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Review Article

Dying in hospital or at home? a systematic review of the literature on the motivations for choosing the place of end of life for patients with chronic diseases

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ABSTRACT

In many countries, palliative care is provided in hospitals and hospices. Over time, palliative care has developed outside general health care and is provided in the patient's home. We examine the motivations for preferences for place of care at the end of life, and the reasons for changes in these preferences in so-called developed and developing countries. Pubmed, Google Scholar and Social Sciences Citation Index databases were searched as of January 2021. Qualitative and mixed studies on terminal care, preferences for end-of-life care settings and palliative care settings were considered. The inclusion criteria were studies published between 1980 and 2021 in English or French and dealing with preferences for place of care at the end of life and negotiations around the choice of end-of-life location. Place of residence and environment motivated the choice of home, while the socioeconomic position of patients and families partly motivated the choice of hospital. The most important reasons for choosing to leave the hospital for the home were structural dysfunction in the delivery of palliative care (developed and developing countries), cultural and belief imprint (developed and developing countries), and the quest for a good death (developing countries). End-of-life care at home was the most common preference. Return to hospital was the second preference, especially for advanced diseases such as genetic diseases, cancer, chronic hepatitis, malignant neoplasm. Study designs in this area need to be improved, especially in French West Africa.

Keywords: Place of end-of-life, Chronic illness, Motivations

INTRODUCTION

The main idea that emerges from the end-of-life (EOL) context is that the ‘dying’ person must be accompanied by his or her family and by the nursing staff. In addition to public health policies, in each country there are different places dedicated to the accompaniment of people at the EOL: ‘palliative structures, general care facilities, the home and residential structures’.[1] The EOL involves perceptions, practices and actors that interact with the sole aim of relieving the physical and emotional suffering of the patient and his or her family.

Depending on the context and the community, the EOL involves the interaction of three management models: a strictly biomedical model, a strictly social model and/or an intermediate model (medical pluralism).

The particularities that determine each of these contexts raise questions about the legislative framework, the actors and the practices that take place in them and how their interactions lead to transformations within palliative care.

The prognosis and/or diagnosis of the terminal phase of a chronic disease triggers a series of reactions and interactions between the patient, the nursing staff and the family (who often occupy a mediating position) leading to the decision on where to provide EOL care.

This choice is influenced by a series of underlying factors, namely: doubts about the vital prognosis from a purely technical point of view, without taking into account the socio-cultural or psycho-spiritual realities of the actors and the effectiveness of medical treatments for pain.[2]

The aim of this review was to report on the issues surrounding this ‘choice’ of EOL care setting between hospital and home. More specifically, it aims to find answers to the following questions: what are the motivations for choosing home or hospital as the place of care at the EOL? What are the reasons for families and/or patients to change their place of care at the EOL?

The texts examined in this literature review have attempted to provide some answers to these questions by considering, on the one hand, several contexts: America, Europe, Africa, Asia and Oceania, and by taking into account chronic diseases.

METHODS

Data sources

Following the development of a review protocol, three electronic databases (Pubmed, Google scholar and the Social Sciences Citation Index) were selected to search for articles.

These were searched from January 2019 to January 2021.

Research strategies

Searches were conducted in both English and French. Several groups of search terms were used, including: 'home', 'hospital', 'EOL care setting' and 'preferred'.

All these words were combined with 'terminal care', 'EOL care', 'death', 'place of death'. In the first search a total of 1,029 results were found.

The file was integrated into Rayyan- Intelligent Systematic Review®. This eliminated duplicates and facilitated the evaluation of titles and abstracts by two readers.

Inclusion criteria

Articles for inclusion in this review met the following criteria: (i) be published between 1980 and 2021; (ii) use qualitative or mixed methodology; (iii) address chronic diseases; (iv) provide insight into the preferences and perspectives of patients, families, and health care workers at the site of EOL care; (v) explain the reasons or motivations that influence the choice of an EOL care place and/or a change of EOL care places, specifically between home and hospital or hospice.

Exclusion criteria

The exclusion of articles was based on the following criteria: (i) being published before 1980; (ii) using a quantitative or mixed methodology with a qualitative section that did not meet the above inclusion criteria; (iii) article not in English, nor in French; (iv) non-French articles translated into English; (v) studies that focused on discussions about the place of EOL care for non-palliative patients; (vi) studies that did not express the reasons and motivations for choosing home or hospital/hospice as the place of EOL care; (vii) studies are finding improved palliative care for patients due to discussions of other health problems other than chronic diseases.

Two reviewers independently examined all titles and abstracts identified by a systematic search against the inclusion and exclusion criteria.

A third reviewer resolved disagreements about inclusion. At this stage, a final list of 40 articles was selected. A data extraction sheet was developed to sum up the characteristics of the included studies and their results (Table 1).

Data extraction and analysis

Data extraction was carried out by applying the analysis grid to each study selected in the final file.

The information extracted from the articles was summarized, compiled and analysed in a similar way by constant comparison of the results.

In addition, the data extracted from the word file were imported into an excel file to produce descriptive statistics. Finally, summary tables were prepared for detailed analysis.

Four descriptive themes were derived: (i) home, the initial place of EOL care; (ii) return home: from hospital to home; (iii) hospital, the place of initial EOL care; (iv) readmission: from home to hospital.

Table 1: Characteristics of the included studies and their results.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favorite place	Motivations	Change of preference	Reasons for change
Higginson et al[7]	English	2017	Mixed study	Identify and compare factors associated with preferences for EOL location and treatment in three countries.	N/A	Chronic diseases	People aged 65 and over in palliative care services	Home	Improvement of the quality of life itself and by seeking an extension of life; extension of life span; living with someone	Yes	Return to hospital to die
Shih et al[8]	English	2015	Mixed study	Explore patients' preferences regarding the location of EOL care and compare these preferences with their physicians' perceptions	Asia	Chronic diseases	Patients registered with Community Medical Team (CMT) flat doctors; Family doctors	Home	Availability of home care; when death is near; age; place of residence (urban, rural); religion	No	N/A
Gomes et al[10]	English	2012	Mixed study	To examine variations in preferences for the place of EOL internationally.	Europe	Chronic diseases	Individuals aged 16 and over	Home	Younger age (under 70) (Germany, Netherlands, Portugal, Spain); Home seen as a place to maintain a positive attitude (Germany, Spain); family involved in decision making (Flanders, Spain, Portugal)	No	N/A
Cohen et al[15]	English	2010	Mixed study	To examine the proportion of cancer deaths occurring at home in six European countries	Europe	Cancers	Cancer death certificates in 2002 and 2003	Home	Terminal cancer; married; under 60 years of age; higher education level; living in a less urbanized area.	No	N/A
Wilson et al[17]	English	2013	Mixed study	Examine the preferences of the public for the place of the last days.	North America	Chronic diseases	Representative sample of the Alberta population	Home	Marital situation	No	N/A
Cohen et al[12]	English	2006	Mixed study	To study the influence of clinical, socio-demographic, residential and health system factors on the location of the EOL	Europe	Chronic diseases	People who died of chronic diseases in 2001	Home	By place of residence	Yes	Hospital bed availability
Heide et al[19]	English	2007	Mixed study	To understand whether physicians or bereaved relatives	Europe	Cancers	Physicians of patients who died of cancer	Home	Living with a partner	Yes	Preference for home; Desire for EOL at home communicated; EOL at

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favo-rite place	Motivations	Change of preference	Reasons for change
				retrospectively value the death of patients in institutions or at home differently			during follow-up; bereaved parents				home as the process of quality of dying; pain control, avoidance of being a burden on family
Waghorn et al[32]	English	2011	Mixed study	Determining the relative importance of place of death for patients with advanced cancer	Europe	Cancers	Electronic Patient Records; Patients with terminal cancer	Home	The home is the place to end life for a "good death".	Yes	Having pain well controlled; not being a burden on the family; seeking to settle personal affairs.
Howell et al[37]	English	2013	Mixed study	Examine variations in place of death by disease subtype and time from diagnosis to death	Europe	Cancers	Patients with haematologi-cal malignancies who died on or before 31 August 2012	Hospit al	Acute myeloid leukemia, diffuse large B-cell lymphoma and myeloma; time from diagnosis to EOL care	No	N/A
McCaughan et al[3]	English	2019	Qual-itative study	To analyse the experiences and reflections of bereaved relatives of leukemia, lymphoma and myeloma patients around the place of EOL care.	N/A	Leukaem-ia, lympho-ma myeloma	Relatives of bereaved patients	Home	The characteristics of the disease; the occurrence and timing of EOL discussions; the availability of family networks; the availability of resources.	Yes	Being prepared for the possibility of deterioration; inability to cope with deterioration at home; patient involvement in discussions about death; good communication-n from hematologists; working hours not suitable for a caring role
Chapple et al[5]	English	2011	Quali-tative study	Exploring why people with pancreatic cancer at the EOL say they want to die at home or elsewhere, and why preferences may change	Europe	Cancers	Pancreatic cancer patients at the EOL; Bereaved relatives with experience of pancreatic cancer	Home	Perceptions and previous experiences of care available at home, in a hospice or hospital; fear of possible loss of dignity.	Yes	Some people thought that a death at home could leave bad memories for other family members; As death approached
Loh et al[11]	English	2016	Quali-tative study	To describe the perceptions of Singaporean cancer patients and their family members that affect their choice of EOL care setting	Asia	Cancers	Cancer patients; family members of patients	Home	Quality of care at home rated as 'good' or 'excellent	No	N/A
Catalán et al[13]	English	1991	Quali-tative study	To analyse the factors that influenced the	Europe	Cancers	Surviving relatives acting	Home	Place of residence of patients; lower socio-	No	N/A

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favo-rite place	Motivations	Change of preference	Reasons for change
				place of death of cancer patients			as primary caregivers; Patient records		economic level of patients and relatives; social perception of terminal illness		
Papke et al[14]	English	2007	Quali-tative study	To determine the factors influencing the places of death of cancer patients in rural areas.	Europe	Cancers	Death certificates for cancer patients issued between 1997 and 2003	Home	Rural areas offer favorable conditions for dying at home; high costs of therapy and transfer of expensive therapies from hospitals to the outpatient sector.	No	N/A
Hunter et al[22]	English	2005	Quali-tative study	To determine the care needs of sick people receiving domiciliary care and to compare this care with government provision for home and community care.	Africa	HIV/AIDS	Households with patients receiving home care	Home	Informal careers can provide policy provisions involving community clinics - this care.	No	NA
Notter et al[23]	English	2007	Quali-tative study	To analyse the strategy used to evaluate a community-based approach to terminal care at home	Africa	HIV/AIDS	Health workers; Older women - trained home-based terminal care volunteers.	Home	Acceptance of the role of older women trained to provide terminal care at home; enthusiasm and determination of older women; cases of improved quality of life for people with disabilities	No	NA
Kangethe et al[24]	English	2010	Quali-tative study	Exploring community caregivers' attitudes and perceptions of volunteering	Africa	HIV/AIDS	Palliative care volunteers and the nurses who support them	Home	Principle of love from blood and kinship relationships; patriotism and community responsibility; adherence and respect for their culture.	No	N/A
Uwimana et al[25]	English	2008	Quali-tative study	Examine where HIV/AIDS patients wanted to be treated in the terminal phase of the disease	Africa	HIV/AIDS	Terminally ill HIV/AIDS patients	Home	Unmet need for palliative care in hospitals	No	N/A
Murray et al[27]	English	2003	Quali-tative study	To describe the experiences of illness and the needs and use	N/A	Cancers	Patients with advanced cancers	Home	The emotional pain of facing death	Yes	Physical pain and financial worries; free health and social services;

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favorite place	Motivations	Change of preference	Reasons for change
				of palliative care services in patients with incurable cancer							essential equipment and care support were inaccessible and unaffordable; the local community and religious groups met the psychological, social and spiritual needs of patients.
Wheatley et al[28]	English	2007	Quali-tative study	Explore the circumstances in which patients are unable to choose EOL care at home.	Europe	Cancers	Patients with advanced cancers	Home	Discharge planning with carers	Yes	The patient's expressed preference
McCall et al[30]	English	2005	Quali-tative study	Exploring the factors that influence decisions about place of care for terminally ill cancer patients in a rural area	Europe	Cancers	Patients with advanced cancers	Home	The desire to be cared for at home	Yes	Perception of the home as a safe and secure space; feeling of impending death; availability and capacity of relatives
Ali et al[29]	English	2019	Quali-tative study	Comparing the preferred and actual EOL location of patients known to a specialist palliative care service	Europe	Chronic diseases	Records of patients who died in the palliative care service over a 5 year period	Home	Patient preferences	Yes	Respect for the preference of the place of EOL
Balmer et al[34]	English	2020	Quali-tative study	Reporting on death practices and rituals in health facilities	Oceania	Chronic diseases	Health care facilities and personnel	Home	Quest for a good death	Yes	Dying alone was not a good death; Tensions between carers, patients and families; Valuing practices and rituals after death.
Uys et al[33]	English	2003	Quali-tative study	Exploring the provision of palliative and terminal care for people living with HIV/AIDS	Africa	HIV/AIDS	People living with HIV/AIDS; guardians/parents health workers	Home	The home is the place to end life for a "good death".	Yes	Lack of training for carers; stigma associated with this diagnosis.
Wales et al[20]	English	2018	Quali-tative study	Identify the factors perceived to influence the likelihood of patients dying at home	North America	Chronic diseases	Palliative care physicians	Home	Having a strong support network to complement professional care; safe and sustainable housing; high socio-economic	No	N/A

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favo-rite place	Motivations	Change of preference	Reasons for change
									status for access to resources.		
McCaughan et al[36]	English	2018	Quali-tative study	Explore the experiences of clinicians and relatives to determine why deaths in hospital predominate.	Europe	Cancers	Clinical staff in hematology, palliative care and general medicine; Relatives of deceased patients	Hospital	Hospital experienced as a place of safety and security; wish not to go to another environment where new relationships would have to be established; satisfaction of nursing staff to be able to provide terminal care to patients they have known for a long time.	No	N/A
Kipp et al[16]	English	2007	Quali-tative study	To examine the burden and related health problems of families for AIDS patients	Africa	HIV/AIDS	Caregivers of HIV/AIDS patients	Hospital	Burdens and health problems experienced by carers	Yes	Family careers found it difficult to provide the necessary psychological, social and economic care at home.
Lysaght et al[41]	English	2014	Quali-tative study	To examine the beliefs and practices of older people and their carers regarding transitions between home and hospice services.	North Ameri-ca	Chronic diseases	Patients, carers and members of the interdiscipli-nary palliative care team	Hospital	N/A	Yes	Developing a plan for future needs; increased need for medical care
Evans et al[40]	English	2006	Quali-tative study	Describe the reasons why patients are transferred from home to the hospice.	North Ameri-ca	Chronic diseases	Relatives of deceased palliative care patients transferred to a care hospital.	Hospital	Patient distress related to clinical challenges at the EOL	Yes	Acute medical event; uncontrolled pain; imminent death; inability to provide necessary care safely at home; satisfaction with care in transfer facilities.
Phongtankuet al[39]	English	2017	Quali-tative study	To understand the events surrounding the hospitalization of patients discharged from hospice at home.	North Ameri-ca	Chronic diseases	Patients who received services from a non-profit home hospice in New York	Hospital	Patient distress related to clinical challenges at the EOL.	Yes	Signs and symptoms difficult to notice; need for palliative interventions not feasible at home; family caregivers not comfortable with patient's death at home.
Hinton et al[38]	English	1994	Quali-tative study	To assess the comfort provided by EOL care at home in advanced cancer patients.	Europe	Cancers	Terminally ill cancer patients and their carers	Hospi-tal	Distress of the patient and relatives	Yes	Distress felt by patients (pain, depression, dyspnoea, anxiety);

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favo-rite place	Motivations	Change of preference	Reasons for change
											distress felt by relatives (grief, tension or ill health)
Gott et al[42]	English	2004	Qualitative study	Exploring older people's attitudes towards the home as a place of care at death	Europe	Chronic diseases	Elderly people with chronic diseases	Hospital	Patients' moral issues	Yes	Wishing not to be a 'burden' on family and friends; home care perceived as low quality; presence of strangers' in the home was seen as intrusive and compromising the ideal of 'home'.
Woodman et al[4]	English	2016	Document review	To systematically synthesize the qualitative literature exploring family carers' preferences and perspectives towards the place of EOL care.	N/A	N/A	Scientific papers published	Home	Availability of relatives to support the patient; Perception of the hospital as an unsuitable palliative care environment; Lack of knowledge about palliative care service provision; Insufficient consideration of patients' needs.	Yes	High emotional cost of home support; deterioration of relationships; family conflict.
Higginson et al[6]	English	2000	Document review	Conduct a systematic review of the literature on preferences for place of care and death in patients with advanced cancer	N/A	N/A	Scientific papers published	Home	Experience of death or EOL of a close friend or relative; expressed wishes of patients	No	N/A
Gomes et al[9]	English	2013	Document review	Examining the heterogeneity of preferences for dying at home.	N/A	Chronic diseases	Scientific papers published	Home	Desire to meet social needs in the family; difficulty for families to balance patient's wishes with carers' recommendations; EOL at home seen as a sense of fulfilment.	No	N/A
Gomes et al[18]	English	2006	Document review	To determine the relative influence of different factors on the place of death in cancer patients	N/A	Cancers	Scientific papers published	Home	Low functional status of patients; patients' wish to end their life at home; presence of relatives to support the patient at home	No	N/A

Continued.

Authors	Language	Year	Study type	Study description	Region	Relevant disease	Population	Favo-rite place	Motivations	Change of preference	Reasons for change
Candy et al[21]	English	2011	Document review	Identify current evidence on the effectiveness, including cost-effectiveness, of hospice and palliative care in a patient's home and in nursing homes.	N/A	Chronic diseases	Scientific papers published	Home	Home care programs reduced the use of general health care.	No	N/A
Costa et al[26]	English	2014	Document review	To assess the determinants of EOL location for adult patients diagnosed with advanced disease.	N/A	Chronic diseases	Scientific papers published	Home	The patient's preference to end their life at home; having a caregiver and the caregiver's ability to cope with the patient's terminal phase.	Yes	Involvement of home care services; longer time between referral to palliative care and death
Fang et al[31]	English	2016	Doc-ument review	To explore attitudes, behaviours and patterns of use of EOL care by culturally and spiritually diverse groups.	N/A	Chronic diseases	Scientific papers published	Home	Culture and spirituality	Yes	under-use of culturally appropriate models designed to improve EOL care; personal racial and religious discrimination; lack of culturally appropriate EOL information to facilitate decision-making
Chochinov et al[35]	English	1998	Doc-ument review	Review the literature on the costs of different models of palliative care	N/A	Chronic diseases	Scientific papers published	Hospit al	Care costs become more expensive the further away you are from home	No	N/A

RESULTS

Characteristics of the studies

Table 2 and Table 3 present the main characteristics of the studies included in this review. The majority of the studies (38%) were from Europe and 15% from Africa. Ninety-nine per cent of the studies are in English.

An analysis of the study designs shows a predominance of qualitative studies (57.5%). Mixed-method studies are represented by 20%. The remaining share includes literature reviews (quantitative or qualitative) on epidemiological, psychological, sociological and ethnographic data.

Table 2: Distribution of included studies by origin.

Origin	N	%
America (North)	5	13
Europe	15	38
Africa	5	13
Asia	2	5
Not mentioned	11	28
Total	40	100

Table 3: Distribution of included studies by type of design (type of study).

Type of study	N	%
Document review	9	22.5
Qualitative studies	23	57.5
Mixed method studies	8	20
Total	40	100

Home: the initial place for EOL care!

Several of the motivations mentioned in the studies make the home a primary place for EOL care.

Experiences of illness and bereavement

A link has been shown between home and the illness and bereavement experiences of relatives.[3-7] In Taiwan, the experience of families enrolled in community support services motivates the preference for home.[8] Other surveys have shown that terminally ill patients in England prefer to live at home because they rely on the ability of family members to care for them.[9] The priority of maintaining a positive attitude of the relatives and the patient towards the ordeal, the willingness to involve the technical and emotional knowledge of the family in decisions, and the involvement of religious institutions guide the preference for home.[9]

A telephone survey of a random sample of people aged 16 years and over in several European countries shows that self-determination and 'co-determination' of relatives in EOL care underpins the preference for the home.[10] It is based on the desire not to move from home, cultural and religious beliefs involving dying at home, the desire of the family to assist in the management of the dying person's pain and body in the home, and the perception of 'poor' logistical and material conditions in the hospital.[11]

Zone of residence, family and social environment

Geographical variations in the community influence the choice of a home, according to different studies.[12] In Spain, native patients and residents of a semi-urban or rural area are more likely to choose the home.[13] The same conclusion is found both in Germany and in the Chinese region.[8,14]

The influence of place of residence is even more visible when the contribution of traditional family units and community support is added.[15,16] Living with relatives is seen as a cross-cutting motivation.[7,14,17-20] Because it offers ‘favorable’ living conditions, including the presence of a spouse or ‘carers’ and the support of at least three ‘informal carers’.[18]

EOL care programs at home

Home-based palliative care programs support the retention of patients dying of chronic illness at home and give the patient a sense of meaning and purpose.[21,22] In Kenya, the development of low-cost and highly sustainable home-based care is a motivation.[23] The same observation is made in Botswana and Rwanda.[24,25]

These programs enable families and palliative care nurses to better adapt to the clinical and emotional state of the patient at the EOL.[21-25]

For example, referral to EOL care at home was more motivated by the apathy and counselling provided by care professionals and volunteers in these programs, as opposed to the lack of counselling in hospital, which added more grief and confusion.[25]

Return home: from hospital to home

The change in the location of EOL care from hospital to home is a matter of debate.

Dysfunctions of hospital-based palliative care

Insufficient resources in the health system are a cross-cutting reason for shifting EOL care.[26] In addition, the non-existence or inadequacy of inpatient beds explains the return of patients to the home.[12] In Kenya, the inaccessibility of analgesia, essential equipment, appropriate food and care support prompted patients to return home.[27]

Respect to advance directives

Ethically, the change in the place of EOL care is based on the patient's preference.[19,28,29] At this level, patient autonomy and discharge planning ensure the patient's return home.[28] In Scotland, communication of wishes, reinforced by the experience of impending death, is the main reason.[30]

Discussions with the nurses about the desired place of EOL care reinforce inpatients' expectations about the choice of home.[29] However, when the wish to continue EOL care at home is not communicated to carers, the family or close friend becomes the guarantor of respect for this choice.[19]

Cultural identity of families

Cultural differences between carers and families are barriers to the use of hospital-based EOL care services.[31] Language barriers compound this, under-utilization of the culturally appropriate model of EOL care.[31] Finally, the exclusion of families in the decision-making process, racial and religious discrimination and the lack of culturally appropriate EOL information limit the use of hospital-based EOL care services at the expense of EOL care at home.[31]

Quest for a good death

The institutionalization of the EOL is regularly evaluated as unfavorable to a good death.[32,33] Some studies have found that death-related rituals, resolution of family conflicts, preparation for death, and the wish not to die alone are limited in hospices.[34] The patient's desire to maintain a link to his or her previous identity, the quest for autonomy and control over EOL management decisions and the desire not to be overwhelmed by the physical management of the EOL process are also cited motivations for returning home.[32-34]

Hospital- the place for EOL care

Some authors have debated the motivations guiding the choice of hospitals.

Influence of socio-economic position

The interaction between 'low' socio-economic status and the location of patients' EOL care has been demonstrated in different qualitative studies.[20]

In a review of the literature on the costs of EOL care, it is concluded that: the palliative care system pushes low-income families to opt for hospital-based EOL care.[35]

Disease requirements and length of diagnosis period

Some patients perceive the hospital as a place of safety and security because of the resources available to manage distressing symptoms that are difficult for families to manage at home.[36] Admission to hospital for the management of these symptoms creates a close relationship between hematology staff, patients and relatives.[36]

The time from diagnosis to EOL care was a major determinant of the choice of hospital as the place for EOL care.[37] It is explained that patients surviving longer, and in particular beyond one year, were less likely to die in hospital and this corresponded to an increase in the proportion.

Readmission: from home to hospital

Clinical difficulties and self-perception promote the mobility of patients from home to hospital.

Clinic and emotional distress

Hinton's qualitative study showed that patient distress (pain, depression, dyspnea, anxiety and weakness - extreme fatigue) drove patients and families to return to hospital.[38] Other studies have shown that signs and symptoms such as difficulty breathing, pain, lethargy/change in mental status, falling, lack of appetite, bleeding, nausea/vomiting, hypoglycemia are reasons for readmission.[39,40] In addition, the inability of family caregivers to recognize the patient's medical needs also motivates readmission.[41]

For other authors, the psychological, physical, emotional, social and economic demands that constitute overwhelming daily challenges for caregivers and families also motivate return to hospital.[16]

Not being a burden on the family

The return to the hospital is also motivated by patients' concern not to make their families, witnesses to their suffering, nor to let children provide intimate care.[5,42] In addition, concern for quality of care regarding pain relief at home at the EOL was perceived as 'low' by people at the EOL.[42] In addition, the presence of health workers in the home was seen by some as intrusive and compromising the ideal of home.[42]

DISCUSSION

Relatives, families and patients have described EoL care at home as an experience that can be both painful and pleasant.[43] In this literature review, the majority of studies showed that terminally ill patients and their relatives prefer EOL care at home (76% of the 40 included studies). The consistency of these results, observed by different researchers in different settings and using different samples, reinforces the likelihood that this finding is true.[44] The results showed that the preference for EOL care at home in Europe and North America is more likely to be explained by the existence of home-based palliative care programs. Whereas in Asia and Africa, especially in sub-Saharan Africa, it is much more explained by alternative healing solutions, socio-cultural beliefs.

The results also suggest that there may be less consensus among health workers, patients and families when it comes to choosing a preferred place for EOL care. This suspected divergence of views between these actors suggests that the circumstances and contexts underlying the social construction of decisions about the 'ideal' EOL place need to be taken into account.[45] Data on terminally ill patients and patients' families from the same study allowed more direct and explicit comparisons. Although statistical significance was rarely tested and accounted for, the preference for home was higher among patients in developed countries than in developing countries. Even so, the opposite situation is observed among relatives and families. This corroborates earlier findings by Gomes et al.[18]

On the other hand, families feel obliged to care for their patients in an ‘ideal’ way. This ‘ideal’ way is a return home where family and community members can use their knowledge and therapeutic skills to support the dying patient. Several studies included in this review have shown that the endogenous knowledge and therapeutic skills of relatives and family members are the basis for the decision to return home.[24,34] However, although this offers a range of perspectives, few studies have revealed the importance of the knowledge and skills of associations, non-family organizations and community groups in managing the symptoms, pain and suffering of EOL patients and their families. The integration of knowledge and insights from the wider community (including community groups) would better position EOL care in the local social and cultural context of families and patients, especially in developing countries. A research perspective that needs to be better documented.

Data from qualitative studies have shown that families who received formal and/or informal support from home care professionals reported a largely positive experience of EOL care at home, as confirmed by the work of Murtagh et al.[46] In settings where health systems lack the resources to support EOL care, this attitude, including informal support from caregivers, is most noted, the study found. An analysis of the economic factors at the heart of the interaction between the health care system, the hospital, the home, care professionals, families and patients at the EOL could help to understand how the socio-economic position of each stakeholder shape the decision on where to provide EOL care.

In addition, the studies in Africa were conducted in East Africa (Kenya, Uganda, Rwanda), Southern Africa (Botswana) and South Africa. No French-speaking West African countries are represented. Most articles on EOL care settings in French West Africa have focused on home-based care and the experience of family caregivers, and on where people die in order to improve population mortality.[47-49] This highlights the lack of research on EOL care settings and contexts of EOL care in French West African countries.

As well, it should be noted that many of the studies included in this review focused on cancer (35%) and human immunodeficiency virus - HIV/AIDS (15%) and other chronic diseases (40%) such as respiratory diseases, dementia, chronic hepatitis, while other chronic diseases were underrepresented, such as diabetes and its complications. While not all of these studies can address EOL care in relation to all chronic diseases, it would be interesting to analyse the construction of EOL decisions in patients with terminal diabetes in French West Africa. This could provide a basis for the development of EOL care in specific settings where the prevalence of diabetes is very high.[50]

Finally, prior to this review, two reviews of the literature had already reported that patients at the EOL and their families had unmet needs for palliative and EOL care in hospitals.[4,9] The present review confirms this trend. However, in contrast to these two reviews, this review identifies social and economic reasons (insufficient support network, financial difficulties and inequalities in care) rather than medical reasons as the cause of hospital admissions for EOL care, particularly in sub-Saharan Africa.

CONCLUSION

Through this literature review, several sub-themes were identified as the motivations and reasons for the choice of the place of care at the EOL according to different stakeholders: care professionals, families and patients. This work also showed that the majority of people with chronic diseases and their relatives prefer EOL care at home. This is particularly true considering the number of studies that define policies, programs and strategies for community-based EOL care. At the same time, however, this conclusion should be put into perspective, as some families were less likely to prefer home care. This highlights the need to explore strategies by which health professionals can support families and patients outside the hospital in the context of limited health system resources. The availability of EOL care in hospitals increased the likelihood of hospitalization for patients with malignant diseases. Although this finding needs to be contextualized, especially for developing countries, it may suggest further research to understand whether the availability of palliative care units in hospitals would increase the choice of hospitals as the preferred place for EOL care.

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