recommendations drawn from them are listed below in table 5:

Table 5: Guidelines for practice with people with problematic alcohol use

| Category | Practice guidelines |
|--|---|
| Universal screening for alcohol misuse | Universally screening for alcohol misuse using a validated tool (For example, CAGE). |
| Ongoing screening and monitoring for alcohol use | <ul style="list-style-type: none"> • Routine CAGE screening (younger patients are particularly at high risk of being CAGE positive). • Frequent pain assessment. • Assessment and treatment of alcohol withdrawal. |
| Safety plans for identified patients with alcohol problems or high risk patients | <ul style="list-style-type: none"> • Assess for mental disorders. • Involve and refer to specialist Multi-disciplinary team support that may include psychiatric/ psychological, or drug rehabilitation services. • Frequent review of symptom distress. |

Conclusion

This Rapid Evidence Assessment set out to explore current responses to, and models of practice for, people living with problematic substance use 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 disparate in focus, with a wide range of research populations, research questions and methodological choices. The available evidence resulted in three clear, but limited, groups of papers; those focussing on pain management and prescribing, alcohol and end of life care, and a small body of work on end of life care for marginalised groups including homeless people, people with mental ill health or HIV-related conditions.

This is clearly an area of work where far more research is needed. The gaps identified are considerable and need to be filled in order to provide an evidence base on which to build future policy and good practice, both in the UK and internationally.

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