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Key Points

- Individuals living in the most deprived areas are more likely to access acute hospital services in the last three months of life and die in hospital rather than at home, compared to those living in the least deprived areas.
- Individuals living in a high area of deprivation or with a lower level of education are less likely to receive specialist palliative care.
- Further research should aim to improve access to appropriate end-of-life care for those identified within a lower socio-economic position.

Introduction

End-of-life care can be defined as the care of people in the last period of their life; for many this is identified in weeks or months, whereas for some with incurable conditions, it can be a period of years (NICE, 2021). The specifics of such care are flexible, and require an individualised approach (Buiting & Sonke, 2014). For healthcare professionals, recognising the end-of-life period, and providing individualized and collaborative care, often between different healthcare settings and specialties can be challenging (Leadership Alliance for the Care of Dying People, 2014). These challenges can be further magnified by health inequalities; systematic and avoidable disparities in health outcomes between different groups of people, or between gradients of socio-economic ranking (McCartney et al. 2019). Health inequalities may originate from differences in education, occupational class, geographical location or income with the potential to impact on access and quality of healthcare (Stolz, et al., 2016; Williams et al., 2020). In the UK, socio-economic inequalities are associated with a 6-year reduction in healthy life and up to a 4.5 times increased likelihood of avoidable death (Williams et al., 2020). The differences in health experiences persist into end-of-life care, pertaining to increased barriers to accessing services, less personalized care, and an increased symptom burden in some conditions (Buck et al., 2020; Care Quality Commission, 2016; Lloyd-Williams et al., 2021). A systematic review and meta-analysis was undertaken by Davies et al. (2019) to explore the association between indicators of socio-economic position (SEP) and the use of healthcare by those in the last year of life. This commentary aims to appraise the methods used in the review and discuss the findings in the context of clinical practice.

Methodology

The review authors undertook a multi-database search including Medline, Embase, PsycINFO, CINAHL and ASSIA from inception until February 1st, 2019. Relevant literature, reference lists and grey literature were also searched with no limits on language. The review included observational studies of adults with advanced or incurable illness, receiving or not receiving specialist palliative care, and within in-patient or community settings. Other inclusion criteria were: studies took place in a high-income country (to limit contextual differences such as availability of services), a report of SEP (for example, income, education, area-based deprivation) and an outcome related to end-of-life care such as place of death, acute care admission, use of specialist or non-specialist end-of-life care, advance care planning or quality of care. Patient-reported measures were taken as indicators of quality of care.

Screening of studies was undertaken by two authors independently, with disagreements resolved by a third author. Quality of the included studies was also assessed independently by two authors using the Newcastle-Ottawa Scale (NOS). Overall strength of evidence was graded using an adapted algorithm based on quality, quantity and consistency of the evidence (Gomes and Higginson, 2006). Data was extracted by one author and independently checked by another author using a 20% sample. Meta-analysis was undertaken on studies of medium to high quality, defined by use of the evidence strength algorithm. An adjusted odds ratio (OR) was utilized for the lowest versus the highest SEP group and an OR >1 represented a pro-high SEP association. Direction of evidence was summarized by the categories of pro-high or pro-low SEP. Sub-group analysis was undertaken for exposure and outcome where possible and sensitivity analysis by country. Heterogeneity was reported using Higgins' I-squared (I^2).

Results

In total, 14,450 articles were screened for inclusion, 682 full-text articles were assessed for eligibility and 209 included in the review. Of the included studies, most (75.6%) used one type of SEP measure (range of 1 to 6). These measures were categorized as area deprivation (29.7%), education (28.9%), income (16.8%), insurance (12.8%), occupation (4.4%), housing (3.3%), social class (3.7%) and literacy (0.4%).

Studies rated to be of “medium” or “high quality” (112 studies) were included in the meta-analysis, and commonly reported the following outcomes: place of death (50.7%), use of specialist palliative care services (25.4%), use of acute care services (13.4%), use of non-specialist end of life care (7.7%) and use of advanced care planning (2.8%). The included studies were international, and predominantly from the United States (34.5%), Europe (21.1%) and Canada (19%), with 9.9% from the UK.

There was “strong evidence” identified that people living in the most deprived areas were more likely to die in hospital rather than at home or a hospice, compared to those in the least deprived areas (OR 1.30, 95%CI 1.23-1.38, I^2=97.1%). A dose-response was also observed, with a statistically significant increase in the odds of dying in hospital versus home with a 1 quintile increase in area deprivation (Log-Odds 1.07, 95% CI 1.05–1.08). There was “moderate evidence” of association between high area of deprivation and the use of acute care in the last 3 months of life (OR 1.16, 95%CI 1.08-1.25, I^2=80.1%), and not receiving specialist palliative care (OR 1.13, 95%CI 1.07-1.19, I^2 =86.3%). There was also a dose-response, with a statistically significant increase in the odds of not receiving specialist palliative care with a 1 quintile increase in area deprivation (Log-Odds 1.03, 95% CI 1.02–1.05). There was no evidence of effect for not receiving non-specialist end of life care (OR 1.09, 95% CI, 0.83- 1.43, I^2=98.7%). Heterogeneity (I^2) was high (>80%) for all sub-group analyses of area deprivation.

There was “moderate evidence” that the least educated were less likely to receive specialist palliative care when compared to the most educated (OR 1.26, 95% CI 1.07-1.49, I^2 =32.1%). No association was found between level of education and place of death e.g. hospital vs home or hospice (OR 1.08, 95% CI 0.91-1.27, I^2=99.9%). However, on sub-group analysis, data from South Korea were found to be contradictory to the other studies. After omission of the South Korean data, there was a significant association between place of death, with individuals who had the lowest levels of education most likely to die in hospital (OR 1.16, 95% CI, 1.12-1.21). “Moderate evidence” of a pro-high SEP association was reported between education level and advanced care planning and between housing quality and place of death although statistical findings were not provided. Heterogeneity (I^2) for the sub-group analysis of education level was high for place of death (99.9%) and moderate for specialist palliative care (32.1%).

Commentary

Using the JBI appraisal checklist for systematic reviews (2020), the review was assessed to be of good quality, with 10 out of the 11 quality parameters identified. The review did not stipulate whether there had been an assessment for publication bias or reasons for not assessing. Further limitations acknowledged by the authors included: the influence of confounding factors on the results (severity of illness, treatment availability); high levels of heterogeneity between studies (due to differences in how measures of SEP and end of life outcomes were reported); assumptions about adverse outcomes (e.g. dying at home is better than in hospital), and the related exclusion of low-middle income countries (availability of services means that assumptions such as these may not apply). The evidence-base for end-of-life care is clearly variable and with some limitations. However, it was deemed that this systematic review provides an accurate and comprehensive summary of the results of the available studies that address the question of interest.

This review has synthesized the associations between SEP and end-of-life care, finding that in high income countries, lower SEP is a risk factor for death in hospital, increased use of acute care in the last year of life, and decreased involvement with specialist palliative care services. A recent narrative synthesis identified similar findings including increased use of emergency healthcare services in the last year of life and more difficulties in accessing palliative care and support for those with lower SEP (French et al. 2021). Furthermore, an analysis of the English Longitudinal Study of Ageing suggested that worse health and function could partly explain why people with a lower SEP have more hospital admissions (Davies et al. 2021). These findings echo a report by Pring and Verne (2012) that socio-economic deprivation is a major determinant of when, where and how people die, with those from lower SEP being more likely to die younger, in a hospital setting and from smoking related cancers or respiratory disorders.

These disparities in health outcomes are also reflected in the patient experience. Inequities in accessing end-of-life care for groups experiencing structural vulnerability such as those living in poverty have been described previously, with those outside the ‘normative palliative-patient population’ facing significant barriers to access (for example through stigmatization), resulting in discontinuity of care and system navigation issues (Stajduhar et al. 2019). Furthermore, individuals from a socioeconomically disadvantaged group may be less likely to understand palliative care, have less desire for information, tend to accept information more passively, and rely on relatives with a higher level of education to negotiate healthcare barriers (French et al. 2021; Kesler et al, 2005). Conversely, having a higher SEP may influence the likelihood of a home death such as strengthening support networks, contributing to a more stable home environment and increasing patient comfort with home death (Wales et al. 2018). Given these effects on patient experience, it is necessary for health practitioners to understand the influence of structural social determinants on end-of-life care, such as the inhibiting effects of shame and stigma on access to services (Rowley et al. 2021; Stajduhar et al. 2019). Greater support is also required to develop partnerships between palliative care and community based social services, including an expansion of education and training to identify those in need of palliative care (Stajduhar et al. 2019).

Methods to improve end-of-life care are often underpinned by patient-centred communication with the aim of exploring the views of patients and relatives (Black et al. 2018; Donnelly et al. 2018). Such communication enables the patient and family to establish their care needs to the healthcare team. In a small study supportive of this finding, Ali et al. (2019) found that direct enquiry and identification of preferred place of death by the healthcare professional was associated with a patient achieving that place of death; patients whose preferred place of death was unknown were more likely to die in hospital. Clinicians should therefore aim to explore and identify a patient's preferred end-of-life care needs through a holistic needs assessment that considers all aspects of a person's well-being including spiritual, health and social care needs (NICE, 2019). Specialist palliative care services are ideally placed to explore these questions with patients and develop a preferred plan of care. Means to accomplish this are varied but broadly include education of clinicians, patients and relatives on the role, benefits and accessibility of palliative care services (Hawley, 2017; NICE, 2019). Specialist palliative care units are also a means of providing a rapid and personalised response to these complex and multi-faceted needs in the acute setting, offering targeted and individual care, and have led to improved patient experience, discharges and a decrease in deaths in acute hospital beds (Paes et al. 2018).

Within current practice, patient-centred care for individuals from a lower SEP should be explored from a broad perspective, reviewing methods of communication and location of services (French, 2021). Interventions to improve outcomes for socially disadvantaged groups such as patient education or shared and informed decision-making have proved successful in other specialities (Durand et al., 2014) and could be considered for palliative care. Finally, the timeliness of health communication and patient engagement should also be reviewed, as whilst disparities in health may be more visible with older age groups, they are often a result of long-term health inequalities; hence targeted improvements in access to healthcare, health education and health engagement should be achieved earlier in life (McMaughan et al., 2020)

Future research in end-of-life care should consider the impact of SEP and incorporate a clear rationale for chosen measures in relation to the outcomes, for example using a measure of income to determine if financial equity relates to increased access to specialist services. It is also important to note that area-based measures of deprivation may have different patterns of effect to individually based measures of SEP and this should be considered when planning future analyses. A more detailed analysis of causative factors could help to develop interventions designed to improve access to appropriate care. This could also include more qualitative research to explore the personal impact of socio-economic conditions on end-of-life decision-making. Finally, further systematic reviews of SEP and end-of-life care would benefit from an exploration of factors causing high heterogeneity, given the high levels of variance identified in this review.

CPD Questions

- What are the main limitations of the primary studies included in this review?
- How could your service or workplace be improved to enhance access to end-of-life care for those from lower SEPs?

- How do we engage patients, service users and key stakeholders from lower SEPs to develop more equitable interventions and services?

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