Barriers to accessing palliative care: A review of the literature

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Barriers to Accessing Palliative Care: A Review of the literature

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Running Header: Barriers to Palliative Care

Abstract

The aim was to review factors affecting patients’ access to palliative care. First, the benefits of palliative care for comprehensive care of patients and their families are identified. Despite these benefits, universal standards for access are lacking and referral typically occurs later than is recommended, limiting access to best practice care. Factors relating to access are reviewed in detail. They are grouped conceptually, combining those related to organisational factors, patient and family-related issues, which include characteristics of patients, preferences for curative care, and willingness to discuss and participate in palliative care, and factors attributed to physicians and health professionals, such as communication styles, sense of efficacy, perceptions of patient readiness, and knowledge of palliative care. Despite the accumulated evidence, the existing studies share methodological weaknesses, which are reviewed. Finally, recommendations for further work in this area are made.

(Word count = 138)

Key Terms

Access to Palliative Care
Symptom complexity
Treatment models
Communication styles
Patient characteristics

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Supportive care needs of patients and their carers may be addressed by earlier consultation with palliative care (PC) services.(1) Yet referrals to PC can still be untimely, poorly managed, or delayed. An earlier review of the literature has identified the problems and issues associated with accessing PC.(2) The aim of this paper is to review the literature published in the decade since, addressing factors associated with access to PC services and to suggest aspects of access to PC requiring further investigation.

Referral to palliative care

Many studies have demonstrated that earlier access to palliative care may have positive benefits, addressing issues such as anticipatory grief and loss throughout the trajectory, facilitating improved symptom management, improved mood, and overall quality of life.(3,4) Despite the demonstrated benefits, PC use is often less than optimal and opportunities are frequently missed.(5,6) Conceptually, people living with life-limiting illnesses comprise three broad groups.(7) The majority have their care needs met by their support networks and primary care providers, including generalist, specialist, and allied health staff. A second group comprise those with more episodic increases in level of need that require access to PC services while continuing to receive care from their health care team. The third group consists of people with complex needs requiring individualised plans implemented by specialist practitioners. Individuals can move between these groups as their statuses change. Hence PC can be considered an approach to care and support during all phases of treatment and not simply as an exclusively post-curative treatment measure.

Methodology

Electronic databases were searched from the beginning of 2004 to December 2012. The databases included Medline, Embase, Psychinfo, and CINAHL. Key terms for the searches were (Palliative care *or* hospice *or* end of life care) *and* (access *or* barriers). The initial search provided 4499 results. The searches were then further refined, using inclusion criteria such as problems of access, physical and psycho-social needs, cultural issues, communication, and minority ethnic groups. Exclusion criteria included trials of medication and technology, historical perspectives, and economic factors. Bibliographies were examined and earlier papers were included if deemed pertinent to the review. This search resulted in 93 unique papers. After reviewing each of these articles, 45 were retained for inclusion in the review and are listed in Table 1.

Insert Table 1 about here

Factors affecting access to palliative care services

In order to conceptualise the many interrelated factors that have been identified as affecting access to PC services, a theoretical model was devised (Figure 1). Patients are considered as part of a family system, including carers and other family members. Health care teams are spearheaded by treating physicians and are part of health organisations. Communication factors between patients and families and health care teams create the foundation on which relationships are formed. There is a broader context: the wider health care system and social and cultural factors are important influences on access to PC services. Although it must be acknowledged that these categories are somewhat arbitrary and overlap considerably, this conceptual model forms the framework for the review.

Insert Figure 1 about here

Patient and Family-related Issues

Some of the barriers to PC services can be attributed to the patients and families, as they must ultimately accept or reject these services.(8) Moreover, while both physicians and families generally want earlier referrals, each party believes that the other is responsible for delays.(9) Some have speculated that patients and their families may have limited understanding of the options for care and treatment available to them.(9) Factors affecting these issues may include the unwillingness of doctors to discuss the options, and the willingness of patients and carers to hear about, discuss, and adopt these options.

Patients and families may prefer to continue receiving curative treatment even where palliative care may be more appropriate and thus may be less likely to pursue it.(5) For example, cancer patients tend to seek life-prolonging treatments if options are dichotomised into curative and palliative approaches, as the latter is considered equivalent to giving up on hope of a cure.(10) The term palliative care might have negative connotations that act as a barrier both to doctors suggesting referral and also for patients and families in taking up a referral option.(8,11) A primary challenge for caregivers in deciding whether to access palliative care remains the fear of losing their loved ones and acknowledging that death may be faced, feeding a tendency to continue seeking active treatment regardless of the prognosis.(10) Most believe that despite short stays in hospice, referral occurred at about the right time.(5) The negative perceptions of patients and families with regard to palliative treatment are reflected in the view that accepting referral relates to giving up hope. Despite the prevalence of such beliefs, there is little firm evidence concerning how families and patients actually do perceive the concept of PC referral; this is a topic worthy of further research.(5)

The willingness of patients and families to engage with PC may impact utilisation and timing of these services. For instance, doctors in one study considered the greatest barrier to palliative care referral to be patients and their carers, and believed that families and patients were often unwilling to discuss the possibility.(9) Another reported that medical staff members frequently believe that patients have preconceived, usually negative, ideas about utilising palliative services.(12)

Conflicting findings on this topic have emerged, however. In one example it was argued that early palliative care consultation is acceptable to patients and thus should not be avoided.(3) When an initial outpatient palliative care consultation was available to individuals with metastatic non-small cell lung cancer within eight weeks of diagnosis, virtually all patients offered the service accepted. Although it is unknown if individuals with less aggressive types of cancers would act similarly, these results are supportive of advocating for palliative care service very early in the disease trajectory.(3) The role of practitioners in this reluctance is also unclear. Ambiguous language may add to the misconception that curative treatments may still be effective, or that it is too early for palliative care.(13) These possibilities require careful evaluation before definitive claims can be made.

The findings around predictors of PC access have also been contradictory. One study found that patient age was not a predictor of access to PC, whereas another found that age and gender did significantly predict use of these services.(10) It has also been reported that ethnicity had no bearing on timing of access, while other findings are that palliative care services have been disproportionately accessed by Caucasians.(10) While these contradictions are probably related to the social contexts of the studies,(14) comparative research might help identify the underlying factors that contribute to these superficial differences.

Barriers to PC utilisation may also occur around patients' and families' acknowledgement of the terminal nature of illnesses in cases where cure cannot be effected.(9) For the most part, studies have indicated that patients and families may have difficulty accepting the option of palliative care. For instance, doctors considered the major barrier to palliative care referral to be patients and their carers themselves, as they are often unwilling to discuss and accept palliative care services.(9) This effect helps explain why doctors may be hesitant in speaking about these issues. Over 10% of doctors in one study reported being hesitant in speaking about terminal prognosis or believed that talking about palliative care may signal a loss of hope for patients and their families.(15) Other papers reported patient fear of palliative care, and difficulty accepting need for palliative care with cessation of curative treatment, to be barriers to patients accessing these services.(11)

Variations in uptake of PC services exist across types of cancer tumour stream.(10) For example, individuals with hematologic malignancies are less likely than those with other tumour types to access palliative care services and when they do, access is much later in the disease trajectory.(10) Later referral for this group has been attributed to levels of communication between specialist physicians and palliative care staff, which points to the importance of health professionals’ contributions to these barriers. Non-cancer illnesses are usually less likely to access PC services.(10,16–23) For example, patients with chronic obstructive pulmonary disease are less likely to access the services because discussion of end of life care is often delayed.(16,18,23)

Factors attributed to doctors and health professionals

Doctors play an integral part in providing links with palliative care services. They are mainly responsible for providing information about treatment options, providing referrals where appropriate, and coordinating a care plan to meet the needs of the patient.(24) In many countries, the multidisciplinary care team also has a responsibility to plan together for access to palliative care.(25,26) Factors related to the practice styles of medical and allied health professionals may facilitate referral, or lead to referral delays.(27,28) Despite their gate-keeping role, 78% of doctors in one US study felt that palliative care services were underutilised.(15)

Medical professionals' communication styles potentially impact on referrals to PC services.(24,29) For example, communication and interpersonal issues was one of six themes in an analysis of factors impacting on the decisions of general practitioners and cancer specialists to refer to palliative care.(24) Participants were concerned that referral could lead to emotional damage for patients and their families. The authors conjectured that doctors may find verbalising recommendations to seek palliative care particularly challenging because they perceive that it may be seen as 'giving up'. Difficulties in communicating prognoses with patients and families have been reported in other studies.(9,26) The ability to communicate honestly and openly in regards to prognosis, end-of-life issues, and information about PC is an important aspect of access to PC services.(24)

A survey of US doctors revealed they tended to be optimistic regarding prognosis, especially where the doctors perceived their patients as optimistic regarding the outcome of treatment.(30) As a result of prognosis uncertainty, noted earlier, doctors may favour optimistic prognoses and fail to discuss palliative care options, which may be a major barrier to accessing these services. Overall, these authors recommended that doctors develop improved methods of communication with patients and their carers.

Doctors' knowledge about palliative care may be a barrier to earlier referral.(10,12,31,32) One finding showed that 28% of doctors and residents believed their own lack of knowledge about hospice services limited their referrals.(15) Doctors may indeed not have the skills, training or experience to recognise when referral to PC should occur and it has been shown that doctors undertaking training and professional development around end-of-life issues are more likely to practice earlier referral to PC.(8) Medical staff considered level of knowledge about hospice to impact on referral to palliative care, which was considered predominately for the treatment of physical symptoms.(24) This study indicates that those patients without physical symptoms, but perhaps other unmet supportive care needs, may not be referred as readily and that psychosocial wellbeing is not a primary consideration for medical professionals. Other studies have reported that psycho-social needs are less likely to be triggers for referral to PC services,(12,33) that physicians' ratings of patient concur poorly with patients' ratings,(34) and that carers' needs are not routinely documented.(35)

Problems also relate to insufficient trained staff with knowledge about referral to palliative care.(31) Late referrals may result in poorer transition between acute and palliative care services, indicated by lower satisfaction with care received and a higher number of unmet needs than those referred earlier.(8) Late admission may impede hospice staff developing relationships with individuals and families, which is a particular concern.(5,24) Earlier referral can allow sufficient time for relationships and better understanding of the service to develop.

A survey of doctors in the US was undertaken to consider both how attitudes toward and knowledge of palliative care might impact on referral rates.(9) Participants generally were uncertain about most areas of PC and also recognised that their level of knowledge affected their propensity to refer to PC services. Inadequacies in training may account for this perceived lack of knowledge. For example, studies conducted in rural Australia found that a minority of doctors interviewed believed that their preliminary training provided adequate knowledge and skills to perform services related to palliative care and they required more training.(36,37) On the other hand, a survey of medical oncologists showed that they perceived poor assessment, reluctance to prescribe opioids, and excessive regulation as important barriers.

Symptom complexity and severity may affect clinicians' decisions to refer to PC services. Both complexity and severity of symptoms frequently triggered referrals by the doctors surveyed and all respondents cited purpose of treatment, capacity of the individual, stage of cancer, and physical symptoms (e.g., pain, bleeding, and constipation) to have influenced their past decisions to refer to PC services.(24) Patients that appeared well physically and did not complain of symptoms were likely to be overlooked, although respondents acknowledged that they may have benefited from referral too. Physical symptoms were given greater consideration than psycho-social symptoms in making the decision to refer, as was noted previously.

Medical practitioners’ sense of efficacy or confidence in their capacity to treat patients’ symptoms can be a factor in their decisions. For example, one study reported that many doctors interviewed had stated that their limitations and feelings of the symptoms being beyond their knowledge resulted in earlier PC referrals.(24) In cases where they felt that the patients’ problems were within their expertise and could be managed effectively, doctors were less likely to refer. Indeed, the authors suggested that referrals often occurred when the problems were perceived to be unmanageable.

Factors related to contextual aspects

As noted, delayed access to PC services may be influenced by the longstanding dichotomy between cure-oriented treatment and PC.(9,24) Lack of integration between services tends to produce numerous barriers to continuity of care.(38) Difficulties include those around transition between types of care, leading to delay and fragmentation, often combined with doctors’ uncertainty regarding prognosis. As referral is often perceived as giving up hope on curative treatment, then uncertainty can contribute to optimistic judgements about prognosis exacerbating delayed referral. A divide between services may mean that patients feel a need to choose which type of care they receive when they are still not ready to acknowledge their incurable conditions.(39) Even within systems, local differences can affect PC access.(40–42)

Social and cultural factors play major roles in access to PC services. Rurality and physician availability is related to services provision, for example.(43) Discrepancies between what is offered by PC services and what patients would actually prefer point to important cultural factors.(44,45) Cultural beliefs about death and dying are also factors to be considered.(14,46) Nevertheless, not all differences apparently related to ethnicity are a consequence of cultural beliefs.(47) Language barriers have been reported.(17,48) Factors such as income, welfare status, religion, gender, age, and perceived discriminatory practices all contribute to the differential access of ethnic and minority groups to PC services.(14,17,46,48–53) The complex interrelationships between these contextual factors require a great deal of further investigation.

Limitations and Directions for Further Research

Several limitations of the work reviewed here can be identified. Several, for example, do not indicate whether those receiving PC services achieved better outcomes. Some were conducted at a limited number of sites, a single site, or a specific geographic area. Factors such as community norms and cultural differences influence generalisations that can be drawn regarding best practice. In general, samples tended to be small and replication was rare. Given the role that social and community context can play in access to PC services, these weaknesses do constrain many generalisations that can be made. Despite these limitations, the studies have utility in facilitating an understanding of access to PC, as well as suggesting areas for further investigation.

Some of the areas identified in the review as likely to benefit from further research include more work on the knowledge and attitudes of families to PC and the role that psycho-educational interventions can play in changing those factors. Also, more work on the link between physicians’ attitudes, values, and actual practices in relation to PC referral and communication with patients and families would aid understanding of these barriers. More specialised training seems necessary and further research on perceived needs for PC education and training is required. The literature also suggests that, compared with those having complex psycho-social needs, individuals with pain or other physical symptoms may be more commonly referred to PC. While the immediacy of patients' pain understandably can motivate physicians to review their treatment plans, relative neglect of psycho-social needs requires closer investigation and intervention. Such work might include further exploration of physicians' sense of efficacy and perceptions of control in relation to identifying and assessing comprehensively the PC needs of patients and their families.

Conclusions

Complex factors interact to affect access to PC services for patients and families. These factors relate to patients and families themselves, as well as to medical professionals and health care teams, and to broader features of the social and cultural context. They include stereotypical beliefs and attitudes to PC of clinicians, patients and carers. They also relate to normative practices and cultural traditions. Service models, training opportunities and level of knowledge of professionals can all be barriers to PC access. Identification of these factors has progressed in the last decade although many barriers identified in the past persist today. Further exploration that may help improve timely access to PC services is undoubtedly warranted. There is much to be gained by integrating PC services earlier than often occurs, and further study on this topic could help address identified barriers.

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Table 1: Barriers to Palliative Care

Study	Methodology	Theme	Location	Participants	Reported Outcomes
Adams, Horn, & Bader, 2006a	Survey study	Hispanic Americans' experience of hospital pre admission to Hospice.	USA	50 Hispanic and 50 White Medicare Patients.	*Compared to White patients, prior to hospice admission, Hispanics had less access to health services known to be associated with hospice access involving structural as well as attitudinal factors.*
Adams, Horn, & Bader, 2006b	Retrospective chart study	Comparative study of access to Hospice in El Paso, Texas.	USA	500 charts were reviewed.	*Hispanic patients differed on factors known to influence access to health services but only one difference in access to hospice emerged – volunteer services – attributed to unique aspects of the region.*
Arber, Faithfull, Plaskota, Lucas, & Vries, 2010	Case review study	Investigation of the symptom experience and access to supportive care services of patients with primary malignant brain tumour and carers.	UK	70 cases were reviewed.	*Needs of carers were not routinely documented within case notes. For some patients, referral occurred late in the trajectory suggesting the full range of supportive services would not be available.*
Baile, Palmer, Bruera, & Parker, 2011	Assessment reliability study	Examines discrepancies between patients and physicians' ratings of patient concerns regarding supportive care needs.	USA	N = 137 patients assessed and their results compared with physicians' ratings.	*Generally poor concordance between patients' and physicians' rating of patient concerns.*
Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004	Focus group and qualitative analysis study	Explores end-of-life preferences and barriers among urban African and Latino Americans.	USA	Focus groups with 53 participants.	*Participants reported low hospice utilization because of lack of awareness of hospice and the prohibitive cost of health care. Latinos*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
					were more likely to report language barriers, while African Americans were more likely to report mistrust of the system.
Bradley, Frizelle, & Johnson, 2011	Semi-structured interviews and qualitative analysis	First-hand accounts of referrers' reasons for making referrals to Specialist PC day care.	UK	Phenomenological analysis of 8 referrers' responses to semi-structured interview questionnaire.	*Different emphases on the physical and psycho-social domains emerged. Need for more standardised assessment apparent.*
Breuer, Fleishman, Cruciani, & Portenoy, 2011	Survey study	Evaluates the attitudes, knowledge and behaviour of medical oncologists in relation to management of cancer pain.	USA	Analyses of responses to questionnaire with N = 354 initially and N = 256 after follow-up (RR: 32%).	*Rated the speciality highly for ability to manage cancer pain and peers as more conservative than themselves. Saw barriers as poor assessment, reluctance to prescribe opioids, & perceived excessive regulation.*
Brickner, Scannell, Marquet, & Ackerson, 2004	Survey study	Studies physicians' perceptions of hospice utilisation and their referral patterns.	USA	N = 111 (RR: 89%) physicians in two internal medicine departments.	*78% thought hospice care was under-utilised; 84% were unable to identify appropriate hospice diagnoses. Identified barriers included: difficulty predicting death; family concerns about cost-cutting measures.*
Broadbent & McKenzie, 2006	Database study	Reports on the development of a visiting medicine specialist outreach service.	Australia	Analyses of patient files from the first 12 months.	*Referrals were considered appropriate, with >75% having a PC issue.*
Buxton et al., 2010	Survey study	Considers the current and planned provision of palliative care services for patients with COPD.	UK	N = 239 acute hospital units in the UK.	*Service provision to this patient group is poor and access is hindered by lack of proactive initiation of discussion of end of life care.*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
Campbell, Merwin, & Yan, 2009	Data base analysis	Identifies factors that influence the presence of a hospice in three rural-urban areas.	USA	3,140 counties for the 2005 Area Resource file database.	*The most rural communities and those with low physician rates are least likely to have a medicare-certified hospice. Physician availability is a common barrier to end of life care worldwide.*
Casarett et al., 2008a & 2008b	Survey study	Considers patients' views on preferences for supportive care.	USA	(a) N = 300 patients receiving treatment for cancer. (b) N = 203 seriously ill pts.	*Patients' preferences for alternative services were higher than those for traditional hospice services.*
Cohen, Wilson, Thurston, MacLeod, & Deliens, 2011	Retrospective study of patient records	Examines hospital charts for one year to compare patients who could benefit from PC services and who did or did not receive them.	Canada	All patient records over a 12-month period at two mid-sized hospitals in a large city.	*A significantly lower proportion in one hospital was referred to PC services, especially older and non-cancer pts.*
Currow, et al., 2008	Survey study	Explores whether or not caregivers of patients who had not accessed specialist PC services had their needs met.	Australia	N = 18,224 (RR: 71%) in a population health survey.	*Specialist PC service uptake significantly lower with non-cancer diagnosis, lower income, English not first language, but this did not always mean needs were unmet.*
Davies et al., 2008	Survey study	Explores barriers to palliative care experienced by pediatric health care professionals.	USA	Analyses of questionnaire responses from nurses (N = 117) and physicians (N = 81).	*Four barriers reported by almost half the respondents as occurring frequently or always: prognoses, treatment goals, communication, time constraints.*
Fadul et al., 2007	Retrospective study of patient records	Determines predictors of patients' access to PC services.	USA	N = 1453 patients' records at a comprehensive Cancer Center.	*Access to PC services was lower for patients with hematologic malignancies and admission to ICU.*
Fadul et al., 2009	Survey study	Considers physicians' perceptions of	USA	N = 66 medical oncologists and 74	*The name PC was seen as a barrier*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
		the name PC and supportive care.		midlevel providers (RR: 70%).	*to referral, decreasing hope, and causing distress. Supportive care was the preferred term.*
Feeg & Elebiary 2005	Survey study	Considers professionals' perceptions of barriers to PC.	USA	N = 101 (RR: 51%) health professionals.	*Three major barriers were: physician reluctance to make referrals; physician lack of familiarity with hospice suitability; and association of hospice with death.*
Francoeur, Payne, Raveis, & Shim, 2007	Survey study	Surveys inner-city enrolees in an outpatient PC unit.	USA	N = 146 African-American and Latino patients.	*Less hopeful attitudes, religious affiliation, Medicaid-covered patient status associated with coping difficulties.*
Funk, Allan, & Stajduhar, 2009	Interview study	Explores family caregiver accounts of experiences within the healthcare system.	Canada	Qualitative analyses of N = 31 interviews with family caregivers.	*Sense of security was associated with timely access to needed care, sense of identity and self-worth, and trust in the healthcare system.*
Gagnon, Mayo, Hanley, & MacDonald, 2004	Database study	Examines whether age is a factor access to PC by women with breast cancer.	Canada	N = 2291 case files .	*Younger women were less likely, and 75% had few indicators of access to PC. Older women were more likely and younger women less likely than middle-aged women to access PC.*
Gott et al., 2009	Focus group study	Explores barriers to ACP in COPD patients.	UK	Focus groups with health care professionals (N = 39) involved in care of patients with COPD.	*ACP discussions were rarely initiated with COPD patients. Identified barriers included: uncertainty of course at diagnosis; lack of consensus regarding who should initiate discussions, fear of comparing COPD and cancer and ambiguity of EoL in*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
					COPD.
Green, Gardiner, Gott, & Ingleton, 2011	Qualitative interview study	Explores the views of health care professionals on the transition of heart failure patients to PC approach.	UK	Qualitative analyses of interviews with health care professionals (N = 24).	*Barriers identified: Uncertain trajectory; use of structured pathways; comparison with cancer pts.*
Gysels & Higginson, 2008	Qualitative interview study	Investigates the experiences of patients with COPD.	UK	Semi-structured interviews with COPD patients (N = 18) qualitatively analysed.	*Access to services affected by the nature of breathlessness, the stigma attached, and attitude of services. Suggests promotion of a palliative approach is appropriate.*
Hall et al., 2008	Qualitative Interview study	Explores the barriers to quality care in rural areas as perceived by GPs and patients	Australia	Analyses of age and gender matched samples – rural (N = 22) and metro (N = 21).	
Hanratty et al., 2006	Focus group study	Explores medical practitioners' conceptions of PC.	UK	Focus group discussions with doctors in general practice (N = 40).	*Participants had a broad grasp of the PC concept but the specialists' role was ill-defined outside of cancer.*
Hui et al 2012	Retrospective study of patient files	Determines the proportion of cancer patients who received PC.	USA	Patient charts (N = 816) at a comprehensive Cancer Center.	*Majority of cancer patients did not access PC before they died and referral occurs late in the process with many opportunities for referral missed.*
Jacobsen et al., 2011	Document analysis study	Describes a clinical practice of early PC consultation.	USA	Analyses of documentation of 7 PC clinicians provided consultation to pts with metastatic lung cancer (N = 67).	*Consultations largely addressed symptom management, pt and family coping, illness education. Lower QoL predicted longer consultations.*
Johnson, Girgis, Paul, & Currow,	Survey study	Surveyed the perceived barriers referral patterns to PC of cancer	Australia	Self-report questionnaire completed by cancer specialists (N = 699).	*Frequent reasons for referral were symptom control, or terminal illness.*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
2008		specialists.			*Psycho-social issues rarely triggered referral. Reasons of not referring included managing symptoms and rapid deterioration.*
Johnson et al., 2011a	Focus group study	Explores health care professionals' views on palliative care.	Australia	Focus groups of health care professional PC providers (N = 46).	*Participants considered community perceptions of PC to be a key barrier to timely specialist PC services.*
Johnson, Girgis, et al., 2011b	Survey study	Considers the views of physicians in general practice regarding access to specialist PC services.	Australia	Semi-structured interviews with GPs (N = 40) qualitatively analysed.	*Referral and access affected by open and honest communication, availability and location of services, and expertise.*
Kapo, Harrold, Carrol, Rickerson, & Casarett, 2005	Survey study	Canvasses patients' and families' opinions regarding referral to hospice.	USA	Interviewed patients and families at enrolment (N = 274).	*Despite late enrolment and very short lengths of stay, most patients and families believed that enrolment occurred at the right time.*
Keating, Herrinton, Zaslavsky, Liu, & Ayanian, 2006	Retrospective study of patient records	Examines hospice use within a regional integrated health care delivery system.	USA	Reviewed 3805 charts of cancer pts.	*65% enrolled in hospice care before death with substantial variation among local health centers. Understanding factors at the local level can ensure equal access to hospice care for cancer patients.*
Kumar et al., 2012	Survey study	Studies the rates of utilisation and barriers to access among oncology patients.	USA	Cross-sectional survey of patients in three outpatient medical oncology clinics (N = 313).	*Over half had not used PC services, with nutrition, counselling, and physical therapy most commonly used services. Barriers were lack of awareness, and physician non-referral.*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
Le & Watt, 2010	Retrospective study of patient records	Assesses care provided to dying patients and clinician decision-making around referral to PC.	Australia	Retrospective chart audit (N =190) and interviews with clinicians (N = 27).	*Demonstrates a need for more frequent and earlier referrals to PC and need for generalist staff to become more skilled in PC delivery.*
McCarthy, Burns, Davis, & Phillips, 2003	Retrospective study of patient records	Identifies factors associated with hospice enrolment and length of stay.	USA	Studied case records of Lung (N = 62,117) and colorectal (57,260) cancer.	*Later hospice enrolment was associated with being male, non-white, having fee-for-service insurance, and rural residence.*
McCarty & Volicer, 2009	Survey study	Considers factors associated with hospice access for individuals with dementia.	USA	Pilot study of hospices (N = 14) and the provision of services to people with dementia.	*Hospices with Bridge and Transition programs had 4 times the number of patients with dementia. Greatest barriers were prognosis, education, and finance.*
Neergaard, Olesen, Jensen, & Sondergaard, 2008	Focus group study	Analyses bereaved relatives' experiences of delivery of good palliative home care.	Denmark	Qualitative analysis of focus group interviews with bereaved relatives (N =14).	*Relatives' experience of insufficient PC was related to organisational and cultural problems.*
O'Connor & Lee-Steere, 2006	Qualitative interview study	Considers physicians' in general practice views of PC in rural areas.	Australia	Qualitative analyses of in-depth interviews with GPs (N = 10).	*Concerns included maintaining patients' QoL, providing continuity of care, experiencing emotional issues, team collaboration, need for training acknowledging the wider context.*
Ogle, Mavis, & Wyatt, 2002	Survey study	Explores physician barriers to hospice care.	USA	Analyses of surveys regarding hospice care physicians' (N = 190; RR: 72%) views on hospice care.	*Physicians had positive attitudes towards PC and perceived the main barriers as patient and family readiness.*
Periera, 2005	Survey study	Describes PC services in a rural area	Australia	Analyses of questionnaire responses	*Generalist doctors treat many dying*

Study	Methodology	Theme	Location	Participants	Reported Outcomes
		of NSW.		from generalist doctors in the rural area (N = 19; RR: 38%).	*pts and provide a unique continuity of care. These factors could be included in models for rural PC.*
Rhodes, Teno, & Welch, 2006	Survey study	Examines whether African-American patients are informed about hospice services.	USA	A mortality follow-back survey (N = 1578) including African-American patients (N = 111).	*More than half stated they were not informed about hospice services and 9% were informed but did not enrol. Barriers are both structural and attitudinal.*
Richardson, Thomas, & Richardson, 2006	Focus group study	Explores the views and experiences of health and social care staff in working with minority ethnic groups.	UK	Analysis of health and social care staff focus groups (N = 28).	*Found that fear of miscommunication was common and awareness of not being fully sensitive to cultural differences. Training in this area was welcomed.*
Rosenwax & McNamara, 2006	Retrospective cohort study	Compares people in WA who received and did not receive SPC services in the last 12 months of life.	Australia	Analysis of records (N = 27,971) to reveal use of SPC services	*68% of people who died with cancer but only 8% of non-cancer deaths received SPC. This confirms international evidence of inequities in PC.*
Shipman et al., 2005	Survey study	Examines the views of district nurses about availability of services available to PC patients enabling them to die at home.	UK	Analysis of survey responses (N = 651).	*Just over a half thought that GP home visits and SPC assessment were always available. Wide variation in access to all services was reported between networks.*

Abbreviations

ACP: Advance Care Planning; COPD: Chronic Obstructive Pulmonary Disease; EoL: End of Life; PC: Palliative Care; QoL: Quality of Life; RR: Response Rate

Figure 1: Conceptual Model of Barriers to Accessing Palliative Care