

# Barriers in Palliative Care: Means to Integrate it into Health Care Mainstream

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## Abstract

Although palliative care has significant and positive effects on patients and their families, as it is scientifically proven, however, it is not a permanent part of health care mainstream. The aim of this systematic literature review was to describe barriers in palliative care that stops it from becoming a permanent component of healthcare mainstream. **Method:** two electronic data base (Medline, Embase) were searched for potentially relevant records published after 2010. Barriers were categorized, and the means to overcome such barriers were also categorized. 36 studies were searched among them 10 CAT studies that are of high quality and specialized in doctor-patient communication, barriers related to physician attitudes, nursing, policies, technology and heavy case load. Means are categorized to minimize the negative effects of such barriers and the possibility of becoming part of healthcare mainstream. **Results** revealed the importance of palliative care, and the possibility and opportunity is available to become a component and integral part of medical care main stream.

**Keywords:** Palliative care, Barriers, healthcare mainstream.

## Introduction

Among important public health issues is palliative care. It is important part of healthcare process and palliative care is involved with the dignity, care needs, suffering and quality of life of people who are terminally ill such as cancer patients or at the end of their life.

Palliative care was defined by the world health organization in 2002 report as:

“An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early

Identification and impeccable assessment and treatment spiritual” (WHO, 2000)

Furthermore, WHO report (2002) presents many facts, challenges and barriers in palliative care such as: every patient is unique, has own story, relationships and culture. They deserve dignity and best health care ... and health care professionals must understand that, otherwise, patient’s improvement will be hindered.

Reviewed literature, unfortunately, shows that the introduction of palliative care into mainstream medicine is lacking at present (Visser et al, 2014, Dean & street 2015; Freeman, 2016). Although population in the developed countries, Australia included, are living longer, ageing and living beyond 65 years. Also pattern of disease is changing such as heart disease, lung cancer and host of other fatal illnesses, besides the technology revolution that is taking place in health care facilities and institutions, which has resulted in healthcare professionals to rely greatly on technology in their treatment and dealing with patients. This report argues that there are many challenges and obstacles that hinder palliative care to be part of health care mainstream. Also it argues that the chances for palliative care to become a permanent part of health care mainstream is possible through activating tools for spreading awareness and for stimulating debates and policy development and action.

## Literature Review

The purpose of this section is to explore all aspects surrounding this study’s problem which is “palliative care barriers constitute a high wall in the face of palliative care to become integral part of healthcare mainstream and means to be so. Thus, literature review section, reviews studies relevant to the subject with the support of several subtitles that deal with the subject directly. These studies are mined from specialized data base and organizations in the field. Reliance on online means is evident.

## Palliative care with patients

The main purpose of palliative care is to relief suffering, psychosocial support and closure near the end of life (Lo et al 2011) by using communication techniques healthcare providers, mainly physicians, ought to, constructively explore their patients’ experience with compassion.

Thus physicians ,nurses and other healthcare providers should recall that the term compassion comes from the Latin words for “feel with” or “suffer with” the patient (Visser et al, 2014). However, physicians do not have sole responsibility for responding to the patient’s suffering but seek help in this matter from social workers, nurses and other experienced personal.

The Robert Wood Johnson Foundation (RWJF) identified seven specific domains of ICU palliative care quality: adequate communication with the team and with patients and families, patient and family- centered

decision – making. RWIF findings comes into agreement with communication accommodation Theory (CAT) authors such as: Gallois, Ogay & Giles, 2005; Mc Glane & Glies, 2011, define CAT as: “a framework for understanding the interpersonal and intergroup dynamics of speakers and communicators adjusting their language and nonverbal pattern to each other” CAT, in addition, defines psychological accommodation as individuals beliefs that they are integrating with differentiating from others. This study, as it is mentioned earlier, used CAT to help in selecting studies for this study.

As shown in table 1

**Table 1**

Study	Year	Use of Theory	Design	Data Collection Method	Data Analysis	Sampling			
Size	Participants	Technique	Setting	Country					
Qualitative non-experimental studies									
Hemsley Balandin Worrall	2012	CAT	Descriptive	In-depth free-style interviews	Narrative analysis	15 Nurses	Purposive sampling	Hospital	Australia
Cretchley Gallois Chenery Smith	2010	CAT	Descriptive	Interviews with un-prearranged questions	Principles of grounded theory Thematic analysis	34 People with chronic Schizophrenia & care providers	Judgment sampling	Psychiatric facility	Australia
Jones Woodhouse Rowe	2007	CAT	Descriptive	Semi-structured interviews	Content analysis	33 Parents of prematurely born babies (20 mothers, 13 fathers)	Accidental sampling	Neonatal intensive care unit (NICU)	Australia

These studies and twenty more are used in order to achieve the objectives of the study.

In order to achieve the goals of palliative care, there are many crucial elements need to be cited or must be available for that, such as: primacy of competence in professional caring along with genuine concern, openness and a willingness to connect with others (Hung- Ru Lin et al 2003).

Hung repeats the saying “Medicine is an art whose magic and creative ability have long been recognized as residing in the inter personal aspects of patient – physician relationship.” This, along with reviewed literature prove that palliative care is important to the patients’ health. and helps patients and their families achieve an optimal level of quality of life and psychosocial adjustment.

In addition to doctors- patient communication, nurses, social workers and psychologists –proper communication is important element that contributes to patient health improvement.

In regard to nursing- patient communication, there are several theories, models and best practices that examine nursing- patient communication such as:

Peplau’s Interpersonal Relations Theory

Dyadic Interpersonal Communication Model ( Visser et al 2014 )

According to a 2013 study published in the Journal of Patient Safety, as many as 440,000 people die each year from preventable medical errors, representing the third leading cause of death in the U.S. on the list from the Centers for Disease Control and Prevention (CDC). of deaths due to medical errors,

The Joint Commission estimates that 80 percent involve miscommunication. The Joint Commission’s analysis of 2012, 2013 and first-quarter 2014 data revealed that in all three time frames, communication was one of the top three leading causes of sentinel events, a patient safety event unrelated to the patient’s illness or condition that results in death, permanent harm or another qualifying negative outcome.

Increases in nursing communication can lessen medical errors and make a difference in positive patient outcomes. In a 2014 study published by the New England Journal of Medicine, medical error rates in nine children’s hospitals decreased by 23 percent after a handoff program was instituted to enhance and standardize communication. According to Ros Wright, the body of literature in nursing communication points to “increased recovery rates, a sense of safety and protection, improved levels of patient satisfaction and greater adherence to treatment options” as well-documented results of effective communication.

## Results

Reviewed studies have shown several findings as revealed in tables below

Table Two

**Communication Barriers**

Physician- patient communication

- Struggling in initiating complex emotionally laden discussion about palliative care with seriously ill patients and their families.
- Physician reluctance to acknowledge suffering or death.
- Inability of healthcare providers (nurses, doctors) to use open ended questions in eliciting patients concerns and emotions.
- not paying proper attention to patients spiritual, existential and religious issues which are crucial component of palliative care
- Insufficient physician training in communication about end-of-life issues
- No familiarity with skilled and timely communication
- Not knowing how to deal with ‘feeling helpless’ with families pressuring ICU teams to withhold treatment or when family members are upset about aggressiveness of care provided to their unwilling loved ones
- No knowledge of management of critical illness by referring specialists; confounding factors in decision-making
- Not being at ease in talking to patients and their families about limitations of therapy
- Insufficient clinician training in techniques for forgoing life-sustaining treatment without causing patient suffering

Table Three

End of life care in ICUs is often inadequate because

- Lack of communication between patients and health care provides
- Lack of patient and family centered care
- Lack of emotional and psychosocial support
- increasing economic incentives on health care organizations to control costs at the end of life
- structure and process of care (facilitate or hinder good quality of care)
- Technical process and decision making process
- Information provided about options, risks benefit of each.

Pain and sufferings

- palliative care delivery is often inadequate
- pain and other suffering often are unrelieved
- palliative care is often unsatisfactory
- lack of active listening and empathic communication
- Perceived disproportionate care was the most shortcoming indicated by physicians.

As tables of study’s results show that there are many obstacles face palliative care from being effective in healthcare process. Most of these obstacles are related to health care providers’ communication with their terminally ill patients. Such obstacles can be minimized and in a degree that paves the way for palliative care to be an integral component of healthcare mainstream. The means to achieve this purpose are listed below, It must be noted that, in preparing this section author relied on WHO report (2002)

**Recommendations and means that allow palliative care to become an integral part of healthcare mainstream.**

In order to achieve the objectives of this research and after extensive review of relevant previous studies in general and CAT studies and WHO reports in particular, the following recommendations are put in place in the hope to be a contributing element to have palliative care be an integral component of healthcare mainstream:

- Palliative care must now be offered more widely and integrated more broadly across the health care services
- Health policy must pay more attention to palliative, after long times of relative neglect.
- public health approach must be considered so as to addressing information fatal and chronic illnesses, trends, staffing issues, quality improving methods and community responses.(WHO, 2002).
- Policy-makers must begin to plan now to meet the needs of ageing populations for care towards the end of life.
- Health care systems must place much greater emphasis on the care of people of all ages who are living with and dying from a range of serious chronic diseases. (WHO, 2002).

Policy-makers must invest in providing publicly funded palliative care services as a core part of health care and not as an “add-on extra”.

. Policy-makers must take steps at a population level to ensure that unmet needs for care are identified for all common serious diseases, including cancer, ischemic heart disease, cerebrovascular disease, chronic obstructive respiratory disease, end-stage liver and kidney disease, infectious diseases and dementia.

Policies need to identify people living with serious chronic illnesses in widely different settings such as the community, nursing homes and hospitals, including intensive care. Policies must also recognize the work of families and caregivers and support them to help care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities. (WHO 2002)

Furthermore, Dame Cicely Saunders pays significant importance to the role of patient's family in relief process of their loved ones

The family, itself the main caring team in the community, needs the advice of a multidisciplinary group of professionals if it is to reach its own potential for enabling patients to live as fully as possible to the end of their lives. Sound memories will then enable the bereaved to experience a satisfaction that helps them live on. This requires both a social and a political impetus, entailing changes in attitudes and widespread education of all professionals involved with patients who have a life-threatening illness. It demands human commitment rather than expensive drugs and interventions, and should be a concern for all governments." People in charge or policy makers should take in consideration to implementing some logic procedures into practicing the process of healthcare, for instance, implementing some measures that can be described as simple measures: support for family and coordinated service, encouraging communication skills with pain and symptom control. All of these can be more effective when Policy-makers promote the development of palliative care skills in staff working across all settings, especially in pain and symptom control and communication. Along with Palliative care services be coordinated across different settings of home, hospital, inpatient hospice, nursing home and other institutions.( WHO report, 2002)

Policy-makers need to invest in the funding of the full range of effective palliative care services, including specialist teams to ensure that patients and their families have access to the services they need. At the meantime, poor people should have access to palliative care as well as all members of society. This must be monitored and be improved especially, the quality of services provided to these populations.

Many innovative ways of improving the quality of care towards the end of life are being developed and must be shared across teams, organizations and countries.

The aforementioned cannot be sustained without effective leadership, staff involvement and funding. Such changes and improvement do not occur rapidly and it may take several years for knowledge to be assimilated, new skills and practice to be learnt and accepted, and supporting structures and networks to evolve (WHO report ,2002)

Health professionals need to be trained well in palliative care to a degree that they become specialists in this field, so as to ensure that palliative care is a core part of the training and continuing professional education of doctors, nurses, social workers, chaplains and other health professionals.

Health care organizations need to develop cultures and working practices that allow the best use of the palliative care skills of health professionals, including spending sufficient time with patients and families.

Research and training in palliative care should be considered a priority, and funded in line with that for potentially curative interventions

Good quality care towards the end of life must be recognized as a basic human right. Some countries are now developing national and regional palliative care strategies, and each country needs to decide which options for care are priorities and can be offered or planned for. However, if people do not receive information on what care is available, it is difficult to argue that the best care has been offered.

Currently, most health care systems are not set up in a way that makes it easy for people to receive palliative care or to die where they would wish. In many countries data on place of death are not collected nationally. Finally, policies for palliative care need to be developed as part of an innovative global public health policy

## **Conclusion**

The problem of this research is about palliative care is not an integral part of healthcare mainstream in present time.; however, there is significant opportunities that allow palliative care to be an integral part of health care main-stream. Literature reviewed proves that and the recommendations of World Health Organization (2002) cited above proves that.

The entire matter needs from everybody involved and concerned with palliative case: including policy and decision makers, concerned organizations and medical professionals to have determination and willingness for change and devote their sources and abilities to promote and enhance the awareness culture of palliative care, do their best to integrate palliative care into health care main stream, as the case of Saint Vincent Hospital in Sidney Australia.

"The patient will never care how much you know, until they know how much you care." (Terry Canale in his American Academy of Orthopaedic Surgeons Vice Presidential Address) (Fong et al)

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