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Thesis Title:

Patient referral to palliative care and perception of professional care giver on the terminal condition

LONG ABSTRACT

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TABLE OF CONTENTS

Key words: end-of-life care; end-of-life conversation; palliative care; ethical decision making; doctor- patient communication; truth telling; medicine in Israel; Terminally-Ill Patients Act, 2005; oncology; oncologist; advanced care planning, Advance Medical Directives, Theory of Planned Behavior.

INTRODUCTION

The Introduction first sets out what palliative care (PC), as defined by the WHO:"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". PC's role within the overall care and treatment of illness and the main current difficulties in expanding its provision in Israel are set out and the environment of the present study is outlined by describing the current provision of palliative care in Israel.

The present study's research aims are:

- To investigate how Israel's Terminally-Ill Patients Act, 2005, which regulates end-of-life care is being implemented
- to identify barriers to this implementation
- to examine whether the Theory of Planned Behavior can be used as a framework to predict physicians' referral of patients to end-of-life palliative care and identify potentially modifiable variables.

The research questions are:

1. How does physicians' knowledge of palliative care and its associated legislation affect their referral of terminally-ill patients to palliative care?
2. How do physicians' attitudes to and beliefs about palliative care and related issues affect their referral of terminally-ill patients to palliative care?
3. To what extent does training in palliative care and its associated legislation impact on physicians' knowledge of end-of-life care?
4. To what extent does training in palliative care and its associated legislation impact on physicians' attitudes to and beliefs about end-of-life care?
5. How do physicians' knowledge of, attitudes to and beliefs about palliative care affect their patterns of decision-making and their implementation of the PC-related provisions of Israel's Terminally-Ill Patients Act, 2005?
6. To what extent can Ajzen's Theory of Planned Behavior (1991) predict physicians' referrals of terminally-ill patients to palliative care?

The research hypotheses are:

(a) Barriers will be found, set in physicians' daily practice, to the referral of patients to palliative care (PC).

(b) The above barriers will be found to be associated with the carers' knowledge of, attitudes to and beliefs about PC, about the 2005 Act and related issues.

(c) The above attitudes and beliefs will be found to be associated with the carers' training in PC and related legislation and skills.

(d) The referral of patients to PC will be found associated with physicians' manner of decision-making about patient treatment methods, and in particular with their sharing of information with the patient.

The prime contribution to healthcare that this study expects to make is to improve patients' quality of life, allow them a dignified death and respect their last wishes.

CHAPTER l: LITERATURE REVIEW

Section l.l introduces the concept of palliative care, presents a glossary of key terms and two models of PC provision. Palliative care is a dynamic field and is now recognized as a medical specialty of a interdisciplinary nature. Coordination and partnerships with hospice programs are major features. As an interdisciplinary endeavor, the field of palliative care includes medicine, nursing, social work, psychology, nutrition, and rehabilitation. New physician, nursing, and social worker specialties and certification processes in both hospice care and palliative medicine have emerged to help meet the need for palliative care. Although there has been enormous expansion of hospital palliative care programs, not all hospitals have palliative care teams, and workforce shortages combined with tenuous funding may limit the spread and sustainability of existing programs.

Subsection l.la sets out PC's basic principles and then explains the content of primary, secondary and tertiary palliative care.

Subsection l.lb presents the WHO public health model of national palliative care policy and then reviews the provision of PC across the Middle East. It goes on to report on the development of PC in Israel from 2004, when the Israel Ministry of Health appointed the Palliative Care Guidelines Committee to review the provision of such services in Israel and make recommendations for their future development, through to the 2005 Terminally-Ill Patients Act which wrote into law the right of patients and their close family members to palliative care, through to the present day. There are currently 7 home-hospice units in Israel caring for the terminally-ill. One result of the coming into effect of the Terminally-Ill Patients Act has been the appearance of privately-run hospices across the country which sell their services to all the HMOs. The Shvartzman Committee recommended that Israel aim for the Oxford Textbook of Palliative Medicine's recommended ratio of 5 PC beds per 100,000. Long-term care facilities, Home Care units and Further-Care and Monitoring units, and Oncological nurses in the community are also described.

Finally, Subsection l.lc previews the future development of PC in the developed world, considering three possible strategies—(a) the Systems-change approach, (b) Integrated care pathways**;** and (c) Screening for need.

Section l.2 reviews the referral to palliative care. After briefly discussing the benefits of palliative care, **Subsection 1.2a** reports current thinking on where and when hospice care fits into the overall continuum of medical care. Palliative care is appropriate for patients throughout the illness continuum, including cure, remission, control of disease, and end-of-life (EOL) care. Unfortunately, many healthcare providers are slow to initiate PC consultations with their patients. These delays contribute to unrelieved symptoms, moral distress for bedside providers, and financial shortfalls for healthcare institutions. Early consultation with PC providers facilitates the development of trusting and therapeutic relationships with patients and families.

The World Health Organization adheres to the belief that palliative care is intended for all of the seriously ill, not just the dying. In other words, palliative care is a large umbrella that shelters modern treatment protocols (curative and non-curative) as well as hospice care services.

Hospices offer multidisciplinary, holistic care in a variety of settings and focus on relieving the substantial symptom burden patients face at the end of life, as well as meeting advanced care planning needs, existential concerns, and family and social stressors. Hospice care focuses on holistic care in preparation for death. Philosophical convictions may lead them to focus on the later stages of illness and oppose certain treatments as the medicalization of dying.

Subsection l.2b considers when and how to make the transition from curative to palliative care. Appropriate timing is important to ensure that the EOL conversation does not take place too late in the disease trajectory. Delaying the discussion can result in unnecessary treatment and associated suffering, as well as delays to hospice enrollment. People with life-limiting cancer are able to make decisions regarding EOL care if given the information in a timely manner. The fact that some patients with cancer would prefer death over living in a coma, in a nursing home, with a feeding tube, or on a ventilator illustrates the need for timely discussions.

Subsection l.2c sets out the barriers to the provision of palliative care, which cause late or non-referral to PC and thence low family satisfaction with care. Studies have identified the following obstacles to hospice referral—the difficulty of predicting prognosis, lack of physician acceptance of terminal diagnosis and death, physician’s unfamiliarity with hospice care (their training does not include it) and their negative opinion of it, a medical system that does not include hospice care as standard care, patients’ and families' prejudice against hospice care and their preference for life-prolonging treatment, their denial of a terminal diagnosis, their uninformedness about hospice care, and social attitudes toward death.

Several studies have explored the barriers to hospice utilization by surveying or interviewing physicians, caregivers, hospice and home health care staff, and the family survivors of patients who have died in hospice and home care, and these studies have added a further barrier to hospice utilization—problems and shortcomings in hospice service provision. The care of the dying patient is fragmented across multiple settings with little communication by the different providers across the trajectory of the illness.

Physicians as the gatekeepers to hospice care: Physicians' perceptions of hospice care and the value they place on patients staying at home, along with their ability to accept terminal diagnoses and communicate them to patients, also surface as themes in hospice enrolment decision-making. Studies have found that at least one-quarter of physicians do not discuss hospice options with their terminally-ill patients, and the other three-quarters do so selectively. Physicians admit their tendency to delay the discussion of hospice options until they think their patients are prepared to accept such options. One study's finding that 85% of patients expressed preferences for palliative care over curative treatment suggests that patients may be more receptive to hospice care than physicians and caregivers expect.

Shifting the goal of care to palliation—why is it so difficult for physicians? Clinicians often struggle with initiating EOL discussions with patients about changing treatment goals and, in particular, about transitioning to palliative care. Not surprisingly, physicians may respond to their patient's imminent death, particularly those with whom they have shared a long-term relationship, with powerful emotions of their own. Most physicians seem to view hospices as an alternative rather than an addition to traditional medical care. Several studies have documented that oncologists refer patients to hospice later than surgeons, internal medicine physicians and family practitioners. The combination of physicians' difficulty in broaching the subject of hospice care and their instrumentalist orientation has led to a well-recognized barrier to hospice utilization, the late timing of hospice discussions. Another major reason for this is physicians' difficulties in predicting survival accurately. Physicians recognize their tendency to suggest hospice care too late in the disease course.

Patient and Patient Family Barriers: Patients may delay enrolling in hospice care because patients or families tend to have overly optimistic expectations of treatment, which even the most careful and persistent communication efforts fail to change. Patients/families often reject hospice care as "giving up". When multiple other lines of therapy are available they may resist the notion of hospice care and decide not to engage in discussions about EOL care. However, families who are provided hospice care information before and during their relative's terminal illness are much more likely to consider hospice care than families who knew of the hospice option before the illness but did not receive further information during the illness.

Healthcare System Barriers: The palliative care infrastructure is still in its infancy, leaving many patients and families with no guarantee of access to this type of care.

Section l.3 discusses the effect of physician and patient attitudes to and knowledge about PC on decision-making about it. Physicians may limit referring terminally-ill patients to hospices if, for instance, they are unaware or uncertain about available hospice services or believe that hospice referral is a signal for patients and their families to lose hope, or if they expect that patients and families will be unwilling to elect hospice services.

Subsection l.3a reviews recent attitudinal research among healthcare workers in the context of PC, for instance, attitudes and beliefs regarding communication with terminally-ill cancer patients and attitudes to death and dying.

Subsection l.3b reviews research into doctors' and nurses' knowledge of palliative care: Although some studies have assessed physicians' knowledge and attitudes concerning various aspects of terminal care few have examined the influence of this knowledge and these attitudes on physicians' behaviour. Some researchers have examined physicians' self-reported educational needs in the area of hospice care. Others have looked into why newly qualified doctors are unprepared to care for patients at the end of life and what the specialist or aspiring specialist wants and needs from an education programme. This subsection concludes by summarizing what an Education in Palliative Care program would need to comprise.

Section l.4 presents the difficulties of doctor-patient and doctor-family communication in EOL care. Subsection 1.4b sets out the importance of good communication in EOL care. Effective communication is essential for patients to make informed decisions about their healthcare and life planning, and communication skills are vitally important for both providers and patients. Medical language can be confusing but it is not enough for doctor and patient to use the same language, it is necessary to include the experience, values and emotions contributed by each side. **Subsection l.4c** sets out the current state of affairs with regard to doctors' communication skills. A wide variety of empirical studies document that physician-patient communication is suboptimal. Physicians and nurses typically miss the full range of concerns held by people with cancer. Oncologists lack accuracy in detecting patient distress. Poor communication also hampers a physician's ability to provide pain and symptom management. Many physicians have not had effective teaching in communication skills and continuing medical education consisting of lecture-style presentations consistently fails to change physician behaviour. Yet the responsibility for breaking difficult news may come early in training. Many doctors have difficulty handling their own emotions and there is little evidence that these difficulties get easier with experience.

*Telling the truth***:** Doctors frequently censor information they give to patients about their outlook on the grounds that what someone does not know cannot harm them. Such traditional paternalistic attitudes can still be seen even in hospice care. Doctors are unaware that a failure to disclose information honestly to patients might be an attempt to protect their own emotional survival as much as help protect the patient. The truth may hurt but deceit hurts more.

Subsection l.4d is a brief review of the concept of patient-centred care. Research and theory on effective interpersonal care are identifying elements of patient-centered medicine characterized by mutual participation relationships which encourage informed choice and patient autonomy. At the heart of the patient centered approach is the need to understand the meaning of the illness for the patient. Key to a patient-centered clinical method is responding in a way in which patients sense that their ideas, feelings, expectations and fears are understood—essential elements of all EOL conversations.

Subsection l.4e discusses patients' and families' communication needs. Patients expect health professionals in palliative care settings to provide psychological and emotional support through excellent communication, and are well aware when a health care professional is not able to deal with issues adequately or comfortably. Anyone charged with breaking bad news needs to be able to cope with theirs and the patient's/family's emotions. No two patients or relatives will respond in the same way. There is a broad research consensus as to how patients want to hear news and what they need to hear. Poor communication when breaking bad news may leave patients unaware of their diagnosis and outlook. Failure to give adequate information can leave them isolated and scared that nothing can or will be done to help them. No news is not good news, it is an invitation to fear. Information sharing with the patient should not be a one-off occurrence, but regular. The terminally-ill patient should be offered psychological care if needed. *Families' communication needs and role*: One cannot plan good patient care without taking the family into account. The physician needs to find out what the family already know about the condition of the patient and then brief them on the patient's current state of health.

Subsection I.4f reminds us that provider team members need to communicate well amongst themselves. Team members frequently have little awareness of each other’s informational roles and responsibilities, and what has been communicated to the patient about the diagnosis and prognosis is usually not well documented in hospital records. Mutual agreement and clarity of goals are necessary and a model for the resolution of conflicts should be in place.

Subsection I.4g discusses how to break bad news. Many studies have been carried out to clarify patients’ preferences and experiences in receiving bad news and several clinical guidelines and expert recommendations have been published. Moreover, recent trials have demonstrated that structured skill training can actually improve physicians’ clinical skills in this area. Like any medical procedure, giving bad news requires a coherent strategy.
EOL Conversations: EOL conversations are a corollary of patient-centered medical practice. They include many emotionally charged topics, such as unfavorable prognoses and treatment failure, treatment choices and family responses to them, advance care planning, concerns about ability to cope, life goals and other life-closure issues, anticipatory mourning, and the meaning of the illness and its suffering. When these often difficult discussions are delayed or avoided or are managed poorly the quality of remaining life for patients can be seriously jeopardized. The reasons why health care professionals avoid EOL conversations are laid out along with some current countertrends.

Subsection I.4h sets out the specific communication skills needed by doctors and nurses.
Subsection I.4i provides an overview of the current state of research into EOL communication.

Section l.5: Advance Care Planning and Advance Medical Directives

After providing a short glossary of relevant terms, **Subsection l.5b** of this chapter explicates that Advance Care Planning (ACP) is a process that allows people to make decisions in advance regarding their medical treatment at the end of life. Advance care planning protects patient autonomy and communicates to doctors patient preferences for care. It includes clear discussions about prognosis, information about AMDs, explanation of the do-not-resuscitate (DNR) option, information about palliative care options (e.g., hospice care), and discussion about where patients would prefer to die. Such discussion and planning needs to take place before a crisis develops. However, the quality of EOL and ACP discussions between patients and their care team are rather rare and predominantly poor, and there is a substantial gap between what patients want to discuss and what is actually discussed. One of the chief reasons for this is doctors' lack of knowledge and competence. Patients who have discussed their preferences for EOL care with a physician are more likely to choose palliation over aggressive measures at EOL , to die at home or under hospice care, and to receive care that is consistent with their preferences.

Subsections l.5c-d set out what Advance Medical Directives (AMDs) are and what they do. AMDs are one component of Advance Care Planning, whose goal is to promote patient autonomy in healthcare decisions, match personal values with EOL choices, increase the likelihood that patients' wishes are respected, and ease the burden on families and healthcare providers when a patient is unable to make decisions. AMDs are legal documents.

Although a study of patients with cancer found that 95% of patients admitted to hospital believed that discussing AMDs was important completion rates remain low at 18 to 36% of adults. The barriers to AMD completion include the patient's inadequate language, lack of knowledge, poor communication, perception that family involvement obviates the need for AMDs, and that signing an AMD would result in inferior care. Other barriers stem from physicians: **d**iscussions about prognosis, ACP, and EOL issues are difficult for them: they tend to be overly optimistic, avoid these discussions, communicate with euphemisms, and/or delay conversations until patients are near death.

Subsection l.5e explains the concept of Shared Decision-Making (SDM). SDM is a recent approach that generally involves discussing and respecting patient preferences for participation in the medical decision-making process.

Subsection l.5f explains the role of Informed Consent in EOL care. It is not only a legal requirement but a moral imperative, based on the values of patient autonomy and self-determination. Every human being of adult years and sound mind has a right to determine what shall be done with their own body. A second goal of informed consent is to empower patients to exercise their right to autonomy rationally and intelligently. Without such a requirement, the likelihood of rational decision making diminishes. **Subsection l.5g** lays out the provisions of Israel's Patients' Rights Act, 1996, as they pertain to informed consent.

Section l.6: A good death and ethical issues: Subsection l.6a sets out what is considered to be a good death. From the limited literature, researchers have identified several domains, for example, preparation for death, personal growth, meaning of life, peace, sense of completion, timeliness, and issues of spirituality. The hospice model of a good death includes an open awareness of dying, open communication, a gradual acceptance of death, and a settling of both practical and interpersonal business. The needs of dying people may include knowing when death is coming, understanding what can be expected, being able to maintain a sense of control and have their wishes respected, having access to information, high-quality care and spiritual and emotional support.

Can there be a good death? Dying, like most other human acts, can be done well or badly. We only die once, so it is important to get it right. While death is inevitable, how we die is dependent on the virtues, skills, planning and attention we bring to it, so that the best deaths are well-prepared ones. One view is that ‘good deaths’ are those in which the subject is not only kept free of pain but retains a high measure of control, autonomy and independence over their fate. Needless to say, not everyone is able to have such a death. People who die in an accident, or succumb slowly to Alzheimer’s or require heavy sedation have little opportunity for leave-taking. The aim is that the dying person should leave this world in a state of maximum physical and mental comfort. A good death is unlikely to be realized without access to pain management and good medical care, but the tools that allow us to find meaning and purpose in death are unlikely to be medical or scientific. All research emphasises the importance of open and honest communication about life and death issues between family members and patients.

Subsection l.6b lays out the factors promoting a good death and the barriers to it: Knowing the dying person, following their wishes and providing individualised care sensitive to their needs is key. Staff must take time to listen. *The barriers to a good death* are firstly doctors' and nurses' personal fears and concerns about death and dying, which may lead to a self-protection process, what Renzenbrink refers to as 'relentless self-care'.

Subsection l.6c sets out the ethical issues pertinent to EOL care. Four self-evident ethical principles represent the main values underlying medical ethics: (a) Nonmaleficence – do not harm (minimize the harm); (b) Beneficence – do good (always act in the patient's best interest); (c) Autonomy – acknowledge the patient's rights to self-determination; (d) Justice – allocate healthcare resources equitably and according to need.

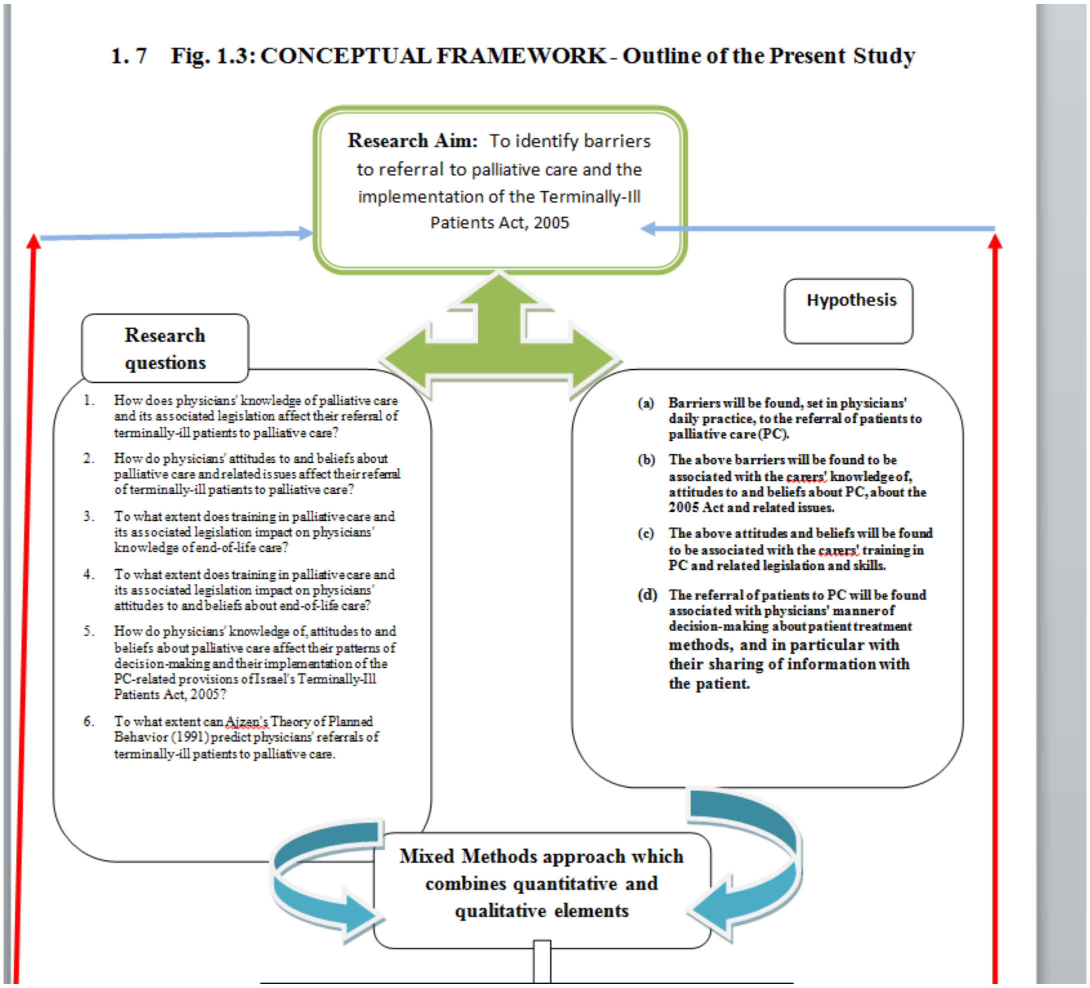
Subsection l.6d describes the professional responsibilities of the oncologist, which include making explicit evidence-based decisions and employing highly-developed communication skills.

Subsection l.6e discusses truth-telling: Truth-telling is a basic moral rule in the western healthcare system. Not to tell the truth can be viewed as jeopardizing trust in the staff-patient relationship, intruding on the patient's existential integrity and undermining the their autonomy. However, in practice the truth is often withheld to protect patients from diminished hope, suffering, physical impairment, as well as to enhance compliance. The protection of staff from discomfort has also been shown to be a motive. Truth-telling is also thought to give patients the chance to prepare for and deal with their approaching death. Patient autonomy is now considered the norm in patient-centered cancer care in Western countries but cultural differences modify this dominant view. For instance, in Italy, Spain and Greece traditional medical practice is not to disclose a cancer diagnosis and prognosis to the patient. Disclosing a prognosis without waiting for the patient's explicit request is also widespread but controversial.

Subsection l.6f reviews the issue of the depth of palliative sedation at the end of life. There are important questions, such as how deep the sedation must be to relieve suffering and how important it is for the patient to maintain a certain level of consciousness.

Subsection l.6g considers the doctrine of double effect, the essence of which is that an act performed with good intent can still be moral despite negative side-effects. For instance, the need to relieve pain may be such that it warrants accepting the risk of hastening death. The doctrine is generally accepted in the medical profession but has been subjected to trenchant criticism by philosophers, lawyers and clinicians.

Subsection l.6h discusses the withholding of nutrition and hydration at the end of life which physicians often find disturbing and this reluctance to withhold or withdraw persists even though professional organizations have repeatedly stated that artificially provided nutrition and hydration are medical treatments that can be withheld or withdrawn under appropriate medical and ethical circumstances.



1.7 Fig. 1.3: CONCEPTUAL FRAMEWORK - Outline of the Present Study

Research Aim: To identify barriers to referral to palliative care and the implementation of the Terminally-Ill Patients Act, 2005

Research questions

1. How does physicians' knowledge of palliative care and its associated legislation affect their referral of terminally-ill patients to palliative care?
2. How do physicians' attitudes to and beliefs about palliative care and related issues affect their referral of terminally-ill patients to palliative care?
3. To what extent does training in palliative care and its associated legislation impact on physicians' knowledge of end-of-life care?
4. To what extent does training in palliative care and its associated legislation impact on physicians' attitudes to and beliefs about end-of-life care?
5. How do physicians' knowledge of, attitudes to and beliefs about palliative care affect their patterns of decision-making and their implementation of the PC-related provisions of Israel's Terminally-Ill Patients Act, 2005?
6. To what extent can Ajzen's Theory of Planned Behavior (1991) predict physicians' referrals of terminally-ill patients to palliative care.

Hypothesis

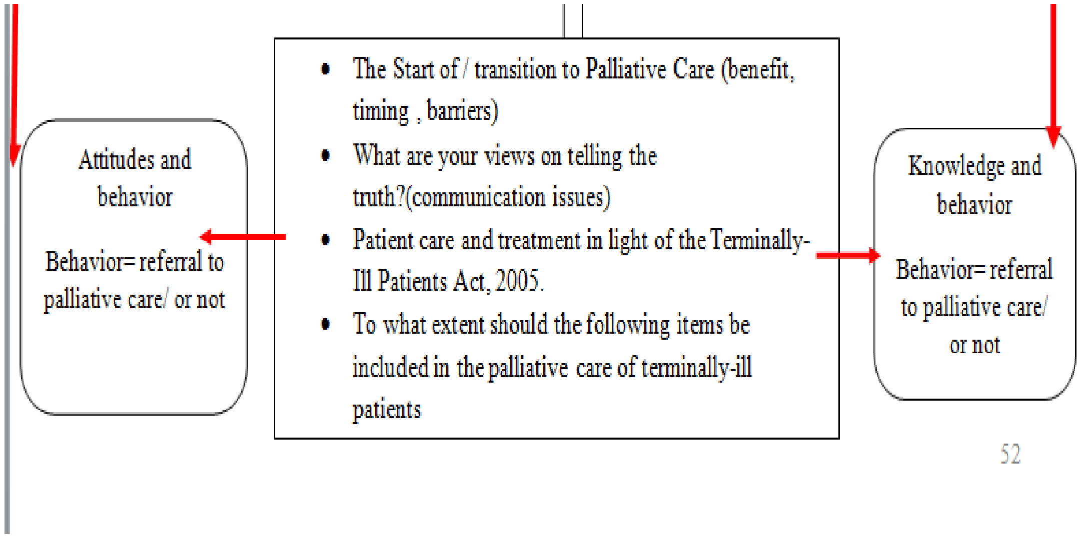
(a) Barriers will be found, set in physicians' daily practice, to the referral of patients to palliative care (PC).

(b) The above barriers will be found to be associated with the carers' knowledge of, attitudes to and beliefs about PC, about the 2005 Act and related issues.

(c) The above attitudes and beliefs will be found to be associated with the carers' training in PC and related legislation and skills.

(d) The referral of patients to PC will be found associated with physicians' manner of decision-making about patient treatment methods, and in particular with their sharing of information with the patient.

Mixed Methods approach which combines quantitative and qualitative elements



CHAPTER ll: THEORETICAL FRAMEWORK

Section ll.1 sets out a full presentation of Azjen's Theory of Planned Behavior which furnished the present study its theoretical framework.

Section ll.2 summarizes the core principles of PC and then sets out the main provisions of Israel's Terminally-Ill Patients Act, 2005, the legislation which currently governs the operation of PC in Israel.

CHAPTER lIl: METHODOLOGY AND METHODS

Section lIl.1 sets out the study's research approach: The study follows the Mixed Methods approach which combines quantitative and qualitative elements. **(A) The qualitative research element** rests on the constructivist paradigm according to which many simultaneous realities exist, especially if the research topic is the behavior of human beings. **(B) The quantitative fieldwork element** follows an *ex post facto* design and is descriptive and correlational. It follows the positivist paradigm, which argues that there exists one absolute reality independent of its context and that the researcher's task is to uncover that reality by objective means and tools.

Section lIl.2 sets out the study's research aims.

Section lIl.3 reviews the number and distribution of Israeli doctors in day-to-day practice with oncology patients about whom EOL decisions need to be taken.

Section lIl.4: Research Procedure: Stage 1: The qualitative phase when fifteen doctors were in-depth interviewed, five family doctors, five oncologists and five home care specialists. At **Stage 2** 90 doctors from hospitals across the country and from all the four major health management organizations (30 hospital oncologists, 30 home care hospice specialists, and 30 family medicine specialists) completed a structured self-administered quantitative questionnaire. Sampling for this stage was a combination of cluster sampling, directed sampling and convenience sampling.

Section lIl.4a Research population and sample: The research population is all the doctors working regularly in the Israeli healthcare system in the field of palliative care, in both hospital, community and home care settings. The hospital sector is represented by hospital doctors working in a range of departments (family medicine, geriatrics, internal medicine, oncology and others). The community medicine sector is represented by doctors working (a) in community clinics and (b) home care units. The sample is also representative of the Israeli population in that 20% of the doctors sampled were Arab-Israelis. It is also geographically heterogeneous**.** *Persuading doctors to participate*: It was not easy to persuade doctors to fill out a questionnaire. Firstly, doctors everywhere are always operating under a heavy workload. A second difficulty, in this particular instance, was the sensitiveness of the issues the doctors were being asked to open up on, e.g. thoughts on death, their knowledge/ignorance and observance of legislation, etc. The chief way the researcher overcame doctors' reluctance to participate was to exploit his extensive personal contacts and acknowledged status in the field of PC teaching.

Section lll.5 describes the two research instruments: The qualitative instrument was a semi-structured questionnaire constructed by the researcher on the basis of a literature review, his own long experience in the field of palliative care and the research questions. The quantitative instrument was a structured self-administered, five-part questionnaire composed by the researcher for the present study. It was peer-reviewed and the reviewers' comments incorporated into a second version. This version was then submitted to the thesis advisor, whose observations were taken into the final version.

Section lll.6. Data analysis: The qualitative data analysis was based on four principles drawn from Grounded Theory—juxtaposition, theoretical sensitivity, longitudinality and multiplicity, and reflexivity. These principles generate basic guidelines for the analyst-researcher-interpreter working within the constructivist paradigm. The Critical Incident Technique was also made use of, which is a systematic, inductive method that involves collecting descriptions of events and behaviours, which are then grouped and analysed using contextual, content or thematic analysis. This analysis may involve repeated stages of reading and ascribing meaning. Miles and Huberman's (1994) qualitative analysis approach was also drawn on to provide a framework for coding and data display.

As for the quantitative Stage 2 questionnaires, an SPSS package was used to analyse their data by a range of quantitative statistical techniques—means and standard deviations, frequencies and percentages, t-tests, Spearman correlations, ANOVA and regression analysis.

Section lll.6 then reviews the problems of (a) validity, reliability and generalization; (b) researcher positionality; and (c) the ethical issues the study entailed and their solution.

CHAPTER IV: FINDINGS

Part 1: Quantitative Findings: A main component of the quantitative effort of the present study was to measure eight main research variables, that is, the doctor-respondents' knowledge about and attitudes to (a) starting/transitioning to palliative care, (b) telling patients and their family the truth about the patient's medical condition, (c) the provisions of the Terminally-Ill Patients Act, 2005, as they relate to palliative care, and (d) the ethical issues entailed in applying the provisions of this Act. Chapter 4, Part 1, sets out all the questions asked in the main quantitative questionnaire and tabulates the responses. For instance, Overall, the doctor-respondents demonstrated a high level of knowledge about when to transition to palliative care and a more-than-moderately positive attitude to the matter. The knowledge they demonstrated about telling patients and their family the truth was also high but their attitude to the matter was markedly less positive. As for the content of the Terminally-Ill Patients Act, 2005, the doctors' knowledge was no more than moderate and their attitude to the Act and its implementation even lower. Their knowledge of the ethical issues involved in implementing the Act was also low. Correlational analysis showed that the more doctors knew about the various aspects of palliative care, e.g. when to start it, how much truth to tell the patient, the ethical dilemmas involved, the more positive were their attitudes to palliative care and its various aspects. Secondly, the more doctors knew of the provisions of the Terminally-Ill Patients Act and their connection to the implementation of palliative care the more they wanted to implement the Act's provisions and refer patients to hospice care.

A second line of quantitative inquiry was to measure the association between the doctor-respondents' above-mentioned knowledge and attitudes and the specialism they worked in. Doctors' knowledge about transitioning to palliative care differed significantly by specialism—doctors working in home care and family medicine knew markedly more than oncologists. The same is true with respect to telling patients the truth—oncologists knew least and also scored lowest on attitudes to telling patients the truth, with family medicine specialists having the most positive attitudes. On knowledge about the provisions of the Terminally-Ill Patients Act, it was the family medicine specialists who scored lowest and the home care experts who scored highest.

The study also measured the association between the doctors' knowledge and attitudes and whether they had been specifically trained in palliative care:

Table 4.4: Doctors' knowledge about and attitudes to aspects of palliative care by whether trained in palliative care

T	**SD**	Mean (Range=0-4)	**N**	Training in PC	Aspect of PC
3.030*	0.44	3.26	40	Yes	Knowledge: Starting palliative care
	0.44	2.98	50	No	
1.494	0.40	2.86	40	Yes	Attitudes: Starting palliative care
	0.38	2.74	50	No	
1.419	0.44	3.10	40	Yes	Knowledge: Telling
	0.54	2.95	50		

				No	the truth
0.415	0.51	2.81	40	Yes	Attitudes: Telling the truth
	0.46	2.77	50	No	
1.955*	0.38	2.44	40	Yes	Knowledge: Terminally-Ill Patients Act
	0.33	2.30	50	No	
0.615	0.46	2.23	40	Yes	Attitudes: Terminally-Ill Patients Act
	0.46	2.17	50	No	
2.702**	0.48	2.70	39	Yes	Knowledge: Ethical issues
	0.40	2.45	50	No	
0.442	0.54	2.78	39	Yes	Attitudes: Ethical issues
	0.51	2.74	50	No	

*p<0.05, **p<0.01, ***p<0.001

Doctors trained in palliative care (a) had considerably more knowledge about transitioning to palliative care than doctors without this training; (b) knew more about the contents of the Terminally-Ill Patients Act and about the ethical issues associated with implementing it; (c) were, overall, more positive in their attitudes to palliative care and its various aspects. The researcher also tested for whether the doctor-respondents' knowledge and attitudes was associated with specific training in the provisions of the Terminally-Ill Patients Act, 2005. Doctors trained in the Act had significantly more knowledge than doctors without this training with respect to transitioning to palliative care, telling patients the truth, and to the provisions of the Terminally-Ill Patients Act.

The study tested for the influence of a number of sociodemographic variables—gender, years of employment in medicine, self-designated religion, self-designated extent of religious observance—on doctors' knowledge and attitudes. None of these variables attained a statistically significant effect.

Table 4.12: Doctors' replies to Questionnaire, Part 3, on Telling Patients the Truth

Frequently / To a great extent/ Definitely/ Always	Some-times/ To some extent	Definitely not/ Very seldom/ To a very small extent		
32	36	22	Disclosing the truth to the patient can cause me	20.

(35.6%)	(40.0%)	(24.4%)	embarrassment and unease at how they will react.	
45 (50%)	32 (35.6%)	13 (14.4%)	Disclosing the truth to the patient can cause me fear as to how they will react.	20b.
74 (82.2%)	9 (10.0%)	7 (7.8%)	When the essence of a conversation is to reveal bad news I prepare myself for a range of reactions, such as anger, shock, denial, distrust, acceptance.	21.
40 (44.4%)	30 (33.3%)	20 (22.2%)	In my opinion concealing information from the patient can sustain his/her hope and prevent harm.	22.
60 (66.7%)	26 (28.9%)	3 (3.3%)	A doctor's work with terminally-ill patients is made more complicated by ethical, social and religious issues.	23.
81 (90.0%)	9 (10.0%)	0 (0%)	The key to resolving ethical issues is cooperation and communication between all team members (doctor, social worker, nurse and any other).	24.
33 (36.7%)	30 (33.3%)	25 (27.8%)	I encourage my terminally-ill patients to draw up Advance Medical Directives (a 'Living will')	25.
79 (87.8%)	11 (12.2%)	0 (0%)	It is important to me to know my patient's desires, beliefs and preferences with respect to his/her medical condition.	26.
56 (62.2%)	25 (27.8%)	9 (10.0%)	It is my opinion that an open end-of-life conversation and fulfilling the patient's Advance Medical Directives makes it easier to opt for the palliative care approach over the aggressive treatment approach.	27.
59 (65.6%)	27 (30.0%)	4 (4.4%)	An open end-of-life conversation and fulfilling the patient's Advance Medical Directives makes it likely that most patients will opt to die at home and not in hospital.	28.
77 (85.6%)	11 (12.2%)	2 (2.2%)	Every patient has the right to know how terminal their condition is and to have their Advance Medical Directives respected.	29.
72 (80.0%)	14 (15.6%)	4 (4.4%)	I prefer to be told all the details of a patient's personal story.	30.
52 (57.8%)	27 (30.0%)	11 (012.2%	I think the quality of life of a patient who knows what his/her condition is higher than that of a patient who does not know.	31.
72 (80.0%)	15 (16.7%)	2 (2.2%)	If I myself had a life-threatening illness I would ask to be told the full truth about my condition.	32.
52 (57.8%)	25 (27.8%)	13 (14.4%)	Non-referral to hospice care can sometimes be the result of not knowing that option exists.	33.
60 (66.7%)	18 (20.0%)	12 (13.3%)	An end-of-life conversation with the patient raises the issue for us of our own death.	34.
53	23	14	An end-of-life conversation with the patient is	35.

(58.9%)	(25.6%)	(15.6%)	frightening because it makes us think about pain, suffering and loss of control.	
52 (57.8%)	31 (34.4%)	7 (7.8%)	I accept death as part of life and so have no problem talking to patients about their condition.	36.
65 (72.2%	15 (16.7%)	8 (8.9%)	I fear that referring a patient to hospice care accelerates their death.	37.

Table 4.12 shows how fearful and conflicted doctors are over telling their patients the truth about their condition.

Analysis of the quantitative questionnaire responses

- Almost every doctor agreed *in principle* that it was important to empower patients by giving them information about changes in treatment goals, but *in ward practice* did not always observe this principle. In practice almost 80% of doctors gave their patients partial information only.
- Only 54% of the doctors agreed that "Terminally-ill patients should get palliative care in the last 6 months of their life" (core to the 2005 Act).
- Every doctor thought it another doctor's job to inform the patient of a change in treatment site and goals, with the result that patients lost the chance to get palliative care at the correct juncture.
- Almost every doctor agreed that often it was the family that was the main obstacle to referring a patient to hospice care". Yet the Act lays down that the family has no right to prevent a doctor discussing care options with a cognitively competent patient.
- Almost 70% of doctors agreed *in principle* that "A multiplicity of treatment options is an obstacle [sic!] to holding a conversation with the patient about EOL and a change in treatment goals".
- Over 75% of doctors stated that "Disclosing the truth to the patient can cause me embarrassment and unease at how they will react" and over 85% said that it caused them fear. Over 77% were also of the opinion that "concealing information from the patient can sustain his/her hope and prevent harm". Yet the 2005 Act requires that all patients be fully explained their treatment options.
- The doctors' fear of ethical, social and religious issues deterred them from opening EOL conversations with the patient and two-thirds of doctors agreed that "An EOL conversation with the patient raises the issue for us of our own death". Other declared obstacles to opening an EOL conversation were the doctors' "limited ability to predict

when a patient will die, their "lack of time" and their "lack of communication skills training".

- Further, only 37% of doctors frequently encouraged their terminally-ill patients to draw up Advance Medical Directives. Yet over 85% of doctors agreed that "Every patient has the right to…have their Advance Medical Directives respected". We see repeatedly a wide gap between declared principles and behavior in practice.
- 72% of doctors agreed that they "fear that referring a patient to hospice care accelerates their death". This is clearly a serious roadblock to referrals to hospice care. What the doctors may in fact be afraid of, without admitting it in so many words, is euthanasia.
- No more than 29% of doctor-respondents were confident that they had mastered the provisions of the Terminally-Ill Patients Act**.** This highlights that doctors' uninformedness is an obstacle to patients' drawing up AMDs and being referred to hospice care. 61% of doctors felt confused as to EOL care terminology, unable to distinguish accurately between 'hospice care', 'terminal care', 'palliative care' and 'supportive care'.
- 80% of doctors stated that "I do not see that there is a clear national/organizational agenda on palliative care".

Part 2: Findings from the Qualitative Data Analysis

The following five themes emerged most prominently from these in-depth interviews:

1. Awareness of the Act's provisions and of the importance of its implementation

100% of doctor-respondents reported only superficial knowledge of the Act and inadequate mastery of its detailed provisions. Their knowledge of it came from study days or was picked up by the way. Most doctors reported that they were not in a position to initiate an EOL conversation with a patient because the Act was not clear enough on when curative treatment should give way to EOL care.

2. DRAWING UP AMDs AND THE TRANSITION TO PALLIATIVE CARE

80% of doctors reported difficulty in drawing up AMDs because of the sensitivities involved. Many of them stated their preference that AMDs be drawn up during hospital inpatient care. 20% of these latter were home care specialists for whom AMDs were especially important.

3. THE COMMUNICATION SKILLS NEEDED

As to what communication skills would make it easier to transfer patients to hospice care and get AMDs drawn up, the doctors cited the following:

- 75%--Medical training which teaches communication skills;
- 72%--The ability to explain a shift in the objective of care and treatment, not only a procedure's percentage success;
- 70%--The ability to put questions and to negotiate;
- 66%--Instruments for managing EOL conversations;
- 55%--Listening skills;
- 30%--Confidence in the way one practises medicine, not necessarily in one's medical knowledge;
- 20%--Self-awareness.

4. BARRIERS TO THE IMPLEMENTATION OF THE TERMINALLY-ILL PATIENTS ACT
    - 80%--Palliative care is not taught in basic medical training;
    - 75%--Doctors are inadequately trained in the Act, they lack basic knowledge;
    - 62%--The Ministry of Health's position on the matter is unclear;
    - 55%--Halting curative treatment is perceived as taking away the patient's hope;
    - 45%--Higher budgets for palliative care beds, staff, and training;
    - 45%--Medical staff delay too long the decision on transfer to palliative care;
    - 35%--The doctor's fear of death and sense of professional failure;
    - 30%--The patient's family; their values and religious beliefs.
5. ETHICAL ISSUES IN THE ACT'S IMPLEMENTATION

Asked how they dealt with ethical issues when they arose in practice:

- 66%, i.e. all family doctors and oncologists, responded by avoiding them;
- 33%--Home care specialists (and only home care specialists) were unafraid to face up to whatever occurred.

CHAPTER V: DISCUSSION

Four hypotheses were proposed at the outset of the research and the materials of this Discussion chapter are set out in accordance with these hypotheses. The chapter includes both the researcher's own views and the main themes featuring in the debate in the published literature. In this summary only the researcher's views are given.

Hypothesis (a): *Barriers will be found, set in physicians' daily practice, to the referral of patients to palliative care (PC).*

The study identified many barriers to the implementation of the 2005 Act and the referral of terminally-ill patients to PC. Some of the barriers were indeed "*set in physicians' daily practice*", others were inbuilt into the structure of the Israeli healthcare system or the culture and beliefs of the system's consumers. *The barriers set in physicians' daily practice were*: not giving patients full information about their condition and treatment options; avoiding EOL conversations (perceived obstacles to opening an EOL conversation were a lack of knowledge about palliative care and uninformedness about the 2005 Act; limited ability to predict when a patient will die; lack of time; lack of communication skills); doctors' negative beliefs about and prejudice against palliative care; lack of multidisciplinary teamwork; doctors' widespread ignorance of the requirements of the 2005 Act and their ;negative assessment of what they did know; doctors' widespread avoidance of persuading patients to issue Advance Medical Directives. *The systemic and cultural barriers identified were*: Patients and their families who did not want the patient told the full truth or hear the word 'hospice', or who were in denial; Infrastructure shortcomings; medical training (Palliative care is not taught in basic medical training).

Despite the 2005 Act PC is yet to be generally perceived in Israel as an integral component of EOL care, even though PC services and hospice care are part of the state health-insurance-funded basket of drugs and services. Furthermore, hospice care is frequently perceived by doctors as 'hastening the end'. It is also unfortunately the case that there is a national shortage of hospice care beds. The halting of curative treatment and the transition to PC is an issue which both patients, their families and their doctors find very hard to cope with. Many doctors' medical knowledge and training often combines with their personal attitudes and beliefs to work against the transition. This makes it all the more important that the doctor share his/her knowledge (a) with the patient so that the patient can plan for the end of their life, and)b) with their colleagues on the multidisciplinary team, who may have other views. Although the 2005 Act makes the "personal physician" responsible for informing the patient of a change in treatment goals, the sensitivities and fears and ethical problems surrounding EOL issues make it best for the responsibility to be shared among the team, with their diverse range of training, points of view and approaches. The findings show that the different categories of doctor involved in EOL care—oncologist, family doctor and hospice home care specialist—cannot agree on which of them bears the responsibility for opening an EOL conversation. Patients, however, are agreed in expecting that the oncologist will do it. This is especially true if the patient has been and is now in long-term hospital inpatient care.

The deficiencies in providing dying patients the quality and place of death they would prefer threaten to become a national issue of disrespect for patients' and families' wishes for death with dignity. Part of the problem is that Israel is very much a multicultural society. If PC is to expand it has to find a way to adapt its principles to divergent cultural and religious beliefs, practices and customs.

Hypothesis (a) was fully confirmed.

Hypothesis (b): *The barriers to referring terminally-ill patients to palliative care and implementing the 2005 Act will be found to be associated with physicians' knowledge of, attitudes to and beliefs about PC, the 2005 Act, and related issues.*

The first key finding in relation to this hypothesis is that the more the professionals know of the provisions of the Terminally-Ill Patients Act, 2005, and their connection to the implementation of palliative care (a) the more they want to implement the Act's provisions and refer patients to hospice care and (b) the more they appreciate the importance of telling their patients the truth about their medical condition. It goes almost without saying that doctors who have taken specific training in the 2005 Act have much deeper knowledge of the Act than doctors who have not had such training. A second key finding is that the more professionals know about the 2005 Act and the various aspects of palliative care, the more positive are their attitudes to palliative care and its components. It would seem that it is harder to use training to alter doctors' attitudes than to increase and improve their knowledge. Among the negative attitudes among doctors which act as a barrier to the greater utilization of PC are (a) most doctors' belief that "concealing information from the patient can sustain his/her hope and prevent harm"; that "A multiplicity of treatment options is an obstacle to holding an EOL conversation; and their "fear that referring a patient to hospice care accelerates their death". What the doctors may in fact be afraid of, without admitting it in so many words, is euthanasia.

Doctors report a moderate level of knowledge about the 2005 Act but an even less positive evaluation of the Act as a whole and the advantages of its implementation. They also report a moderate level of knowledge about the ethical issues associated with that implementation but a slightly more positive evaluation of those issues. It is evident that some barriers to the implementation of the 2005 Act are rooted in the doctors' knowledge, or lack of knowledge, about PC and the 2005 Act's provisions, in their confidence that the Act can help them take difficult decisions, in their communication skills, in their suspicion that transferring a patient to PC is sentencing them to euthanasia, and in their confusion between key terms and concepts relevant to EOL care. And the end result of all these negative attitudes and beliefs is to delay or entirely prevent the referral of terminally-ill patients to PC.

Hypothesis (b) was confirmed.

Hypothesis (c): *Physicians' attitudes and beliefs about PC, the 2005 Act and related issues will be found to be associated with their training in PC, its legislation and related skills.* The findings indeed show that not only did doctors trained in palliative care have considerably more knowledge than doctors without this training about transitioning to palliative care, about the contents of the Terminally-Ill Patients Act, and about the ethical issues associated with the Act, but that they were, overall, more positive in their attitudes to palliative care. Further, doctors trained in the 2005 Act also scored higher than doctors without this training on *attitudes* on every PC variable tested for.

Since 2005 the Israeli healthcare system has been making an effort to improve its medical training but current training programmes still need to be investigated to see what is available and what still absent. New graduates are very soon involved in clinical care, of which the care of terminally-ill patients will be part. But only a small minority of them will have been trained for this element of their daily ward practice, a deficiency which will show itself in their management of pain, in knowing when to open an EOL conversation and when to refer a patient to hospice care, and so on. 93% of the doctor-respondents in the present study felt that their "lack of communication skills training is an obstacle to holding EOL conversations". It is clear that EOL training is more conspicuous by its absence than presence and that what does exist is not powerful enough to alter entrenched attitudes. Hypothesis (c) was confirmed.

Hypothesis (d): *The referral of patients to PC will be found associated with their physicians' manner of decision-making about patient treatment methods, and in particular with their sharing of information with the patient.*

No less than 78% of doctor-respondents admitted giving their patients only partial information about their medical condition 'in order to keep their hopes up'. The findings relevant to Hypothesis (d) are the following:

- The more doctors knew about when to start palliative care the more positive their attitudes to telling patients the truth.

- The more doctors knew about telling patients the truth the more positive their attitudes to doing so.
- Family doctors and hospice home care specialists had a markedly more positive attitude to telling patients the truth than oncologists. It is plausible that doctors who worked more with patients in the outside world had greater respect for them and their rights than hospital oncologists, who were more concerned with their own professional difficulties.
- Doctors who decided alone about choice of treatment methodology, or who allowed the patient to decide after consultation between patient and doctor, had more knowledge about telling patients and their family the truth than doctors who were accustomed to let the patient decide alone.

A patient suffering from a life-threatening illness requires and deserves full, accurate and honest information about his/her condition but the findings show that relatively few patients get this. Open and candid communication with the patient is the heart and soul of palliative care and the basis of doctor-patient trust. It is the patient's right to choose how they will be treated (or not) and how they will die. It is their right to issue Advance Medical Directives. If they are not given full information about their medical condition and the options available to them, they cannot decide if they want curative treatment 'to the bitter end' or prefer the dignity of hospice care. For the aim of PC is to prevent unnecessary suffering and to provide maximum quality of life.

Empathic and compassionate communication with the patient requires from the attending physician not only the readiness and skills for this difficult task but a considerable degree of self-awareness. He/she must be willing to listen to the patient's views, fears and preferences for their future care and treatment. Despite all the difficulties of such communication it is an established finding that this removal of uncertainties in the end brings the patient and their family more calm and satisfaction. Effective communication which makes a point of being patient- centered and sharing decision-making between patient and doctor not only minimises uncertainties, it also reduces conflict and makes for better EOL choices.

Truth telling by the physician is an absolutely core requirement for the patient's informed choice-making and good EOL planning. The frequent claim by oncologists in general and the oncologist-respondents in the present study in particular that the whole truth is liable to harm the patient is in the majority of cases incorrect. Most patients prefer the truth and want it undecorated by euphemism and medical jargon. They want to talk about their quality of life and the circumstances of their death. Yet truth-telling in general and breaking bad news in particular is a source of painful anxiety to physicians, and shying away from this anxiety is one of the reasons for their tendency to avoid EOL conversations and take care and treatment decisions alone. This in turn means that relatively few patients draw up AMDs, or discuss the option of hospice care or their place of death. It follows from this that the holding of EOL conversations is critical for one of the core ethical pillars of modern medicine, which is the autonomy of the patient. The concept of Shared Decision-Making (SDM) is vital to EOL care and treatment, as well as helping the physician share the responsibility for treatment choices. It is also known that terminally-ill patients who have been allowed the option of SDM tend to choose PC over aggressive curative treatment, and hospice care over hospital care.

According to the findings of the present study two decision-making strategies were predominant—the doctor deciding alone about choice of treatment methodology and the doctor allowing the patient to decide after doctor- patient consultation. In the one the attending physician controlled the truth and what was shared with the patient, in the second decision-making was regularly shared. But the study's findings also make it clear that for terminally-ill patients the oncologist—even with his/her fears, anxieties and prejudices—remains the key figure. It is clear that before truth telling and breaking bad news in the proper manner and at the proper time can become the norm oncologists need long-term training in communication with patients and in teamwork with their multidisciplinary colleagues.

Hypothesis (d) was confirmed.

Ajzen's Theory of Planned Behavior

This section explains the Ajzen theory and then discusses how far the theory fits the empirical findings of the present study. It concludes that the theory predicts that doctors would tend to neglect the provisions and recommendations of the 2005 Act and that most terminally-ill patients would therefore not be referred to palliative care.

In light of such a gloomy conclusion the only obvious recourses are (a) to work on doctors' attitudes though their training and education and (b) deploy the different understanding and skills of nurses, social workers, counselors and other colleagues on the doctors' multidisciplinary team to, firstly, relieve them of the burden of exclusive responsibility, and, secondly, to counter the doctors' negative evaluation of palliative care. Training has not been very successful so far in changing entrenched medical thinking. The inner world of oncologists and other doctors needs to be thoroughly investigated as regards their perceptions of death and of dying patients. The expansion of the provision of hospice care beds and facilities would also help to modify doctors' subjective norms.

It is also still true, in the main, that patients and their families accept and respect the authority, views and decisions of their doctors, so that pressure in favour of hospice care is unlikely to come from the direction of the patient. However, within the ranks of the medical profession itself there is a group of doctors and oncologists who believe in Shared Decision-Making and in sharing the full range of treatment options with the patient. They are less committed to their own authority and more open to taking the time to listen to the patient. Perhaps their influence could in some way be turned on their colleagues.

Chapter VI: CONCLUSIONS AND CONTRIBUTIONS

A. Conclusions

1. National provision and awareness of palliative care

It is evident from the findings that the application of PC in Israel is still limited by a general failure to implement the 2005 Act. The WHO's Public Health Model for integrating palliative care into society requires clear national policy, adequate drug availability, the education and training of health workers and the general public, and the provision of more facilities and services. In Israel all this is the responsibility of the Israel Ministry of Health. Thus, the first major conclusion is that little will improve in the provision of PC in Israel until the Ministry of Health commits itself actively to that goal.

2. Medical training and education

The content and teaching methods of current PC training programmes need to be reviewed. Learning communication skills will not be enough on its own to change the attitudes absorbed by doctors during clinical training. Doctors need to start asking themselves why they hold the attitudes they do and whether they are the ones most suited for their patients' welfare. Training will optimally cover the following elements: knowledge and understanding; skills and competencies; attitudes and professional behavior; personal and professional development.

3. The role and responsibilities of the hospital oncologist

The Ministry of Health must make it clear to hospital oncologists that a key component of their responsibility as the chief provider of care and treatment to terminally-ill patients is their duty from beginning to end to maintain regular and open communication with patient and family and build up relations of trust so that, at the required moment, they, the doctor, are in a position to open an EOL conversation. In that conversation they must be equipped to, if necessary, persuade/inform the patient and family that treatment goals have to change from cure to palliation and preparation for death. To achieve this trust and open communication truth-telling is a sine qua non.

4. The multidisciplinary care team

One resource which already exists but which is under-exploited by oncologists to help them with the above-mentioned responsibilities is the multidisciplinary care team. Oncologists need to understand the roles/contributions of other disciplines and the advantages of the interdisciplinary approach in health care.

5. Continuity of care

Operational methods need to be devised to ensure the continuity of care between hospital and community-sited facilities, including hospice care and home care.

B. Contributions made by this study

It is claimed that the contributions to knowledge made by this study are universal because the issues are similar all over the world.

Doctors' attitudes: The negative attitudes of doctors (and the general public) and their cure-oriented training is as big a barrier to the expansion of PC as any other.

Oncologist as 'commander': Leaving the oncologist in sole charge of hospital-sited EOL care is a recipe for failure in terms of fulfilling the necessary role of PC. The physicians interviewed for the present study themselves admitted to being untrained in team-working.

Medical training: The present study has made very clear that to date, all efforts to use training to modify doctors' attitudes—and hence practice—in the areas of palliative care have met with little success. The effectiveness of even the modified training approaches attempted and proposed is untested and unproven. Additional research is therefore urgently required as to how this modification can be achieved (see *Research Follow-Up* below).

The effectiveness of the 2005 Act: The findings of the present study show convincingly that passing legislation is one thing and getting it implemented in daily practice is quite another. To date, almost a decade on from the coming into effect of the legislation, the hopes invested in it have been largely dashed. The findings of the present study show that the responsibility for this state of affairs can be attributed to three factors. Firstly, the Act itself, argue oncologists, does not provide them a clear and precise enough framework for their care and treatment of terminally-ill patients. Secondly, doctors admit to not having familiarized themselves with the Act in any depth. Thirdly, this very semi-ignorance of the medical profession points to the Israel Ministry of Health not having made sufficient efforts to ensure that the Act is both implemented and implementable.

Action recommendations submitted to Israel Ministry of Health

With the aim of having the findings of the present study applied to current practice a multidisciplinary panel was appointed (including the researcher) to submit recommendations for action to the Israel Ministry of Health. The panel drew up the following recommendations:

1. To prevent doubt and speculation as to which doctor has what responsibility it should be clearly defined which doctor has overall charge of the patient's care and treatment.
2. The breaking of the bad news to the patient that he/she is terminally-ill is an extremely painful task and one which requires relations of trust between doctor and patient. It is our opinion that the task of breaking the bad news should be given to the hospital specialist who has been treating the patient's illness.
3. According to doctors the 2005 Act's definition of a 'terminally-ill patient' is insufficiently clear. The Ministry of Health must therefore revisit and review the current definition. We also propose that further emphases and modifications be introduced into the Act so as to eliminate uncertainties in its interpretation.
4. <u>Training for doctors in the 2005 Act</u>

There are many doctors who have not made even a basic study of the Act and these are doctors who work in almost daily contact with the issues of the care and treatment of dying patients:

   1. The Ministry of Health should require (and enforce) doctors to take periodic short study courses and/or longer training programs in the implementation of the Act.
   2. The Ministry of Health and institutes of higher education must introduce changes into the core medical training program which will make palliative care an integral element of medical education, raise doctors' awareness and knowledge of it and teach the necessary skills at an early stage in their career.

5. <u>Ensuring continuity of care and information between hospital and community</u>
   1. The Ministry of Health should set up a computerized databank of patient information accessible to all formal community carers, who would all have the right to add data in order to keep a patient file up to date.
   2. Updating a patient's file with respect to the determination of his/her status as a terminally-ill patient shall be carried out by a multidisciplinary team, comprising doctor, nurse and social worker.
   3. We propose that all formal carers maintain joint medical records so as to expand the drawing up of Advance Medical Directives and that all carer-patient

communications be also recorded in order to make it easier for patients to make treatment choices.

Issues and subjects for research follow-up

- The PC-related behavior and beliefs of the categories of doctors' not selected to participate in the present study.
- Attitude modification in the medical profession.
- The negative attitudes of patients and families to palliative care (actual and anticipated) and how these attitudes might be educated.
- When doctors were asked *in principle* what they felt about referring patients to PC many expressed support for PC but *in practice* felt strongly constrained by a number of obstacles. This gap and these obstacles need exploration.
- Doctors' own attitudes to and fears and beliefs about death.

Methodological limitations of the present study

- The first limitation is that death and dying are taboo subjects in Israeli society and hard to talk about.
- Sample size and composition: the sensitivity and complexity of the research topics made it hard to recruit research participants.
- The notion of investigating whether doctors are carrying out their legal duties is new, in Israel at least. The questions the researcher wished to put could also be interpreted as an invasion into the privacy of a doctor's personal beliefs, feelings and attitudes. Most objectionable of all, they could be taken as an examination of the doctor's level of professional knowledge—of both palliative care and the 2005 Act—and that by a fellow professional.
- A fourth source of difficulty is the issue of national medical policy—who makes it? The Israeli government drew up and passed into law a very serious and complex piece of legislation to regulate the care and treatment of dying patients. But in hospital wards up and down the country daily practice is very different from that prescribed by the legislation.

REFERENCES

1. Johnson, R. B., Onwuegbuzie, A. J. & Turner, L. A. (2007). Towards a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.
2. Golafshani, N. (2003). *Understanding Reliability and Validity in Qualitative Research*, 8(4), 597–606.
3. Ahluwalia, S. C., Levin, J. R., Lorenz, K. A, & Gordon, H. S. (2012). Missed opportunities for advance care planning communication during outpatient clinic visits. *Journal of General Internal Medicine*, 27(4), 445–51. doi:10.1007/s11606-011-1917-0
4. Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50, 179–211.
5. Ajzen, I. (2006). *Constructing a TPB Questionnaire: Conceptual and Methodological Considerations*. Retrieved June 27, 2011 from the World Wide Web: http://www.people.umass.edu/aizen/pdf/tpb.measurement.pdf.
6. Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice-Hall.
7. American College of Physicians (1998). Ethics Manual. 4th Ed. *Annals of Internal Medicine*, (128), 576–594.
8. Anthony, L.B; Robert, M. A; Walter, F.B; James, A.T;& Kelly , F.E. (2005). Approaching Difficult Communication Tasks in Oncology. *Cancer Journal for Clinicians*, 55,164–177.
9. Asch , D.A., Faber-Langendoen, K., Shea, J.A.,& Christakis, N.A.(1999). The sequence of withdrawing life-sustaining treatment from patients. *American Journal of Medicine*, (107),153–156.
10. Baile, W. F., Palmer, J. L., Bruera, E., & Parker, P. A. (2011). Assessment of palliative care cancer patients' most important concerns. Supportive care in cancer: *Official Journal of the Multinational Association of Supportive Care in Cancer*, 19(4), 475–81.
11. Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Hull, J. G., Tosteson, T. D., et al. (2013). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer. *JAMA*, 302(7),741-749.

12. Baughman, K. R., Ludwick, R. E., Merolla, D. M., Palmisano, B. R., Hazelett, S., Winchell, J., & Hewit, M. (2012). Professional judgments about advance care planning with community-dwelling consumers. *Journal of Pain and Symptom Management*, 43(1), 10–9. doi:10.1016/j.jpainsymman.2011.03.023.
13. Bell, C. L., Somogyi-Zalud, E., & Masaki, K. H. (2010). Factors associated with congruence between preferred and actual place of death. *Journal of Pain and Symptom Management*, 39(3), 591–604. doi:10.1016/j.jpainsymman.2009.07.007
14. Bharadwaj, P., Shinde, A., Lill, M., & Schwarz, E. R. (2011). Palliative care: it is time to move toward a comfort and cure model. *Journal of Palliative Medicine*, 14(10), 1091–3. doi:10.1089/jpm.2011.9645
15. Black, K. (2007). Health care professionals' death attitudes, experiences, and advance directive communication behavior. *Death studies*, 31(6), 563–72. doi:10.1080/07481180701356993
16. Block, S. D., & Sullivan, a M. (1998). Attitudes about end-of-life care: a national cross-sectional study. *Journal of Palliative Medicine*, *1*(4), 347–55. doi:10.1089/jpm.1998.1.347
17. Bowen, A. G. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative methods*, 5(3), Article 2. URL: http://www. ual-berta.ca/~ijqm.
18. Bradley, E. H., Cramer, L. D., Bogardus, S. T., Kasl, S. V, Johnson-Hurzeler, R., & Horwitz, S. M. (2002). Physicians' ratings of their knowledge, attitudes, and end-of-life-care practices. *Academic Medicine : Journal of the Association of American Medical Colleges*, *77*(4), 305–11
19. Braun, M., Gordon, D., & Uziely, B. (2005). Associations between oncology nurses' attitudes toward death and caring for dying patients. Oncology Nursing Forum37(1), , 43–50.
20. Bruera, E., & Hui, D. (2010). Integrating supportive and palliative care in the trajectory of cancer: establishing goals and models of care. *Journal of Clinical Oncology*: official journal of the American Society of Clinical Oncology, 28(25), 4013–7. doi:10.1200/JCO.2010.29.5618
21. Bruera, E., Control, S., Care, P., & Cancer, M. D. A. (2000). Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Journal of Palliative Medicine*, 2163(00), 287–298.

22. Bruera, E., Neumann,C. M., Mazzocato, P., & Stiefel, F. (2000). Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliative Medicine*,14, 287–298.
23. Bryman, A. (2008). *Social research methods* (3rd ed.). Oxford: Oxford University Press.
24. Byock, I.,R .(1996). The nature of suffering and the nature of opportunity at the end of life. *Clinical Geriatric Medicine*,(12), 237-252.
25. Callaway, C. (2012). Timing is everything: When to consult palliative care. *Journal of the American Academy of Nurse Practitioners*, (24), 633–639. doi:10.1111/j.1745-7599.2012.00746.x
26. Casarett, D. J., & Quill, T. E. (2007). " I ' m Not Ready for Hospice ": Strategies for Timely and Effective Hospice Discussions, *Annals of Internal Medicine Academia and Clinic* 146(6).
27. Casey, D., Murphy, K., Ni Leime, A., Larkin, P., Payne, S., Froggatt, K. a, & O'Shea, E. (2011). Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland. *Journal of Clinical Nursing*, 20(13-14), 1824–33. doi:10.1111/j.1365-2702.2010.03628.x
28. Chan, A.,& Woodruff, R.K.(1997): Communicating with patients with advanced cancer .*Journal of Palliative Care,* 13(3),29-33.
29. Rj, C., & Webster, J. (2013). End-of-life care pathways for improving outcomes in caring for the dying. The Cochrane Collaboration and published in The Cochrane Library 2013, Issue 11.
30. Chou, W.-C., Hung, Y.-S., Kao, C.-Y., Su, P.-J., Hsieh, C.-H., Chen, J.-S., Liau, C.-T., et al. (2013). Impact of palliative care consultative service on disease awareness for patients with terminal cancer. Supportive care in cancer: *Official Journal of the Multinational Association of Supportive Care in Cancer*. doi:10.1007/s00520-013-1733-7
31. Ciałkowska-Rysz, A., & Dzierżanowski, T. (2013). Personal fear of death affects the proper process of breaking bad news. *Archives of Medical Science*, 9(1), 127–31. doi:10.5114/aoms.2013.33353
32. Clarke, A,.& Ross, H. (2006) .Influences on nurses' communications with older people at the end of life: perceptions and experiences of nurses working in palliative care and general medicine. *International Journal of Older People Nursing*, (1), 34–43.

33. Clayton, J. M., Adler, J. L., O'Callaghan, A., Martin, P., Hynson, J., Butow, P. N., … Back, A. L. (2012). Intensive communication skills teaching for specialist training in palliative medicine: development and evaluation of an experiential workshop. *Journal of Palliative Medicine*, 15(5), 585–91. doi:10.1089/jpm.2011.0292
34. Clayton, J.M., Butow, P.N., Arnold, R.M., & Tattersall, M.H. (2005). Discussing end-of-life issues with terminally ill cancer patients and their carers: A qualitative study. *Supportive Care in Cancer*, 13, 589–599. doi:10.1007/s00520-004-0759-2
35. Clayton, J.M., Butow, P.N., Tattersall, M.H.N., Devine, R.J., Simpson, J.M., Aggarwal, G., . . . Noel, M. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, 25, 715–723.
36. Cohen, A., & Nirenberg, A. (2011). Current practices in advance care planning: implications for oncology nurses . *Clinical Journal of Oncology Nursing* ,15(5), 547–554.
37. Callahan, M. F., Breakwell, S., & Suhayda, R. (2011). Knowledge of palliative and end-of-life care by student registered nurse anesthetists. *AANA Journal*, *79*(4 Suppl), S15–20. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22403962
38. Costello , J. (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35, 59–68.
39. Creswell, J. W. & Plano-Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks: Sage Publications.
40. Creswell, J. W. (2003). *Research design : qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, Calif., Sage Publications.
41. Dahlin, C.M. (2010). Communication in palliative care: an essential competency for nurses. In: Ferrell BR, Coyle N, eds. *Oxford Textbook of Palliative Nursing*. 3rd ed. New York, NY: Oxford University Press;107–133.
42. Dalal, S., Palla, S., Hui, D., Nguyen, L., Chacko, R., Li, Z., Fadul, N., et al. (2011). Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *The Oncologist*, 16(1), 105–11. doi:10.1634/theoncologist.2010-0161
43. Davis, D., O'Brien MA, Freemantle N, et al.(1999).Impact of formal continuing medical education:do conferences, workshops, rounds, and other traditional continuing

education activities change physician behavior or health care outcomes?.*JAMA* ,282,867– 874.

44. de Veer, A.J., Francke, A.L., &Poortvliet, E.P. (2008). Nurses' involvement in end-of-life decisions. *Cancer Nursing*, 31, 222-228. doi: 0.1097/01.NCC.0000305724.83271.f9
45. Denzin, N. K., & Lincoln, Y. S. (2000b). Introduction: The discipline and practice of qualitative research. In: N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 1-28). Thousand Oaks, CA: Sage.
46. Denzin, N. K., & Lincoln, Y. S. (Eds.), (2002). *The Qualitative Inquiry Reader*. Thousand Oaks, CA: Sage
47. Denzin, N. K., & Lincoln, Y. S. (Eds.). (2000a). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage
48. Di Leo, S., Beccaro, M., Finelli, S., Borreani, C., &Costantini, M. (2011). Expectations about and impact of the Liverpool Care Pathway for the dying patient in an Italian hospital. *Palliative Medicine*, 25(4), 293–303. doi:10.1177/0269216310392436
49. Douglas, R., & Brown, H.N. (2002). Patients’ attitudes toward advance directives. *Journal of Nursing Scholarship*, 34(1), 61–65.
50. Dow, L.A., Matsuyama, R.K., Ramakrishnan, V., Kuhn, L., Lamont, E.B., Lyckholm, L., & Smith, T.J. (2010). Paradoxes in advance care planning: The complex relationship of oncology patients, their physicians, and advance medical directives. *Journal of Clinical Oncology*, 28, 299–304. doi:10.1200/JCO.2009.24.6397
51. Drought, T.S., & Koenig, B.A.(2002) .‘Choice’ in end-of-life decision making: researching fact or fiction? *Gerontologist*, 42(Spec. no 3), 114–128.
52. Eliott, J. A., & Olver, I. (2011). Dying cancer patients talk about physician and patient roles in DNR decision making. *Health Expectations*: an international journal of public participation in health care and health policy, 14(2), 147–58. doi:10.1111/j.1369-7625.2010.00630.x
53. Fallowfield, L.J.& Clark A.W.(1994). Delivering bad news in gastroenterology. *American Journal of Gastroenterology*, 89, 473–79.
54. Fallowfield, LJ, Lipkin M, Hall A.(1998). Teaching senior oncologists communication skills: results from phase 1 of a comprehensive longitudinal program in the UK. *Journal of Clinincal Oncology*, 16, 1961.

55. Fallowfield, L. J., Jenkins, V. A, & Beveridge, H. A. (2002). Truth may hurt but deceit hurts more: communication in palliative care. *Palliative medicine*, 16(4), 297–303
56. Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *Lancet*, 363(9405), 312–9.
57. Fawole, O. A, Dy, S. M., Wilson, R. F., Lau, B. D., Martinez, K. A, Apostol, C. C., … Aslakson, R. A. (2013). A systematic review of communication quality improvement interventions for patients with advanced and serious illness. *Journal of General Internal Medicine*, 28(4), 570–7. doi:10.1007/s11606-012-2204-4
58. Ferris, F. D., Bruera, E., Cherny, N., Cummings, C., Currow, D., Dudgeon, D., Janjan, N., et al. (2009). Palliative cancer care a decade later: accomplishments, the need, next steps. *Journal of Clinical Oncology,* 27(18), 3052–8.
59. Fine, E., Reid, M. C., Shengelia, R., & Adelman, R. D. (2010). Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. *Journal of Palliative Medicine*, 13(5), 595–603. doi:10.1089/jpm.2009.0388
60. Fineberg, I. C., Wenger, N. S., & Forrow, L. (2004). Interdisciplinary education: evaluation of a palliative care training intervention for pre-professionals. *Academic Medicine : Journal of the Association of American Medical Colleges*, *79*(8), 769–76. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15277134
61. Finestone, A. J., & Inderwies, G. (2008). Death and dying in the US: the barriers to the benefits of palliative and hospice care. *Clinical Interventions in Aging*, 3(3), 595–9.
62. Fischer, S. M., Gozansky, W. S., Kutner, J. S., Chomiak, A., & Kramer, A. (2003). Palliative care education: an intervention to improve medical residents' knowledge and attitudes. *Journal of Palliative Medicine*, 6(3), 391–9.doi:10.1089/109662103322144709
63. Fischer, S. M., Sauaia, A., Min, S.-J., & Kutner, J. (2012). Advance directive discussions: lost in translation or lost opportunities? *Journal of Palliative Medicine*, 15(1), 86–92. doi:10.1089/jpm.2011.0328
64. Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention and behavior: An introduction to theory and research.* Reading, MA: Addison-Wesley.

65. Foley, K.M.& Gelband, H.(2001) *.Improving palliative care for cancer: summary and recommendations*. Washington DC: National Academy Press.
66. Forte, D. N., Vincent, J. L., Velasco, I. T., & Park, M. (2012). Association between education in EOL care and variability in EOL practice: a survey of ICU physicians. *Intensive Care Medicine*, 38(3), 404–12. doi:10.1007/s00134-011-2400-4
67. Gardiner, C., Gott, M., Ingleton, C., Hughes, P., Winslow, M., & Bennett, M. I. (2012). Attitudes of healthcare professionals to opioid prescribing in end-of-life care: a qualitative focus group study. *Journal of Pain and Symptom Management*, 44(2), 206–14. doi:10.1016/j.jpainsymman.2011.09.008
68. Gaston, C., & Mand, M .G.(2005). Information giving and decision-making in patients with advanced cancer: A systematic review. *Social Science and Medicine*, 61: 2252–2264.
69. Gaveton, D. (2001). Grounded theory: the meaning of data analysis and theory construction in qualitative research. In: Tsabar- Ben Joshua, N. (ed.) (2001) *Traditions and schools in qualitative research* (pp. 195-228). Lod: Dvir.
70. General Medical Council. (2002). *Tomorrow's Doctors: Recommendations on Undergraduate Medical Education*, 2nd edn. London: GMC.
71. General Medical Council. (2009). *Tomorrow's Doctors: Outcomes and Standards for Undergraduate Medical Education*. London: GMC.
72. Gerst, K., & Burr, J.A. (2008). Planning for end-of-life care: Black-White differences in the completion of advance directives. *Journal of Aging Research*, 30, 428e449.
73. Gibbins, J., McCoubrie, R., & Forbes, K. (2011). Why are newly qualified doctors unprepared to care for patients at the end of life? *Medical Education*, 45(4), 389–99. doi:10.1111/j.1365-2923.2010.03873.x
74. Giddings, L. S. (2006). Mixed-methods research: positivism dressed in drag? *Journal of Research in Nursing*, 11(3), 195-203.
75. Gochman ,D.S. & Bonham G.S. (1988) .Physicians and the hospice decision: awareness, discussion, reasons, and satisfaction. *Hospice Journal* 4 (1), 25–53.
76. Goelz, T., Wuensch, A., Stubenrauch, S., Ihorst, G., de Figueiredo, M., Bertz, H., … Fritzsche, K. (2011). Specific training program improves oncologists' palliative care communication skills in a randomized controlled trial. *Journal of Clinical Oncology*, 29(25), 3402–7. doi:10.1200/JCO.2010.31.6372

77. Griffie J, Nelson-Marten P, Muchka S. Acknowledging the “elephant”: communication in palliative care. *American Journal of Nursing*, 2004;104:48–57.
78. Hannon, K. L., Lester, H. E., & Campbell, S. M. (2012). Recording patient preferences for end-of-life care as an incentivized quality indicator: what do general practice staff think? *Palliative Medicine*, 26(4), 336–41. doi:10.1177/0269216311406990
79. Hanson, L., Henderson ,M., & Menon, M. (2002). As individual as death itself: a focus group study of terminal care in nursing homes. *Journal of Palliative Medicine*,(5), 117–125.
80. Harrington, S. E., Smith, T. J., & Story, T. H. (2012). At the close of life: clinician's corner: the role of chemotherapy at the end of life: “When Is Enough , Enough?”.JAMA, 299(22), 2667-2678.
81. Hauser, J., Sileo, M., Araneta, N., Kirk, R., Martinez, J., & Finn, K. (2011). Navigation and Palliative Care. *Cancer*, August, 3585–3591. doi:10.1002/cncr.26266
82. Heaven C., Green, C. (2009). Good communication: patients, families and professionals. In: Walsh D. *Palliative Medcine*. Expert Consult. Elsevier Health Sciences, 613–619.
83. Higginson, I. J., & Evans, C. J. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer Journal* (Sudbury, Mass.), 16(5), 423–35. http://www.health.gov.il/LegislationLibrary/Zchuyot_01.pdf

84. Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., … Bruera, E. (2014). Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. *Journal of Pain and Symptom Management*, 47(1), 77–89. doi:10.1016/j.jpainsymman.2013.02.021
85. Hyman R.B. & Bulkin W. (1991) Physician reported incentives and disincentives for referring patients to hospice. *Hospice Journal* 6 (4), 39–64.
86. E. C., Butler, J., &Ahluwalia, J. S. (2004). Knowledge, attitudes and beliefs about end-of-life care, *Palliative Medicine* 7(2).
87. Jaarsma, T., Beattie, J. M., Ryder, M., Rutten, F. H., McDonagh, T., Mohacsi, P., Murray, S. A, et al. (2009). Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure*, 11(5), 433–43. doi:10.1093/eurjhf/hfp041
88. Jaiswal, R., Alici, Y., & Breitbart, W. (2014). A comprehensive review of palliative care in patients with cancer. *International Review of Psychiatry*, 26(1), 87–101. doi:10.3109/09540261.2013.868788
89. Jenkins VA, Fallowfield LJ, Poole K. (2001).Are members of multidisciplinary teams in breast cancer aware of each other’s informational roles? *Quality in Health Care*,10, 70–75.
90. Keating, N.L., Landrum, M.B., Rogers, S.O., Jr., Baum, S.K., Virnig, B.A., Huskamp, H.A., . . . Kahn, K.L. (2010). Physician factors associated with discussions about end-of-life care. *Cancer*, 116, 998–1006. doi:10.1002/cncr.24761
91. Kelly, K. H. & Eileen, D. H. (2010) . Helping patients with cancer prepare for hospice. *Clinical Journal of Oncology Nursing* ,12,2 ,180-188.
92. Kirk, P., Kirk, I., & Kristjanson, L. J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* (Clinical research ed.), 328(7452), 1343. doi:10.1136/bmj.38103.423576.55
93. Kissane , D., Treece , C., Breitbart, W., McKeen, N. & Chochinov, H.M . (2009) . Dignity, meaning and demoralization:Emerging paradigms in end-of-life care . In H. Chochinov & W. Breitbart (Eds). *Handbook of Psychiatry in Palliative Medicine*, (pp. 101 – 112). New York: Oxford University Press .

94. Kleja, J., Filipczak-Bryniarska, I., & Wordliczek, J. (2009). Communication in palliative care. Advances in Palliative Medicine, 8, (4),147–152.

95. Kolarik, R. C., Arnold, R. M., Fischer, G. S., & Hanusa, B. H. (2002). Advance care planning. *Journal of General Internal Medicine*, 17(8), 618–24.

96. Kutner, J. S., Chomiak, A., & Kramer, A. (2003). Palliative care education: an intervention to improve medical residents' knowledge and attitudes. *Journal of Palliative Medicine*, 6(3),391-399.

97. Lamont, E. B., & Christakis, N. A. (2002). Physician factors in the timing of cancer patient referral to hospice palliative care. *Cancer*, 94(10), 2733–2737. doi:10.1002/cncr.10530

98. Larson, D. G. (2000). End-of-life conversations: evolving practice and theory. *JAMA*, 284(12), 1573–1578. .

99. Leon, M., Florez, S., De Lima, L., & Ryan, K. (2011). Integrating palliative care in public health: the Colombian experience following an international pain policy fellowship. *Palliative Medicine*, 25(4), 365–9. doi:10.1177/0269216310385369

100. Lesley, F & Valerie, J.(2004). Communicating sad, bad, and difficult news in medicine. *The Lancet*, 363, 312–19.

101. Leung, K.-K., Tsai, J.-S., Cheng, S.-Y., Liu, W.-J., Chiu, T.-Y., Wu, C.-H., & Chen, C.-Y. (2010). Can a good death and quality of life be achieved for patients with terminal cancer in a palliative care unit? *Journal of Palliative Medicine*, *13*(12), 1433–8. doi:10.1089/jpm.2010.0240

102. Leung, K.-K., Liu, W.-J., Cheng, S.-Y., Chiu, T.-Y., & Chen, C.-Y. (2009). What do laypersons consider as a good death. *Supportive Care in Cancer*, 17(6), 691–9. doi:10.1007/s00520-008-0530-1

103. Levitzki, N. (2010). Building theory from narrative research. In: L. Katan & M. Cromer-Nevo (eds), *Analysing qualitative data*, (pp. 383-412). Be'er Sheva: Ben Gurion University Press. (in Hebrew)

104. Lincoln, Y. S. (2002). Emerging criteria for quality in qualitative and interpretive research. In: N. K. Denzin & Y. S. Lincoln (Eds.), *The Qualitative Inquiry Reader* (pp. 327-345). Thousand Oaks, CA: Sage.

105. Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions and emerging confluences. In: N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 163-188). Thousand Oaks, CA: Sage.

106. Mack, J. W., Cronin, A., Taback, N., Huskamp, H. A., & Keating, N. L. (2012). End-of-life care discussions among patients with advanced cancer: a cohort study. *Annals of Internal Medicine*; 156(3):204-210. doi:10.7326/0003-4819-156-3-201202070-00008

107. Mack, J.W., Weeks, J.C., Wright, A.A., Block, S.D., &Prigerson, H.G. (2010). End-of-life discussions, goal attainment, and distress at end-of-life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28, 1203–1208. doi:10.1200/JCO.2009.25.4672

108. Maguire, P.,, Faulkner, A., Booth, K., et al.(1996). Helping cancer patients disclose their concerns. *European Journal of Cancer*,32,78–81.

109. McCarthy EP, Phillips RS, Zhong Z, et al.(2000).Dying with cancer: patients' function, symptoms,and care preferences as death approaches. *Journal of the American Geriatrics Society*, 48, 110 –121.

110. Mccarthy, B. E. P., Burns, R. B., Davis, R. B., & Phillips, R. S. (2003). Barriers to Hospice Care Among Older Patients Dying With Lung and Colorectal Cancer, . Journal of Clinical Oncology, *21*(4), 728–735. doi:10.1200/JCO.2003.06.142

111. McGorty, E. K., & Bornstein, B. H. (2003). Barriers to physicians' decisions to discuss hospice: insights gained from the United States hospice model. *Journal of Evaluation in Clinical Practice*, 9(3), 363–72.

112. McNeilly, D.P. & Hillary K. (1997) .The hospice decision: psychological facilitators and barriers. Omega 35, 193–217. National Statistics on Death and Hospice (1994) National statistics on death and hospice. *Thanatos* 19 (3), 35.

113. Meyers-JDC-Brookdale Institute, 2005; *Report of the Palliative Care Guidelines Committee*, 2005. Jerusalem.

114. Miles, M. B. & Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook* (2nd ed.). Thousand Oaks: Sage Publications.

115. Miyashita, M., Hirai, K., & Morita, T. (2008). Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis. *Support Care Cancer*, 16,217–222 .

116. Morgan, D. L. (2007). Paradigms lost and pragmatism regained: methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, 1(1), 48-76.

117. Morita, T., Akechi, T., Ikenaga, M., Kizawa, Y., Kohara, H., Mukaiyama, T., … Uchitomi, Y. (2005). Late referrals to specialized palliative care service in Japan.

Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, *23*(12), 2637–44. doi:10.1200/JCO.2005.12.107

118. Morita, T., Akechi, T., Ikenaga, M., Kizawa, Y., Kohara, H., Mukaiyama, T., Nakaho, T., et al. (2004). Communication about the ending of anticancer treatment and transition to palliative care. *Annals of Oncology*, 15(10), 1551–7.
119. Morrison, L. J., Thompson, B. M., & Gill, A. C. (2012). A required third-year medical student palliative care curriculum impacts knowledge and attitudes. *Journal of Palliative Medicine*, 15(7), 784–9. doi:10.1089/jpm.2011.0482
120. Morse, J. (2001). Situating grounded theory in qualitative inquiry. In: R. Schriber & P. N. Stern (Eds.), *Using grounded Theory in Nursing* (pp. 1-16). New York: Springer.
121. Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A.(2005) Clinical review Illness trajectories and palliative care. *BMJ*, 330, 1007–1011.
122. Ogle, K. S., Mavis, B., & Wyatt, G. K. (2002). Physicians and Hospice Care: Attitudes, knowledge, and referrals. *Journal of Palliative Medicine*, 5(1),85-93.
123. Olson, J. M., & Zanna, M. P. (1993). Attitudes and attitude change. *Annual Review of Psychology*, 44, 1 17- 154.
124. Paice, J.A., Ferrell, B.R., Coyle, N., Coyne, P., & Callaway, M. (2008). Global efforts to improve palliative care: The International End-of-Life Nursing Education Consortium Training Programme. *Journal of Advanced Nursing*, 61, 173-180. doi: 10.1111/j.1365-2648.2007.04475.x
125. Patel, B., Gorawara-Bhat, R., Levine, S., & Shega, J. W. (2012). Nurses' attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals. *Journal of Palliative Medicine*, 15(4), 432–7. doi:10.1089/jpm.2011.0336
126. Patton, M. Q. (2002). *Qualitative Evaluation and Research Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
127. Payne, S., Seymour, J., & Ingleton, C. (2004). Palliative care nursing- Principles and evidence for practice .In M.Sneddon, *Specialist Professional Education in Palliative Care*, pp.636-654.
128. Peng, J.-K., Chiu, T.-Y., Hu, W.-Y., Lin, C.-C., Chen, C.-Y., & Hung, S.-H. (2013). What influences the willingness of community physicians to provide palliative care for patients with terminal cancer? Evidence from a nationwide

survey. *Japanese Journal of Clinical Oncology*, 43(3), 278–85. doi:10.1093/jjco/hys222

129. Peretti-Watel, P., Bendiane, M. K., Obadia, Y., Lapiana, J. M., Galinier, A, Pegliasco, H., Favre, R., et al. (2005). Disclosure of prognosis to terminally ill patients: attitudes and practices among French physicians. *Journal of Palliative Medicine*, 8(2), 280–90. doi:10.1089/jpm.2005.8.280
130. Pergert, P., & Lützén, K. (2012). Balancing truth-telling in the preservation of hope: a relational ethics approach. *Nursing Ethics*, 19(1), 21–9. doi:10.1177/0969733011418551
131. Phillips, J., Davidson ,P., Ollerton ,R., Jackson, D., & Kristjanson, L .(2007). A survey of commitment and compassion among nurses in residential aged care. *International Journal of Palliative Nursing*,(13), 282–290.
132. Pousset, G., Mortier, F., Bilsen, J., Cohen, J., & Deliens, L. (2011). Attitudes and practices of physicians regarding physician-assisted dying in minors. *Archives of Disease in Childhood*, 96(10), 948–53. doi:10.1136/adc.2009.182139
133. Ptacek , J.T., Ptacek, J.J., Ellison, N.M. (2001). “I’m sorry to tell you...” Physicians’ reports of breaking bad news. *Journal of Behavioral Medicine*,24,205–217.
134. Ptacek JT, Eberhardt TL.(1996). Breaking bad news. A review of the literature. *JAMA*, 276,496–502.
135. Quenot, J. P., Rigaud, J. P., Prin, S., Barbar, S., Pavon, a, Hamet, M., Jacquiot, N., et al. (2012). Impact of an intensive communication strategy on end-of-life practices in the intensive care unit. *Intensive Care Medicine*, 38(1), 145–52. Retrieved December 16, 2006, from http://www.nova.edu/ssss/QR/QR4-3/winter.html
136. Roberts, C.S., Cox, C.E., Reintgen, D.S., et al.(1994). Influence of physician communication on newly diagnosed breast patients’ psychologic adjustment and decision-making. *Cancer* ,74,336–341.
137. Salmond, S.W., & David, E. (2005). Attitudes toward advance di- rectives and advance directive completion rates. *Orthopaedic Nursing*, 24, 117–127. doi:10.1097/00006416-200503000-00007
138. Scarre, G. (2012). Can there be a good death? *Journal of Evaluation in Clinical Practice*, 18(5), 1082–6. doi:10.1111/j.1365-2753.2012.01922.x

139. Schapira, L., Moynihan, T. J., von Gunten, C. H., & Smith, T. J. (2009). Phase I versus palliative care: Striking the right balance. *Journal of Clinical Oncology*, 27(2), 307–308.

140. Schüklenk, U., Van Delden, J. J. M., Downie, J., McLean, S. A M., Upshur, R., & Weinstock, D. (2011). End-of-life decision-making in Canada: the report by the Royal Society of Canada expert panel on end-of-life decision-making. *Bioethics*, 25 Suppl 1, 1–73. doi:10.1111/j.1467-8519.2011.01939.x

141. Schulman–Green, D., McCorkle, R., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E.H. (2005). Nurses' communication of prognosis and implication for hospice referral: *American Journal of Critical Care*, 14, 64–70.

142. Sesterhenn, A.M., Folz, B.J., Bieker, M., Teymoortash, A., & Werner, J.A. (2008). End-of-life care for terminal head and neck cancer patients. *Cancer Nursing*, 31, E40-E46. doi: 10.1097/01.NCC.0000305709.37530.a7

143. Shetty, A. A., & Shapiro, J. (2012). How to break bad news – tips and tools for resident physicians. *Journal of Medical Education Perspectives,* 1(1), 20-23.

144. Shkedi, A. (2003). *Words that move—qualitative research, theory and practice*. Tel Aviv: Ramot Publishing. (in Hebrew)

145. Silbermann, M., Khleif, A., Tuncer, M., et al (2011). Can we overcome the effect of conflicts in rendering palliative care? An introduction to the Middle Eastern Cancer Consortium (MECC). *Current Oncology Reports*,13(4),302-307.

146. Siminoff, L.A., Rose, J.H., Zhang, A., & Zyzanski, S.J. (2006). Measuring discord in treatment decision-making; Progress toward development of a cancer communication and decision-making assessment tool. *Psycho-Oncology*, 15, 528–540.

147. Slomka, J. (2003). Withholding nutrition at the end of life. *Cleveland Clinic Journal of Medicine*, 70(6), 548–552.

148. Slort, W., Schweitzer, B. P. M., Blankenstein, a H., Abarshi, E. a, Riphagen, I. I., Echteld, M. A, … Deliens, L. (2011). Perceived barriers and facilitators for general practitioner-patient communication in palliative care: a systematic review. *Palliative Medicine*, 25(6), 613–29. doi:10.1177/0269216310395987

149. Smith, S., Kuehn, B. M., & Jr, G. W. S. (2014). ASCO : Patients With Advanced Cancer Need Advice on End-of-Life Care Options. *JAMA, 305*(12), 7–8.

150. Smith, T. J., Temin, S., Alesi, E. R., Abernethy, A. P., Balboni, T. A, Basch, E. M., Ferrell, B. R., et al. (2012). American Society of Clinical Oncology provisional

clinical opinion: the integration of palliative care into standard oncology care. *Journal of Clinical Oncology*, 30(8), 880–7. doi:10.1200/JCO.2011.38.5161

151. Stillman M.J. & Syrjala K.L. (1999) .Differences in physician access patterns to hospice care. *Journal of Pain and Symptom Management* 17, 157–163.

152. Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. *Journal of Pain and Symptom Management*, 33(5), 486–93. doi:10.1016/j.jpainsymman.2007.02.016

153. Street, A. F., & Ottmann, G. (2006). *State of the Science: Review of Advance Care Planning Models*. La Trobe University, Bundoora.

154. Sullivan, A. M., Lakoma, M. D., Billings, J. A., Peters, A. S., & Block, S. D. (2005). Teaching and learning end-of-life care: evaluation of a faculty development program in palliative care. *Academic Medicine*, 80(7), 657–68. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15980082

155. Swart, S. J., Van der Heide, A., Van Zuylen, L., Perez, R. S. G. M., Zuurmond, W. W. a, Van der Maas, P. J., Van Delden, J. J. M., et al. (2012). Considerations of physicians about the depth of palliative sedation at the end of life. *Canadian Medical Association Journal*, 184(7), E360–6. doi:10.1503/cmaj.110847

156. Sykes, N., & Thorns, A .(2003). Sedative use in the last week of life and the implications for end-of-life decision making. *Archives of Internal Medicine*, (163),341-4.

157. Symonds, J. E. & Gorard, S. (2008). *The death of mixed-methods: research labels and their casualties*. Paper presented at the British Educational Research Association Annual Conference, Heriot Watt University, Edinburgh, September 3-6, 2008.

158. Teddlie, C. & Johnson, R. B. (2009). Methodological thought since the 20th century. In: C. Teddlie & A. Tashakkori (Eds.), *Foundations of mixed methods research: integrating quantitative and qualitative approaches in the social and behavioral sciences*. Los Angeles: Sage Publications.

159. Temel, J. S., Greer, J. A, Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A, Dahlin, C. M., et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733–42. doi:10.1056/NEJMoa1000678

160. Teno, J.M., Shu, J.E., Casarett, D., Spence, C., Rhodes, R., & Connor, S. (2007). Timing of referral to hospice and quality of care: Length of stay and bereaved family

members' perceptions of the timing of hospice referral. *Journal of Pain and Symptom Management*, 34, 120–125.

161. Thalhuber ,W.H. (1995). Overcoming physician barriers to hospice care. *Minnesota Medicine* 78, 18–22.

162. Trade, I. (2011). Regulating end of life decisions in Poland: legal dilemmas. *Advances in Palliative Medicine*,(10), 49–56.

163. Tsabar- Ben Joshua, N. (ed.) (2001) Traditions and schools in qualitative research. Lod: Dvir. In: Yin, R.K. (1989) *Case study research – Design and methods*. Thousand Oaks, CA: Sage

164. Walling, A.M., Asch, S.M., Lorenz, K.A., Roth, C.P., Barry, T., Kahn, K.L., & Wenger, N.S. (2010). The quality of care provided to hospitalized patients at the end of life. *Archives of Internal Medicine*, 170, 1057–1063. doi:10.1001/archinternmed.2010.175

165. Watson, J., Hockley, J., & Dewar, B .(2006). Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing*, (12), 234–240.

166. Watts, T. (2012). End-of-life care pathways as tools to promote and support a good death: a critical commentary. *European Journal of Cancer Care*, 21(1), 20–30. doi:10.1111/j.1365-2354.2011.01301.x

167. Weber, M., Schmiedel, S., Nauck, F., & Alt-Epping, B. (2011). Knowledge and attitude of final-year medical students in Germany towards palliative care - an interinstitutional questionnaire-based study. *BMC Palliative Care*, 10(1), 19. doi:10.1186/1472-684X-10-19

168. Weggel, J.M. (1999). Barriers to the physician decision to offer hospice as an option for terminal care. *Wisconsin Medical Journal* 98, (3), 49–53.

169. Weissman, D. E., & Meier, D. E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine*, 14(1), 17–23. doi:10.1089/jpm.2010.0347

170. Weissman, D. E., & Story, T. H. (2012). Decision making at a time of crisis near the end of life. *JAMA*, 298,(14),1732-1743.

171. Wentlandt, K., Burman, D., Swami, N., Hales, S., Rydall, A., Rodin, G., … Zimmermann, C. (2011). Preparation for the end of life in patients with advanced

cancer and association with communication with professional caregivers. *Psycho-Oncology*, 876 (June 2011), 868–876. doi:10.1002/pon.1995

172. White, B. P., Willmott, L., & Ashby, M. (2011). Palliative care, double effect and the law in Australia. *Internal Medicine Journal*, 41(6), 485–92. doi:10.1111/j.1445-5994.2011.02511.x
173. Wicker, A., W. (1969). Attitudes versus actions: the relationship of verbal and overt behavioral responses to attitude objects. *Journal of Social Issues*, 25, 41–47.
174. Wilkinson, A., Wenger, N. and Shugarman,L.R. (2007). *Literature review on advance directives*, Rand Corporation, United States.
175. Winter, G. (2000). A comparative discussion of the notion of 'validity' in qualitative and quantitative research. [58 paragraphs]. *The Qualitative Report*, 4,(3/4).
176. Wittenberg-Lyles, E., Goldsmith, J., & Ragan, S. (2011). The shift to early palliative care: a typology of illness journeys and the role of nursing .*Clinical Journal of Oncology Nursing*, 15(3),304-310.
177. Woods, L.W., Craig, J.B., & Dereng, N. (2006). Transitioning to a hospice program—Identifying potential barriers to a seamless transition. *Journal of Hospice and Palliative Nursing*, 8, 103–111.
178. World Health Organisation. *National cancer control programmes: policies and managerial guidelines*. 2002. Retrieved 19 November 2003, from http://www.who.int/ cancer/media/en/408.pdf.
179. World Health Organization. (2011). *Definition of Palliative Care*. Retrieved from http://www.who.int/cancer/palliative/ definition/en..
180. Yedidia, M. J. (2007). Transforming doctor-patient relationships to promote patient-centered care: lessons from palliative care. *Journal of Pain and Symptom Management*, 33(1), 40–57.
181. Kam, L. Y. K., Knott, V. E., Wilson, C., & Chambers, S. K. (2012). Using the theory of planned behavior to understand health professionals' attitudes and intentions to refer cancer patients for psychosocial support. *Psycho-Oncology*, *21*(3), 316–23. doi:10.1002/pon.1897
182. Zeinah, G. F. A., Al-Kindi, S. G., & Hassan, A. A. (2013). Middle East experience in palliative care. *American journal of Hospice & Palliative Care*, 30(1), 94–9. doi:10.1177/1049909112439619

183. Zhang, A.Y., & Siminoff, L.A. (2003). The role of the family in treatment decision making by patients with cancer. *Oncology Nursing Forum*, 30, 1022–1028.