Manchester Metropolitan University

RESEARCH BRIEFING NO. 2

Scoping review of existing database evidence:
End of Life Care for People with Alcohol and Drug Problems

"People with problematic substance use and end of life care needs cannot currently be directly identified in any single health or population database or dataset."

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Key findings

1. People with problematic substance use and end of life care needs cannot currently be directly identified in any single health or population database or dataset.
2. Using freely available data, such target cases can only be estimated using proxy variables such as disease type, cause of death and place of death. This presents sensitivity and specificity problems for identification of all cases (sensitivity) and excludes non-cases (specificity).
3. Data from the Office for National Statistics and Hospital Episode Statistics are currently the most reliable sources of freely available data from which to identify and calculate prevalence and incidence of end of life care for people with substance use problems, using cause of death and treatment episodes as indirect indicators of cases.
4. Other direct sources of medical diagnostic data for this target population stem from end of life care records but these are currently poorly reported and do not facilitate accurate surveillance or monitoring.
5. Reliance on medically determined diagnoses and cause of death excludes target cases where their end of life care need is unrelated or only indirectly related to substance use.
6. People with problematic alcohol use may be easier to identify via morbidity and mortality diagnoses than people with problematic illicit drug use. This is because there is a narrower range of chronic diseases associated with alcohol use than drug use.
7. For people with problematic illicit drug use, existing data relating to disease type are not useful for case identification because of the wide range of diseases associated with illicit drug use. As there is no 'typical' disease profile, it is not possible to extract these cases from others in which there is no illicit drug use (decreased specificity).
8. Databases monitoring problematic illicit drug users receiving treatment for their substance use only identify cases within drug treatment services, and only record their substance use treatment and reason for treatment exit, such as 'died'. Therefore, end of life care is not traceable via these databases, and such databases will not record people with problematic illicit drug use who do not use treatment services.
9. To obtain more accurate and reliable prevalence and incidence of end of life care for people with problematic substance use it will be necessary to combine existing datasets and access patient records.

Background

Public Health England states that life expectancy has increased in the last 30 years for older adults (at ages 65, 75, 85 and 95) and continues to rise incrementally for both genders (PHE, 2016a). At the same time, the demographic age profile of the UK is changing, with a disproportionate growth of people over 65 (Dixon et al., 2015). This ageing profile is mirrored in the population of drug users in the UK. According to Beynon and Lawson, (2010), evidence from sources such as the National Drug Treatment Monitoring System (NDTMS) and the British Crime Survey indicates that the average age of drug users accessing treatment is rising, with higher proportions of treatment admissions for people over 40. This is likely to be explained by the reduction in younger people using drugs and needing treatment, and the cohort of users from the 1980s and 1990s surviving into older age. Among alcohol users, while the estimates for rates of alcohol use among young people have started to reduce (NHS Digital, 2015), older people still drink more frequently than younger people (Fuller, 2015) and alcohol is currently among the top three lifestyle risk factors of death, contributing 10% of the burden of disease and death in the UK (Baker, House of Commons Health Committee, 2017).

Methodology

The aims of this scoping study were to:
  i.   Identify key sources of quantitative data on prevalence and incidence of end of life care delivered to people with problematic substance use;
  ii.   Identify end of life care needs for people with problematic substance use;
  iii. Identify the prevalence and incidence of people with co-existing problematic substance use and end of life/palliative care needs.

The main objectives were to:
  i.   Identify and appraise key sources of patient data indicative of end of life treatment received and disease type;
  ii.   Identify and appraise key data sources of end of life care delivery;
  iii. Identify key sources of care delivery to people with substance use morbidity;
  iv.   Critically analyse the value of the data, relating to end of life care and substance user care needs and identify anomalies and gaps in the evidence;
  v.   Identify possible service gaps that indicate poor access or uptake of end of life care for people with substance use problems;
  vi.   Make recommendations for the improvement of data collection and availability;
  vii. Make specific recommendations for more detailed interrogation of existing data.

This investigation focused on freely available data which typically exist from single sources such as the Office for National Statistics (ONS) or Hospital Episode Statistics (HES). Where analysis of existing data has already been performed and reported by third parties, these findings have been included in this reporting. For example, The National End of Life Care Intelligence Network has performed an analysis of liver disease deaths based on ONS data (Effiong et al., 2012), and their findings are incorporated into this report.

This exploration and analysis followed a five-stage strategy as follows:

Stage 1. A broad search for all relevant sources of primary data and available reports based on primary or secondary data.

Stage 2. Appraised potential sources for relevance to the study and evaluated their quality and type of data.

Stage 3. Key sources of data were identified for inclusion. The exclusion criteria was a lack of identification of patients with substance use problems for whom end of life care was an identified need (target cases).

Stage 4. Interrogation of the data.

Stage 5. Analysis and evaluation of findings.

Findings

Aim 1: Identify key sources of quantitative data on prevalence and incidence of end of life care for people who have problematic substance use.

No whole-population datasets directly identify people with problematic substance use and end of life care needs. The most useful data source to identify possible cases are cause of death records from the Office for National Statistics (ONS), and deaths and treatment episodes from the Hospital Episode Statistics (HES).

Hospital Episode Statistics currently include two indicators of palliative care delivery in hospital which are then reported to the Health and Social Care Information Centre (HSCIC). Palliative Care treatment episodes recorded by HES give a breakdown of finished consultant episodes by basic patient details (sex, age, length of stay).

The Office for National Statistics uses the International Classification of Diseases 10 (ICD-10) to define an alcohol-related death. These are medically-determined diagnoses which are recorded as the underlying cause of death where alcohol is

regarded as the direct or underlying cause. These are mostly chronic diseases and conditions, reported using 4-character ICD-10 coding.

The ONS definition of a drug *misuse*-related death is where drug use or dependence is the underlying cause or where drug poisoning is the underlying cause of death (ONS, 2015). 'Drug' is defined as a substance controlled under the Misuse of Drugs Act 1971. These data only record acute deaths directly attributable to drug use (such as overdose). This data does not capture chronic deaths indirectly associated with drug misuse.

The National Drug Treatment Monitoring System (NDTMS) collects data on structured substance use treatment provided by substance use treatment service providers. The National Drug Evidence Centre collates these data on behalf of Public Health England. This data only captures patients receiving drug or alcohol treatment. It does not record deaths or palliative care treatment.

Data on end of life care are collected by the ONS and HES. Both inform Public Health England and the National End of Life Care Intelligence Network (NEoLCIN). Public Health England aggregate mortality cause into only three categories: cancer, respiratory and circulatory. This does not allow identification of cases of patients with problematic substance use directly or indirectly via proxy variables of disease type.

The Minimum Dataset (MDS), produced by the National Council for Palliative Care (NCPC) and PHE, collates end of life and palliative care data from providers in the statutory, private and voluntary sector. However, the most recent report (NCPC, 2016a) on the MDS states that the current reporting rate at 66% of all services is neither consistent across the country, nor across service types. MDS provides a good record of hospice provision but misses a large proportion of patients receiving end of life care in hospital settings. Data collected only relates to demographics and primary diagnosis. Therefore, there is no clear indicator of patients who may have problematic substance use. The MDS is being discontinued.

The EPaCCS report (The Whole System Partnership, 2016) evaluates the EPaCCS system using qualitative and quantitative sources including ONS place of death records, HES and the EPaCCS' own in-depth interviews. EPaCCs may offer a source of evidence for local and regional monitoring of end of life care. However, this does not appear to differ significantly from data which are already available via ONS and HES.

The Palliative Care Registers record primary care patients who are recognised by the general practitioner as requiring end of life care in their last year of life. The Palliative Care Register system and the palliative care coding for hospitals are recorded inconsistently across services, with many categories open to

interpretation. This resource is demonstrating clinical improvements but is criticised as an audit tool as it relies on medical recognition of cases

Audit data are collected periodically from HES and the National Cancer Audit. Register on specific cancer types, treatment interventions, incidence, prevalence and care pathways. Current audits do not report end of life or palliative care consistently. Only the Head and Neck Cancer Audit reports the treatment and care incidence as a percentage of treatment incidents overall. There is no breakdown of diagnoses, causes of death or co-morbidities which would aid identification of cases.

Other disease types that present occasional audit for this patient group will be respiratory diseases and liver diseases.

In summary, appraisal of existing data found that no directly accessible sources are available that gives direct information on people with problematic substance use and their use of and access to end of life care. Proxy variables of disease type give some indication of proportions of people who may have alcohol-related diseases such as liver disease. Data relating to cancers generally, or cancers with a higher relation to alcohol or drug use than others, lack the evidence to make any calculations of estimates currently. People with drug-related terminal illnesses are not traceable via proxy variables as the disease types are too varied to identify cases. Specific data from end of life sources lack the detail to identify cases and is poorly reported, with a bias towards hospice care.

Aim 2: Identify end of life care needs of people with substance use problems

For people with substance use problems at end of life, the nature of the diseases typically faced by the majority may present a degree of unpredictability and complexity that makes care planning and delivery for end of life difficult for services more commonly equipped to manage cancer patients.

Data relating to palliative and end of life care services indicate that almost 80% of people accessing inpatient care have a cancer diagnosis, either seen as day care, community care, hospital support or outpatients. The greatest number of non-cancer diagnoses patients are reportedly seen for hospital support.

Disease type:
ONS (2016b) data on cause of death indicate that alcohol was partly attributable to death in 1.2% of all deaths in 2014. Most of these deaths were a result of ischaemic heart disease (38.5%) or liver cancer (26.9%). The likelihood of having an alcohol-related condition is higher among those who die from liver cancer than ischaemic heart disease (1.0%). Among people who die from mouth and throat cancers, alcohol is recorded as a contributory factor in 2.2% of deaths, and other cardiovascular diseases (hypertensive diseases,

ischemic stroke, haemorrhagic stroke) are linked to underlying alcohol use at 1.4%, 1.0% and 0.9% respectively.

Forty-one percent of hospital admissions for alcohol-related conditions for alcohol-related cancer occur amongst the lowest three socio-economic deciles, with a high proportion of these admitted for cancer of the larynx (48%), and cancer of the liver (41%). Of all alcohol-related liver disease admissions, 53% were from the lower three socio-economic groups according to Public Health England.

Research evidence is needed to explore deaths among drug users beyond the acute deaths used by ONS and PHE to denote a drug-related death. Typical acute disease types that lead to mortality among drug users are found to be cellulitis, pneumonia, alcohol-related liver disorders (Beynon and Lawson, 2010; Stenbacka et al., 2010). Research findings indicate that that deaths often classified as non-drug-related are likely to result from substance use - particularly infection.

Key population findings indicate that drug users die at a younger age than the general population, and often include problematic alcohol use (Beynon et al., 2010). The biggest cause of death among drug users is indicated to be cardiovascular disease, in line with the general population. Further evidence indicates that chronic terminal diseases for drug users were respiratory disease, circulatory disease and liver disease; all typically at a younger age than the general population. Drug users may be more at risk of morbidities and mortality than the general population due to their history of drug use and associated lifestyle.

In summary, people with substance use problems are as likely to die from cardiovascular disease as the general population, however, those with drug use histories are likely to die at a younger age.

People with alcohol use disorders are more likely to die from liver diseases (including cancers) than the general population. People with drug use histories are also vulnerable to chronic liver or respiratory diseases, possibly due to their drug lifestyle. Many of the diseases associated with substance use can be unpredictable in their progress (with the exception of cancers or dementia) and may explain why this population is more likely to receive end of life care in a hospital setting.

Aim 3: Identify the prevalence and incidence of people with co-existing problematic substance use and end of life/palliative care needs

Due to the lack of directly accessible data on end of life care for this patient group, it is not possible to identify the specific prevalence and incidence of people with problematic substance use and end of life care needs. However, the

data available indicates that, for people with certain disease conditions, hospice or planned end of life care is less likely to be available. Extrapolation of disease type associated with substance use, prevalence of substance use within the general population, and evidence from end of life care services, gives some indication of needs for this patient group.

There were approximately 293,879 people aged 15-64 using opiates or crack cocaine in England, with 2.5/1,000 injecting drugs between these age ranges. These figures do not include adults over 64 years of age (PHE, 2013).

Evidence from sources such as the National Drug Treatment Monitoring System (NDTMS) and the British Crime Survey indicates that the average age of drug users accessing treatment is rising, with higher proportions of treatment admissions for people over 40 (Beynon and Lawson, 2010). This is likely to be explained by the cohort of users from the 1980s and 1990s surviving into older age. Among alcohol users, older people still drink more frequently than younger people and alcohol is currently among the top three lifestyle risk factors of death, contributing 10% of the burden of disease and death in the UK.

Approximately one per cent of the population in England and Wales die per year, equating to half a million deaths. The majority of deaths (85%) occur for people aged over 75. The main causes of death are cancer (28%) and circulatory diseases (26%) (ONS, 2016a). Just under half of deaths take place in hospital (48%), with roughly a quarter at home (23%), or in care homes (22%), and only about 6% of people die in a hospice (ONS, 2016a).

Data from the Public Health England End of Life Care Profiles (2017) indicate that, in 2015, 46.7% of end of life care patients died in hospital, 5.6% died in a hospice, 22.8% died in their own home, 22.6% died in a care home, and 2.2% died in 'other' places (not specified).

The data illustrate the spread of end of life care delivery at the point of death, and it is not to be assumed from this data that there is a difference in quality of care associated with different localities of death, as they may be explained equally as clinical need, preference or lack or resources, but the differences need to be explored in the light of concerns over disproportionate delivery of care in hospices to cancer patients.

The 2013 Health Survey of England Palliative Care Services report identifies patients' reasons for not receiving end of life care services were either that the person died in hospital (36.5% of all respondents) or that the death was sudden (27% of all respondents) (ONS, 2014a). Approximately 12.5% said the patient did not want end of life care; that end of life care was not available (12.5%); or that they did not know about the service (4%). This survey's findings further illustrate, however, that specialist end of life care availability is heavily weighted

towards cancer cases and suggests that people with other illnesses are less likely to access specialist end of life care.

Implications and recommendations

Implications for practice

Findings from end of life care services illustrate that specialist end of life care availability is weighted towards cancer cases and that people with other illnesses are less likely to access specialist end of life care. While this bias may be due to clinical reasons, it underlines the fact that people with cardiovascular and non-cancer liver diseases are less likely to receive end of life care. Chronic causes of death for people with problematic alcohol or drug problems is most likely to be cardiovascular or liver disease, therefore statistically, people with problematic substance use tend to have less access to specialist end of life care than people with a cancer diagnosis. The implications for practice are that specialist end of life care services need to develop the skills and resources to deliver care to patients with less predictable or more complex disease conditions.

Recommendations for practice

Greater capacity is required in specialist end of life care services for complex and less predictable end of life conditions.

Implications for policy and service commissioning

The Palliative Care Clinical Dataset commencing in 2017/18 may provide more detailed data on patients accessing specialist palliative services and enable some analysis of complexity of care or data linkage via NHS patient identifiers.

The Palliative Care Register system and the palliative care coding for hospitals are recorded inconsistently across services, with many categories open to interpretation. Both systems need to be standardised for consistent data collection and accurate analysis across services.

The TOPS recording tool for the reporting of patient treatment episodes in the NDTMS is not sensitive enough to identify co-morbidities. While there is a focus on mental health and blood borne viruses in the NDTMS, the inclusion of physical co-morbidities would enable improved health and wellbeing monitoring of patients receiving substance use treatment.

The replacement of the MDS with the Palliative Care Clinical Dataset (PCCD) may facilitate data linkage between the PCCD and ONS, HES and CPRD data through use of patient NHS identifiers. Other data proposed for collection on the

PCCD does not appear to improve identification of co-morbidities or otherwise give the patient's health history.

Greater detail of patient demographics, social and medical history and co-morbidities would enable more accurate audit of service access for end users.

Recommendations for policy and service commissioning
Improved monitoring and surveillance of service accessibility for disadvantaged patient groups will require more detailed and specific data collection at service delivery level.

Implications for future research

In order to obtain more accurate data on this population group it is recommended that direct access to datasets held by HES, ONS and GP records would enable more accurate identification of target cases. This may be achieved by:

Use of existing data:
Access HES palliative care (finished consultant episodes) data and link with ONS mortality data to obtain a measure of incidence of disease type and hospital provision of end of life care.

Data linkage:
Develop/use proxy variables to support the analysis of existing data. Conduct a review of links between diseases and substance use to obtain estimates on which to calculate sensitivity and specificity of proxy variables and produce estimates of incidence and prevalence.

Direct access to patient records:
Invest in data linkage and analysis between HES and ONS mortality data using the HESID index. Access to case identifiers (via patient records) removes the necessity of using proxy variables.
Recommendations for future research
Further research will require greater accessibility of data and capacity to combine datasets.

Conclusion

In the absence of systematic screening and recording of alcohol and drug use among all patients with end of life conditions, and the omission of end of life care or physical co-morbidity surveillance by substance use treatment services, it is not possible to determine accurately the scale of the end of life care need for people with alcohol or drug problems without more detailed data analysis.

A more accurate estimation of end of life care delivery to people with substance use problems can only be obtained if patients with problematic substance use can be identified with a high degree of accuracy. This requires routine collection and recording of patient histories that extends beyond the disease diagnosis related to their end of life care. These data are most likely to stem from services delivering end of life care at any stage of the process, therefore including primary care, hospitals and specialist palliative care services. In the meantime, a more accurate monitoring of end of life care delivery to these patient groups requires improved identification of cases using existing data. These data are currently collected in different monitoring systems which use different definitions of drug- or alcohol-related disease, direct causal links or indirect causes, and include cases either only by first disease type or where drugs or alcohol may be mentioned on medical certificates of cause of death. This means that data linkage requires compatibility in the first instance to permit merging of databases, or a degree of detail such as history of alcohol or drug use, or treatment for an alcohol or drug addiction. Estimates made for this report indicate that there is likely to be an operationalised discrimination against people with a history of substance use problems receiving end of life care in a timely manner. The evidence reviewed for this report indicates that this is likely to be due to the disease type and clinical presentation of these patients that results in a higher degree of hospital deaths among this population. The implication is that end of life and palliative care services are not currently equipped to manage the complex needs presented by this group of service users.

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