Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world.

Joanne M Lewis, RN, BN, MpallC, PhD Candidate, School of Nursing & Midwifery, Curtin University, Sydney Campus, Australia; Department of Palliative care, Sydney West Area Health Service, Sydney, NSW.
Patricia M Davidson, PhD, RN, Professor of Cardiovascular and Chronic Care, School of Nursing & Midwifery, Curtin University, Sydney Campus, Australia.
Michelle DiGiacomo, BA, MHSc (Hons), PhD, School of Nursing & Midwifery, Curtin University, Sydney Campus, Australia.
David C Currow,

Context: Low socioeconomic groups have poorer health outcomes and are likely to be over represented for end of life care needs. Low socioeconomic groups are identified as being limited in the capacity to access needed healthcare services.
Objective: To evaluate the developed world literature, for barriers to access for low socioeconomic groups.
Method: 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', 'terminal Illness'. Articles were analysed 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 integrative review. Literature identifying discourse for end of life care and socioeconomic deprivation was limited. Findings from the review were summarized under the headings for the dimensions of access.
Conclusions: Low socioeconomic groups experience barriers to access palliative care services. Identification and evaluation of interventions aimed at reducing this disparity is required.

Key words: Socioeconomic deprivation; poor; end of life care; palliative care; dimensions of access; provider-patient interaction; health literacy

Introduction

Improved health outcomes and increased life expectancy in developed countries over the previous decades have done little improve the disparity in health for low socioeconomic groups. Socioeconomic status remains a determinant for health and ill-health, with the risks associated with morbidity and mortality for low socioeconomic 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]. As a result they are most likely to be over represented for end of life care needs.

The collective experience of dying in poverty raises many questions around the nature, meaning and outcomes for individuals and their families. The limited resources available for the socioeconomically deprived highlights the potential burden of a terminal diagnosis for this group. Evidence supports the notion that the healthcare needs of the socioeconomically deprived are greater than those of the general healthcare population [4-6]. Recognizing socioeconomic disadvantage as a significant factor in influencing health outcomes, underscores the importance of focusing of the distinctive characteristics that the illness and death experience has for this group.

Confidence that palliative care is currently well positioned to meet the needs of the socioeconomically deprived, is challenged by statements that suggest its middle class underpinnings [7]. Palliative care models have been derived from the experiences of the least disadvantaged, for whom needs at the end of life are clearly not the same as those of the most disadvantaged[8]. The socially and economically disadvantaged require care that acknowledges not only a lifetime of disadvantage, but also the vulnerabilities, challenges and resiliency peculiar to this group. The additional layer of socioeconomic disadvantage in end of life care provision, requires that services seek a better understanding the needs of this vulnerable group and develop approaches to care that address the impact of social and economic factors for the patient and their family.

Identifying and understanding the experience of the socioeconomically deprived at the end of life, will underscore the issues most likely to contribute to barriers in access for this group. Low socioeconomic groups are identified as being limited in their capacity to access needed healthcare services [9, 10]. The considerable risks established for this group, when being underserved for services at the end of life, is therefore likely to impact on the quality of their end of life care. With many competing for palliative care services and with resources limited; there is uncertainty around whether end of life care resources are taken up by that in greatest need or by the most advantaged.

Identifying the state of the science of poverty and dying is important in highlighting needs, and realizing appropriate services for low socioeconomic groups at the end of life. Knowledge of the appropriateness of care, and challenges to access for low socioeconomic groups is central to understanding the causal relationship between low socioeconomic status and the impact of care at the end of life. The purpose of this integrative literature review aims to identify factors in the developed world which affect access and to identify the nature of provider-patient interaction. This knowledge will guide the establishment of goals to support policy, practice and research in this area.

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’, ‘terminal Illness’. Additional data was obtained by manual searches of bibliographies from articles identified in electronic searches. The topic of health literacy was included in the search as it was an important link between the two concepts and considered the nature of provider-patient interaction. The concepts of socioeconomic deprivation and palliative care were analyzed within the dimensions of access to health services. These concepts include availability, affordability, acceptability and geographical access [11]. These dimensions identify a set of specific areas, which link the patient and their family; and the health care service; essentially a supply-demand relationship which recognizes both service and user requisites. Health care service characteristics are recognized as one of the fundamental social determinants of health [12].

Inclusion and exclusion criteria

Literature was included in the review if it met one or more of the following criteria:
(1) describes socioeconomic disparities in end of life care;
(2) describes the experience of socioeconomic deprivation and palliative care;
(3) identifies dimensions of access to palliative care for low socioeconomic groups;
(4) identifies the relationship between socioeconomic status and place of death.
(5) identifies 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 socioeconomic status 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.

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

Results

A total of 67 articles were included in the review. Forty nine percent (49%, n=33) of articles originated from the United States. Nineteen percent (19%, n=13) originated from the United Kingdom (One article was a UK/US collaborative). Twelve percent (12%, n=8) from Europe. Seven articles originated from Australia (10%), and 3 articles from Canada, two from Asia and one from Ireland. Only 2 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 grey literature documents included two Australian government documents, one *Palliative care Australia* publication, one US report on access to Hospice care, and one US report brief on health literacy (See Table 1). Not all of the articles identified in the literature review were included in the analysis.

Dimensions of access

Barriers to access in end of life care for the socioeconomically deprived have been well described in the identified literature. Practical and/or geographical barriers to access, as well as financial, social, organizational and informational barriers, are recognized. For the purposes of this review access is defined as the ability to secure services, quality of the service, inconvenience and cost; and the tenure of information; with barriers to access accounting for the unacceptable variation in the use of services [13]. The recognized dimensions or descriptions of access highlight four or five main topics of a framework, which aim to capture specific areas of supply and need [11, 12, 14]. Four dimensions of access will be used as a framework to source themes from the literature. Often utilized within the contexts of developing countries and rural and remote areas, the dimensions of availability, geographical access, acceptability and affordability will be considered within this developed world context (See Table 2).

Availability

The limitations of the availability of palliative care resources were identified in the literature [15-17] and were found to be further exacerbated by the increasing aging population[17-19] . 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 [18]. Two studies in the UK in 1998 and 2002 by Grande et al [20, 21], 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 US [15] and fewer home visits in poorer areas in a palliative care service Canada [22], 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 [23]. 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 entail utilization, in order to satisfy access requirements [12]. Low socioeconomic 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 [24-28]. A recent US study identified that palliative care service registration reduced the likelihood of emergency department presentations in a cohort of low income men [29]. Limited or lack of awareness of services at the end of life highlights that the dimension of availability must encapsulate both actual and potential demand for service availability[30]. The phenomena of limited service utilization for this group, was often considered in parallel with concerns for the acceptability of services[9, 31-34]. A lack of informed choice to forgo end of life care services constitutes a barrier to access such services [35].

Preference for a home death was identified across all socioeconomic groups [24, 36, 37]. Resoundingly, the likelihood of a home death was least likely for low socioeconomic groups in countries with and without universal health care programs [21, 25, 28, 32, 34, 37-39]. One study that compared factors affecting place of death in London and New York found that the odds of a home death for low socioeconomic groups were reduced by 22% and 39%, respectively [37]. Overall the literature in this area was limited in exploring the reasons for this disparity, but considered that inadequate palliative care resources, referral bias, limited informal care arrangements and greater service demand by low socioeconomic groups, were likely causes.

Geographical access

Location and distance of health services significantly determine utilization of service, and are strong determinants of access [40]. The ad-hoc nature in which palliative care services have developed worldwide has supported disparities in access based on geographical location [41, 42] A meta-analysis by Higginson and Constatini [36] 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 . Poor Indigenous groups in rural and remote areas in Australia, held very strong cultural and spiritual preferences for home deaths, but were least likely to achieve this aim, due to a lack of local services [25]. A study by Wood et al [41] established that longer drive times to services and increased demand for those services were more likely in areas with high levels of deprivation in North-West England. Geographical access was a more likely determinant of disparity for low SE groups compared to others.

In a review of the literature describing challenges to receiving palliative care in the US, a lack of transportation was highlighted as a practical barrier for the poor wishing to access services [43]. 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 [44]. The current fragmentation of medical care, resulting in multiple outpatient visits for patients, was likely to further exacerbate the costs of transportation and thus geographical access for this group. Costs were often paired in the literature with geographical access issues [17, 41, 44]. Costs of end of life care increased where distances to service locations were greatest [17]. The impact of transport costs for low socioeconomic groups is therefore most significant. Literature that specifically considered geographical access problems for low socioeconomic 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

Acceptability of health care services, as a dimension of access, is dependent on the alignment between the characteristics of the service and the user's attitudes and expectations of that service. The responsiveness of the service to the needs of the consumers of that service, will impact on the willingness to seek care [12].

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 [43, 45]. Those most likely to be without an informal carer or those who had care arrangements which were tenuous, were most likely to come from a low socioeconomic group [28, 43]. Lack of informal carers were identified as barriers to home hospice services for low income groups [45]. Living alone often indicated an overall absence of informal care options with this group unlikely to have children, siblings or spouse and would invariably progress to institutional care[46]. Barriers to discharging patients from low socioeconomic groups with appropriate hospice services in the US, identified the basis of the *Balm of Gilead project*; a project to support terminally ill, vulnerable populations, who were at risk for poor end of life care [45]. The report by Kvale and others[45] found that palliative care had the capacity to overcome socioeconomic barriers. Analysis of evidence in the UK of home nursing referral by Grande and others[21] identified that the relationship between low socioeconomic groups and limited home care referral was consistent and did not reflect the differences in need for referral.

Acceptability: 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 socioeconomic deprivation, with the disentanglement of race and socioeconomic deprivation considered to be impractical [46, 47] The large representation of African American groups in the US literature, identified in the review, highlighted the relationship between culture and socioeconomic status. Racial and ethnic minority groups in the US were most likely to lack healthcare insurance, however access to palliative care was not completely explained by income and insurance status of this group[48]. Questions concerning how patients of marginal groups, invariably low socioeconomic 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 [26, 43, 49].

The US literature identified that low socioeconomic populations viewed palliative care suspiciously, considering it an inadequate substitute for aggressive, curative treatment [49]. What was perceived as deprivation of technologically advanced services over supportive palliation, further compounded an established mistrust of healthcare services for the poor in the US [48]. Gibson[48] in a review of pilot programs to improve access to palliative care services for the poor and disenfranchised in the US 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.

Acceptability: 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 [50]. Communication practices in palliative care were seen to facilitate further barriers to access for the poor [51]. Limitations for socioeconomically disadvantaged groups to engage in communication required for open discussion around diagnosis and prognosis, were highlighted in the literature [52]. Mc Quillan et al [26] explored views of Irish travelers towards palliative care in the UK 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 [26]. Challenges in communicating with the socioeconomically disadvantaged at the EOL, has 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 providers [53]. 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 [35].

Health literacy issues extend across all socioeconomic domains, yet are most profound in lower socioeconomic groups [54] and are linked to education and general literacy levels, but are not exclusive of them [55]. 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” [56]. 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 and yet literature informing these issues is particularly limited. Volandes et al[57] identified that health literacy was an independent predictor of end of life preferences. The lack of relevance of some end of life care services for the socioeconomically deprived may underscore the limited understanding of their literacy needs by end of life care providers.

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 [11]. High costs of end of life care for the uninsured and underinsured in the US are well described in the literature [43, 45, 48, 58, 59]. Countries that have universal health coverage also identified financial burdens for the poor accessing end of life care services[5, 17, 60-62]. 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[17, 63]. Chochinov et al [17] found that high income groups were most likely to financially support home deaths.

Givens and Mitchell [64] in their recent study in the US 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 [65].The impact of costs of end of life care for the elderly was particularly challenging with somewhat limited savings of this group depleted to care for a dying spouse [66]. One of the main risk factors for poverty and ill-health in the elderly was bereavement [58, 67]. A national panel survey in the US 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[58]. A study by Chao et al [66] found that hypothetically, the elderly felt spouses should forgo EOL care if it would deplete savings.

Health care expenditure on end of life care for low socioeconomic groups was identified in several studies, as being higher than for other socioeconomic groups [17, 68, 69]. A US study in 2001 identified end of life care costs based on the socioeconomic status of ZIP codes. It found that EOL care expenditure for high poverty ZIP codes were 20 percent higher than for ZIP codes with the lowest poverty rates[68]. Higher healthcare costs for lower socioeconomic groups may reflect the costs of managing the health outcomes for late presentation with malignant disease [69], the existence of multiple co-morbidities [68], lack of uptake of services and support payments [61], the lack of attention to social factors, not amenable to current models of care [70], the increased support required from primary care providers[5, 44, 71], and a higher percentage of acute admissions and hospital deaths for low socioeconomic groups [18]. Two studies from Sweden contrasted these findings with Felder et al [72] and Hanratty et al [73] identifying increased healthcare expenditure for higher income groups at the EOL. 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 healthcare expenditure for low SE groups.

Discussion

The US and UK contribute the majority of evidence for low socioeconomic groups and access to end of life care services. The small number of studies from Australia, Europe and Canada were comparable to these. The literature identified in the integrative review, yielded themes for factors that impact dimensions of access; namely, accessibility, availability, accessibility and acceptability. The nature of socioeconomic 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. 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 care services. Evaluation of services for barriers to access requires ongoing commitment to investigation and improvement, highlighting the need for further research in this area.

The dimensions of access identified in the review are most broadly covered in literature from the US. In particular the US evidence most strongly identifies themes around stigma and mistrust (acceptability), and costs or affordability of healthcare services. The health and social funding systems in the US are certainly most likely to contribute to evidence for economic pressures for seriously ill people accessing healthcare services. The cultural and racial demographics of the US, which include significant African American and Hispanic groups, describe a landscape of mistrust and disparity well understood in the literature [74, 75]. The ambiguity around palliative care as both a service and philosophy and the separation of the service from a curative focus is likely to contribute to the skewed attitudes and beliefs of palliative care, held by vulnerable, marginalized groups.

Evidence from the UK contributed the second largest body of research in this area. Geographical dimensions of access and place of death for low socioeconomic groups were well considered in the literature from the UK. Affordability was also indentified strongly in a UK context with the evidence highlighting that a national health system, as is the case in the UK, did not exclude the need for payment or gap payments for healthcare services. 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 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 EOL 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 healthcare disparities for low SE groups. Both of these outcomes support further discourse, on the impact for low SE groups, of comprehensive social welfare and health systems peculiar to Sweden. The Australian literature overall included a greater proportion of studies concerned with Indigenous 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 healthcare outcomes between Indigenous Aboriginal and white Australians, and the vast expanse of the Australian continent.

Disparities in home deaths based on socioeconomic status and the limited discussion of health literacy in the palliative care literature was a most alarming outcome of the integrative review. Both entities fit within the framework of palliative care advocacy, which reveres both choice and communication at the end of life. Literature which considered these 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 individuals' socioeconomic status [17, 76]. The potential for gains in these areas, for low socioeconomic groups, are therefore large.

Limits of informal care arrangements , most particularly for low SE groups, will provide increasing challenges for home based palliative care services [77]. The socially disadvantaged have a differential access to home care which cannot be ignored[19]. The necessity therefore to consider how best to accommodate the needs of patients without family support is imperative[78]. 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. They will be unlikely to achieve this aim, without first acknowledging the disparity in care that currently exists for this group.

Overall, the international literature was generally defined by population studies, and research which considered the relationship between socioeconomic status 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 literature in the area of health inequity, which has a tenacious history of definition without analysis [79]. Further descriptive studies in this area are still very necessary to identify trends and the range of access issues. Exploration and investigation of the relationship that underpins low socioeconomic status and access to palliative care will however support interventions which seek to reduce disparity in this area.

The increasing chronicity of certain cancer diagnoses present a context not previously considered for this group and require care that more appropriately reflects a chronic care model. Patients with malignant disease have well defined specialist palliative care service use and constitute the biggest consumers for palliative care. 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, on social and economic resources and arrangements is therefore an area for concern and action, but was not identified in literature found in the review. Future service provisions for palliative care will be required to acknowledge the increasing chronicity of its patient population and the socioeconomic consequences this brings about. Future projections of palliative care service need, call for urgent planning for large increases in an ageing population and deaths[19].The needs of the most vulnerable must be considered in future palliative care service planning or they will continue to compete for EOL care services with unfair disadvantage.

Conclusion

Knowledge of access to palliative care services for poor and marginalized populations in a developed world context is limited in the literature. This integrative review of literature does identify levels of inequity in access for low socioeconomic groups at the EOL. Further analysis and understanding of the experience of the dying poor and their families is required, with a focused commitment to both identify and evaluate interventions aimed at modifying and eliminating disparity.

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Table 1. Literature search outcomes

	Search strategy 1: MEDLINE, CINAHL, PsychINFO, Cochran reviews, and EMBASE	Search strategy 2: Grey literature	Search strategy 3: Health literacy articles	Total number of articles considered in 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.	58	0	0	58
Total in review	**67**	**5**	**4**	**76**

Table 2. Literature depicting dimensions of access

Availability (demand for service)	Hospice enrolment reduced emergency room visits for low SE groups (Bergman *et al* 2009)
	Utilisation of palliative care services was lower for low SE groups (Currow et al 2008, Freeman 2004, Gallo *et al* 2001)
	Home death was less likely for low SE individuals (Decker et al 2007, Higginson *et al* 1999 & 2000, Motiwala *et al* 2007, Silveira *et al* 2006, Houttekier *et al* 2009)
	Referral to home palliative care services was more likely in less deprived areas (Grande *et al* 1998 & 2002)
	Low SE groups were more likely to utilise acute care services at the end of life (Hanratty *et a*l 2008, Houttekier *et al* 2009)
	Limited representation of low SE groups carers in research, despite the willingness to participate (Johnson *et al* 2006)
	Awareness of palliative care services was low amongst least affluent (Hughes 2005,Koffman *et al* 2007)
	Lack of informal carers for low SE groups are barriers to home hospice services (Kvale *et al* 2004, Hughes 2005)
	Limited respite services in rural remote areas to support low SE groups (McGrath *et al* 2007*)*
	Limited hospice services in low income urban areas (O'Mahony *et al* 2008)
	Variations in referral were found to be inequitable for socially disadvantaged groups (Grande *et al* 1998 &2002)
	Emotional and financial concerns about EOL care were associated with support for Euthanasia (Givens *et al* 2009)
	Increased demand for palliative care services for low SE groups (Wood *et al* 2004, Higginson *et al* 1999, Worrall *et al* 1997, Clark 1997)
	Palliative care patients in poorer areas received fewer home visits (Burge *et al* 2005)
	Cumulative vulnerabilities for low SE groups contribute to persistent health disparities (Meyers 2007)
	Suboptimal recruitment of low SE groups into clinical studies (Sloan 2009)
	Institutional care more likely for those without informal care arrangements (Seale 2000, Houttekier *et al* 2009)
	SE deprived groups required more resources to achieve the same level of palliative care (Higginson *et al* 2008)
Geographical access	Lack of transportation problematic for patients in poverty (Hughes 2005)
	Longer drive times to palliative care services for patients in SE deprived areas (Wood *et al* 2004)

(Accessibility)	Location and distances to Palliative care services determines utilisation and access and can exacerbate disparity (Cinnamon *et al* 2008, Hughes 2005)
	Distribution of palliative care services was inequitable across Europe (Higginson *et al* 2008, Beccaro *et al* 2007)
	Transportation costs were burdensome for patients and carers (Emanuel *et al* 2000, McGrath *et al* 2007)
Acceptability (characteristics of health service/user beliefs and attitudes)	Patients from low SE groups reported lower quality of communication in EOL care (Curtis *et al* 1999, Parker *et al* 2009)
	Low income residents in aged care facilities were less likely to have an Advanced Care Directive (Dobilian *et al* 2006)
	Living in a low income area was associated with an increased likelihood of an institutionalised death (Gallo *et al* 2001, Houttekier *et al* 2009)
	Palliative care is viewed as a substitute for aggressive treatment for the poor and disenfranchised (Gibson 2001)
	Health service referrals for community palliative care services was lower in deprived areas (Grande *et al* ,1998 & 2002)
	Patients from the most deprived areas with heart failure spent more days in hospital and patients with cancer had more admissions to hospital, compared to those from other SE areas (Hanratty *et al* 2008)
	Mistrust and stigma limits use of palliative care services for low socioeconomic groups (Born *et al* 2004, O'Mahony *et al* 2008, Houttekier *et al* 2009)
	Fragile or non existence support systems common for the urban poor exclude access to palliative care services (Hughes 2005)
	Limited education and literacy impaired the ability to negotiate palliative care services (McMullan *et al* 2007)
	Low income groups were more uncertain about treatment and goals of care (Rosenzweig *et al* 2009)
	Limited data in the literature on the special needs of low SE groups (Sloan 2009)
	Groups with limited health literacy were more likely to have preferences for aggressive EOL care (Volandes 2008)
	The middle class underpinnings of palliative care may not connect with the social experience of the dying poor (Williams 2004)
Affordability (costs of service and users willingness and ability to pay)	Elderly would hypothetically forgo EOL care if it would deplete savings (Chao *et al* 2008)
	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, Emanuel *et al* 2000, Mc Grath *et al* 2007, McGarry *et al* 2005)
	Costs of EOL care can be considerable and were dependent on the model of care (Chochinov *et al* 1998).
	Low income elderly were more likely to be widowed (Evans *et al* 2008)

	Transportation costs were a significant burden for low SE groups (Chochinov *et al* 1998,Emanuel *et al* 2000, Lin *et al* 2008, McGrath *et al* 2007)
	Out of Pocket expenses for low income groups negotiating EOL care were significant (Giogi-Rossi *et al* 2007, Lin *et al* 2008, Slutsman *et al* 2002)
	Limited literature outside the US for financial stress at the EOL (Hanratty *et al* 2007)
	Health care expenditure for higher income groups at the EOL was greater (Felder *et al* 2000, Hanratty *et al* 2007)
	Financial strain in EOL care was common, yet benefit uptake was low (Hanratty *et al* 2008, Wilson *et al* 2008)
	Healthcare expenditure was higher for low income groups (Hogan *et al* 2001, Chocinov *et al* 1998)
	Primary care workload costs were higher with lower SE groups, reflecting increased workload and drug costs (Worrall *et al* 1997)
	Patients in the highest quartile for net worth had fewer symptoms and pain at the EOL compared to others (Silveira *et al* 2005)