

Review Article

Dying in the Margins: Understanding Palliative Care and Socioeconomic Deprivation in the Developed World

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Abstract

Context. Individuals from low socioeconomic (SE) groups have less resources and poorer health outcomes. Understanding the nature of access to appropriate end-of-life care services for this group is important.

Objectives. To evaluate the literature in the developed world for barriers to access for low SE groups.

Methods. Electronic databases searched in the review included MEDLINE (1996–2010), CINAHL (1996–2010), PsychINFO (2000–2010), Cochrane Library (2010), and EMBASE (1996–2010). Publications were searched for key terms “socioeconomic disadvantage,” “socioeconomic,” “poverty,” “poor” paired with “end-of-life care,” “palliative care,” “dying,” and “terminal illness.” Articles were analyzed using existing descriptions for dimensions of access to health services, which include availability, affordability, acceptability, and geographical access.

Results. A total of 67 articles were identified for the literature review. Literature describing end-of-life care and low SE status was limited. Findings from the review were summarized under the headings for dimensions of access.

Conclusion. Low SE groups experience barriers to access in palliative care services. Identification and evaluation of interventions aimed at reducing this disparity is required. *J Pain Symptom Manage* 2011;42:105–118. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Socioeconomic deprivation, poor, end-of-life care, palliative care, dimensions of access, provider-patient interaction, health literacy

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Introduction

Improved health outcomes and increased life expectancy in developed countries over the previous decades have done little to improve the disparity in health for low socioeconomic (SE) groups. Socioeconomic status (SES) remains a determinant for health and ill-health, with the risks associated with morbidity and mortality for low SE groups identified by robust and consistent evidence.^{1,2} The poor die younger; have a higher disease burden; are less likely to act to prevent disease; and are less likely to present early in the symptomatic phase.³ The poorer health outcomes of low SE groups extend across the lifespan.⁴ Understanding the experience of SE deprivation at the end of the lifespan is consequently important.

The collective experience of dying in poverty raises many questions around the nature, meaning, and outcomes for individuals and their families. Evidence supports the notion that the health care needs of the socioeconomically deprived are greater than those of the general health care population.⁵⁻⁷ Recognizing SE disadvantage as a significant factor in influencing health outcomes underscores the importance of focusing on the distinctive characteristics that the illness and death experience has for this group. As a multidimensional construct, SE disadvantage is complex in definition and measurement. Definitions of disadvantage and poverty although diverse are generally inclusive of income, societal arrangements such as social participation, health behavior, education, and occupational class.^{8,9} Understanding the impact of a terminal diagnosis in such a broad context is, therefore, challenging; however, despite a lack of consensus for understanding SE deprivation, it is consistently viewed in terms of constraints to make choices over health care.¹⁰

The potential risks for limited utilization of specialist palliative care services is likely to impact on the quality of end-of-life care for low SE groups. With many competing for palliative care services and with those resources limited, there is strong uncertainty around whether end-of-life care services are accessed by those in greatest need. Access to palliative care services is dependent on referral, with constraints in referral to services being well

described in groups such as the elderly¹¹ and those with noncancer diagnoses.¹² Broadly, referral patterns to palliative care are nonstandardized, are dependent on numerous patient and service provider characteristics, and are not necessarily dependent on need.^{13,14} Low SE groups are identified as being limited in their capacity to access needed health care services^{15,16} and are, therefore, at a distinct disadvantage for access, in a referral-based service.

Confidence that palliative care is well positioned to identify and meet the needs of the socioeconomically deprived is challenged by statements that suggest that it has middle-class underpinnings.¹⁷ Accessibility of palliative care services by low SE groups is not well understood. Evidence identifying needs for low SE groups at the end of life is limited, and the impact of social and economic deficits are unclear.¹⁸ The aim of this article was to identify evidence from the developed world literature that identifies issues of access to palliative care for low SE groups. Themes will be explored in the literature under the dimensions of access headings.

Dimensions of Access

Access to health care services is a topic that has been explored in the literature for many decades, with multiple definitions of the phenomenon identified across several disciplines.¹⁹ Many definitions of access do, however, identify common themes in supply and demand and realized need for service use.¹⁰ For the purposes of this review, access is defined as the ability to secure services; quality of service; inconvenience and cost; and the tenure of information.²⁰ Concepts or dimensions of access are commonly described within the contexts of developing countries and rural and remote areas. These dimensions, as they are known, identify a set of specific areas that link the patient and their family and the health care service, essentially a supply demand relationship, which recognizes both service and user requisites. The four main dimensions of access include availability, affordability, acceptability, and geographical accessibility.^{10,21} The access dimensions identified by Penchansky and Thomas²¹ are summarized by Peters et al.¹⁰ as follows:

- Availability—the demand for services and the adequacy and appropriateness of service providers, facilities, and consumables.
- Affordability—the relationship between the price of services and the willingness and ability to pay.
- Acceptability—the relationship between the users' attitudes and expectations and the characteristics of the health service.
- Geographic accessibility—the distance or travel time from the user's location to the service location.

Methods

Electronic databases searched in the review included MEDLINE (1996–2010), CINAHL (1996–2010), PsycINFO (2000–2010), Cochrane Library (2010), and EMBASE (1996–2010). Publications were searched for key terms “socioeconomic disadvantage,” “socioeconomic,” “poverty,” “poor” paired with “end-of-life care,” “palliative care,” “dying,” and “terminal illness.” Additional data were obtained by manual searches of bibliographies from articles identified in electronic searches. The gray literature was searched for published documents using the key terms listed. The topic of health literacy was included in the search, as it was an important link between the two concepts and considered a significant aspect of the provider-patient interaction.²²

Inclusion and Exclusion Criteria

Literature was included in the review if it met one or more of the following criteria:

1. Described SE disparities in end-of-life care;
2. Described the experience of SE deprivation and palliative care;
3. Identified dimensions of access to palliative care for low SE groups;
4. Identified the relationship between SES and place of death; and
5. Identified issues of health literacy in end-of-life care.

Publications were excluded from the review if they met one or more of the following criteria:

1. Did not explore SES as a significant issue;
2. Had a developing world focus;
3. Were not relevant to palliative care, that is, had a treatment or oncology focus only.

The terms hospice, end-of-life care, and palliative care and poverty, poor, and low SE are used interchangeably in the review to ensure that none were excluded and to reflect the individual articles' contexts correctly.

Results

A total of 67 articles were included in the review (Table 1). Forty-nine percent (49%, $n=33$) of the articles originated from the United States (U.S.). Nineteen percent (19%, $n=13$) originated from the United Kingdom (U.K.) (one article was a U.K./U.S. collaborative). Twelve percent (12%, $n=8$) were from Europe. Seven articles originated from Australia (10%), three articles from Canada,

Table 1
Literature Search Outcomes

Exclusion Criteria	Search Strategy 1: MEDLINE, CINAHL, PsycINFO, Cochrane Reviews, and EMBASE	Search Strategy 2: Gray Literature	Search Strategy 3: Health Literacy Articles	Total Number of Articles Considered in the Review
Total found	156	5	4	165
Excluded: developing country context.	16	0	0	16
Excluded: not relevant to palliative care (oncology or treatment focus).	15	0	0	15
Excluded: socioeconomic impact considered a minor issue and not explored or not distinct from other variables for analysis.	58	0	0	58
Total in review	67	5	4	76

two from Asia (Japan and Taiwan), and a single article from Ireland. Only two articles were identified in a search on health literacy and palliative care; one was a short commentary and the other was included in the review. Three general health literacy articles were included. The gray literature documents included two Australian government documents, one *Palliative Care Australia* publication, one U.S. report on access to hospice care, and one U.S. report brief on health literacy. Key outcomes from articles in the review were summarized using the dimension of access framework headings: availability, accessibility, acceptability, and affordability (Table 2).

Availability

The limitations of the availability of palliative care resources were identified in the literature^{23–25} and were found to be further exacerbated by the increasing aging population.^{25–27} The demands for palliative care services are such that many compete for limited resources, and those with the greatest need did not necessarily realize available services at the end of life.²⁶ Two studies in the United Kingdom in 1998 and 2002 by Grande et al.^{14,28} found that referral to home palliative care services was less likely for low SE groups. Limited availability of hospice services in certain low-income urban areas in the United States²³ and fewer home visits in poorer areas in a palliative care service in Canada²⁹ emphasized the potential for disparity in service availability for these groups. The availability and use of palliative care services exerts an important influence on the patterns of care for the terminally ill; yet much of this systems level influence remains hidden.³⁰ Adequacy of supply of palliative care services is an important factor in identifying limits in access for this group; however, discussion of this issue in the literature was limited to describing the relationship between low SE groups and potential service availability bias.

Service availability entails uptake and usage to satisfy access requirements.¹⁹ Low SE groups' reliance on acute care services during illness progression and the likelihood of death in acute care facilities were identified by many authors in the review.^{31–35} A recent U.S. study identified that palliative care service registration reduced the likelihood of emergency

department presentations in a cohort of low-income men.³⁶ Limited or lack of awareness of services at the end of life highlights that the dimension of availability must include both the actual and the potential demand for service availability.³⁷ Limited service utilization for this group was often considered in parallel with concerns for the acceptability of services.^{15,38–41} A lack of informed choice regarding the ability to decline end-of-life care services constitutes a barrier to access such services.⁴²

Preference for a home death was identified across all SE groups.^{31,43,44} Resoundingly, the likelihood of a home death was least likely for low SE groups in countries with and without universal health care programs.^{14,32,35,39,41,44–47} One study that compared factors affecting place of death in London and New York found that the odds of a home death for low SE groups were reduced by 22% and 39%, respectively.⁴⁴ Overall, the literature in this area was limited in exploring the reasons for this disparity, but considered that inadequate palliative care resources, financial costs of home deaths, referral bias, limited informal care arrangements, and greater service demand by low SE groups were likely causes. Literature identifying limits for home deaths for low SE groups is outlined in Table 3.

Geographical Access

Location and distance of health services significantly determine service utilization and are strong determinants of access.⁴⁸ A meta-analysis by Higginson and Costantini⁴³ found that the distribution of palliative care services in Europe was inequitable and that services were not necessarily located in areas based on greatest need. In Australia, poor indigenous groups in rural and remote areas held very strong cultural and spiritual preferences for home deaths, but were least likely to achieve this aim, because of a lack of local services.³² A study by Wood et al.⁴⁹ established that longer drive times to services and increased demand for those services were more likely in areas with high levels of deprivation in Northwest England. A geo-coding study in 2008, in a Canadian province of British Columbia, found that, overall, 20% of the population did not have reasonable access to a specialized palliative care service, and in

Table 2

Dimensions of Access/Literature Outcomes Summary

Availability (demand for and adequacy of service)	<p>Utilization of palliative care services was lower for low SE groups (Currow et al., 2008; Freeman, 2004;⁷⁹ Gallo et al., 2001³⁹)</p> <p>Home death was less likely for low SE individuals (Decker and Higginson, 2007;⁴⁴ Gallo et al., 2001;³⁹ Higginson et al., 1999⁴¹ and 2000; Motiwala et al., 2006; Silveira et al., 2005;⁴⁶ Houttekier et al., 2009³⁵)</p> <p>Referral to home palliative care services was more likely in less deprived areas (Grande et al., 1998²⁸ and 2002¹⁴)</p> <p>Low SE groups were more likely to use acute care services at the end of life (Hanratty et al., 2008;⁴⁰ Houttekier et al., 2009³⁵)</p> <p>Awareness of palliative care services was low among the least affluent (Hughes, 2005;⁵¹ Koffman et al., 2007³⁷)</p> <p>Lack of informal carers for low SE groups are barriers to home hospice services (Kvale et al., 2004;⁵³ Hughes, 2005⁵¹)</p> <p>Limited respite services in rural remote areas to support low SE groups (McGrath et al., 2007²⁴)</p> <p>Limited hospice services in low-income urban areas (O'Mahony et al., 2008²³)</p> <p>Emotional and financial concerns about EOL care were associated with support for euthanasia (Givens et al., 2009⁷⁴)</p> <p>Increased demand for palliative care services for low SE groups (Wood et al., 2004;⁴⁹ Higginson et al., 1999;⁴¹ Worrall et al., 1997⁶)</p> <p>Palliative care patients in poorer areas received fewer home visits (Burge et al., 2005²⁹)</p> <p>Cumulative vulnerabilities for low SE groups contribute to persistent health disparities (Meyers, 2007)</p> <p>Suboptimal recruitment of low SE groups into clinical studies (Sloane, 2009¹⁶)</p> <p>Institutional care more likely for those without informal care arrangements (Seale, 2000;⁵⁴ Houttekier et al., 2009³⁵)</p> <p>SE deprived groups required more resources to achieve the same level of palliative care (Clark, 1997⁸¹)</p>
Geographical access (accessibility)	<p>Longer drive times to palliative care services for patients in SE deprived areas (Wood et al., 2004⁴⁹)</p> <p>Location and distances to palliative care services determines utilization and access, and can exacerbate disparity (Cinnamon et al., 2008;⁴⁸ Hughes, 2005⁵¹)</p> <p>Distribution of palliative care services was inequitable across Europe (Higginson and Costantini, 2008;⁴³ Beccaro et al., 2007⁵⁰)</p> <p>Transportation costs were burdensome for patients and carers from low SE groups (Emanuel et al., 2000⁶⁸; McGrath et al., 2007²⁴)</p>
Acceptability (characteristics of health service/user beliefs and attitudes)	<p>Lack of transportation was identified as problematic for patients in poverty (Hughes, 2005⁵¹)</p> <p>Hospice enrollment reduced emergency room visits for low SE groups (Bergman et al., 2009³⁶)</p> <p>Patients from low SE groups reported lower quality of communication in EOL care (Curtis et al., 1999;⁶⁰ Parker et al., 2009⁶²)</p> <p>Low-income residents in aged care facilities were less likely to have an advanced care directive (Dobilian et al., 2006)</p> <p>Palliative care is viewed as an inadequate substitute for aggressive treatment for the poor and disenfranchised (Gibson, 2001⁵⁶)</p> <p>Health service referrals for community palliative care services was lower in deprived areas (Grande et al., 1998²⁸ and 2002¹⁴)</p> <p>Patients from the most deprived areas with heart failure spent more days in hospital and patients with cancer had more admissions to hospital, compared with those from other SE areas (Hanratty et al., 2008⁴⁰)</p> <p>Mistrust and stigma limits use of palliative care services for low SE groups (Born et al., 2004;⁵⁷ O'Mahony et al., 2008;²³ Houttekier et al., 2009³⁵)</p> <p>Fragile or nonexistence support systems common for the urban poor exclude access to palliative care services (Hughes, 2005⁵¹)</p> <p>Limited education and literacy in low SE groups impaired the ability to negotiate palliative care services (McQuillan and Van Doorslaer, 2007³³)</p> <p>Low-income groups were more uncertain about treatment and goals of care (Rosenzweig et al., 2009⁵⁵)</p> <p>Limited data in the literature on the special needs of low SE groups (Sloane, 2009¹⁶)</p> <p>Groups with limited health literacy were more likely to have preferences for aggressive treatment at the EOL (Volandes et al., 2008⁶⁶)</p> <p>The middle-class underpinnings of palliative care may not connect with the social experience of the dying poor (Williams, 2004⁸⁰)</p> <p>Elderly would hypothetically forgo EOL care if it would deplete savings (Chao et al., 2008⁷⁶)</p>

(Continued)

Table 2
Continued

Affordability (costs of service and users willingness and ability to pay)	<p>SES was associated with difficulties sustaining costs of treatments and/or use of savings in caring for a terminally ill relative (Chini et al., 2007;⁷³ Emanuel et al., 2000;⁶⁸ McGrath et al., 2007;²⁴ McGarry and Schoeni, 2005⁶⁷)</p> <p>Costs of EOL care can be considerable and were dependent on the model of care (Chochinov and Kristjanson, 1998²⁵).</p> <p>Income and health inequalities were identified in elderly, caregiver widows (Evans et al., 2008⁷⁷)</p> <p>Transportation costs were a significant burden for low SE groups (Chochinov and Kristjanson, 1998;²⁵ Emanuel et al., 2000;⁶⁸ Lin et al., 2008;⁵² McGrath et al., 2007²⁴)</p> <p>Out-of-pocket expenses for low-income groups negotiating EOL care were significant (Giorgi Rossi et al., 2007;⁷⁵ Lin et al., 2008;⁵² Slutsman et al., 2002⁷²)</p> <p>Limited literature outside the United States for financial stress at the EOL (Hanratty et al., 2007⁶⁹)</p> <p>Health care expenditure for higher-income groups at the EOL was greater (Felder et al., 2000;⁸² Hanratty et al., 2007⁶⁹)</p> <p>Financial strain in EOL care was common, yet benefit uptake was low (Hanratty et al., 2008;⁴⁰ Wilson and Amir, 2008⁷¹)</p> <p>Health care expenditure was higher for low-income groups (Hogan et al., 2001;⁷⁸ Chochinov and Kristjanson, 1998²⁵)</p> <p>Primary care workload costs were higher with lower SE groups, reflecting increased workload and drug costs (Worrall et al., 1997⁶)</p> <p>Patients in the highest quartile for net worth had fewer symptoms and pain at the EOL compared with others (Silveira et al., 2005)</p>
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SE = socioeconomic; SES = socioeconomic status; EOL = end of life.

one regional area, this was greater than 50%.⁴⁸ The ad hoc nature in which palliative care services have developed worldwide has supported disparities in access based on geographical location.^{49,50}

In a review of the literature describing challenges to receiving palliative care in the United States, a lack of transportation was highlighted as a practical barrier for the poor wishing to access services.⁵¹ The poor were most vulnerable to transportation costs associated with location of services and this was described as a frequently reported barrier to treatment in poor populations.⁵² The current fragmentation of medical care, resulting in multiple outpatient visits for patients, was likely to further exacerbate the costs of transportation for this group. Costs were often paired in the literature with geographical access issues^{25,49,52} and these costs increased where distances to service locations were greatest.²⁵ The impact of transport costs for low SE groups is, therefore, most significant. Literature that specifically considered geographical access problems for low SE groups for end-of-life care services was overall inadequate in describing the extent of the problem for this group.

Acceptability

Absence of Informal Carer. The literature in the review identified concerns for the limits of

informal care arrangements for low SE groups, and the subsequent impact this had on palliative care home services.^{51,53} Those most likely to be without an informal carer or those who had care arrangements that were tenuous were most likely to come from a low SE group.^{35,51} Lack of informal carers was identified as a barrier to home hospice services for low-income groups.⁵³ Living alone often indicated an overall absence of informal care options, with this group unlikely to have children, siblings, or a spouse, and would invariably progress to institutional care.⁵⁴ Barriers to discharging patients from low SE groups with appropriate hospice services in the United States, identified the basis for the *Balm of Gilead* project, a project to support terminally ill, vulnerable populations, who were at risk for poor end-of-life care.⁵³ The report by Kvale et al.⁵³ found that palliative care had the capacity to overcome SE barriers. Analysis of evidence in the United Kingdom of home nursing referral by Grande et al.¹⁴ identified that the relationship between low SE groups and limited home care referral was consistent and did not reflect the differences in need for referral.

Stigma and Mistrust.

Issues of stigma and mistrust of palliative care are well considered in the literature and are often linked to culture

and poverty. Race and culture were considered to run in parallel with SE deprivation, with the disentanglement of race and deprivation considered to be challenging.^{54,55} The large representation of African American groups in the U.S. literature, identified in the review, highlighted the relationship between culture and SES. Racial and ethnic minority groups in the United States were most likely to lack health care insurance; however, access to palliative care was not completely explained by income and insurance status of this group.⁵⁶ Questions concerning how patients of marginal groups, invariably low SE groups, are viewed and how they view their health care providers, is important for understanding potential barriers to access. Mistrust of hospice or palliative care, arising from misconceptions of practice or concern at the absence of curative or life-prolonging intent, was an established theme in the international literature and reflected a lack of acceptability of palliative care services for this group.^{33,51,57} Prejudicial treatment was identified as a barrier to accepting palliative care services by homeless⁵⁸ and transient groups.³³

The U.S. literature identified that low SE populations viewed palliative care suspiciously, considering it an inadequate substitute for aggressive, curative treatment.⁵⁷ What was perceived as deprivation of technologically advanced services over supportive palliation further compounded an established mistrust of health care services for the poor in the United States.⁵⁶ Gibson,⁵⁶ in a review of pilot programs to improve access to palliative care services for the poor and disenfranchised in the United States, recommended models of care for the dying poor, which incorporated both curative and palliative intent to treatment, in an attempt to modify perceptions that palliative care was not part of “mainstream” health care services.

Communication and Health Literacy. Mistrust in palliative care for the socioeconomically deprived was often paired in the literature with concerns around communication and the cultural implications for communication strategies in end-of-life care.⁵⁹ Communication practices in palliative care were seen to facilitate further barriers to access for the poor.⁶⁰ Limitations for socioeconomically disadvantaged groups to

engage in communication required for open discussion around diagnosis and prognosis were highlighted in the literature.⁶¹ McQuillan and Van Doorslaer³³ explored views of Irish travelers (“Gypsies”) toward palliative care in the United Kingdom and identified patient concerns associated with the openness of communication about death in palliative care, and the difficulties experienced by this group in understanding information delivered by palliative care service providers. The limited education and literacy levels of the travelers were considered likely barriers to palliative care services.³³ Challenges in communicating with the socioeconomically disadvantaged at the end of life have received attention more recently in the literature. Vulnerable populations, which include the poor, the disenfranchised, and those with minimal education have high levels of unmet information needs and have expressed dissatisfaction with the information received from the providers.⁶² There has been little discourse in the palliative care literature, which acknowledges or seeks to address communication strategies for this group. This lack of investigation sits within the context of an impetus to address health literacy worldwide. Misinformation and misperceptions about end-of-life care, based on “unaddressed” poor health literacy, represent barriers to access.⁴²

Health literacy issues extend across all SE domains, yet are most profound in lower SE groups⁶³ and are linked to education and general literacy levels, but are not exclusive of them.⁶⁴ Health literacy is a requirement for a patient-centered health care system and the characteristics of that system can limit or promote access to the service based on its commitment to meeting health literacy needs. Health literacy is a measure by which an individual has the “capacity to obtain, process and understand basic health information, and use that information to access services and make appropriate health decisions.”⁶⁵ Communication and education of patients and carers are foundational components of the palliative care and hospice domain; thus, attempts to improve health literacy should be highlighted as a priority. Yet, literature informing these issues is particularly limited. Volandes et al.⁶⁶ identified that health literacy was an independent predictor of end-of-life preferences. Evidence for unmet communication needs in palliative care for low SE

groups highlighted limits in decision-making ability and uncertainty about treatment goals, all of which were considered to impact on quality of life for these groups.^{55,60,62}

Affordability

The affordability dimension of access describes the relationship between the cost of the service and the ability and willingness of the user to pay for those services.¹⁰ High costs of end-of-life care for the uninsured and underinsured in the United States are well described in the literature.^{51,53,56,67,68} Countries that have universal health coverage also identified financial burdens for the poor accessing end-of-life care services.^{6,18,24,25,69–72} Expenses included bridging costs of the gap payments and costs of services and goods exceeding those provided by a government health service. These include the services and goods required to support a patient and their family through an advancing terminal illness and death.^{25,73} Chochinov and Kristjanson²⁵ found that high-income groups were most likely to financially support home deaths. Givens and Mitchell,⁷⁴ in their recent study in the United States, identified an association between social and economic concerns and support for euthanasia.

The impact of costs were not only significant in end-of-life care, but also on the survivor's future financial position, with an Italian study identifying that 26% of families used all or most of their savings to cover the costs of care of a terminally ill loved one.⁷⁵ The impact of costs of end-of-life care for the elderly was particularly challenging, with the somewhat limited savings of this group depleted to care for a dying spouse.⁷⁶ One of the main risk factors for poverty and ill-health in the elderly was being a surviving spouse.^{67,77} A national panel survey in the United States found that disparities in economic status that existed prior to widowhood, and as a result of medical expenditure, accounted for increased levels of poverty for elderly widows.⁶⁷ A U.S. study by Chao et al.⁷⁶ found that, hypothetically, the elderly felt spouses should forgo end-of-life care if it would deplete savings.

Health care expenditure on end-of-life care for low SE groups was identified in several studies as being higher than for other SE groups.^{25,78,79} A meta-analysis by Higginson

and Costantini,⁴³ to determine the effectiveness of palliative care services in Europe, found that more resources were required in low SE areas to achieve the same level of palliative care service. A U.S. study in 2001 identified end-of-life care costs based on the SES of ZIP codes. It found that end-of-life care expenditures for high poverty ZIP codes were 20% higher than for ZIP codes with the lowest poverty rates.⁷⁸ Higher health care costs for lower SE groups may reflect the costs of managing the health outcomes for late presentation with malignant disease,⁷⁹ the existence of multiple comorbidities,⁷⁸ lack of uptake of services and support payments,⁷⁰ the lack of attention to social factors, not amenable to current models of care,⁸⁰ the increased support required from primary care providers,^{6,52,81} and a higher percentage of acute admissions and hospital deaths for low SE groups.²⁶ Two studies from Sweden contrasted these findings with Felder et al.⁸² and Hanratty et al.,⁸³ identifying increased health care expenditure for higher income groups at the end of life. Sweden's comprehensive welfare system may account for these differences and investigation of this comparative phenomenon would certainly support understanding of the impact of appropriate social welfare strategies on health care expenditure for low SE groups.

Discussion

The United States and United Kingdom contribute the majority of evidence for low SE groups and access to end-of-life care services. Although the number of studies from Australia, Europe, and Canada were less, the issues were comparable. The literature identified in the review yielded themes for factors that impact dimensions of access; namely, accessibility, availability, affordability, and acceptability. The nature of SE deprivation and its influence on access to health services has the potential to contribute further to the disproportionate burden of suffering for this group. Literature identified in a developed world context finds challenges very similar to those experienced in the developing world.⁸⁴ These similarities indicate that supply or availability of a service is not sufficient for access. The pursuit of equity for access to palliative care services must be a central objective of health

Table 3
Limits in Home Death for Low SE Groups

Limitations	Findings/Outcomes	Author, Date, Country
Inadequate palliative care resources	Relocation of Aboriginal patients to metropolitan hospitals for EOL care was due to a lack of local services.	McGrath et al., 2007 ²⁴ (Australia)
	Lack of respite services in rural and remote areas to support Aboriginal groups	McGrath et al., 2007 ⁴⁷ (Australia)
	Limited inpatient and community hospice services in low-income urban areas	O'Mahony et al., 2008 ²³ (US)
	Inequitable distribution of palliative care services across Europe	Higginson et al., 2008 ⁴³ (UK, meta-analysis of European data)
	Low-income communities had an increased likelihood of an institutionalized death, influenced by available health resources	Gallo et al., 2001 ³⁹ (US)
Limited informal care arrangements	Lack of informal carers for low SE urban people in the United States were considered barriers to home hospice services	Kvale et al., 2004 ⁵³ (US), Hughes, 2005 ⁵¹ (US)
	Institutional care was more likely for those without informal care arrangements	Seale, 2000 ⁵⁴ (US, worldwide demographic review), Houttekier et al., 2009 ³⁵ (Brussels)
	Fragile or nonexistent support systems common for the urban poor in the United States excluded access to palliative care services	Hughes, 2005 ⁵¹ (US)
	Patients without informal care support were less likely to die at home	Grande et al., 1998 ²⁸ (UK)
Referral bias	Fewer medical home visits for palliative care patients in lower SE areas	Burge et al., 2005 ²⁹ (Canada)
	Patients in lower SE areas were less likely to access home palliative care services	Grande et al., 1998 ²⁸ and 2002 ¹⁴ (UK)
Service demands	Demands for palliative care services were increased in low SE groups	Wood et al., 2004 ⁴⁹ (UK), Higginson et al., 1999 ⁴¹ (UK), Worrall et al., 1997 ⁶ (UK).
	More resources were required to achieve the same level of care for palliative patients in SE deprived areas	Higginson et al., 2008 ⁴³ (UK, meta-analysis of European data)
Costs of a home death	SE deprivation influenced the use of hospital services in the last year of life	Hanratty et al., 2008 ⁴⁰ (UK)
	High-income groups were likely to support a home death	Chochinov and Kristjanson, 1998 ²⁵ (Canada)
	Home care services incurred significant costs at the EOL	Hanratty et al., 2008 ⁴⁰ (UK)
	Health care expenditures are high at the EOL and constitute a large proportion of the income of low SE groups.	McGarry and Schoeni, 2005 ⁶⁷ (US)
	Prohibitive costs for power utilization at the EOL were incurred by Aboriginal groups in remote areas in Australia	McGrath et al., 2007 ²⁴ (Australia)

SE = socioeconomic; EOL = end of life; US = United States; UK = United Kingdom.

care services and should begin by engaging a need-based system of referral rather than the current referral-based system of access.¹³ The complexity of needs for disadvantaged groups at the end of life would be best supported in such a context.

The dimensions of access identified in the review are most broadly covered in literature from the United States. In particular, the U.S. evidence most strongly identifies themes around stigma and mistrust (acceptability), and costs or affordability of health care services. The limitations of health and social funding systems in the United States are certainly most likely to contribute to evidence for economic pressures for seriously ill people accessing health care services.⁶⁹ Health

insurance coverage for hospice services is available for the uninsured in the United States, but is limited in length of service provision and requires patients to forgo curative treatments to receive hospice benefits.⁸⁵ The cultural and racial demographics of the United States, which include significant African American and Hispanic groups, describe a landscape of mistrust and disparity well understood in the literature.^{86,87} The financial separation of palliative care from a curative treatment option is likely to contribute to the skewed attitudes and beliefs of palliative care held by these groups.

Evidence from the United Kingdom contributed the second largest body of research in this area. Geographical dimensions of access and

place of death for low SE groups were well considered in the literature from the United Kingdom. Affordability was also identified strongly in a U.K. context. Despite a National Health Service funding model in the United Kingdom, the need for payment or gap payments for health care services was identified. Funding and service provision for hospice in the United Kingdom has the longest history and is a mix of charitable, not-for-profit and government-funded generalist care.⁸⁸ Charitable and voluntary health funding models do potentially support a level of service disparity, whereby more affluent areas fund and support services locally and as such may be disconnected spatially and socially from areas of greatest need.²⁷

Access to end-of-life care services and resources, based on affordability, most profoundly impacts the socioeconomically deprived and although measured in several studies, exploration of the impact of financial hardship was limited in the literature internationally. The amount of income and net worth that was expended in caring for a family member at the end of life is proportionally higher and as such more significant in low-income groups. The capacity for low SE groups to both afford and recover from the costs of end-of-life care requires further investigation.

The small number of articles from other developed countries identified similar outcomes to the larger body of literature, with some contributing specific contextual variations. The Italian studies identified the variation of SES across the country and the impact of financial burdens for end-of-life care comparatively. The articles from Sweden not only contrasted the other literature, finding that health care expenditure in Sweden was greater for high SE groups, but also identified health care disparities for low SE groups. Both of these outcomes support further discourse on the impact of terminal illness for low SE groups in the context of the comprehensive, fully funded, social welfare and health system peculiar to Sweden. The Australian literature overall included a greater proportion of studies concerned with Aboriginal peoples' access to services and the limitations of palliative care services in rural and remote areas. This is not surprising considering the large gap in health and health care outcomes between Aboriginal

groups and other Australians, and the vast expanse of the Australian continent. Research investigating disparity in end-of-life care within countries contributes important contextual understanding that is likely to describe the problem(s) and highlight strategies for change. More country-specific research in this area is, however, required.

Disparities in home deaths based on SES and the limited discussion of health literacy in the palliative care literature were alarming outcomes of the review and compel exploration of novel and appropriate solutions. Literature that considered issues of choice and communication referred to the potential for a "two-tiered" health system, which provided different services and different quality of service, based on an individual's SES.^{25,89}

Limits of informal care arrangements, most particularly for low SE groups, will provide increasing challenges for home-based palliative care services.⁹⁰ The socially disadvantaged have a differential access to home care, which cannot be ignored.²⁷ The necessity, therefore, to consider how best to accommodate the needs of patients without family support is imperative.¹¹ The developed world is likely to be further challenged to provide care for those people from low SE groups for whom informal care is not an option. The increase in numbers of people living alone is contributing to a fall in the number of home deaths,²⁷ and the needs of this group require that they receive specialized support and approaches to home care.⁹⁰ The literature is limited in identifying impetus to address this current and likely future trend in health service disparity. Research evidence identifying individual level data in this area is imperative to ensure that the individual's goals for end-of-life care are understood and shared at the policy and service provision levels.

Overall, the international literature was generally defined by population studies and research that considered the relationship between SES and challenges and risks for accessing end-of-life care services, and the trends for these over time. The determinants that underpin this relationship and the analysis of interventions to support access were poorly considered in the literature. This is certainly not a new criticism of the literature in the

area of health inequity, which has a tenacious history of definition without analysis.⁹ Further descriptive studies in this area are still very necessary to identify trends and the range of access issues. Research is required, however, to investigate the relationship that underpins low SES and access to palliative care and the outcomes of interventions that seek to reduce disparity in this area.

The increasing chronicity of certain cancer diagnoses presents a context not previously considered for this group and will require care that more appropriately reflects a progressive disease model. Patients with malignant disease have well-defined specialist palliative care service use and constitute a large consumer area of palliative care services. Longer periods of illness require resources beyond those previously considered necessary and will place greater demands on palliative care services and informal care arrangements. The impact of increasing chronicity of cancer and the appropriate demand for services by nonmalignant groups is, therefore, an area for concern and action. Future service provisions for palliative care will be required to acknowledge the increasing service demands and chronicity of its patient population, and the SE consequences this brings about. Future projections of palliative care service need have begun to call for urgent planning for the large increases in an aging population and deaths.²⁷ The needs of the socioeconomically deprived, as a subgroup of this increasing population, must be considered in future palliative care service planning or they may “miss” the opportunity for appropriate care at the end of life.

Conclusion

Knowledge of access to palliative care services for low SE populations in a developed world context is limited in the literature. This review of the literature identified levels of inequity in access for low SE groups at the end of life. Further analysis and understanding of the experience of the dying poor and their families is required, with a focused commitment to research that both identifies and evaluates interventions aimed at modifying and eliminating disparity.

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