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END OF LIFE CARE ISSUES

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INTRODUCTION

The projection of patients' life expectancy is of the highest importance to patient's family and health care professionals, particularly in the context of serious disease. Many important health care decisions, such as those regarding chemotherapy use, hospice referral, advance care planning, discharge planning, and personal finances, are dependent on life-expectancy. The care of patients with incurable illness places a lot of stress on health professionals (both generalist and specialist). More importantly, the situation is beset by ethical issues and the element of uncertainty for patients and their family. Finally, some professional care givers do not refer patients to palliative care in time, so that the patient gets no palliative care at all.

Palliative care has been defined by the WHO as "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" (WHO, 2002).

Hence, palliative care involves prolongation of life, improvement or maintenance of function, enhancing quality of life, reducing psychological distress and relieving pain, and meticulous symptom control. Optimal care requires addressing the needs of both the patients and their informal carers. A systematic review of randomized controlled trials indicates that, compared to conventional care, specialist palliative care services improve patient and family satisfaction, reduce family anxiety, provide better pain control and symptom management, and increase the likelihood of the patient being cared for at his/her place of choice.

Patient referral to palliative care depends on local legislation, caregiver attitudes and perceptions, professional training and the availability of

hospital beds for patients suffering from terminal illnesses, such as end-stage cancer, lung disease, renal disease or neurological disease. In a recent survey palliative care specialist ranked highly the terms 'end of life', 'terminally ill', 'terminal care', 'active dying', and 'transition of care' in regard to both their frequency of use and the relative importance. A better understanding of the defining features and concepts for these five terms could help to standardize them and thus improve communication among clinicians, researchers, and policy makers (Hui et al., 2014).

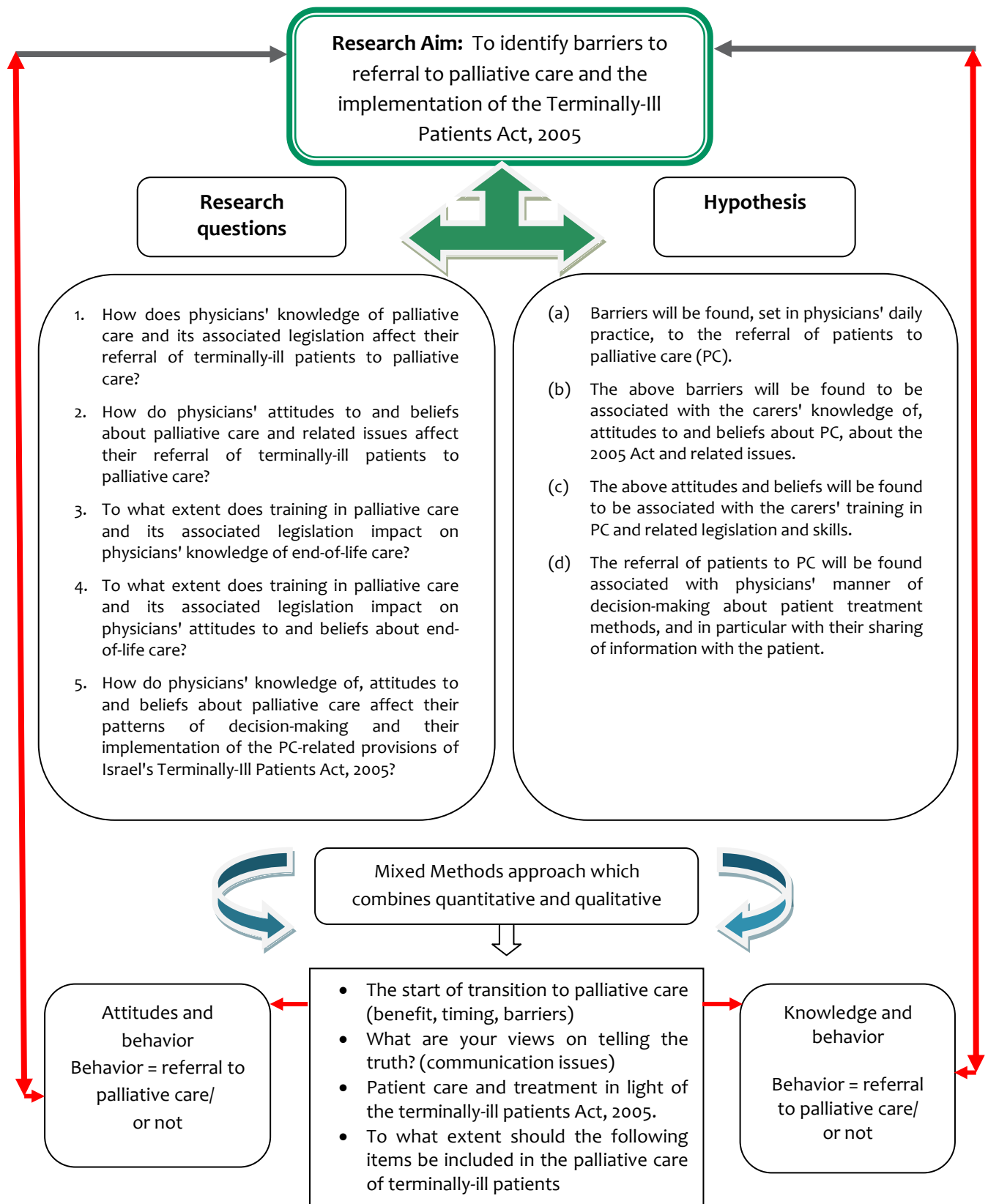
The background to the present book is Israel, where hospice care is available for the six months before death but, in practice, its duration varies widely, suggesting that there are different perspectives on the appropriate timing for the transition from curative care to palliative care. Palliative care focuses on the quality of life and the alleviation of symptoms in patients with serious illness. It aims to take into account the physical, mental, spiritual, and social well-being of patients and their families, with the aim of maintaining hope while ensuring the patient dignity and respect for their autonomy.

Palliative care encompasses both consultative palliative care for patients with serious illnesses and hospice care for patients at the end-of-life (EOL). Palliative care is appropriate at any stage of a serious illness, whether the goal is curing or maximizing quality of life. It is a fundamental component of the practice of medicine in all disciplines and at all levels of health. When cure or life-prolongation is no longer possible, palliative care becomes the central component of treatment. Whereas a hospice is only appropriate for patients whose prognosis is six months or less, consultative palliative care can assess and treat patients anywhere along the chronic disease trajectory, regardless of prognosis. Palliative management focuses on the care of patients with advanced illness or a significant symptom burden by emphasizing medically appropriate goal setting, honest and open communication with patients and families, and meticulous symptom assessment and control. (T. J. Smith et al., 2012).

The commonly-held belief is that palliative and hospice care is only for the dying, but in recent years the scope of palliative care has been broadened and, coupled with supportive care, it is now incorporated in the provision of

care at early stages of the disease trajectory. The prevalent approach in Israel is the conservative one, that is, patients are referred to palliative care only in the terminal phase. Fig. 1 below depicts two models for palliative care.

Fig. 1. Conceptual Framework - Outline of the Present Study



For all gravely-ill patients the goals of their care need to be clarified and their symptoms assessed and managed. When it is difficult to clarify these goals and the symptoms are difficult to manage, consultation with a palliative care specialist may be warranted and he/she will work to the principles described further in this book (Chapter 1, point 1.1.a The basic principles of palliative care)

Research environment - Palliative care in Israel

According to the WHO (World Health Organization) the palliative approach has been adopted in Israeli health care with adjustments to fit its peculiar and multicultural character. This was finalized in December 2005, when the Knesset (parliament) passed the Terminally-Ill Patients Act. The Act regulates the care and treatment of incurable, terminally-ill people, striking a balance between the values of the sanctity of life, recognition of the patient's autonomy of choice, and the importance of the quality of life beyond the importance of life itself. The Act sets out the rights of a competent person (i.e. fully conscious, lucid, not legally incompetent, who can make known their wishes/instructions of their own free will) to issue prior instructions as to what shall be done with them should they become terminally-ill (i.e. suffer from an incurable illness with a life-expectancy of less than six months) and incapable of issuing medical instructions at that time, being unconscious, lacking power of judgment or suchlike.

The Act institutes the instrument of Advance Medical Directives (AMDs) by which an individual state his/her wishes as to how he/she should be medically treated should they become terminally-ill and lose lucidity of mind. These advance instructions may be designed to rule out life-prolonging treatment or, on the other hand, to constrain attending physicians to give such treatment even when they do not consider it medically justified (See Biography, Terminally-Ill Patients Act, 2005).

In Israel, a patient's right to consent or not to any particular form of treatment had already been recognized by the Patients' Rights Act of 1996 (Ministry of Health, 1996). The Terminally-Ill Patients Act, 2005, extended that right to enable individuals to state in advance their wishes as to their

future treatment if and when they are determined to be terminally-ill within the meaning of the Act. The Act further laid down that any decision on this issue shall be made only by the individual himself and of their free choice, not by their family members and not according to any other consideration.

The individual's wishes in this regard can be ascertained in a number of ways but the most satisfactory is their issuance in person of explicit written instructions. It is an important reservation that the Act does not grant the instructing individual absolute freedom of choice. In most cases their wishes to rule out certain types of treatment will be respected but not in the following circumstances:

- Any procedure intended to bring about the patient's death or whose probable outcome is death is prohibited.
- Any assistance in suicide is prohibited.
- It is prohibited to halt any continuous medical treatment whose cessation is liable to cause the patient's death (it is permitted, however, to not resume a continuous medical treatment which has been stopped unintentionally and not in a manner prohibited in law; it is also permitted not to resume a periodic medical treatment, such as dialysis, chemotherapy or the administration of antibiotics).
- It is prohibited to not give an incompetent terminally-ill patient food and liquids, or palliative care or any associated care, even if the patient has made a specific prior request for such care not to be given, except in their last two weeks of life. (citation of the Act as publication).

The present book aims to investigate the obstacles raised to the implementation of the palliative approach as laid down by Israel's Terminally-Ill Patients Act. The better we understand where these obstacles arise the more likely we shall be able to improve patients' quality of life, allow them a dignified death and respect their last wishes.

Another important addition to knowledge provided by this book will be the current views of the formal caregivers of terminally-ill patients and

the education/training required in order to give those caregivers the skills, authority and readiness to discuss end-of-life issues with their patients. It is hoped too that the findings of this study will reveal the training and education staff need to handle the ethical issues entailed by the implementation of the 2005 Act. They may need, for example, communication skills or skills in dealing with loss and grief. The research findings can be used to develop training programs for formal caregivers.

How to die and where to die are topics that people can be prepared for and the professional caregiver has a great impact on terminally-ill patients' decision-making.

Chapter 1: LITERATURE REVIEW

1.1: Introduction to Palliative Care

One of the pioneers of palliative care movement clearly articulated the comprehensive goals of palliative care: “Palliative care provides the infrastructure of care where current knowledge of symptom management, psychological and spiritual care and family support can be applied to improve the quality of living for patients and families.” (Baile, Palmer, Bruera, & Parker, 2011). Since the modern hospice movement began in the 1960s, palliative care has emerged on the international scene in many shapes and forms. In any given country, the development or a lack of development of palliative care models and services, may be related to social, economic, cultural, geopolitical and health system realities (Bakitas et al., 2009). Given these contextual influences, palliative care is in different stages of development throughout the world.

Palliative care is a dynamic field and is now recognized as a medical specialty with an inherent interdisciplinary nature. Coordination and partnerships with hospice programs is a major feature, as palliative care continues across the trajectory of disease. As an interdisciplinary endeavor, the field of palliative care includes medicine, nursing, social work, psychology, nutrition, and rehabilitation, although the depth of support available from each discipline varies from institution to institution.

New physician, nursing, and social worker specialties and certification processes in both hospice 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 (Ferris et al., 2009).

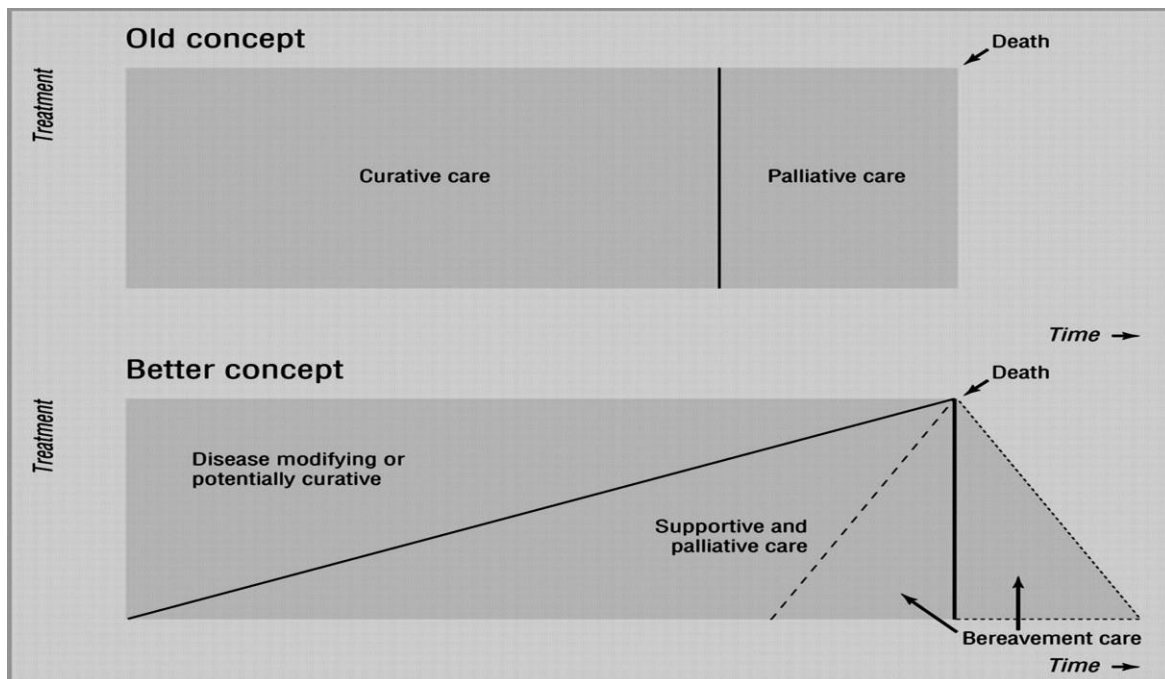
1.1.a Terminology, Concepts and Definitions:

- Terminal care: care during the last days or weeks of the patient's life.
- Supportive care: care focusing on alleviating symptoms, complications, and side-effects of HF interventions, including supporting patients and families to cope with the disease and the effects of treatment.
- End-of-life care: a term variously used either signifying terminal care of dying patients and/or also interchangeably as 'palliative care'. End-of-life care may begin as soon as an irreversible progressive illness is diagnosed.
- Hospice care: a word describing service models, inconsistently used for mobile outpatient hospice teams, inpatient hospices, and also describing a financial model in some countries.
- Palliative cancer care: the integration into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and have an impact on the quality of their lives. Palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near (WHO, 2002)

There are two models of referral to palliative care:

Fig. 2 shows that under the old concept of palliative care patients were referred to palliative care only in the last stages of their illness, once it had become evident that there was nothing more to be done curatively. Under the 'better concept' palliative care begins at the diagnostic stage and the deployment of palliative care increases as the illnesses develops. The advantage of this concept is that the patient learns what palliative care does at a much earlier stage and can build up familiarity and trust in it, which makes for fuller communication with medical staff about treatment possibilities.

Fig. 2: Two models of referral to palliative care (Murray et al., 2005)



1.1.b The basic principles of palliative care

Dame Cicely Saunders, the founder of the modern palliative care movement, explained: "Palliative care begins from the understanding that every patient has his/her own story, relationships, and culture and is worthy of respect as a unique individual. This respect includes giving the best available medical care and making the advances of recent decades fully available, so that all have the best chance of using their time well." (Higginson & Evans, 2010). Ethics, public policy and the law have all given strong support to the need to control pain, retain dignity and avoid futile and burdensome treatment for people who are dying, provided that death is not *intentionally* caused in the process. (White, Willmott, & Ashby, 2011)

Palliative care is defined by the World Health Organization (WHO) as “an approach that improves the quality of life (QOL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”(Zeinah, Al-Kindi, & Hassan, 2013).

Implementation principles:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (Jaarsma et al., 2009).

Palliative cancer care is the integration into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and have an impact on the quality of their lives. Palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near.

In order to ensure the implementation of the palliative care approach there are several levels of intervention:

Primary palliative care: The basic skills and competencies required of all physicians and other health care professionals; the day-to-day care of seriously-ill patients provided by attending physicians, nursing staff, social workers, chaplains, and other professionals involved with routine patient care.

Secondary palliative care: Consultation and specialty care provided by specialist clinicians.

Tertiary palliative care: Care provided at tertiary medical centers where specialist knowledge for the most complex cases is researched, taught, and practiced (Dalal et al., 2011).

The most prevalent model of palliative care service delivery in acute care hospitals is the consultation service, designed to provide specialty (also called secondary or tertiary) level care for difficult-to-manage symptoms, complex family dynamics, and challenging care decisions regarding the use of life-sustaining treatments. It is neither sustainable nor desirable that palliative care specialists manage *all* the palliative care needs of all seriously ill patients. Thus, there is an urgent need to improve basic palliative care assessment and treatment skills among clinicians caring for seriously ill patients, with the goal of reserving specialty-level palliative care services for problems beyond the capabilities of these regular clinicians.

1.1. c Overall policy: palliative care in the Middle East

The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommend palliative care referral at the time a life-threatening diagnosis is made and disclosed. Other core elements include a multidimensional assessment to identify, prevent, and alleviate suffering; interdisciplinary team evaluation and treatment in selected cases; effective communication skills and assistance with medical decision making; skill in the care of those dying and bereaved; continuity of care; equitable access; and commitment to continued improvement and excellence (Ferris et al., 2009). A simultaneous care model with integration of palliative care services in early stages of the cancer patient's illness trajectory has also been advocated by leading national organizations (Bruera & Hui, 2010).

Palliative care relieves suffering and improves the quality of life of patients and families suffering from malignant and nonmalignant illness. However, access to palliative care is limited in many countries. Before starting any investigation of the obstacles to full implementation of legislation we must remind ourselves that three key factors predict the successful implementation of palliative care:

1. Professional training and education;
2. The availability of the necessary technologies, e.g. opioids and other pain management resources;
3. Policy or legislation enabling patients to state their wishes as to further treatment and to sign a 'living will', known as Advanced Care Planning or Prior Medical Instructions.

In the majority of Middle East countries, over 70% of all patients with cancer seek medical attention only when the tumor has reached an incurable stage, where the only treatment option left, but not necessarily available, is palliative care (Silbermann et al., 2011). Palliative Care in Middle East countries needs urgent planning and major expansion. No country has an optimal palliative care delivery option (Zeinah et al., 2013). According to the guiding principles of palliative care provision, most of the countries of the Middle East are undeveloped. Some lack legislation, others - drugs or training staff. Israel has already passed the necessary legislation and the necessary drugs are available. In recent years, progress has been made too in staff training and education.

Along with other states of the Western world, Israel has witnessed in recent decades sharp changes in its pattern of morbidity and causes of death, as its population has aged. The frequency of infectious diseases has declined and that of chronic illness (including cancer) has climbed steeply. The outcome has been that many Israelis are having to spend their later years struggling with the steady development of an illness which brings with it a variety of suffering and difficulties - physical, mental, functional, social, psychological and financial - for both the patient and their close family. This challenges the state and its healthcare system to find ways of maintaining the patients' quality of life at the same time as supporting their family (Meyers-JDC-Brookdale Institute, 2005; Report of the Palliative Care Guidelines Committee, 2005). Given the absence of widespread palliative care provisions as well as Israeli physicians' hesitation to discuss dying (Wittenberg-lyles, Goldsmith, & Ragan, 2011), patient illness trajectories can vary greatly.

In 2004 the Israel Ministry of Health appointed the Palliative Care Guidelines Committee, chaired by Pessakh Shvartzman (2009), to review

the provision of such services in Israel and make recommendations for their future development in light of forecast need. One of the Committee's fundamental conclusions was that "comprehensive palliative care had to become an integral component of current national healthcare provision and that the state had to ensure access to such care and treatment". Among its recommendations were:

- to increase the number of palliative care beds in hospitals;
- to increase the number of home-hospice units and the number of patients cared for by each unit;
- to provide a service with 24-hour access and availability over a reasonable geographical spread;
- to define the role and functions in each medical institution of a palliative care team to give advice and treatment in complex cases;
- to define the necessary staffing for home-hospice care and an inpatient palliative care ward in each medical institution;
- to define the basic training needs for expert palliative care staff (Ury, Reznich, & Weber, 2000).

Article 25 of the Terminally-Ill Patients Act lays down the right of patients and their close family members to palliative care, as follows:

- "(a) The physician in charge must ensure that everything is done to relieve the terminally-ill patient's pain and suffering, including medications, analgesics, and psychological, nursing and environmental care, even if this entails a probable risk to the patient's life, all the foregoing to obey the accepted principles of palliative care and to conform to the conditions and arrangements obtaining in the Israeli healthcare system as these change over time, as well as to the wishes of the terminally-ill patient, as set out in this Act and the Patients' Rights Act, 1996.
- (b) The physician in charge must ensure that, as far as possible, everything is done to help the terminally-ill patient's family members and promote their wellbeing while the patient is hospitalized, all the foregoing to obey the accepted principles of palliative care and social

care and to conform to the conditions and arrangements obtaining in the Israeli healthcare system as these change over time."

The Shvartzman Committee represented the following agencies: the National Community Health Advisory Council, the National Advisory Council on the Prevention, Diagnosis and treatment of Malignant Disease, the National Advisory Council on Geriatrics, the National Advisory Council on Child Health and Pediatrics.

Palliative care is currently provided in Israeli general hospitals. There are three home-hospice units with a total of 76 beds in the three largest cities. These 3 units admit about a thousand patients per year. In addition, some general hospitals provide palliative care advice via a nurse specially trained in palliative oncology care and/or an anesthetist or physician trained in pain management.

However, the availability of this service is inadequately known, even to most hospital staff. As a result, many inpatients die without receiving it. The 76 beds in these three units make up a nationwide bed-population ratio of 1.02 per 100,000, lower than the ratio of 5 per 100,000 recommended by the Oxford Textbook of Palliative Medicine. The Shvartzman Committee recommended that Israel aim at increasing the number of beds from 76 to 370. One suggested strategy consisted of converting existing beds in oncology, internal medicine, neurology, geriatric and pediatric wards and complex case beds. Yet, general hospitals already suffer from an overall shortage of beds so that this strategy would only worsen the existing shortage.

Although a high proportion of hospital inpatients suffer from a range of symptoms most medical institutions persist with a conservative care strategy confined largely to drug therapy of pain and other physical signs. A few geriatric hospitals and centers have recently taken up the more modern hospice approach and bolster their drug therapy with psychological/emotional support.

In Israel there are four main health management organizations that operate some eighty Home Care units (providing medical, nursing and rehabilitation care) across the country to care for bed-ridden persons. Most

patients are elderly and suffer from a range of morbidities and functional disabilities. 3,000-4,000 patients have metastasized cancer and require palliative care. Some of these are cared for directly by the Home Care Unit but the majority are under the care of a local GP or community clinic who get advice, instruction and back-up from Home Care unit staff. In most cases, the home care staff is available to give care and treatment only during normal working hours. Only in a few units do staff give advice on telephone in the evenings, but they do not consult at the patient's home.

Altogether, there are currently 42 specialist palliative care nurses in the community and hospitals in Israel. Some Home Care units include an oncology nurse who cares directly for terminally-ill patients but mostly, as noted above, the nurse provides back-up to other professional and informal carers, providing advice, assistance and instruction on serious cases and on problems having no straightforward solution. Israel has 20-30 such nurses, all trained in oncology and/or palliative care. All are accessible by telephone call 24 hours a day, but most will not provide direct service outside normal working hours since they are not paid to do so. They have additional roles in coordinating inpatient and community care, in operating special oncology and palliative care projects in their area, in training other medical staff and in supervising the provision of home care on behalf of their HMO employer.

As noted, there are currently three home-hospice units in Israel caring for the terminally-ill. One is run by the largest HMO (which sells its services to other HMOs), and two by voluntary associations. The units are funded from a variety of institutional and charitable sources and in some cases the funding is so precarious that it prevents any expansion of their provision. One result of the coming into effect of the Terminally-Ill Patients Act has been the appearance of privately-run hospices, which sell their services to all the HMOs.

By 2020, the United States and several other countries plan that palliative care will form a routine part of comprehensive cancer care for all patients, available in every cancer center around the country. Palliative cancer care is to be consistently delivered to prevent and relieve the

suffering of patients and families from the day of diagnosis. The medications needed to provide palliative cancer care are to be readily available, without cost to the patient or family (Bruera & Hui, 2010).

With respect to the delivery of these plans, education alone is unlikely to substantially change practice patterns. Ideally, education would be one component of a more comprehensive systems-change approach (Dalal et al., 2011). Systems-change approaches work to address complex problems by combining evidence-based assessment and treatment algorithms, checklists of key tasks, quality improvement initiatives, provider and patient education, and other systematic processes geared to reducing variation in care. The use of checklists in hospitals is gaining acceptance; data indicate that the rigorous use of checklists can lead to improved quality outcomes, such as reductions in infections and improved clinical team communication (Temel et al., 2010). Palliative care programs are experimenting with checklists as a means of identifying the patients most in need of a specialty-level consultation (Weissman & Meier, 2011).

Although palliative care services may start in one or more health care organizations which will become centers of palliative care excellence, it is always important to keep in mind the vision that the process of implementing palliative care within a country should strive to integrate palliative care into all levels of society, from the community level upward, and from the palliative care expert in the health care system downward. It will be impossible to develop a palliative care system separate from the existing health care system and social support network - there is simply not the capacity to do this. It will be critical for all palliative care experts to spend 40%-50% of their time educating and supporting other health care professionals and community support systems, in addition to providing consultation and direct patient/ family care (T. J. Smith et al., 2012).

1.2: The Referral to Palliative Care

1.2.a Benefits of referral to palliative care

In recent decades much effort has gone into improving the quality of end-of-life (Kelly & Eileen, 2010). One example is the Medicare Hospice Benefit which was established in 1982 in the USA. Since then, the number of hospices in the United States has increased from 500 to more than 3,000, and the number of patients receiving hospice care has increased from 25,000 to 700,000. Today, the hospices' interdisciplinary approach to palliative care is a widely accepted model of care for terminally-ill patients in both the UK and the USA. According to the Hospice Information Service's palliative care facts and figures, at least 60% of cancer deaths in the United Kingdom occur under inpatient or outpatient hospice care. In comparison, 42% of cancer deaths in the USA occur under hospice care (McCarthy, Burns, Davis, & Phillips, 2003). These percentages demonstrate the scope of hospice care in both the UK and the USA.

Although palliative care is rooted in compassionate care for dying patients, its primary aim is to minimize patient and family suffering at all stages of life-threatening illness. Early referrals to specialized palliative care service, that is, immediate referrals to palliative care specialists when patient and family require specialized care for adequate symptom relief, could be useful in achieving this goal through early and systematic detection of unmet needs, prevention of symptoms, and the strengthening of emotional connections between patients and families. Patients with advanced cancer often require palliative care services. A significant point of debate within the global medical community is *when* palliative care should begin (Wittenberg-lyles et al., 2011).

Patients living with serious illness face challenges including symptom management, advance care planning, existential concerns, and family and social stressors. The 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 (Kelly & Eileen, 2010). In

the United States, Medicare insures most hospice patients, and Medicaid and many commercial insurers offer similar hospice coverage. For instance, hospice patients receive medications related to their hospice diagnosis, durable medical equipment, home health aide services, and care from an interdisciplinary team. Families also receive emotional and spiritual support and bereavement counseling for at least a year after the patient's death (Teno et al; 2007).

Israel has a unified national health care system where the care and treatment of the dying patient is regulated by the Terminally-Ill Patients Act (2005). Supportive care is available everywhere, allowing the patient and family to make the choice according to their ability between care at home and in a hospital setting.

Hospice care focuses on holistic care in preparation for death. Philosophical convictions may lead hospices to focus on the later stages of illness and oppose certain treatments as the medicalization of the dying process. Because they function as small, independent, community-based organizations, many hospices may not be able to directly or contractually support the staff and other resources to deliver intensive medical treatments and may have little experience delivering such complex care (Mccarthy et al., 2003). Death from cancer typically follows a course of progressive debility and rapid decline. Patients fear losing control over how and when their death will occur and that their preferences will not be respected. They fear their prolonged dying will cause substantial financial hardships to family members. Hospice care provides an alternative, and perhaps an optimal, approach to caring for terminally-ill patients.

Under the hospice model of care, dying is affirmed as a natural part of life, and the emphasis shifts from curative and life-prolonging treatments to palliative care. Ideally, hospice patients die comfortably, often at home, and surrounded by loved ones. Family members are prepared for the patient's death and assisted through the bereavement process.

Despite all the above-mentioned benefits, hospice provides care for only one-third of all dying patients in the USA and patients who register for hospice care generally do so very late in the course of their illness. The

median length of hospice stay is approximately 3 weeks and 10% of patients enter hospice only in their last 24 hours of life (Harrington, Smith, & Story, 2012). Although no one knows what proportion of patients should be admitted in hospice or what the optimal length of stay is, there is widespread agreement among experts in the field and physicians that more patients could be admitted to hospices and that their admission should occur at an earlier stage of illness (McCarthy et al., 2003).

Hospice is a desirable form of care because of its ability to meet the psychological and emotional needs of patients and their families in a cost-effective manner. A meta-analysis of studies on cost savings from hospice revealed that hospice care can save up to 40% of health care costs during the last month of life and 17% over the last 6 months of life (McGorty & Bornstein, 2003).

Hospice offers high-quality end-of-life care that leads to high levels of patient and family satisfaction. Although satisfaction with hospice care is high regardless of the timing of patient admittance, caregivers report more satisfaction when the patient has been enrolled 30 days or more (Stillman & Syrjala, 1999). A late transfer may result in harmful discontinuity in care and oblige hospice nurses to provide hyper acute death care rather than palliative care. In addition, a longer hospice stay allows the hospice staff to implement a comprehensive care plan and allows hospices operating under daily reimbursement to be compensated for large up-front admission costs.

Palliative care is appropriate for patients throughout the illness continuum, including cure, remission, control of disease, and end-of-life care. Although palliative care accepts and incorporates the hospice philosophy of care, it is separate from hospice care (Callaway & Navy, 2012). Unfortunately, many healthcare providers are slow to initiate palliative care consultations. These delays contribute to unrelieved symptoms for patients, moral distress for bedside providers, and financial shortfalls for healthcare institutions.

Research has shown that, although the majority of health care professionals consider that patients should be told their prognosis as far as

physicians can predict this, in practice many avoid discussing this topic or withhold information (Clayton et al; 2012). Another study has found that balancing hope with honesty is an important skill for health care professionals and that patients mostly prefer honest and accurate information, provided with empathy and understanding. (Slort et al., 2011).

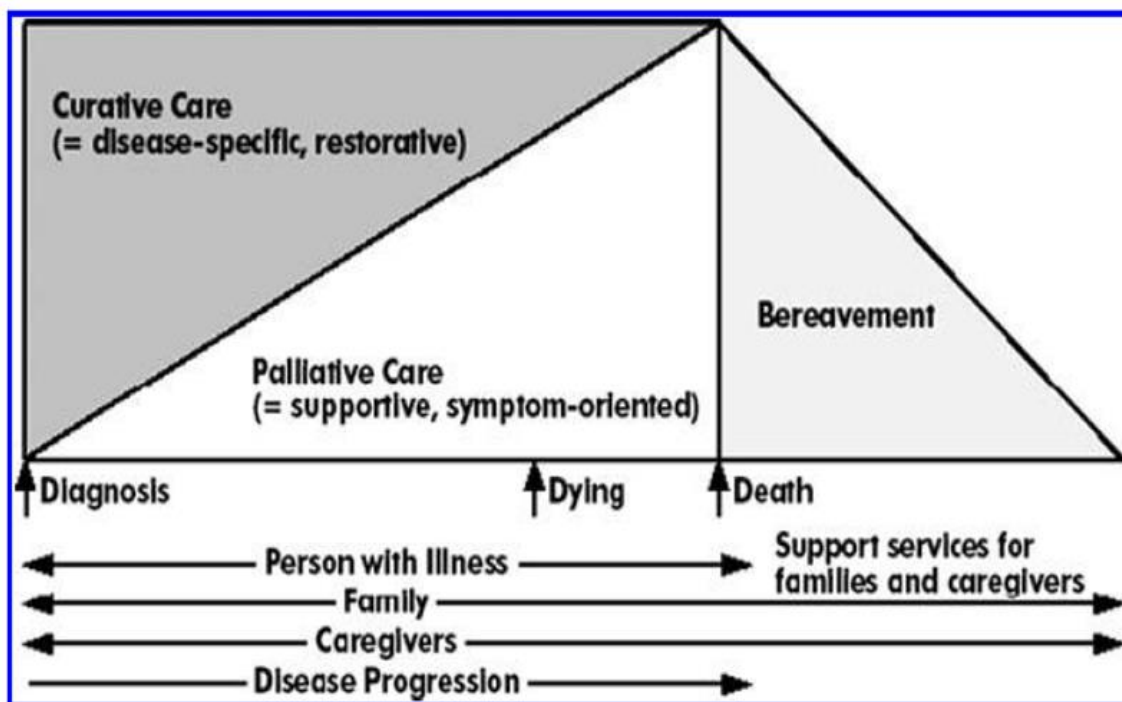
Early consultation with palliative care providers facilitates the development of trusting and therapeutic relationships with patients and families. Palliative care providers routinely assess patients and communicate new and relevant findings to providers treating the patients' diseases. In addition, palliative care providers help patients and families identify immediate and long-term goals. When appropriate, skilled palliative care providers may also initiate end-of-life conversations, which are essential to the quality of life and dignity of the chronically-ill (Callaway & Navy, 2012).

While not all palliative care patients are admitted to hospitals and/or assessed as death imminent, palliative care helps to prepare patients for death. Schapira, Moynihan, von Gunten, and Smith (2009) wrote, "In listening to our patients, we hear their hopes and wishes, their dreams and dilemmas. Patients have taught us they frequently hope to have some control over their time remaining, to minimize the burden of their situations on loved ones, and to preserve their dignity until the very end". Furthermore, Schapira and colleagues (2009) believe that patients enrolled in Phase I and II trials may benefit from palliative care's abilities to manage systems, set goals, and communicate honestly.

Clinicians often struggle with initiating discussions about changing treatment goals and, in particular, about transitioning to palliative care. Patients may also respond negatively to such a change, with denial, anger, or sadness. These are all normal responses to the loss of control, a fear of the immediate future, or an underlying fear of death. For the most part, patients and families will have their own timetable and method for processing this information. Clinicians should respond with patience, emphasizing support and assurance of aggressive symptom management (Harrington et al., 2012).

The figure below shows the importance of early palliative care for improving quality of life over the disease trajectory.

Fig. 3: World Health Organization Palliative Care Model
 (Source: Bharadwaj, Shinde, Lill, & Schwarz, 2011).



Not surprisingly, physicians may respond to their patient's imminent death, particularly those with whom they share a long-term relationship, with powerful emotions of their own. These can include a personal and professional sense of failure and frustration and powerlessness against the illness, guilt, grief, a need to rescue the patient, or a desire to separate from and avoid the patient to escape these feelings. Many providers perceive palliative care referrals as personal failure (Kelly & Eileen, 2010). Both physicians and nurses have voiced fears that discussing hospice care could negatively impact the patient's level of hope or result in anger or denial (Schulman-Green et al., 2005). Clinicians' feelings of medical ineffectiveness can lead to failure to identify patient-specific and family-specific values influencing decisions, which may lead to a lack of clarity about care goals. Their avoidance of end-of-life conversation end-of-life discussions altogether can lead to their patients mistrusting the health care

system and medical profession, to inappropriate use of life-sustaining medical technologies, to increased medical complications, and long hospital stays. Recognizing, accepting, and reflecting on the normality of such feelings allows the professional to make a conscious choice about how to proceed in the relationship with the patient. Finding a trusted colleague in whom to confide can be part of a plan to prevent isolation, improve objectivity and avoid burnout (Harrington et al., 2012).

1.2.b Making the transition to palliative care

Communicating with patients is clearly an integral part of physicians' practice, and it becomes especially important in treatment situations such as the challenging transition from curative to palliative care in oncology (Goelz et al., 2011). The appropriate role of chemotherapy near the end of life is a complex issue. As chemotherapy is increasingly available, and better tolerated, its use at life's end involves sophisticated oncological assessment, a focus on the patient's goals of care, and a balancing of perspectives of the patient and the treating oncologist. Ultimately, it may involve judgments about the use or restraint of use of costly resources when there is little chance of benefit (Harrington et al., 2012).

As for end-of-life conversations, given the physician's role in determining treatment options and prognosis, it seems logical that physicians would initiate such discussions. Research supports this: physicians and hospice staff most frequently initiate hospice discussions, followed by nurses (Kelly & Eileen, 2010). A team approach for initiating end-of-life discussions may be highly beneficial. Although physicians most often initiate end-of-life discussions, caregivers of patients in a hospice setting perceive nurses and social workers as most helpful with the transition to hospice (Kelly & Eileen, 2010). Although nurses are accepted as participants in end-of-life discussions, physicians may have the strongest influence on patients and families when it comes to enrolling in hospice care.

Appropriate timing is important to ensure that the conversation does not take place too late in the disease trajectory. Delaying the discussion

could potentially result in unnecessary treatment and associated suffering, as well as delays to hospice enrolment. People with life-limiting cancer are able to make decisions regarding end-of-life 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.

Reaching a consensus regarding end-of-life for patients and their families is not always possible, and conflicts have been documented (Siminoff, Rose, Zhang, & Zyzanski, 2006). Conflict may result in behaviors such as concealing information in an attempt to protect the other (Clayton et al., 2007). Disagreement may exist over pursuing aggressive care versus care aimed at relieving symptoms (Zhang & Siminoff, 2003). Some patients with cancer may be trying to survive longer for the sake of a family member or to live long enough to reach a certain milestone. Although these motivations are not considered negative, they may cause patients to experience internal conflict over making end-of-life decisions. With a better understanding of the issues and conflicts that surround end-of-life planning for cancer patients, nurses can implement strategies to improve the process of preparing for hospice.

Physicians often find these hospice discussions difficult and uncomfortable because patients are being asked to “give up” on disease-directed treatment (Finestone & Inderwies, 2008). However, just as with other 'bad news' discussions, physicians can make hospice discussions more compassionate and more effective by following a structured approach similar to that first described by Buckman, whereby the overall aim of a hospice discussion is to define a patient's treatment goals and needs for care and then to present hospice care as a way to achieve those goals and meet those needs (Buckman, 2005).

The combination of physicians' difficulty broaching the subject of hospice care and their instrumentalist orientation has led to a well-recognized barrier to hospice utilization, the timing of hospice discussions. Physicians recognize their tendency to suggest hospice care too late in the disease course (Weggel, 1999). Because physicians commonly overestimate the life

expectancy of their terminally-ill patients, they do not bring up the subject of hospice care until it has become too stressful for patients to be transferred (Casarett & Quill, 2007). McNeilly & Hillary (1997) found that 28% of physicians did not perceive hospice discussions as appropriate until treatment was no longer effective, and the patient had entered a deteriorating state, whereas 24% perceived the time when the terminal diagnosis was first made as the appropriate time. Many physicians considered patients appropriate for hospice care when they had accepted their terminal illness (41%), as opposed to meeting the 'less than 6 months to live' hospice criterion (26%) (McNeilly & Hillary, 1997).

According to Hyman and Bulkin (1991), the patient's and physician's acceptance of the terminal diagnosis, along with the 6-month hospice care regulation, determined when the physician discusses hospice care with the patient. Some physicians prepare patients early in the course of disease for later hospice options, whereas others wait until the patient has no other options. In any case, most family members of hospice patients reported that they would have welcomed more information about hospice care from their physicians at the time the diagnosis was labeled terminal. Likewise, family members of patients cared at home would have welcomed more information on hospice care at the time of diagnosis (McNeilly & Hillary, 1997). Based on these findings, physicians should be encouraged to raise the subject of hospice care early in the course of the terminal illness, so that patients can decide for themselves if and when the hospice option is right for them.

1.2.c Barriers to palliative care

Palliative care specialists are faced with extensive barriers in the provision of an effective end-of-life care (Miyashita, Hirai, & Morita, 2008). It is important to explore the barriers to referral to hospice care because late referral results in low family satisfaction with care. Many studies have been done regarding obstacles to hospice referral and various barriers have been identified. They include the difficulty of predicting prognosis, lack of physician acceptance of terminal diagnosis and death, physician's

unwillingness to refer to hospice service, physician's unfamiliarity with hospice care, physician's negative opinion of hospice service, insufficient education for physicians about palliative care, a medical system that does not include hospice care as standard care, patient's and family's unwillingness to use hospices and preference for life-prolonging treatment, their denial of a terminal diagnosis, their lack of information about hospice service, and social attitudes toward death (Miyashita et al., 2008).

Several studies have explored barriers to hospice utilization by surveying or interviewing physicians, caregivers, hospice and home health care staff, and the family members of dying patients cared for at home (Finestone & Inderwies, 2008). These studies have revealed further barriers to hospice utilization as well as problems and shortcomings in hospice service provision. For instance, that the care of the dying patient is fragmented across multiple settings with little communication between various providers across the trajectory of the illness.

Physicians as the gatekeepers and physicians as barriers to hospice care: Patients, caregivers, hospice staff and physicians themselves all recognize the role of physicians as the gate keepers to hospice care. Studies have found that over 90% of physicians are aware of hospice care (McGorty & Bornstein, 2003). The majority of patients whose physicians present the hospice option to them choose this alternative. Although 40% of cancer patients and 68% of their families had heard of hospice before their physicians mentioned the option, physicians (80%) were more likely than caregivers (54%) and patients (42%) to view themselves as the initiator of hospice care discussions (McGorty & Bornstein, 2003). 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 to hospice enrolment decision-making (Hyman & Bulkin, 1991).

However, 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 discuss it a selective manner (Gochman & Bonham, 1988; McNeilly & Hillary, 1997). In Weggel's (1999) follow-up interview, physicians

cited their tendency to delay the discussion of hospice options until they thought their patients were prepared to accept such options. Prigerson's (1991) finding that 85% of patients expressed preferences for palliative care rather than curative treatment suggests that patients may be more receptive to hospice than both physicians and caregivers expect.

About 15% of physicians cite their lack of knowledge about local hospice programs (Weggel, 1999), and 4% of physicians cite their lack of knowledge about hospice in general. As barriers to their discussion of this option (McGorty & Bornstein, 2003). McNeilly & Hillary (1997) found that only 24% of physicians had personal experience of working with hospice care, while 28% of physicians were aware of the services and competence of hospice personnel, and 26% were simply aware of the concept of hospice care. Research has found that most physicians and primary caregivers view hospices as an alternative, rather than as an addition, to traditional medical care (Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). Hyman & Bulkin (1991) found that physicians cited perceptions of hospice as 'a last resort' and 'a place where one goes to die' as disincentives to referring patients to hospice. Physicians also cited their perception that hospice care is no different from standard terminal care as a disincentive to referring patients to hospice (Hyman & Bulkin, 1991). Because palliative care providers refer patients to hospice and assist other healthcare providers with hospice referral, many healthcare providers believe that palliative care providers only care for "death-imminent" patients. Such a belief exists in spite of hospice care representing a fraction of all chronic-illness care. It is notable that relatively few healthcare providers know that palliative care manages symptoms for patients with life-limiting illnesses. Some providers have referred to palliative care as the "death service". Instead of viewing hospice as a reduction or cessation of treatment, physicians should be encouraged to recognize its role as an active component of the care continuum (Thalhube, 1995). On the other hand, some physicians believe that they provide themselves high-quality palliative care interventions and do not require palliative care services (Morita, Akechi, Ikenaga, Kizawa, & Kohara, 2005).

All physicians should have expert knowledge in managing the symptoms associated with advanced disease. However, 80% of those surveyed by Snow believed that the majority of physicians lacked such expertise. A limited number of physicians claimed to have gained adequate palliative care knowledge during their training. Although the majority believed that palliative care should begin earlier in illness continuums, physicians also perceived that patients and families associated palliative care with hospice care and a quitting mentality (Callaway et al., 2012).

The majority of the hospice staff in McNeilly & Hillary's (1997) study cited several ways in which physicians impede the discussion of hospice options - deficient physician explanations of terminal illness to patients, insufficient physician education about palliative care, and a lack of physician comfort with death and the hospice concept. According to hospice staff, physicians' discomfort with death stems from their difficulty in admitting their own limitations in dealing with terminal illness. Physicians may also be reluctant to discuss patients' prognoses for fear they will be blamed for poor outcomes (McGorty & Bornstein, 2003). Casarett & Quill (2007) claimed that physicians often do not refer patients to hospice due to their fear that it would diminish their stature in the eyes of their patients and families and due to their own inability to accept the inevitable death of their patients.

However, McNeilly & Hillary (1997) found that 37% of physicians who had held end-of-life conversations with patients felt that the conversation was manageable and generally straightforward, 17% felt the discussion was uncomfortable but manageable, and 11% felt only discomfort.

Several studies have documented that oncologists refer patients to hospice later than surgeons, internal medicine specialists and family practitioners. As a result, patients of these last three categories have longer stays in hospice than patients referred by oncologists (Lamont & Christakis, 2002; Woods, Craig & Dereng, 2006). Other research suggests that primary care physicians have greater levels of awareness of hospice care than specialists and are more willing to discuss hospice care with patients (Finestone & Inderwies, 2008).

A major impediment to hospice referral is physicians' difficulties in predicting survival accurately in patients with advanced illness. They often overestimate life expectancy (Pearlman 1988; Rhymes 1990). Physicians cited this as the most frequent barrier to discussing hospice options (Weggel, 1999). As a result, many patients are never informed about hospice care and others are referred to hospice weeks or months after their care goals made them eligible (Harrington et al., 2012).

Patient and Family Barriers: Patients may delay enrolment in hospice care because reimbursement rates make it difficult for many hospices to provide expensive palliative treatments. However, other barriers are created by the challenges of hospice discussions. For example, it has already been mentioned that some patients and families cannot accept that effective, disease-directed treatment is no longer available or that the patient has fewer than 6 months to live. It is not unusual for patients or families to have overly optimistic goals and expectations of treatment. In these cases, even the most careful and persistent communication efforts often fail to change patients' and families' care goals and a decision to enroll in hospice is unlikely. However, physicians should still discuss the patient's goals for care and can use these discussions to introduce hospice care as an option for the future. In one prospective study this acknowledgment of 'terminality' was an independent predictor of subsequent hospice enrolment in patients (Casarett & Quill, 2007).

End-of-life discussions provide a valuable opportunity to introduce hospice care as an option for the future. Although most hospice discussions occur very close to the time of enrolment, early discussions can promote timelier hospice enrolment and may improve satisfaction with end-of-life care. However, when multiple lines of therapy are available, patients may resist the notion of hospice care and decide not to engage in discussions about end-of-life care. A reason commonly cited for patients not entering hospice is that it would be "giving up" (Kelly & Eileen, 2010). Some patients want to continue chemotherapy even if tumor progression is evident because continuing gives the patient a sense that he or she is doing "something" to fight the cancer. Indeed, with the continuing development

of new cancer drugs and new combinations of drugs, patients often have the option of receiving multiple lines of cancer therapy before treatment is considered unsuccessful (Harrington et al., 2012). These multiple treatment regimens allow for more aggressive therapy closer to EOL. Researchers found that families who were provided hospice information before and during their relative's terminal illness were seven times more likely to consider hospice care than those families who knew of the hospice option before the illness but did not receive further information during the illness (McGorty & Bornstein, 2003).

Another study shows that physicians and primary caregivers cited the patient's lack of knowledge about hospice as the primary patient barrier to hospice use. Even when patients did know about hospices, some physicians (18%) and primary caregivers (26%) claimed that they did not think the patient would consent to hospice enrolment (Casarett & Quill, 2007). Hyman & Bulkin (1991) found that physicians cited the following patient-related factors as disincentives for referring patients to hospice: the patient believes that hospice means death, the patient is emotionally fragile, the patient denies his or her terminal status, and the patient wishes to continue active therapy. McNeilly and Hillary (1997) found that hospice staff (47%), home health care staff (20%), hospice patient family survivors (2%), and home health care patient family survivors (5%), all, to some extent, recognized the patient or family's denial of the terminal diagnosis as a barrier to opting for hospice care.

Similarly, Weggel (1999) found that nearly half of the physicians surveyed reported that (i) the patient's or family's denial of the terminal diagnosis (49%) and (ii) the patient's or family's desire to continue life prolonging treatment (48%) were barriers to their initiation of discussions about hospice options. As with Hyman & Bulkin (1991), the physicians in Weggel's (1999) study also cited their worries that (iii) the offer of a hospice might cause the patient or family anxiety or loss of hope (19%). In addition (iv) the patient's wish that their physician makes all the medical decisions (14%) was reported as a barrier to any discussion of hospice care (Weggel, 1999).

1.3: Attitudes, Knowledge and Referrals

1.3.a The effect of physicians' attitudes on decision-making about palliative care

Potential obstacles to hospice utilization reflect attitudinal, informational, economic, societal, and system barriers that are perceived differently by patients, physicians, and health care administrators. Physicians may be influenced or limited in referring terminally-ill patients to hospice if they are unaware or uncertain about available hospice services; have personal difficulty accepting death or are uncomfortable discussing end-of-life issues with patients and their families; or believe that hospice referral is a signal for patients and their families to lose hope (Kutner, Chomiak, & Kramer, 2003). In addition, referral to hospice may be limited if the physician perceives or expects that patients and families will be unwilling to elect hospice services, either because they cannot accept the terminal nature of the patient's medical condition (Chou et al., 2013) or because they are unwilling to have strangers in the home or they believe that the referral will cause the physician to lose contact with the patient and/or prevent the physician from continuing clinical management of the case (Ogle, Mavis, & Wyatt, 2002).

1.3.b Attitudes and beliefs of palliative care physicians regarding communication with terminally-ill cancer patients

Attitudes are composed of ideas and beliefs that are attached to specific emotions, which together are connected to an action being taken in association with the object of the attitude (Braun, Gordon, & Uziely, 2005). Attitudes give people a sense of order and control and help them build their world perception (Braun et al., 2005a). The attitude of physicians with respect to breaking bad news may be affected not only by deficient knowledge, but also by socio-cultural conditions, religious beliefs, coherence of philosophy of life (conformity between one's conduct and convictions), or attitude towards one's own death. There is evidence that

doctors inexperienced in breaking bad news are afflicted by stress more than experienced ones. Physician's fears may be displayed in physician's gestures and postures, which may influence proper communication. Personal attitude should be addressed within the curriculum of physician-patient communication education. (Ciałkowska-Rysz & Dzierżanowski, 2013).

Although physicians do not solely control the decision to opt for hospice care they are widely believed to be unwilling to undertake the communications required to refer patients to it. Despite many calls for improved physician education (Ogle et al., 2002) remarkably little work has actually measured any of this variable in practicing physicians. Weggel (1999) found that a subset of physicians had deficits in knowledge about hospice programs, including the topics of treatment restrictions, length of allowable coverage, and identification of appropriate referrals. Communication with patient and family is still the primary challenge for the professional care giver in cancer.

Health care professionals' abilities to discuss Advance Medical Directives may be influenced by their personal death attitudes and experiences. There is evidence that discussions about death and dying between health care professionals and patients evoke deeply held personal beliefs; as well as personal experiences with illness and death (Black, 2007). Clinicians discussing potential death and dying issues with patients may be reminded of past events—such as a terminal illness diagnosis or death of a significant other (Katz & Genevay, 2002). Research suggests that inadequate professional training regarding death and dying is a barrier for effective practice in this area for physicians (Carron, Lynn & Keaney, 1999).

1.3.c Physicians' knowledge of palliative care

Palliative care experts have suggested that by influencing physicians' knowledge and attitudes concerning end-of-life care, medical educators may influence the care of terminally-ill patients (Bradley, Cramer, & Bogardus, 2002). An intervention to improve medical residents' knowledge and

attitudes revealed severe deficiencies in care at the end of life—patients received overly burdensome care and experienced moderate to severe pain in the last days of their lives. Other studies have reported poor adherence to AMDs and despite strong preferences to die at home, most persons die in an institution (Kutner et al., 2003).

Palliative care education clearly has the potential to improve the quality of care at the end of life by training physicians and other caregivers to address difficult issues such as suffering and giving him the last gift by dying well. Too often palliative care is understood as limiting options available to the patient and family, rather than as the utilization of optimal clinical knowledge and tools to improve the patient's quality of life (Mahon & McAuley, 2010). Palliative care frequently is perceived as care for people who have "failed" medical treatments (Sesterhenn, Folz, Bieker, Teymoortash, & Werner, 2008) and often is equated with end-of-life care (Paice, Ferrell, Coyle, Coyne, & Callaway, 2008). Of greater concern, palliative care interventions are sometimes understood as hastening death, albeit inadvertently (de Veer, Francke, & Poortvliet, 2008).

Some researchers have examined physicians' self-reported educational needs in the area of hospice care. A commonly reported need is for training in the specifics of pain management, but another frequent finding is a need for improved skills in communication and the management of emotional distress in patients and families (Ogle et al., 2002). Few medical schools and even fewer residency training programs require courses or clinical experience in end-of-life care. Medical students frequently do not feel prepared to discuss end of-life issues with their patients and physician surveys have demonstrated a desire for ongoing education in this area (Kutner et al., 2003). To improve care at the end of life, physicians must be educated in the principles of palliative care and be allowed to embrace the "care model" without feeling that forgoing a plan of cure is a medical failure. Studies have shown that medical students who complete clinical rotations and courses in palliative care feel more comfortable with death and caring for dying patients (Peng et al., 2013). End-of-life education programs for residents have

demonstrated outcomes of improved knowledge of palliative care and improved attitudes toward caring for the dying.

Most people at the end of life are cared for by generalists and die in generalist settings. In Israel, about 80 % of the deaths occur on general wards and it is usually generalist doctors and nurses who spend most time with the dying patients and their families. They are often 'left' to care for these patients, yet many feel unprepared for this role (Gibbins, McCoubrie, & Forbes, 2011). The UK General Medical Council's (GMC, 2002) second edition of *Tomorrow's Doctors* recommended core teaching on 'relieving pain and distress, together with care of the terminally-ill'. Despite these recommendations, we know that undergraduate training in palliative care, death and dying is variable; some schools provide extensive programs, others provide very little (Gibbins, Mccoubrie, & Forbes, 2011). There has been little evaluation of this teaching and studies in the UK have not explored what or how medical students or newly qualified doctors learn about patients at the end of life, or how current doctors develop the skills necessary to care for dying patients.

The UK Department of Health has recently highlighted the need to educate all health care professionals to try and improve 'end-of-life care' and the third edition of *Tomorrow's Doctors* reiterates the need for students to be prepared to care for patients at the end of life (GMC, 2009). A large-scale exercise to determine research priorities in generalist end-of-life care acknowledged that much needs to be done to support generalists in providing care to dying patients. In Israel, there are no formal courses in medicine, nursing and social worker basic training in palliative care. We cannot ignore that attitudes and knowledge and may be affected by medical education.

1.3.d Training needs

A needs assessment identified that research skills were not especially highly valued by potential participants, including nurses, doctors, clergy and allied health professionals. The main interest lay in pain and symptom

management, communication skills, emotional and spiritual care and bereavement. Initially, these aspects provided the main content of the desired program. Generic skills such as critical appraisal and teaching were (Payne, Seymour, & Ingleton, 2004) integrated to some extent throughout and, it could be argued, covertly. The most common reasons for applying for the course were:

- awareness that they could care more effectively, particularly in managing pain and other symptoms;
- to gain confidence in communicating with patients and relatives and responding to emotional and spiritual distress;
- to gain understanding of disease processes and treatment strategies (non-clinical professions, e.g. social work or clergy);
- to gain confidence in their knowledge base to enable them to teach others; and
- to develop research or teaching skills (expressed by more recent students).

Continued efforts on all fronts will be needed to identify compassionate and appropriate care and to disseminate this care to all clinicians caring for cancer patients (Grant, Elk, Ferrell, Morrison, & Gunten, 2009). Training involving communication skills workshops of three or more days' duration has been shown to improve doctors' communication skills and may potentially improve outcomes for patients. The training is highly valued by participants and increases confidence in communication skills (Clayton et al., 2012). Moreover, effective teaching requires not only clinical content expertise but also a range of pedagogic competencies, including proficiency in a variety of didactic and interactive teaching methods (e.g., facility with small and large groups as well as one-on-one teaching), skills in assessing learners' needs and providing appropriate feedback, and ability to promote self-reflection and self-directed learning. In addition, the particular emotional and communication demands of end-of-life care pose further challenges for the clinician– educator.(Sullivan, Lakoma, Billings, Peters, & Block, 2005).

Finally, effective interdisciplinary collaboration and teamwork are important components of high-quality patient care, especially in complex

clinical areas such as palliative care. However, medical education provides little to no preparation for interdisciplinary practice. Understanding the roles of other disciplines is essential to the interdisciplinary approach in health care and may lead to fewer role conflicts in the health care team (Fineberg, Wenger, & Forrow, 2004).

1.4: Communication with the Dying Patient and their Family

Communication has been identified as one of the most important aspects of care for patients diagnosed with advanced life-limiting illnesses. It is a core and fundamental skill. (Clayton et al., 2012). It becomes especially important in treatment situations such as the challenging transition from curative to palliative care in oncology. In this setting, oncologists are confronted with three core challenges: first, patients require adequate medical information; second, patients need to be supported emotionally by their treating oncologists; third, significant others are frequently involved in palliative care, and this may complicate communication. All three demands are challenging and sometimes overstrain the communication skills of oncologists. With regard to the information needs of patients, oncologists tend to avoid providing prognostic information in the palliative situation, even though most patients and their families wish to be informed realistically. Moreover, oncologists tend to avoid elucidating risks and benefits of palliative chemotherapy in detail. Regarding the emotional needs of patients, oncologists have difficulty exploring psychosocial distress in patients with advanced physical illness like late-stage cancer and often do not address patient cues for emotional support (Goelz et al., 2011).

Communication can be either verbal (spoken, written, word processed, printed or displayed on a screen) or non-verbal (gestures, facial expressions or body language).

Whichever process is used, the communicator must be able to express their ideas effectively because patients and their carers are depending on health and social care professionals to convey information specific to their

individual care. Therefore, effective communication is essential, while ineffective communication is a source of complaint for many patients and their carers (Chan and Woodruff, 1997).

Communication is complex. One of the most important components of communication is listening (Dahlin, 2010) which includes not only hearing the verbal message but interpreting nonverbal messages. The gestures, tone of voice, and inflection, through the physical representation of the message by the sender, are evaluated and understood by the person receiving the message. Communication styles vary across individuals, families, communities, and societies. As such, communication is strongly influenced by culture and the cultural context of communication is an important aspect in palliative care. Interdisciplinary team members should also understand the principles of group dynamics as they concern communication. Only by constantly improving communicative competence can the physician achieve genuine contact with the patient and respond as far as possible to all his needs, including emotional and spiritual ones.

1.4.a The importance of good communication

Research in a variety of settings has found that communication is often suboptimal. For example, in a study of audiotaped initial oncology consultations for patients with advanced cancer, fewer than half of oncologists offered alternatives to chemotherapy as an option, only 58 % of patients were informed of their life expectancy, and only 60 % were aware of risks versus benefits of further chemotherapy treatment. This informational gap can affect patient/family-centered outcomes, such as patient satisfaction, family satisfaction, length of hospital stay, treatment intensity (Fawole et al., 2013).

Effective communication is essential for individuals to make informed decisions about their healthcare and life planning. Medical language can be confusing for the person with cancer. Terms such as “DNR,” “Withhold, Withdraw and Discontinue Treatment,” which are frequently used in palliative and end-of-life care settings, can be easily misinterpreted as

terminating all caregiving. The most important function of communication is to coordinate the activities of all participants in this process. It is not enough to use the same language, but it is necessary to include the experience, values and emotions contributed by each side. Communication skills training is associated with less burnout and work-related stress (Anthony et al., 2005).

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 (Maguire et al, 1996). Compounding these problems is the finding that oncologists lack accuracy in detecting patient distress. Finally, poor communication also hampers a physician's ability to provide pain and symptom management (McCarthy et al, 2000). These studies have led to a widespread call for improving communication between clinicians and patients. Many physicians have not had effective teaching in communication skills and lack confidence that an educational intervention could improve their skills. Furthermore, continuing medical education consisting of lecture-style presentations consistently fail to change physician behavior (Davis et al; 1999).

The responsibility for giving difficult news may come early in training when the attending doctor has little experience. Few doctors receive adequate guidance and help during their initial formative experiences (Lesley & Valerie, 2004). Many doctors also have difficulty handling their own emotions - sorrow, guilt, identification, and feeling a failure are just part of the range of emotions reported. There is little evidence that these difficulties get easier with experience. Inadequate training in communication skills is acknowledged by senior hospital doctors as a major factor contributing to their high rates of burnout and psychological morbidity. In one survey, 89 - 95% of physicians indicated that multidisciplinary training sessions would be helpful. "Learning together allows team members to experience the viewpoints, knowledge, skills, and particular pressures of colleagues in other disciplines." Researchers have suggested that to promote the skills of interdisciplinary collaborative practice, attitudes and stereotyping must be addressed early in professional education.

Also, optimum communication is frequently thwarted by the pressures of time constraints in some health-care systems, together with political imperatives to meet targets and contain costs (Lesley & Valerie, 2004).

1.4.b Truth telling

Truth-telling, such as disclosing factual information to patients and/or their families, 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 patient's possibility for autonomy (Pergert & Lützén, 2012).

Researchers have shown that, although the majority of health care professionals are of the opinion that patients should be told their prognosis as far as physicians can predict this, in practice many avoid discussing this topic or withhold information. Doctors frequently censor information they give to patients about outlook on the grounds that what someone does not know cannot harm them (Slort et al., 2011). Such traditional paternalistic attitudes can still be seen despite moves towards increased autonomy and empowerment for patients. In one US study of physicians working in five hospices, even if patients requested survival estimates, physicians said that they would provide frank disclosure only around 37% of the time, favoring instead either no disclosure or a conscious overestimate (Lamont & Christakis ,2001). 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 to help protect the patient. Prognostic errors are nearly always made in an overly optimistic direction, and they increase the better the doctor knows the patient (Christakis & Lamont, 2000).

According to a study carried on in Europe, South America and Canada, all physicians declared that they would like to be told the truth about their own terminal illness. Yet, just 26% of European and 18% of South American physicians thought that the majority of their patients would wish to know the truth. In the process of deciding how much 'truth' to tell at a certain time, the

health care team may be attempting to be sensitive to the needs and wishes of the patient but is also influenced by the individual attitudes and skills of healthcare staff. (Pergert & Lützén, 2012)

1.4.c Breaking bad news

This is perhaps the communication task that has been studied the most extensively. Bad news can be defined as any information that adversely alters one's expectations for the future. The communicating of bad news about diagnosis or recurrence, or discussion of transition from active curative treatment to palliative care with ill and anxious people are not simple tasks. Patients' perceptions of the way in which doctors deliver bad news alter their understanding, their decisions about treatment options, and later their adjustment. The emotional experience of receiving bad news does not seem to overwhelm a patient's ability to distinguish effective communicator from the less effective (Ptacek & Eberhardt, 1996).

Many studies have been carried out to clarify patients' preferences and experiences in receiving bad news in oncology settings and several clinical guidelines and expert recommendations have been published (Morita et al., 2004). Moreover, recent intervention trials have demonstrated that structured skill training can actually improve physicians' clinical skills in breaking bad news (Shetty & Shapiro, 2012) Morita et al., 2004).

Oncologists break bad news thousands of times during the course of a career and it can be highly stressful. In a large survey of oncologists, 20% reported anxiety and strong emotions when they had to tell a patient that their condition would lead to death (Foley & Gelb, 2001). In a more detailed study of 73 physicians, 42% indicated that the stress from a bad news encounter can last for hours - even up to three or more days afterward (Ptacek, Ptacek, & Ellison, 2001). Giving bad news is more difficult when the clinician has had a long-standing relationship with the patient, when the patient is young, or when firm optimism had been expressed for a successful outcome. On the other hand, when bad news is communicated in an empathic manner it can have an important impact on outcomes, such

as patient satisfaction and decreased patient anxiety and depression; and the physician's caring attitude can be more important than the information or reassurance given (Back, 200).

As with any medical procedure, giving bad news requires a coherent strategy in order for it to be accomplished successfully. In one example the strategy encompasses a series of six distinct communication steps, that can be summarized using the mnemonic SPIKES (Setup/ Perception/ Invitation/ Knowledge/ Empathize/ Summarize and Strategize). This protocol has been endorsed by practitioners and patients (Shetty & Shapiro, 2012).

1.4.d Patients' and families' communication needs

Key to a patient-centered clinical method is the doctor responding in a way in which patients sense that their ideas, feelings, expectations, and fears are understood - essential elements of all end-of-life conversations. Patient-centered communication skills are also essential to physicians because they enable physicians to develop the positive relationships and emotional connections with patients that predict physician satisfaction (Larson, 2000). End-of-life decisions are more than simple technical choices, and involve a complex relationship between physicians, who have to select appropriate treatments, and patients/families, with specific wishes and preferences.

Successful end-of-life conversations help patients and family members overcome the "collapse of personal efficacy" (Larson, 2000) and loss of a sense of control that frequently accompany the diagnosis of serious illness. Other tasks for the end of life, such as reconnecting with one's family, making funeral and/or burial plans, or finding meaning in the dying experience, can be conceptualized within a framework of lifelong human development that helps physicians anticipate the issues patients might be struggling with but which could be overlooked if the patient's distress is the sole focus (Byock, 1996).

Patients have high hopes and expect health professionals in specialist palliative care settings to be able to provide psychological and emotional

support through excellent communication as well as possess expertise in symptom control (Quenot et al., 2012). Patients are well aware when a health care professional is not able to deal with particular issues adequately or comfortably.

How difficult information is received depends on many factors, including expectations, previous experiences, and general personality disposition. Shock, horror, anger, stoic acceptance, disbelief, and denial are all possible reactions, and anyone charged with breaking bad news needs to be able to cope with these emotions. No two patients or relatives will respond in the same way to the same news, but the way in which bad news is conveyed can substantially influence their emotions, beliefs, and attitudes towards the medical staff and how they view their future (Kirk, Kirk, & Kristjanson, 2004). Thus, understanding what is important to patients when sad or upsetting news is given can help doctors redefine how this task is best done.

There is a broad consensus of opinion about how patients want to hear news and what they need to hear (Block, 1998). The need for an empathic delivery was reported in an Australian survey, in which patients with breast cancer wanted to be given the diagnosis and prognosis honestly and in simple language but not too bluntly. The relevant words focus the patients on treatment, quality of life issues, or towards threat and death (Fallowfield & Jenkins, 2004). The difficulty for most doctors is getting the balance right, of being honest but at the same time encouraging, hopeful, and supportive. If patients are to make appropriate decisions about their treatment the content of discussions needs to be honest. In the Fallowfield et al. study (2004) of almost three thousand palliative and non-palliative patients 85% or more of both groups wanted as much general information as possible, good and bad. The response was the same for specific information (Specific name of the illness/ Whether it is cancer/ Week by week progress/ Chances of cure/ All possible treatments/ All possible side effects/ How treatment works/ Specific information preferences).

In another survey researchers concluded that patients wanted their doctors to be truthful, caring, and compassionate, to speak in simple

terms, and to use unambiguous language. Ambiguity is common in cancer consultations. We know that euphemistic expressions are commonly used in an attempt to soften the blow (Fallowfield & Clark,1994) but sometimes healthcare professionals are unaware that they have conveyed the wrong meaning, especially if their nonverbal communication has not been congruent. Research has shown that poor communication when breaking bad news means that patients with advanced malignant disease might be unaware of their diagnosis and, therefore, can misunderstand the therapeutic intent of treatment. Some frequently used words such as “positive” and “negative nodes”, and phrases such as “the disease is progressing” have different connotations when used in a medical rather than lay context and might alarm or falsely reassure patients. Therefore, professional care givers have to simplify the medical language. A failure to give adequate information about test results, potential ways of managing symptoms with different treatments and the true therapeutic aim can leave patients isolated and scared that nothing can or will be done to help them.

Reluctance to give bad news probably reflects the difficulty that the doctor experiences in conveying this type of information as much as a desire to protect patients from the distress such knowledge provokes (Fallowfield, Lipkin & Hall,1998). But avoidance of communication about the reality of a patient’s situation does not protect them from experiencing considerable psychological distress.

The contact with the patient should not be a one-off occurrence, but regular. There should be time to express feelings. Showing empathy to the patient causes them to shed much irritation and anger. The physician capable of conducting an appropriate conversation with the patient and dealing with difficult emotions that accompany a serious illness will more quickly succeed in winning the patient's confidence. After the delivery of such difficult information, the physician should try to display compassion and empathy, and then wait for the reaction on the part of the patient, try to read their emotions and to find out to what extent the message was understood (Kleja, Filipczak-Bryniarska & Wordliczek, 2009).

A terminal illness threatens the patient's identity, makes identification difficult and lowers self-esteem. The terminally-ill patient should be offered psychological care at need. The psychologist can suggest appropriate psychotherapeutic interventions, which will permit the patient to better manage their own feelings. The patient who copes better with their own fears, improves their communication skills, both with the family and with the medical staff. The psychologist tries to help the patient to find a new sense of life and to accept a new temporary perspective, more focused on the present.

Good patient care cannot be planned without taking the family into account. The most serious communication problems arise when the physician denies the affective influence on the relationship between the patient, the physician, and the family (Kleja, Filipczak-Bryniarska & Wordliczek, 2009). Family relations need to be worked on because the progress of a serious illness tends to disrupt them. Family members are being forced to accept new roles and learn new responsibilities. It is necessary to try to resolve family conflicts so that they do not cause unnecessary suffering to the patient.

Holistic palliative care consists in supporting the family, in communicating the necessary information concerning the patient's condition, and helping them provide nursing care to the patient. It is essential to prepare the family for the death of their relative and ensure support after that death. The patient, the family and the interdisciplinary team should set common objectives via mutual agreement. The family needs to be updated on the changing health condition and the prognosis. The relationship between the physician and the family should include room for an expression of feelings and the provision of support. In order to ensure that the family and the patient can make the best decisions, they need to be informed about all the advantages and disadvantages of a proposed treatment. The physician needs to find out what the family already knows about the condition of the patient, and then brief them on the current state of health. The family needs to be helped to show feelings, before setting common objectives and ways to achieve them. It is a mistake to delay such a conversation when it is already known that the disease is terminal. Not only the patient, but also the family uses defense mechanisms to reduce emotional tension.

In Israel, family members have a special role in communicating bad news. Although a clinical guideline recommends that physicians disclose the diagnoses first to patients themselves, it is culturally approved that family members receive the information before patients, and families are requested to decide how and to what degree the patient should be told. Thus, while family members typically receive full medical information, including incurability and estimated prognosis, patients receive information gradually, and often partially, based on their preferences.

1.4.e Interdisciplinary team communication

Although the senior attending oncologist is responsible for communication of prognosis many other disciplines may assist with end-of-life preparation and decision making, including nurses, social workers, home care coordinators, palliative care physicians, psychiatrists, psychologists and spiritual care specialists (Wentlandt et al., 2011). Cancer care is frequently delivered by such a multidisciplinary team and this demands excellent continuity of communication and awareness about what has been said within the team and between individual team members, the patient and their family. Yet team members frequently have little awareness about each other's informational roles and responsibilities. Furthermore, what has been communicated about the diagnosis and prognosis is not well documented in hospital records, and collusion with relatives to deceive patients about the reality of their situation is still evident (Jenkins, Fallowfield & Poole, 2001).

The palliative care team: Healthcare units are exposed to a special emotional load. The continual confrontation with suffering and death and special responsibility for decisions, often of ethical nature, may lead to burn-out. Cooperation and good communication are the most important assets. Mutual agreement and clarity of goals are necessary. Unfortunately, the nature of palliative care work often gives rise to tensions and misunderstandings. A model for the resolution of such conflicts should be in place. Strong feelings should not guide actions but discussion. Members of the interdisciplinary team need mutual support and confidence. Sharing

responsibilities may improve satisfaction and reduce the sense of helplessness. The art of making good decisions is a skill that needs to be developed. When palliative care team members demonstrate recklessness, lack of compassion and overconfidence in the decision-making process, then tension and the number of conflicts increase (Kleja, Filipczak-Bryniarska & Wordliczek, 2009).

1.4.f Staff avoidance of end-of-life conversations

A conversation about end of life care is a moral and professional obligation on all caregivers. Nevertheless, as noted above, they have difficulties in managing these conversations. End-of-life conversations are a consequence of patient-centered medical practice. When these often-difficult discussions are delayed or avoided or are managed poorly the quality of remaining life for patients can be seriously jeopardized.

Physicians are trained to maintain health and fight illness but typically receive little guidance on how to communicate with dying patients and their families. Communicating about the transition from curative or life-prolonging treatment to palliative and symptomatic treatment is a particularly difficult task for oncologists. (Lenherr, Meyer-Zehnder, Kressig, & Reiter-Theil, 2012). According to Morrison (Larson, 2000), physicians avoid end-of-life conversations because they:

1. fear causing pain and bearing bad news;
2. lack knowledge of AMDs and training in delivering bad news;
3. view death as an enemy to be defeated;
4. anticipate disagreement with the patient or family;
5. have medical-legal concerns;
6. feel threatened by such discussions.

Quite a few physicians fear that by taking away the patient's faith in recuperation, they will consequently worsen the patient's physical and mental condition. Paradoxically, research results show that it is precisely a heart-to-heart conversation, taking into account the sensibility of the patient, which helps them maintain hope despite an unfavorable prognosis

and prepare for end of life tasks. The patient, aware of his own condition, is more satisfied with palliative care.

A recent study of how physicians communicate about Advance Medical Directives showed that the conversations averaged 5.6 minutes and physicians spoke for two-thirds of this time, Patients' values and attitudes toward uncertainty were infrequently dealt with, rendering the discussions less useful in terms of decision making (Lenherr et al., 2012). Nevertheless, there are countertrends. Increasing attention to palliative care and the education for physicians in end-of-life care programs has been reported by the American Medical Association (Lenherr et al., 2012). Biomedical rhetoric of death as a "medical failure" now competes with the emerging public rhetoric of "death as a part of life". Surveys among doctors and nurses in the US and UK have concluded that they appeared to be more open than previously to communication with terminally ill patients and their families on issues concerning dying and death (Lenherr et al., 2012). Nevertheless, communication about a patient's end-of-life is not yet a routine part of care.

National guidelines recommend that physicians discuss end-of-life care planning with patients who have incurable cancer and a life expectancy of less than 1 year (Mack, Cronin, Taback, Huskamp, & Keating, 2012). Patients who have discussed their preferences for end-of-life care with a physician are more likely to choose palliation over aggressive measures at end-of-life, more likely to die at home or under hospice care, and more likely to receive care that is consistent with their preferences. Less aggressive care at end-of-life is associated with better quality of life near death. However, involving patients in end-of-life decision making remains an often neglected task in clinical practice (Lenherr et al., 2012). Legal and ethical stipulations mandate appropriate doctor-patient conversation and information as a requirement for respecting patient autonomy, yet an on-site study in a major tertiary-care oncology unit revealed that regardless of patient competency, more than 50% of doctor-patient conversations avoided the topic of treatment limitation, a key issue in end-of-life care (Lenherr et al., 2012).

1.5: Advance Care Planning and Advance Medical Directives

1.5.a Advance Care Planning

Patients suffering incurable diseases, especially in a terminal phase, have a right to be honestly informed about their state of health. There is evidence that patients want to receive information regarding not only their diagnosis, but also their chances of cure, the side effects of therapy and a realistic estimate of how long they have to live, even more often than doctors assume (Ciałkowska-Rysz & Dzierżanowski, 2013). The key terms are:

Advance Care Planning (ACP): a process that allows people to make decisions in advance regarding their medical treatment at the end of life

Advance medical directives (Advance Medical Directives): legal documents representing a patient's end-of-life decisions; may include how patients want medical decisions to be made or whom they would like to make those decisions.

Do-not-resuscitate orders (DNR): state that resuscitation should not be attempted if the patient suffers cardiac or respiratory arrest.

Five Wishes document: a living will that includes personal, emotional, and spiritual needs, as well as medical wishes.

Living will: a legal document indicating personal wishes regarding medical treatments at the end of life.

Medical power of attorney: (also known as a healthcare proxy) allows patients to appoint a trusted person to be their healthcare agent, who is authorized to make medical decisions on the patients' behalf.

Advance Care Planning protects patient autonomy and can communicate patient preferences for care at the end of life. Patients who are near the end of life often prefer treatment that is focused exclusively on comfort; frail elderly patients may choose to trade longevity for quality of life. Advance Care Planning Advance Care Planning includes clear discussions about prognosis, information about Advance Medical Directives, explanation of the Do-Not-Resuscitate option, information about palliative care options (e.g., hospice), and discussion about where patients would

prefer to die (Cohen & Nirenberg, 2011). Another strategy for Advance Care Planning is to focus on who will make the decisions rather than on what those decisions should be. The naming of a friend or family member to serve as a health care proxy (also referred to as assigning a durable power of attorney for health care) gives physicians someone to talk to who can apply the patient's preferences to the existing clinical situation (Adapted from Sabatino).

If physicians take seriously their obligation to engage patients in decisions about their health care, they will initiate discussions of goals and preferences before a crisis develops. Once they begin the conversation, advising patients to appoint a health care proxy and determining the scope of that person's authority will follow naturally. And that is all that American physicians need to do — the idiosyncrasies of state law notwithstanding — to enable their patients to be treated in accordance with their wishes (Kolarik, Arnold, Fischer, & Hanusa, 2002). In patients with advanced cancer, it has been found that simply engaging in discussions about wishes at the end of life with their physician increases the likelihood that care will be consistent with the patient's preferences.

A review of the evidence from clinical research studies finds that the quality of End-Of-Life and Advance Care Planning discussions between patients and their care team are predominantly poor and that there is a substantial gap between what patients want to discuss and what is actually discussed. The review further concludes that lack of knowledge and competency of health workers impacts on the quantity and quality of these discussions (Hannon, Lester, & Campbell, 2012). Wilkinson, Wenger and Shugarman's (2007) review of the literature found that practitioners in the United States receive little or no formal training in initiating and undertaking Advance Care Planning discussions. Nurses too reported that they did not receive enough training on Advance Care Planning, related state and federal laws and on the administrative support needed to initiate Advance Care Planning discussions with consumers. Intensive and community-wide interventions that involve collaborative Advance Care Planning mechanisms

have demonstrated positive results in expanding Advance Care Planning (Wilkinson, Wenger & Shugarman, 2007; Street & Ottmann, 2006).

Despite their value, Advance Care Planning conversations usually occur in the very last stages of life or not at all. Studies have consistently shown that these conversations are not happening (Cohen & Nirenberg, 2011). In a study of hospitalized patients on medical or surgical units, 95% reported never having discussions with their physicians regarding end-of-life care and 51% reported never having such discussions with their family members (Salmond & David, 2005). In a study of patients with advanced cancer (N = 322), only 39% reported they had discussed their wishes for end-of-life care with their physicians (Mack, Weeks, Wright, Block & Prigerson, 2010). To make end-of-life issues less difficult for consumers, families, and caregivers requires that Advance Care Planning conversations take place and take place earlier in the disease process when consumers are better able to understand their options and to make their goals of care known. Unfortunately, Advance Care Planning with community-dwelling older adults does not take place in a systematic way. Moreover, Advance Care Planning is often seen as a single event rather than an ongoing process that empowers patients to make decisions as their health changes (Baughman et al., 2012). Although the lack of Advance Care Planning affects all consumers, it is particularly harmful for vulnerable elders and those with low incomes, chronic disease and a lack of resources, who may not be aware of the benefits of Advance Care Planning or may lack the financial, legal, social, and medical resources to initiate such planning (Gerst & Burr, 2008).

In the United Kingdom the Gold Standards Framework (GSF) is a quality tool that addresses the complex issues in palliative care and encourages health professionals to ensure effective communication with the patient, coordinate their care, control symptoms and support carers (Hannon et al., 2012). The GSF advocates Advance Care Planning for the patient and general practice staff.

1.5.b Advance Medical Directives

Advance Medical Directives are one component of Advance Care Planning. The goals of Advance Medical Directives are to promote patient autonomy in healthcare decisions, match personal values with end-of-life choices, increase the likelihood that patients' wishes are followed, and ease the burden on families and healthcare providers when a patient is unable to make decisions.

Advance Medical Directives are legal documents representing those decisions and can be statements written by patients about how they want their medical decisions made (i.e., a living will) or whom they would like to make decisions if they are no longer able to make them themselves (i.e., power of attorney or healthcare proxy), or a combination of both (i.e., Five Wishes document). A Do Not Resuscitate order states that resuscitation should not be attempted should the patient suffer cardiac or respiratory arrest, and it can be instituted on the basis of an Advance Medical Directives. Recent research has demonstrated that Advance Medical Directives do not decrease the duration of survival and can benefit patients at the end of life (Fischer, Sauaia, Min, & Kutner, 2012).

A qualitative study has indicated that social workers and nurses do complementary work in addressing Advance Medical Directives. The nurses provide additional medical information and the social workers assist in family communication about choices (Baughman et al., 2012).

In a study of 65 patients admitted to an oncology service, 95% believed that discussing Advance Medical Directives was very or somewhat important. 48% preferred the discussion be with their oncologist, 34% preferred their primary care physician, and 11% preferred their admitting physician (Wentlandt et al., 2012). In a smaller sample of hospitalized patients 93% agreed that making an Advance Medical Directives should be done when one was healthy. Although evidence demonstrates patients and families want to discuss Advance Medical Directives, they do not initiate discussions or topics of death and dying unless invited by their oncologist (Cohen & Nirenberg, 2011). Following passage of the USA Patient Self-Determination Act (PSDA) in 1990 Advance Medical Directives

became part of the hospital admission process. Since then completion rates of Advance Medical Directives have, however, remained low at 18 to 36% of adults. Less than half of adults with a serious chronic or life-limiting illness have issued Advance Medical Directives and many physicians are unaware their patients have completed them (Fischer et al., 2012). However, those who have issued Advance Medical Directives may not have them documented in their medical records. In a study of hospitalized patients who had completed Advance Medical Directives, only 31% had it so documented (Douglas & Brown, 2002). In the absence of electronic medical records, Advance Medical Directives are not transferred at the next inpatient admission (Fine, Reid, Shengelia, & Adelman, 2010). Central depositories where individuals can voluntarily deposit their directives can assist the identification of people's wishes. There is some evidence that computer-based systems may improve access to and awareness of Advance Medical Directives, including across providers (Wilkinson, Wenger & Shugarman, 2007).

1.5.c Barriers to Advance Medical Directives completion

Multiple barriers to Advance Medical Directives completion have been identified including language, lack of knowledge, poor communication, and a perception that having family involved obviated the need for Advance Medical Directives (Fischer et al., 2012). Some of the patient barriers to Advance Medical Directives are lack of access to information, negative attitudes toward Advance Medical Directives, denial that Advance Care Planning would be useful, and perceptions that signing Advance Medical Directives would result in inferior care and that patients would be treated differently if they had issued Advance Medical Directives (Douglas & Brown, 2002; Salmond & David, 2005).

Physician barriers: Discussions about prognosis, Advance Care Planning, and end-of-life issues are difficult for healthcare providers. Providers may be overly optimistic, avoid these discussions, communicate with euphemisms, and delay conversations until patients are near death. In a national survey of

physicians caring for patients with cancer, most reported they would not discuss end-of-life options (i.e., Do Not Resuscitate status, hospice enrolment, or preferred site of death) with terminally ill patients (i.e., those with 4–6 months to live) who are feeling well (Keating et al., 2010). Cancer specialists were less likely than non-cancer specialists to discuss Do Not Resuscitate status, hospice care, and preferred site of death (Keating et al., 2010). Asked what was important when discussing the future with terminally-ill patients with cancer and their families, only one healthcare professional participant mentioned Advance Medical Directives or cardiopulmonary resuscitation (Clayton et al., 2005).

1.5.d Shared Decision-Making

Shared Decision-Making is a recent approach that generally involves discussing and respecting patient preferences for participation in the medical decision-making process. It encompasses four characteristics: (1) the involvement of the patient and the physician (at least two participants); (2) information sharing between the two parties; (3) the expression of treatment preferences on each side; and finally (4) a consensus over a treatment plan (Bélanger, Rodríguez, & Groleau, 2011). Decision making in palliative care has a special quality, whereby 'the desired outcomes of a dying person will differ from the outcomes desired when prevention of disease is still relevant or cure is still possible' (Schüklenk et al., 2011).

The dilemma of choosing between life-prolonging treatments with potential side effects or maximizing quality of life generates delicate discussions with patients. Terminally-ill decision makers are faced with difficult decisions about a wide range of issues, such as place of care, various options to treat symptoms, the use of opioids, palliative treatments such as chemotherapy, advance directives, etc. Gaston and Mand (2005) conclude that preferences for participation in decision-making should be assessed explicitly because they are variable, and that more randomized clinical trials are needed to establish the impact of decision aids on this population.

Patients in qualitative studies spontaneously mentioned their participation in various decisions, indicating that it is an issue that matters to them (Bélanger et al., 2011). Seven studies have examined whether palliative care patients generally prefer collaborative roles in decision-making. Five of these studies used the same five-point scale about treatment decisions defining a passive role as (1) the patient wanting the physician to make decisions alone or (2) after considering their opinion, as (3) making decisions together with the physician, as (4) the patient making the final decision either after considering the physician's opinion or (5) alone. According to these five studies, between 40% and 73% of the 379 participants prefer to share treatment decisions with their physicians (Schüklenk et al., 2011). The few existing studies suggest that expressing preferences about everyday routines of care was a way for patients to maintain control (Bélanger et al., 2011). In three other studies researchers concluded that shared decision-making and giving informed consent receive little explicit attention. Treatment options and informed consent were discussed explicitly in less than 50% of consultations (S. Smith, Kuehn, & Jr, 2012). Given the documented variations in patient preferences, the meaning of their perceptions becomes difficult to interpret.

Barriers and facilitators to Shared Decision-Making in palliative care: Patients and health care providers seem to prefer a gradual and slow process of information sharing. In practice, this often translates into patients not being adequately informed to make important end-of-life decisions (Schüklenk et al., 2011). Maintaining realistic expectations with regard to palliative treatments was also challenging in decision making, because patients perceived chemotherapy or surgery as their last hope or option (Cohen & Nirenberg, 2011). When the benefits of an intervention are not discussed and understood by patients it threatens not only their ability to participate in decision-making, but also the quality of the decisions that can be made if they do participate. Drought and Koenig (2002) found that: 'options for palliative end-of-life care simply fell into place and ceased to be choices when the patients reached a physical state in which the fact of dying could no longer be ignored or denied'.

The strategies for expanding Shared Decision-Making include presenting bad news in a context of choice, teaching about prognosis and treatment choices to create new expectations, enhancing opportunities for choice, and respecting and advocating patient choices (Bélanger et al., 2011).

1.5.e Informed consent

Informed consent to treatment is not only a legal requirement but also a moral imperative. The legal requirement of informed consent is based on the value of patient autonomy and self-determination (Schüklenk et al., 2011). Every human being of adult years and sound mind has a right to determine what shall be done with his or her own body (Cohen & Nirenberg, 2011). This goal is effectuated by allowing patients to make their own decisions about their healthcare based on their own values for as long as they are able. A second goal of informed consent is to empower patients to exercise their right to autonomy rationally and intelligently. There is no assurance that providing patients relevant information about treatment will result in patients' making intelligent decisions, nor does it guarantee that they will use the information provided, but without such a requirement, the likelihood of rational decision making diminishes. The patient's right to consent presumes that the patient has sufficient information to make a reasonable decision. Consent to treatment is only valid when the patient has the capacity to consent (Fischer et al., 2012).

Competence is not the same as capacity, yet they are frequently considered to be synonymous. The competence to make healthcare decisions is a legal term that is determined only by a court of law. The law presumes that all adults are competent and have the ability to make their own decisions, including about healthcare, and this assumption is ordinarily correct (Wentlandt et al., 2012). To be considered competent, an individual must be able to comprehend the nature of the action in question and understand its significance. However, a patient need not be adjudicated incompetent to lack the capacity to consent to medical treatment (Schüklenk et al., 2011). Capacity is determined not by the courts but rather

by clinicians who assess functional capabilities to determine whether capacity is lacking. Incapacity is not determined solely by a medical or psychiatric diagnosis but by clinical assessment of the ability of the patient to give valid consent (Fischer et al., 2012).

Israel's Patients' Rights Act, 1996, makes clear demands on medical staff with respect to obtaining patients' informed consent. In summary it states:

- No medical care shall be given unless and until the patient has given his informed consent to it and the clinician has supplied the patient - at the earliest possible stage - medical information such as to enable the patient to decide whether to agree to the treatment proposed;
- The strict conditions under which medical treatment can be given without obtaining informed consent;
- The patient is allowed to appoint an official representative who shall have the authority to consent in his place to medical treatment.

1.6: A Good Death and Ethical Issues

1.6.a A good death

Quality-of-life research in terminal patients focuses on two main issues: end-of-life quality and quality of dying (good death). Although the two terms may be used interchangeably, they have some conceptual differences. End-of-life quality is a multidimensional concept which emphasizes terminal conditions, life experiences, and perceived wellbeing in dealing with terminal conditions (K.-K. Leung, Liu, Cheng, Chiu, & Chen, 2009). Quality of dying is defined as a personal evaluation of the dying experience as a whole. Compared to the volume of research on the quality of end-of-life for terminal patients, very few studies have been made into a 'good death'. From the limited literature, researchers have identified several domains of a good death—domains of the dying experience, preparation for death, personal growth, meaning of life, peace, sense of completion, preparation for death, timeliness, and issues of spirituality (K.

Leung et al., 2010). While there is no consensus on the time frame of a good death, it usually refers to conditions in the last week or days of life.

The need to provide high quality end-of-life care during dying is essential. The needs of dying people may include, but are not limited to, knowing when death is coming, understanding what can be expected, being able to maintain a sense of control, having their wishes respected, having access to information and high-quality care, and having access to spiritual and emotional support as required (Chan & Webster, 2011).

Primary variables: (1) Severity of physical symptoms; (2) Severity of psychological symptoms (measured by any instrument); (3) Quality of life (measured by any instrument); (4) Harms (any adverse effects as determined by researchers, health professionals or careers /families). (Chan & Webster, 2011).

Secondary variables: (1) Has advanced care planning happened or not?; (2) Communication between healthcare staff and family; (3) Caregivers' wellbeing; (4) Grief and bereavement; (5) Patient/ staff/ caregivers' satisfaction; (6) Staff confidence; (7) Cost of intervention or cost of care; (8) Medication/ treatment use; (9) Spiritual needs (Watts, 2012).

Achieving a 'good death for all' is a prominent social and political priority across the western world (Watts, 2012). Influenced by concerns regarding the care of dying people as well as by scientific advances and debates about assisted suicide and euthanasia, strategic documents privilege the pursuit of a 'good death' by raising the profile of dying people's needs and preferences, prioritizing choice, inviting individuals to plan for their dying and encouraging the use of end-of-life care pathways (Scarre, 2012).

Factors promoting/ preventing a good death: The thing that staff knows the dying person, respect his/ her wishes and provide individualized care are considered key factors. Offering patients choices and control over decision making is also important (Casey et al., 2011). The main barrier to a good death is staff's personal fears and anxieties about death and dying may lead to a self-protection process which manifests itself as avoiding developing close relationships and emotional engagement with the dying

person (Costello 2001). Staff may resort to using superficial communication, and blocking techniques (Watson et al. 2006), ignore cues or change the topic when clients attempt to discuss death/dying (Costello, 2001). This process creates a closed awareness around death, where everyone knows the client is dying but it is not openly discussed (Costello, 2001). An ethos of open communication between staff and clients regarding bad news, prognosis and treatment options are therefore important for good end-of-life care (Phillips et al. 2007). Other barriers are: role ambiguity and lack of multidisciplinary teamwork, staff shortages, financial constraints, time constraints, short-term relationships in busy acute settings, lack of support and poor communication between nurse and physician. (Casey et al., 2011) In acute hospitals, ensuring privacy when access to single rooms is limited can be difficult (Clarke & Ross 2006). The literature also mentions staff's lack of palliative care and end-of-life training (Hanson et al. 2002), including on medication and symptom management (Watson et al., 2006).

1.6.b Ethical Issues

The four basic principles of contemporary bioethics: Hippocrates thought that the first duty of a doctor is to do good or at least not to harm. Moreover, he deduced from this general duty a number of concrete consequences which are reflected in the Hippocratic Oath. For many centuries the ethical principles and values contained in this Oath were applied without further questioning of their origin or validity. Under the influence of positivism, this approach to medical ethics came to be regarded as 'naive'. Ross' establishment of *prima facie* duties and their robustness under ethical analysis was considered a more 'scientific' approach to ethics, at least in the Anglo-Saxon world (Fasouliotis & Schenker, 2000). As a result of the application of this approach to medical ethics a trend arose known as *principlism*. This approach claims the existence of four self-evident ethical principles that serve to represent and codify the main values underlying medical ethics:

- Non-maleficence – do not harm (minimize the harm);

- Beneficence – do good (always act in the patient’s best interest);
- Autonomy – acknowledge the patient’s rights to self-determination;
- Justice – allocate healthcare resources equitably and according to need (Baumann et al., 2013).

Value in cancer care from a patient-centered perspective might be viewed as the net benefit of the treatment in terms of patient goals, the treatment's negative effects and its economic cost. This includes the value of receiving a treatment, the opportunity costs of forgoing other treatments or of ending a treatment which is no longer effective, and the potential alternative uses of health care resources. It also incorporates elements of fairness. This definition of the value of cancer care not only requires full oncologist-to-patient communication of information about potential treatments, but also imposes on the oncologist a responsibility to evaluate the value of cancer therapies and to offer to patients only those potential therapies that are appropriate. The oncologist must also be in contact with the family physician to make the transition to palliative care easier.

These tasks require making explicit evidence-based decisions and employing highly developed communication skills. The decisions are guided by the physician’s professional responsibility to use healthcare knowledge and resources in a responsible fashion to the benefit of their patient in the context of the entire health care system (Casey et al., 2011). This is a complex process in which the oncologist must accomplish the following tasks:

- Identify the spectrum of treatments indicated for the patient’s condition;
- Understand the patient's preferences and goals in order to inform the patient about options;
- Advise the patient concerning their choice of cancer care.

The oncologist is the central clinical figure in cancer care and plays an essential role - both individually and as member of a professional group - in ensuring value in oncological care and in helping to make resource allocation decisions. Cost-effectiveness analyses frequently inform the physician and patient about the attendant costs of a chosen treatment,

although these are rarely borne to a great extent by the patient, diminishing - to some degree - their relevance (Wenger & Vespa, 2010).

Understanding the goals of the patient with advanced cancer is critical to proposing the next set of treatment options, because strong forces are ranged on the side of providing additional therapy, even when the treatments may not be consistent with the patient's overall goals. Studies in the U.S. and internationally show that patients sometimes want cancer treatment that clinicians might not be willing to accept because of its high toxicity and a low probability of benefit. Furthermore, although a patient's evaluation of their prognosis and their desire for aggressive, life-sustaining treatment both decrease as the end of life nears, patients' prognostic estimates are often unrealistically optimistic (Wenger & Vespa, 2010) When we cannot maintain the above ethical principles dilemmas ensue. We set out here a number of potential dilemmas:

Truth-telling: A good part of the literature on truth-telling deals with the shift in physicians' attitudes and practices toward open disclosure of diagnosis and prognosis with the aim of promoting patients' autonomy, control, and participation in the medical decision-making process. This shift is illustrated by the findings of a survey conducted among a sample of U.S. physicians in 1961. 90% reported a preference for not telling a patient with cancer his/her diagnosis; but in 1977, with the same questionnaire, 97% of responding physicians upheld disclosure of cancer diagnosis. Telling the truth has become especially important in the case of life-threatening diseases (Peretti-Watel et al., 2005).

However, in Italy, Spain and Greece traditional medical practice is not to disclose a cancer diagnosis and prognosis to the patient, so that the problem of communication in oncology is far from solved (Elliott & Olver, 2011). Another study found that 90% of non-cancer patients surveyed wanted complete or partial knowledge of their cancer diagnosis, yet 70% of that same sample also indicated they would prefer that information about the diagnosis be withheld from a relative who had cancer (White et al., 2011). A survey that explored disclosure practice among physicians enrolled in a bioethics course, found that less than half would inform patients of a

cancer diagnosis and their prognosis if the patient wanted to know but the family members were opposed to the patient's knowing.

Palliative sedation: This is considered to be an appropriate option when other treatments fail to relieve suffering but there are important questions associated with it. For instance, how deep must the sedation be to relieve suffering and how important it is for patients and their families for the patient to maintain a certain level of consciousness (Swart et al., 2012). An important reason for continuous deep sedation being thought of as controversial is the possible association of this practice with the hastening of death, although it is also argued that palliative sedation does not shorten life when its use is restricted to the patient's last days of life (Sykes & Thorns, 2003).

Withholding nutrition/ hydration at the end of life: When a person is too ill to eat or drink, a clinical decision must be made about providing nutrition and hydration through intravenous hydration and a feeding tube or total parenteral nutrition. As in the clinical use of any medical device or treatment, this decision should be based on medical need and the burdens and benefits of the treatment. Physicians generally do not have a problem with starting such treatment but withholding or withdrawing it at the end of life is often disturbing for both physicians and family members. Although physicians have become more skilled at medical-ethical decisions to withhold or withdraw treatments such as cardiopulmonary resuscitation, kidney dialysis, and mechanical ventilation, forgoing nutrition and hydration remains problematic for them. One study showed that physicians were reluctant to stop nutrition and hydration even when the burdens of treatment outweighed the benefits (Slomka, 2003). Another demonstrated that physicians have biases about which treatments should be forgone at the end of life and are reluctant to withdraw nutrition and hydration (Asch et al., 1999). This reluctance 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. For example, the American College of Physicians states in its ethics manual, "Artificial administration of nutrition

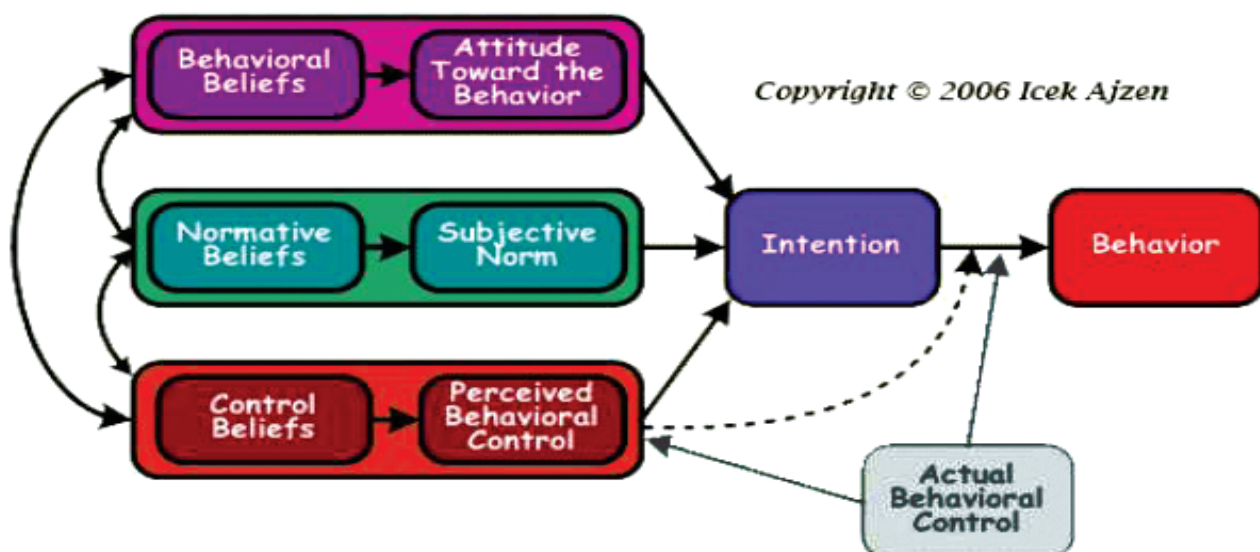
and fluids is a life-prolonging treatment. As such, it is subject to the same principles for decisions as other treatments.” (American College of Physicians, 1998). Nevertheless, some physicians consider medically provided nutrition and hydration a basic human need, and they fear subjecting the patient to a painful death through starvation and dehydration. Other ethical issues are the withholding or withdrawing of treatments such as cardiopulmonary resuscitation, kidney dialysis, and mechanical ventilation. Closely following medicine's ethical principles does not solve all problems but can be a guideline to preserving the autonomy of the patient as much as possible.

Chapter 2: THEORETICAL FRAMEWORK

2.1: The Theory of Planned Behavior

Since Wicker's (1969) review of research into the relations between attitudes and behavior and his conclusion that attitudes probably do not predict behavior, social psychologists have sought to improve the predictive power of attitudes. In recent years, the main approach within this area has been to develop integrated models of behavior, which incorporate, in addition to attitudes, other determinants of behavior, such as social norms and intentions (Olson & Zanna, 1993). Arguably the most widely researched of these models are the Theory of Reasoned Action (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) and the Theory of Planned Behavior (Ajzen, 1988, 1991). The second theory (TPB) essentially extends the first (TRA) by incorporating control beliefs and perceived behavioral control.

Fig. 4: The Theory of Planned Behavior



According to this model, the most significant factor affecting a given behavior is the person's intention to perform that behavior, 'intention' being understood as a conscious decision to implement or try to implement the behavior in question. People with stronger intentions invest more effort to achieve their goals.

Secondly, human behavior is guided chiefly by three kinds of beliefs: (a) beliefs about the consequences of performing a given behavior (Behavioral beliefs), (b) beliefs about the expectations and norms of significant others with respect to that behavior (Normative beliefs), and (c) beliefs about factors that may promote or hinder implementation of the behavior (Control beliefs).

Behavioral beliefs generate the individual's overall stance with respect to a behavior, their overall evaluation, positive or negative, of persons who perform that behavior.

Normative beliefs refer to the individual's subjective perception of social norms with respect to a given behavior, in particular the perceived norms and expectations of their significant others.

Control beliefs refer to the individual's perception of his/her own ability to maintain control of their behavioral intentions, that is, their overall assessment of their ability to decide whether they will perform the behavior and their perception of the ease or difficulty of performing that behavior. These beliefs include the impact of perceived internal control factors (such as self-efficacy and ability) and external control factors (such as encouragement and constraints). In some cases, there is a direct relation between this 'perceived behavioral control' and the behavior itself (Terry & O'Leary, 1995).

The combination of these three types of belief - attitudes, perceived social norms and perceived behavioral control - generates a behavioral intention. Persons who have made a positive assessment of the behavior in question, who believe that their significant others would support them in carrying out the behavior, and who perceive that executing the behavior is under their own control, are likely to have a strong intention to perform the behavior (Ajzen, 2006). According to Ajzen (1991), the relative importance of

these three factors - attitudes, perceived norms and perceived behavioral control - is likely to change according to what behavior is in question and the situation in which it is to be performed. Thus, each of the components of behavioral intention has to be given its due weight in predicting behavioral intention.

Since in many practical situations there are factors/problems which limit an individual's volitional control, a further assumption of the model is that only when perceived behavioral control is sufficiently high can a person be expected to carry out their behavioral intention when the possibility of doing so arises. In other words, intention is only one of the predictors of behavior. If people are realistic in their judgment of the difficulties in performing the behavior, their perceived behavioral control can also contribute to the prediction of the behavior under consideration. It is also important to note that to predict behavior using this model, the behavior must be well-defined.

The model of the Theory of Planned Behavior (Terry & O'Leary, 1995) is also a model of anticipated value. An individual's overall attitude toward a behavior is determined by the product of their perceived probability of the behavior's outcome (the expectation component) and their subjective assessment of this result, namely the importance to them that this outcome will indeed occur (the outcome element).

Subjective norms are determined by the product of the perceived likelihood that people meaningful to the individual approve of/ object to the given behavior and the individual's motivation to comply with these significant others.

Perceived behavioral control is determined by the product of the perceived likelihood of resources for or barriers to performing the behavior and the perceived strength of these resources/ barriers.

As well as indirect indicators of a person's attitudes, subjective norms and perceived behavioral control, these variables can also be directly measured by semantic evaluation scales (Ajzen, 2006). According to Ajzen (1991), studies of the relation between direct and indirect measures of association have generated only moderate results, which, he argues, do

not represent the causal effect either of attitudes, subjective norms or perceived behavioral control. Formulas involving multiples of elements fail accurate description of the process by which beliefs generate the model's features. Therefore, there is a need to develop alternative models to describe this process. As a result, many studies into the model of the Theory of Planned Behavior have deployed direct measures only.

Cancer patients have a range of unmet needs, informational, physical, psychosocial, practical and spiritual. Even those suffering painfully from advanced cancer and who need hospice services fail to receive the care capable of addressing these needs. In my proposed research I will deploy the Theory of Planned Behavior to understand health professionals' attitudes and intentions with respect to patient referral to hospice care. The Theory of Planned Behavior has been suggested as a suitable framework for identifying potentially modifiable variables which predict resort to hospices services at the end of life and the implementation of the Terminally-Ill Patients Act, 2005. In one such study Yu et al. (2012) used the Theory of Planned Behavior to examine oncology professionals' patterns of referral to community and psychosocial support services, including complementary therapies. They found that interventions were necessary to help healthcare professionals develop a culture, which recognizes the importance of addressing a wide range of patient needs across the cancer trajectory. Education and support for health professionals is required to ensure that they feel comfortable with discussing patient support needs and with referring them to appropriate support services.

We have found no research study which specifically investigates physicians' referral of patients to hospice care. The present research will contribute to the understanding of existing barriers that health professionals face in meeting the needs of oncology patients and in coping with both their own and their patients' uncertainties.

2.2: Palliative care and the Terminally-Ill Patients Act, 2005

Palliative care has changed from primarily applying to end of life to becoming applicable at all stages of life-threatening disease. Psychological, social, spiritual, and cultural elements are now as important as the control of pain and physical symptoms (Jaiswal, Alici, & Breitbart, 2014). For instance, Kissane and his group describe a treatment approach for demoralization syndrome that is both multidisciplinary and multimodal. It consists of:

- ensuring continuity of care and active symptom management;
- ensuring dignity in the dying process;
- utilizing various types of psychotherapy to help sustain a sense of meaning, to limit cognitive distortions and maintain family relationships (i.e. meaning-based, cognitive-behavioral, interpersonal, and family psychotherapy interventions);
- using life review and narrative;
- paying attention to spiritual issues;
- using pharmacotherapy for co-morbid anxiety, depression and delirium.

The goal of this approach is to restore hope by valuing and affirming the story of an individual's life, their roles, accomplishments and sources of fulfillment (Kissane et al., 2009).

Trans-cultural palliative care deals with the understanding and evaluation of cultural factors in advanced disease and end-of-life care. It takes into account the different cultural, religious, ethnic, and ethical value systems, and it bridges the gap between different cultural contexts by a more fulfilling communication between the care providers and patients and their families. (Bell, Somogyi-Zalud, & Masaki, 2010).

The key provisions of Israel's Terminally-Ill Patients Act, 2005, which relate to the provision of palliative care, are summarized below: (the full text of this key legislation is given as a link in Biography).

- The Act regulates the medical treatment of the terminally ill patient based on an appropriate balance between the value of the sanctity of

life, the value of the individual's autonomous will, and the importance of quality of life.

- A terminally-ill patient shall not be excluded from the presumption that he wishes to continue living, and medical treatment shall not be withheld from him under the provisions of this Act, except in accordance with the conditions enumerated.
- A responsible physician is authorized to determine that a patient is a terminally-ill patient, if satisfied that the patient is suffering from an incurable medical problem and that his life expectancy, even if receiving medical treatment, does not exceed six months.
- A responsible physician is authorized to determine that a terminally-ill patient is an end-stage patient, if satisfied that he is in a medical condition in which a number of vital systems in his body have failed and his life expectancy, even if receiving medical treatment, does not exceed two weeks
- Where a terminally ill patient who wishes to prolong his life and requests medical treatment that the responsible physician considers to be unjustified under the circumstances, his wish should be respected. When a competent terminally ill patient does not want his life prolonged his wish should be respected and his medical treatment withheld.
- Nothing in these provisions shall permit an act, even if constituting medical treatment, which is intended to cause death, or which will almost certainly result in death. Nothing in the provisions of this Act shall permit any act, even if constituting medical treatment, that contributes to assisted suicide.
- Article E: Palliative care: The responsible physician will make sure that everything possible is done in order to alleviate the pain and suffering of a terminally ill patient, even if this involves a reasonable risk of the patient's death, including by means of medication, pain killers, or psychological methods, nursing, and environmental measures, and all in accordance with the appropriate principles of palliative care and in accordance with the conditions and arrangements prevailing

from time to time in the Israeli health care system, and in accordance with the wish of the terminally ill patient, pursuant to the provisions of this Law and pursuant to the provisions of the Patient's Rights Act.

- The responsible physician will make sure that everything possible is done in order to alleviate the burden on the family members of a terminally ill patient and to ensure their wellbeing during the patient's stay in the medical institution, all in accordance with the appropriate principles of social work and palliative care and in accordance with the conditions and arrangements prevailing from time to time in the Israeli health care system.
- Chapter 5: Advance Expression of Wishes: A competent person is entitled to give advance medical directives in which he explains his wish in detail with respect to his future medical treatment if it is determined that he is an incompetent terminally ill patient. Advance medical directives will be given after the person giving the directives has received from a physician or a certified nurse such medical information as is reasonably required for the sake of providing advance medical directives. Advance medical directives shall remain valid for five years after the signing date and their validity may be extended for additional periods, each one of which shall not exceed five years.
- Advance medical directives that do not comply with all the provisions of this section or advance medical directives that have expired are not valid, but the responsible physician should examine them and may take them into consideration.

Chapter 3: TRUTH-TELLING

3.1: Truth-telling

A study in Israel that examined the truth in doctors showed that Truth-telling, such as doctors telling the truth about a patient's illness, prognosis and treatment plan to the patient and/or their family, 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 patient's capacity for autonomy (Pergert and Lützén, 2012). Non-truth-telling can also mean that no Advance Medical Directives (AMDs) are drawn up and no end-of-life (EOL) planning is carried out. Yet in this 21st century non-truth-telling is still common.

This book explores and measures the extent of non-truth-telling to cancer patients in Israel's modern health care system, why it happens and what consequences it leads to.

3.1.a Investigation methodology and research design

There were two main tools. The first was a qualitative structured in-depth interview of 15 doctors, five each from the fields of oncology, hospice home care and family medicine. It asked how they saw the Terminally-Ill Patients Act being implemented, about their approach to the care of terminally-ill patients and palliative and hospice care, about their conduct of EoL and AMD conversations, about coping with the challenge of truth-telling and communications skills, about the barriers to transferring patients to hospice and palliative care. The second tool was a much longer quantitative self-administered questionnaire for 90 palliative care practitioners (30

hospital oncologists, 30 home care specialists, and 30 family medicine specialists) covering their knowledge of, and attitudes to, topics such as the implementation and core principles of palliative care and Israel's Terminally-Ill Patients Act, communication issues such as truth telling, drawing up AMDs and EoL planning, the handling of ethical issues in palliative care and the Act's implementation, such as the transition from curative to palliative care.

The research population for the study was all the doctors working regularly in the field of palliative care, in both hospital, community and home care settings. The hospital sector was represented by hospital doctors working in a range of departments (family medicine, geriatrics, internal medicine, oncology and others). The community medicine sector was represented by doctors working (a) in community clinics and (b) home-care units. The sample was made representative of the research population by ensuring that 20% of the doctors sampled were Arab-Israelis, that it was geographically heterogeneous and that all four major health management organizations participated. The sampling method combined cluster sampling, directed and convenience sampling. Data were analysed by content analysis and descriptive statistics (chiefly means and correlations).

3.1.b Israeli's health care system and its provision of EOL care

Israel's population has for decades been served by an advanced health care system which aims to emulate American and European best practice. Since 2005 the Israeli healthcare system has been making a strong effort to improve its medical training new graduates are very soon involved in clinical care, of which the care of terminally-ill patients will be part and only a small minority of them will have been trained for this element of their daily ward practice. In Israel as elsewhere it is usually regular doctors and nurses who are often 'left' to care for dying patients, and many feel unprepared for this role (Gibbins et al., 2011). End-of-life training is more conspicuous by its absence than presence and what did exist was not powerful enough to give trainees new insights or alter entrenched attitudes.

Palliative care was provided in the main in Israeli general hospitals. Hospice care was available for the six months before death but, in practice, its duration varied widely, suggesting different perspectives on the appropriate timing for the transition from curative care to palliative care. The four main health management organizations also operated some eighty Home Care Units which provided medical, nursing and rehabilitation care across the country for bed-ridden persons in their own homes.

In 2005 the Terminally-Ill Patients Act was passed. The Act was designed to regulate the care and treatment of incurable, terminally-ill persons, striking a balance between the values of the sanctity of life, recognition of the patient's autonomy of choice, and the importance of the quality of life beyond the importance of life itself. It instituted the instrument of Advance Medical Directives (AMDs) by which an individual state their wishes as to how they should be medically treated should they become terminally-ill and lose lucidity of mind. These advance instructions may be designed to rule out life-prolonging treatment or to constrain attending physicians to give such treatment even when they do not consider it medically justified. A patient's right to consent or not to any particular form of treatment had already been set out in the Patients' Rights Act, 1996, (Ministry of Health, 1996).

The provisions and non-provisions of the 2005 Act most relevant to truth-telling were the following:

1. It required that the patient be given full information as to his/her treatment and care choices, according to their capacity to take that information in. It laid down that the patient had the right to know, the right to be told the truth and the right to prepare for death;
2. It defined the concepts of a “terminally ill patient” and an “end-stage patient”;
3. It introduced the concept of Advance Medical Directives and required doctors to respect them;
4. It laid down that any decision in AMDs shall be made only by the individual themselves and of their free choice, not by their family members and not according to any other consideration;

5. It laid down the importance of alleviating pain and suffering even if this involved a reasonable risk of the patient's death;
6. It stressed the importance of the “personal physician” holding an end-of-life conversation with the patient as a key to enabling the patient to realize the above-mentioned rights, but it did not specify who that physician is.

3.1.c Findings

(a) What truth do patients not get?

We can distinguish here between (a) truth telling about the patient’s illness, its prognosis and treatment plan, and (b) truth telling about EOL planning, AMDs and the resort to palliative care (see Discussion).

- No less than 78% of doctor-respondents admitted giving their patients only partial information about their medical condition;
- For a variety of reasons, most doctors avoided end-of-life conversations, at the best preferring to wait for the patient to broach the issue;
- In the qualitative interview all family medicine practitioners and oncologists declared that they avoided ‘ethical issues’ such as abandoning curative treatment for palliative/ hospice care and planning for death;
- Only 37% of doctor-respondents said that they frequently, or more often, "encourage my terminally-ill patients to draw up Advance Medical Directives";
- In Israel, family members have by custom had a special role in communicating bad news. Although the 2005 Act requires that physicians disclose diagnoses first to patients themselves, whether the family agree or not, it has long been culturally approved that family members receive the information before patients, and families are requested to decide how and to what degree the patient should be told. Thus, while family members typically receive full medical information, including incurability and estimated prognosis, patients receive information gradually, and often partially, based on their preferences.

(b) Why do patients not get the truth?

Potential obstacles to truth-telling reflect attitudinal, informational, economic, societal, and system barriers that are perceived differently by patients, physicians, and health care administrators. Last but not least, we should not forget that every doctor brings his/her own personal values onto the ward.

(b1) Beliefs/attitudes

- Over 77% of doctors believed that "concealing information from the patient can sustain his/her hope and prevent harm";
- Almost 70% of doctors agreed *in principle* that "A multiplicity of treatment options is an obstacle to holding a conversation with the patient about end-of-life and a change in treatment goals";
- Israel oncologists are trained to cure and hate to admit failure in this regard. Respondents claimed in interviews:
 - "Telling a patient their treatment goal has changed is not an automatic thing with me. It's easier to mend a broken leg or give antibiotics, easier to play the role of healer rather than talk about death, with all its sense of medical failure;"
 - "We have been taught to treat to the end. I never give up. Nowadays I have a wide range of treatment options I can offer."

(b2) Doctors' knowledge of the Terminally-Ill Patients Act, palliative care, and EOL planning**The Act:**

- The great majority of respondents reported being given no formal training in the provisions of the Act. They picked up information about it at conferences or study days but had not studied it deeply or systematically;
- Those doctors who had a more thorough knowledge of the Act's provisions said, nonetheless, that it was complicated and hard to understand. Less than 30% of doctors felt "that I have mastered the provisions of the Terminally-Ill Patients Act". No more than 28% were aware of the Act's definition of 'terminally-ill'. Most doctors reported that they were not in a position to initiate an end-of-life conversation

with a patient because the Act was not clear enough on when curative treatment should give way to end-of-life care. 61% were unable to distinguish accurately between 'hospice care', 'terminal care', 'palliative care' and 'supportive care'.

- Doctors versed in the Act and the various aspects of palliative care had positive attitudes to truth telling and palliative care;
- Doctors trained in palliative care and the Act had considerably more knowledge about starting/ transitioning to palliative care than doctors without this training. They also knew more about the ethical issues associated with the Act;
- The more doctors know about the effects of telling patients the truth the more positive their attitudes to doing so.

Palliative Care:

- Doctors trained in palliative care were, overall, more positive in their attitudes to that form of care and its component elements;
- 72% agreed that they "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;
- 69% agreed with the statement that "Not infusing liquids into the patient in hospice care symbolizes for me that this form of care shortens life";
- The more they know about palliative care the more positive their attitudes to it and to telling patients the truth about their prognosis;
- Only 54% of the doctors agreed that "Terminally-ill patients should get palliative care in the last 6 months of their life", i.e. the point in time when palliative care should begin and which is core to the 2005 legislation but more than half the doctor-respondents were unaware that its timing had been so fixed.

EoL planning:

- 91% of doctors felt that their "limited ability to predict when a patient will die holds me back from initiating an end-of-life conversation", that is, they felt the patient was not terminally-ill enough;

- 88% felt that their "lack of time is an obstacle to holding difficult end-of-life conversations";
- 93% of doctors felt that their "lack of communication skills training is an obstacle to holding end-of-life conversations".
- Doctors felt that, lacking knowledge about palliative care, it was best they shied clear of EoL conversations with patients for fear of doing them harm.

(c) Lack of Training

- Almost 70% of doctors agreed *in principle* that "A multiplicity of treatment options is an obstacle to holding a conversation with the patient about end-of-life and a change in treatment goals". Yet this "multiplicity of treatment options" is a sign of progress in healthcare, in that it provides doctors more treatment options to offer a patient than was the case in the past. In other words, they had not been trained in a modern-day approach to EoL care and treatment.
- Two-thirds of doctors agreed that "A doctor's work with terminally-ill patients is made more complicated by ethical, social and religious issues".

Israeli oncologists perceived in themselves a general lack of the skills to handle EoL planning and care. As for which communication skills would make it easier to transfer patients to hospice care and get Advance Medical Directives drawn up the respondents cited the following:

- 75% - Medical training which teaches communication skills, not only medical procedures;
- 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 end-of-life conversations;
- 55% - Listening skills;
- 30% - Confidence in the way you practise medicine, not necessarily in your medical knowledge per se;
- 20% - Self-awareness.

(d) Conditions of work/systemic factors

- Organizational barriers included lack of staff and beds for hospice care, both in inpatient and at home, and hospice care not having a clear place on the agenda either of healthcare institutions or of the Israel Ministry of Health.
- "Passing the Act does not mean it automatically gets implemented. The reality in oncology is that we are dependent on the media, on the state-sanctioned basket of drugs and therapies, on private health insurance policies, and so we find ourselves giving curative treatment to the end."

(e) Doctors' emotional resources

- Over 75% stated that "Disclosing the truth to the patient can cause me embarrassment and unease at how they (patients) will react";
- Over two-thirds agreed that "An end-of-life conversation with the patient raises the issue for us of our own death. As physicians, fears of our own death influence extensively how we face up to the end-of-life issue";
- "I do not initiate discussing such sensitive issues. I stick to the medical facts. I wait for the patient to raise such a matter and then I lay stress on, for example, the importance of quality of life;
- "I wait for the patient or the family to raise such a matter. I know I should take the first step but in practice I am not up to it. I simply do not have the strength for it";
- As for Advance Medical Directives: "I just cannot look the patient in the eyes and say to him. 'Let's fill out some forms about your death.'" So, I just answer questions when I'm asked them and where I think it necessary bring in a social worker."

(f) Patients' attitudes

- Many patients do not want to hear the full truth about their condition (or at least that is what their family maintain);
- Others want their physician to take the decisions alone;

- Still others insist on every possible curative measure being attempted until the end and will listen to no other option.

(g) Family resistance

Almost every doctor agreed that "Sometimes it is the family that is the main obstacle to referring a patient to hospice care". Yet the Act lays down that if a patient is cognitively competent to take decisions for himself/herself the family has no right to prevent a doctor discussing different care options with the patient.

(h) Not clear who is responsible for telling the patient the truth

Every doctor thinks it is another doctor's job to inform the patient of a change in treatment site or goals. Patients themselves, at least those treated in hospitals, have no such doubts: they expect their oncologist to break bad news, after all he/she and their team have usually been caring for the patient for some time. Unfortunately, the 2005 Act is no help: it lays the responsibility on the patient's "personal physician" but does not say which doctor occupies this role.

(i) The gap between what doctors declare and what they practise

We see a wide gap between doctors' principles or at least what they feel they ought to declare as their principles and their behaviour in practice.

- 80% of doctors reported that they "prefer to be told all the details of a patient's personal story". They wanted to know as much as possible about the patient's circumstances in order to manage their own situation vis-à-vis the patient. That is, they wanted more for themselves than they were willing to give the patient.
- Only 37% of doctor-respondents said that they frequently, or more often, "encourage terminally-ill patients to draw up Advance Medical Directives". Yet over 85% of doctors agreed that "Every patient has the right to know how terminal their condition is and to have their Advance Medical Directives respected".

- Almost every doctor agreed *in principle* that it was important to empower the patient by giving them information about changes in treatment goals, thus preventing their uncertainty, but *in ward practice* the great majority of doctors usually failed to observe this principle.

(j) Variation by profession (oncologists v. home care specialists v. family doctors)

Oncologists tended to stress the difficulty of the Act's implementation: "Theoretically, the Act helps but it is hard to put into practice. "I am not the one to take hope away from my patients. If there is no choice, then my preference is to talk with the family and not directly with the patient. As oncologists we prefer to keep making efforts up to the end or until the patient himself takes the initiative to talk about the end of life." The home care specialists were markedly the boldest in implementing the Act, while family doctors thought that implementing the Act was the oncologists' job. The home care specialists agreed with them that the oncologists bore the brunt of the responsibility for preparing the patient for the end but it is clear that oncologists found this very problematic.

In talking about PC, home care specialists reported having more of the necessary skills and resources than oncologists and family doctors. This is perhaps unsurprising since it is the home care specialists who have chosen to face up to the issues of EoL planning and care and equipped themselves for that. One said: "None of my colleagues [hospital oncologists] has attained emotional awareness of their own death and so steer clear of end-of-life conversations." Home care specialists were markedly more willing to persist to the end with the issues raised by the Act in order to give their patients a more dignified death. For instance, they were more willing to give the patient the information which would enable them to make their own choices. They were correspondingly more worried by the advance of the disease bringing about cognitive deterioration, which would prevent the patient expressing their wishes, in which case a guardian or family members would have to make necessary choices. By contrast, all family doctors and oncologists responded by shying away from such issues. Home care specialists (and only home care

specialists) were unafraid to face up to whatever might occur in an EoL conversation - perhaps because they appreciated better what their patients wanted - a true prognosis of the time left to them, to discuss their quality of life and the circumstances of their death.

Home care specialists were more open to ethical problems: "I cope with any issue that arises and even broach the subject as part of my patient intake. I want to give the patient the best care possible and so I need to know their wishes and we talk about that in team staff meetings." This multidisciplinary approach to ethical issues is a hallmark of home care: "Any issue that comes up, no matter how difficult, we face up to it as a team so that we provide the best quality of life we can."

The knowledge displayed in the responses to the quantitative questionnaire about starting/transitioning to palliative care differed significantly by specialism - doctors working in home care and family medicine know markedly more than oncologists. The same is true with respect to telling patients the truth - oncologists know the least of the three specialism groups. And oncologists also score 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.

3.2. Discussion

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

3.2.a The connection between truth-telling per se and truth telling about palliative care

Surely it is just to argue that not telling a patient about the possibilities of palliative and hospice care and not giving them the opportunity to discuss these matters and plan their coming care and treatment and death, surely this is not telling them a very significant part of the truth they should know. Truth-telling and EoL conversations - can you have one without the other? Further, if an oncologist is ignorant, or largely so, of the provisions and requirements of the Terminally-Ill Patients Act then he or she is quite unequipped and unable to tell their patients all the truth they should know.

3.2.b The consequences of non-truth telling

Truth-telling as patients' right and doctors' obligation

Open and candid communication with the patient is the heart and soul of palliative care and the basis of doctor-patient trust. A patient suffering from a life-threatening illness deserves full, accurate and honest information about his condition but the findings show that relatively few patients get this. As soon as the patient does not receive honest, straightforward information the decision-making process is distorted. They cannot plan autonomously for their own future. 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. 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 and quality of life of hospice care.

Non-truth-telling is a serious obstacle to the transfer of terminally-ill patients to palliative care and to other key elements of EoL care. EoL decisions are postponed until too late so that the benefits of palliative and hospice care are not fully exploited. Relatively few patients get the chance to draw up Advance Medical Directives or discuss the option of hospice care and their place of death. The findings of the present study make it abundantly clear that if the oncologist does not take the initiative to

broach the issue of Advance Medical Directives, they will in most cases not be drawn up and registered.

Truth-telling does not cause harm to patients.

On the contrary, most patients want to be involved in decision-making but doctors' awareness and attitudes on this issue and their lack of the communications skills which would help them be open with the patient often deprives patients of this right. 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. Doctors frequently censor information they give to patients about their outlook on the grounds that what someone does not know cannot harm them (Slort et al., 2011) but avoidance of communication about the reality of a patient's situation does not protect them from experiencing considerable the psychological distress of uncertainty (Fallowfield et al., 1998). At the heart of any patient-centred approach is the need to understand the meaning of the illness for the patient, a central goal of any whole-person approach to end-of-life care (Larson, 2000). In other words, doctors must learn how to listen fully as much as to speak truthfully. He/she must be willing to listen to the patient's views, fears and preferences for their future care and treatment. This is perhaps even harder for them than to do most of the talking themselves.

3.2.c Oncologists' training needs

A notable lack mentioned especially by oncologists was training in the skills needed for managing end-of-life conversations: all said this was not a part of current training programs and this and the uses of palliative care ought to be given more place in medical training.

Few Israeli medical schools and even fewer residency training programs mandate courses or clinical experience in end-of-life care. Palliative care is not taught in basic medical training. Medical students, as noted at the beginning of this paper, frequently do not feel prepared to discuss end of-life issues

with their patients and physician surveys have demonstrated a desire for ongoing education in this area (Kutner et al., 2003). In Israel, there are no formal courses in palliative care in doctors', nurses' and social workers' basic training. We cannot ignore that attitudes and knowledge may be markedly affected by medical education.

Studies have shown that medical students who complete clinical rotations and courses in palliative care feel more comfortable with death and caring for dying patients (Peng et al., 2013). The differences between three professions involved in EoL care demonstrates the effectiveness of specifically designed training, although we cannot rule out that the very choice of profession results to some extent from individual beliefs and choices.

The UK General Medical Council's (GMC, 2002) second edition of *Tomorrow's Doctors* recommended core teaching on 'relieving pain and distress, together with care of the terminally-ill'. (Gibbins et al., 2011). The UK Department of Health too has recently highlighted the need to educate all health care professionals to try and improve 'end-of-life care' and the third edition of *Tomorrow's Doctors* reiterates the need for students to be prepared to care for patients at the end of life (GMC, 2009).

Firstly, we need to state that some training clearly works. We have seen that doctors trained in palliative care and the 2005 Act knew much more about and had far more positive attitudes towards core elements of good EoL care and treatment. However, it would seem that it is harder to use training to alter doctors' attitudes than to increase and improve their knowledge. Although some studies have assessed physicians' knowledge and attitudes concerning various aspects of terminal care few have examined the effect of knowledge and attitudes on actual physician practice on the ward, and the results vary (Gardiner et al., 2012). In a study of pain management practices of physicians the authors found no evidence that knowledge or attitudes about pain medication were associated with prescribing behaviours (Bruera et al., 2000). However, in three other studies which examined hospice-referral patterns, physicians' attitudes

concerning disclosure and communication were associated with hospice-referral behaviours (Bradley et al., 2002).

It is clear that education is unlikely *alone* to substantially change practice patterns (Dalal et al., 2011). Ideally, education would be one component of a more comprehensive systems-change approach. 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. It will be critical for all palliative care experts to spend 40%-50% of their time educating and supporting other health care professionals and community support systems, in addition to providing consultation and direct patient/ family care (Smith et al., 2012).

It is clear that when doctors blame their lack of time for not broaching EoL conversations that the true explanation lies elsewhere. Some doctors are self-aware of this inability, but many are not and need self-awareness training. For this to change 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. It is vital too that trainees be active participants in their training, which will include role play, exercises in reflectivity, case analyses, maintaining a personal journal, lectures, and the analysis of video clips and films.

The gap between respondents' declared beliefs and actual ward practice

What does this gap mean or imply? Given that respondents' answers to the intensive qualitative interview were on the whole markedly more negative and sombre than the answers to the self-administered quantitative questionnaire, one possibility is that it was far harder to give self-deceiving answers to a knowledgeable interviewer than to a sheet of paper. A second possibility is that many respondents said what they thought the researcher wanted to hear or what they thought they ought to say. A third possibility is that the respondents are genuinely conflicted, that many feel that what they find themselves doing is not what ideally they would want to do,

3.3: Conclusions and Recommendations

3.3.a Shared responsibility; Teamwork

Oncologist as 'commander': The present study has demonstrated that leaving the oncologist in sole charge of hospital-sited end-of-life care is a recipe for failure in terms of truth telling. From authors' long experience it is fear of what might make its appearance in an EoL conversation that deters most oncologists from this central component of modern patient-centred EoL care. Yet shared decision-making by all members of the multidisciplinary team would take some of the responsibility off oncologists as well as ensure a higher quality of decision-making. This widening of the 'circle of responsibility' to other hospital professionals, including nurses, social workers, home care coordinators, palliative care physicians, psychiatrists, psychologists and spiritual care specialists, each with their own input and experience, is invaluable. (Wentlandt et al., 2011). The caregivers of patients in a hospice setting perceive nurses and social workers as most helpful with the transition to hospice care (Kelly and Eileen, 2010).

The critical value of teamwork lies in this very fact that it avoids the oncologist feeling that he/she faces the patient and their family alone. Teamwork in in-patient care could also involve family doctors and hospice home care specialists, both of whom have demonstrated a universe of attitudes far more sympathetic to palliative care than oncologists display.

The oncologists interviewed for the present study admitted to being untrained in team-working. They and other potential team members frequently have little awareness about each other's informational roles and responsibilities. Oncologists in particular need to understand the roles of other disciplines and the advantages of the interdisciplinary approach in health care (Fineberg et al., 2004).

Medical education and training, however, provides little or no preparation for interdisciplinary practice and this recommended teamwork is unlikely to succeed without training in co-working, coordination and communication. Researchers have suggested that attitudes and stereotyping must be addressed early in professional education. Fineberg et al.

write “Learning together allows team members to experience the viewpoints, knowledge, skills, and particular pressures of colleagues in other disciplines.”

3.3.b Sharing data/ decisions with the patient

A common situation among doctors is that they cannot predict life-expectancy with sufficient accuracy and so fear to take responsibility for initiating an end-of-life conversation. This makes it all the more important that the doctor share his/her knowledge with the patient so that the patient can plan for the end of their life. When the benefits of an intervention are not discussed and understood by patients it threatens not only their ability to participate in decision-making, but also the quality of the decisions made without their input.

Patients in qualitative studies spontaneously mentioned their participation in various decisions, indicating that it is an issue that matters to them (Bélanger et al., 2011). Seven studies have examined whether palliative care patients generally prefer collaborative roles in decision-making. Five of these studies used the same five-point scale about treatment decisions and according to these five studies between 40% and 73% of the 379 participants prefer to share treatment decisions with their physicians (Schüklenk et al., 2011).

3.3.c The Israel Ministry of Health needs to take initiatives

Training oncologists in the 2005 Act

The Ministry of Health has a commitment to setting standards for the study and mastery of the provision of the 2005 Act. In practical terms doctors' mastery of the 2005 Act is currently mediocre and their attitudes to it and to the principles of palliative care embodied in it are even more negative. The Ministry of Health should require doctors to take periodic short study courses and/or longer training programs in the implementation

of the Act and this has to be regularly enforced: doctors should be given positive and negative feedback and penalized if necessary.

Failings of the Act

The 2005 Act makes the "personal physician" responsible for informing the patient of a change in treatment goals, (but does not say who the personal physician is). 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 end-of-life conversation. In that conversation they must be equipped to, if necessary, persuade/inform patient and family that treatment goals have to change from cure to palliation and preparation for death.

The critical sensitivities involved in handling end-of-life care in a manner that supports the patient's dignity and autonomy make it likely that certain **personality traits** are needed in the oncologist. The national regulator has to give thought to how these traits can be encouraged and sustained.

Chapter 4: PALLIATIVE CARE AND EUTHANASIA OF NURSING

4.1: The influence of religion, education, attitudes and opinions of nurses on the end-of-life, palliative care and euthanasia decision-making process

Euthanasia and palliative care are topics of interest and concern to many medical teams at practical levels. However, this subject has been investigated in a very limited manner in Israel.

Treatment of a terminally ill patient raises various moral, medical, halakhic and legal dilemmas. These dilemmas relate personally and directly to almost every individual, whether it is a decision that concerns himself or his close ones about end-of-life. (Steinberg Committee Report, 2002).

In modern medicine, the discussion on the use of euthanasia, in terminally ill patients to shorten the period of their suffering, has existed in the medical world for many years and constitutes a central point of controversy in medical ethics.

There are two main types of euthanasia, the first of which is *active euthanasia*, in which specific actions are carried out that bring about end-of-life. The second type of euthanasia widely used in medicine is the *passive euthanasia* - the prevention of life-prolonging treatments that will not change the condition of the terminally ill patient if he suffers or is unconscious. In addition to these, it is necessary to distinguish between a situation in which the person requesting the euthanasia of his own free will and is sane of mind understands the significance and impact of the issue at hand, and the death of a patient who is unconscious. In such a case, it is necessary to rely on a living will or healthcare proxy if such a legal document exists, or authorization from a legally appointed guardian or

from the family. Euthanasia in Israel and around the world has always been considered a weighty moral dilemma, a dilemma that has grown in the treatment of terminal patients who are aware of the fact that their path to death will include agony and suffering.

The moral discussion on euthanasia raises many arguments, both for and against. Those in favor emphasize to the individual's right to his body and to plan and opt for death, over life without dignity, and the ability to part from the loved ones while still sane and conscious. Those who oppose the use of euthanasia emphasize the sanctity of life and, in particular, warn against permitting the taking of life, which may lead to the use of euthanasia in cases where there is no justification for it. Until 2005, according to the law of the terminal patient, a person who by deeds or omission hastened the death of another person suffering from illness or injury was guilty of his death. The Israeli justice system has never sanctioned active euthanasia, although in many cases passive euthanasia has been permitted - avoiding life-prolonging treatment such as respiration from a respirator, avoiding dialysis and stopping the supply of fluids and food (The Terminal Patient Law 2005).

In 2005, following the Steinberg Committee, the Dying Patient Law was passed, which defined three medical conditions regarding end-of-life and euthanasia:

1. A patient whose life expectancy exceeds 6 months - no permit for euthanasia;
2. A patient whose life expectancy is up to 6 months can be discontinued for life-prolonging treatments/CPR, but oxygen, fluids, pain relief, and treatment of diseases unrelated to death should be provided;
3. A patient whose life expectancy is up to two weeks - the patient may request to stop receiving support and treatment.

In this book we will explore nurse behavior from several countries around the world who have been asked about their attitudes, culture, involvement and feelings about euthanasia. Our goal is to examine how religion, academic education, and professional expertise influence the

decision-making process in palliative care and euthanasia at end-of-life. We chose this topic because we felt that the teams in Israel, the nurses in particular dealing with terminal patients, lack sufficient knowledge and proper education on the subject of law and ethics, euthanasia and dealing with end-of-life. These necessary skills will enable providing the optimal and ethical choice for the patient in need of treatment, rather than by ideas that often stem from a lack of knowledge in the field of palliative care, legislation and ethics (Steinberg Committee Report 2002).

The Netherlands was the first to confirm that euthanasia was used by terminal patients in 2002. According to the Dutch legislation, a doctor will not be prosecuted for the termination of a person's life, provided that he is convinced that the requesting terminal patient is sane and sound of mind along with the fact that the patient has faced and will continue to face relentless suffering and agony and there is no treatment that can improve the condition of the patient (Van der Heide, et al., 2007).

According to a study conducted in Belgium in which 89% of the nurses who responded to the survey felt that there was no correlation between legislation and ethics on the subject. In addition, 90% of the nurses indicated that they were involved in the decision to do so, compared with 50% who said that they were taking part in the decision-making process. Belgium is the first country to allow since 2014 the use of euthanasia in children aged 12 and over, after approving in 2002 the euthanasia of adults as allowed by the Netherlands (Engelbrecht et al., 2009).

According to a study conducted in Brazil, intensive care nurses found it hard to explain the terms:

Dysthanasia: Extending the life of a terminal patient using technology regardless of the quality of his life.

Euthanasia: Termination of a person's life with intent to alleviate his suffering.

Orthothanasia: Natural death without intervention.

The nurses noted that they are not familiar with these issues despite taking part in palliative care and euthanasia. The researchers recommended

to the hospitals that the knowledge of the ICU staff needed to be renewed and supplemented to improve treatment in such complex situations (Biondo, Silva, & Secco 2009).

In another study conducted in Germany, most nurses indicated that they would prefer to treat the symptoms of the disease before they were willing to consider intervention in palliative care and euthanasia. In addition, most of the nurses who participated in the study were not prepared to perform euthanasia on a patient with terminal illness (Zenz, Tryba & Zenz 2015).

In a study conducted in Canada, they found that nurses have a general opinion of euthanasia when it comes to theory, but when making a decision, they noted that the moral principle and family approval were important to them despite the patient's decision and his request for euthanasia (Lavoie, et al 2016).

In Oregon, a study was conducted in the hospice where elderly patients refused to receive food and fluids in order to speed up death by combining palliative care with these patients, resulting in a better death experience than an agonizing and difficult death experience for the patient without palliative intervention during active abstinence from food and drink (Ganzini, et al 2003).

In the United States, there are a number of states that have legalized euthanasia in "Death with Dignity". These states - Washington, Vermont and Oregon - allow terminally ill patients whose lifespan does not exceed six months, their age is over 18 years, and are sane of mind to apply for the drug after being examined by two doctors that are responsible to offer the patient therapeutic alternatives. Two different doctors must diagnose the patient as terminally ill to confirm the request (Antill 2016).

Another study was conducted in 2012 in a number of European countries, in which 386 Christian and Jewish nurses responded from intensive care units from 142 different hospitals from Sweden, the Netherlands, the United Kingdom, the Czech Republic, Israel and Portugal. It was found that nurses that considered themselves religious were more inclined towards providing care and prolonging life as much as possible and less inclined to the option

of euthanasia in its various forms. In addition, the findings showed that nurses living in the Czech Republic, Israel and Portugal had more positive views of euthanasia than nurses who lived in Sweden, the Netherlands and the United Kingdom. Protestant Christian nurses tended to obey the any wish of the patient, while Jewish nurses tended to be receptive to requests that included additional lifelong treatments even if they were useless to the patient (Bülow et al. 2012).

With this in mind, we concluded that when the nurse has acquired sufficient knowledge regarding palliative care and end-of-life care, the more the nurse feels professional and confident while assisting the attending physician to fulfill the request of a patient requesting euthanasia. The department staff will be trained adequately as needed to be able to treat those terminal patients and enable a more efficient and dignified dying process. In addition, we expect that the stronger the nurse's degree of religiosity, the more euthanasia opinions will be negative even if this is the patient's request.

4.2: Literature review and definitions

Chronic illness is defined as a medical condition associated with symptoms or disabilities that require management of a long-term illness of three months or more. Chronic condition is a prolonged illness that cannot be fully healed, due to illness, injury or genetic factors, as well as unhealthy life-style and behavior patterns that began in childhood with long-term consequences that show up at a later age. Managing chronic illness requires the patient to learn how to combine one's life-style with the symptoms or disabilities, supplementing the identity change as a result of the condition of the body with the chronic disease, requires adaptation to a different life-style in order to control the symptoms and prevent complications. Although many people think that chronic illness is a daily condition of patients on the part of the environment, those chronic patients see themselves as healthy and try to live as normal a life as possible. Only when complications or

symptoms develop that interfere with Activity Daily Living (ADL) most people with chronic diseases consider themselves sick or disabled (Hinkle and Cheever, 2014).

Terminally ill and dying patients: Patients whose life expectancy does not exceed 6 months are defined as dying. In these patients, the goal is to improve the quality of life by managing the symptoms, controlling the pain, and providing moral support in order to provide maximum mental and physical comfort to the patient. Nursing at end-of-life is a unique situation that takes into account the wishes of the patient and end-of-life goals. In many cases, end-of-life decisions are deferred until a deterioration or emergency occurs and an impossible situation arises in which the patient does not take an active part in the decision itself and there is no way of knowing whether he is interested in receiving the treatment. Palliative Nursing helps patients and families to think about these possible critical situations, with conversations, expressing opinions and raising points of important information about the contents of end-of-life and patient satisfaction (Hinkle and Cheever, 2014).

Definitions:

Euthanasia - a Greek term that means "good death", which now means helping the patient with an act or inaction to promote one's death, the end of a person's life with intent to alleviate his suffering.

Dysthanasia - Extending the life of a dying person using technology regardless of the quality of his life.

Orthothanasia - Natural death without intervention.

Assisted suicide - Using pharmacological means to speed up the death of a dying patient.

Death with Dignity - Process that involves physicians, psychologists, nurses, etc., which ultimately approves Assisted Suicide. In some US states, this is one legal way to end life for terminally ill patients: receiving drugs to speed up death at the time and place the patient chooses, and two doctors must confirm the diagnosis before Assisted Suicide can be performed.

Palliative Care - Comprehensive treatment for patients whose illness is incurable, and also treats families.

End-of-life treatment - therapy provided during the last days or weeks of the patient's life.

Palliative Sedation - The use of pharmacological means at the request of the dying patient in order to alleviate the situation in which the symptoms cannot be controlled by other means. The goal is not to speed up the patient's death but to relieve the symptoms.

Chronic illness - a medical condition that is associated with symptoms or disabilities that require management of a long-term illness of three months or more.

Terminally ill - an advanced or irreversible disease that, despite comprehensive medical treatment, will result in death.

A terminal patient - a patient who has terminal illness and a life expectancy of up to six months.

(Abu-Rakia, 2014), (Hinkle and Cheever, 2014), (Steinberg Committee Report, 2002), (Law for the terminally-ill, 2005).

4.3: Decision-making processes - the patient and family – the five stages of recognizing the condition of the dying patient.

The palliative care of the dying patient stems primarily from the recognition that each patient has a personal story, a family that cares, relationships and culture, and deserves respect as an individual and unique person who has the right to receive the best medical care available, to enable him and his family to take advantage of the time available to them in the best manner (Abu-Rakia, 2014).

There are many factors that influence the decision-making process in dying patients. The Kubler-Ross model “*Five stages of dying*” deals with coping with illness and death in people who know that they are about to die and in people who are dealing with the grief of other close people.

The model deals with the five stages of coping and acceptance of illness and death:

Denial - The initial reaction. A sense of isolation, at this stage they will seek a second opinion in order to receive a different diagnosis and will try alternative treatments. In terms of nursing, denial is an adaptive response to the new situation, which provides a sense of protection after receiving bad news. This condition can help the patient and his family or cause more pain and distress than coping with the disease itself and may sometimes interfere with further treatment. In this situation, the nursing staff must create a basis for empathy and emotional support in order to help the patient and family cope with the new situation.

Anger - At this point, the patient or family will direct anger, resentment, and jealousy toward God, the health system, the family, and the patient himself. In terms of nursing, the staff must understand that this emotion isolates the patient, which can cause the medical staff or family to be reluctant to approach the patient. The nursing staff should allow the patient and family to express the hard feelings, to relate to them with respect and understanding that the basis for the feelings is the sorrow for the imminent loss.

Bargaining - At this stage, the family and the patient seek to achieve important goals in the remaining time while providing conditions for themselves or God, such as "If I stop smoking now, maybe I will be able to get better." From a nursing perspective, the staff must be patient, allow expression of emotions, positive and realistic hopes.

Depression - Despair and sorrow over the approaching loss. Fearing the fate of their loved ones and families. In terms of nursing, this is a normal and adaptable response to the situation. If a patient experiences clinical depression, he or she should be treated immediately. The nursing staff should encourage the patient and family to express their sadness and avoid encouraging unrealistic hopes.

Acceptance - At the acceptance stage, the patient and the family accept the new situation and do not express anger, depression or regret. From a nursing perspective, at times because the patient has accepted his fate, he will develop a tendency to isolation and reject others. The nursing staff should inform the family that this condition may occur and encourage them to stay with the patient as long as possible.

Denial, sadness, anger, fear and anxiety are normal reactions to situations in which patients and their families feel while coping with a life-threatening disease. The five most common responses to death (denial, anger, bargaining, depression, and acceptance) may be expressed in other cases of loss. Not all patients and families go through all five stages, some go through the stages in a different order or do not even get to the acceptance stage (Hinkle and Cheever, 2014).

Interdisciplinary collaboration (IDC) Presence and care of Interdisciplinary collaboration (IDC) staff in the treatment of dying patients is necessary in order to achieve the desired outcomes with patients and their families. IDC is based on cooperation between the different disciplines and each member of the team contributes to a joint program that focuses on the needs of the patient and family. Typically, IDC staff includes physicians, nurses and social workers (Hinkle and Cheever, 2014).

4.4: Death, Loss, and Trauma.

The Challenges of Adjustment, Recovery, and Resilience

Life is filled with peril and adversities. During the normal course of their lives, most adults face one or more potentially traumatic events (e.g., violent or life-threatening occurrences or the death of close friends or relatives). After the confrontations with the possibility of dying or with the death of significant others, many people find it difficult to concentrate; they may feel anxious, confused, and depressed; and they may not eat or

sleep properly. Some people have such strong and enduring reactions that they are unable to function normally for years. These dramatic reactions have dominated the literatures on loss and trauma and, until recently, the opposite reaction – the maintenance of a relative stable trajectory of healthy functioning following exposure to a potential trauma – has received little attention. When theorists have considered such a pattern, they have typically viewed it either as an aberration resulting from extreme denial or as a sign of exceptional emotional strength. (McFarlane & Yehuda, 1996)

4.4.a Death, Loss, and Grief

Throughout history, attitudes toward death, mourning beliefs, practices, and rituals have facilitated both the integration of death and the transformations of survivors. Some anthropologists believe that religions were invented primarily to help people to accept death, not as a final ending, but rather as a transition to continuing life in another realm.

Every culture and religion, in its own ways, offers assistance to the dying and to the community (Walsh, 2004) of survivors who must move forward with life. The dying and the bereaved are part of a cultural drama that asserts basic ideas about the nature of life and death.

Fear of death is a specific, conscious, and existential fear of the loss of self. Wong, Reker, and Gesser (Wong et al. 1996) made a number of distinctions within the concepts of fear of death and death acceptance, resulting in five different death attitudes: a) *neutral acceptance*, involving the view that death is an integral part of life, b) *approach acceptance*, a positive outlook on death rooted in the belief in a happy afterlife, c) *escape acceptance*, where death is a welcome alternative to a life full of pain and misery, d) *fear of death*, involving feelings of fear evoked by confrontations with death, and e) *death avoidance*, involving avoidance of thinking or talking about death in order to reduce death anxiety.

Many cultures are fortunate in having a world view that helps to face the inescapable fact of death, including it in the rhythm of life. Others, such

as the dominant Anglo-American culture, avoid facing mortality, deny the impact of loss, and encourage the bereaved to quickly regain control and closure.

The decrease of the transcendence thematic is associated with a probable decrease of death thematic, from the Early Middle Ages until the nineteenth century. “In the 1850s, Western society had witnessed a brutal revolution. Death, so omnipresent in the past that was familiar, would be effaced. It would become shameful and forbidden”, wrote Ariès (1974). Since 1950, the dying person was separated from family and home, and people died away from home primarily in hospitals, receiving intensive medical care. In other words, before the advent of hospital and institutional care, people died at home, where all family members, including children, were involved in the preparation for and immediacy of death. In other words, modern societies fostered the denial of death and avoidance of grief processes. As Ariès suggested, death become forbidden and avoided. Physicians sanitized dying and made it more acceptable to the survivors of the deceased. The survivors are then expected to recover from grieving as quickly as possible, and any prolonged grief becomes a suspicious sign of depression.

Sigmund Freud emphasizes that the function of grief is to detach from the deceased the thoughts and hopes of those left behind. So the mourner has to withdraw his psychological energy from the person or thing he has lost (Leick & Davidsen-Nielsen, 1991). A ‘tombstone’ has to be erected, and one has to say goodbye in order later to be able to say hello.

Kübler-Ross (1969) argued that we are fearful of an imagined agony at death and underlined what the death and dying have to teach doctors, nurses, and families of dying person. She identified five stages of dying: denial, anger, bargaining, depression, and acceptance and advocated for healing professionals to recognize them.

Also, times of profound loss may feel unique and research has documented the wide variation in normal individual grief processes (Wortman & Silver, 1989). Grief is the normal and natural reaction to loss of any kind. The problem is that in many cultures people have been socialized to believe that these feelings are abnormal and unnatural. While grief is the

most powerful of all emotions, it is also the most neglected and misunderstood experience, often by both the grievors and those around them.

Grief is the conflicting feelings caused by the end of or change in a familiar pattern of behavior. For example, when someone loved dies after suffering a long illness, people may feel a sense of relief that their loved one's suffering is over. That is a positive feeling, even though it is associated with a death. At the same time, people may realize that they can no longer see or touch that person. This may be very painful. Conflicting feelings, relief and pain, are totally normal in response to death. Despite considerable diversity in individual, familial, and cultural modes of dealing with death and loss, mourning processes promote healing and families are crucial influences in healthy or dysfunctional adaptation to loss.

Life expectancy has increased dramatically, raising the issue of quality of life. The aging of the baby boom generation has prompted a shift in public consciousness of mortality and loss. Medical advances increasingly confront families with unprecedented decisions to prolong or end life and have raised profound questions about what is a "natural" death. Also, the media have brought worldwide catastrophic events into our homes underlying the precariousness of life and death in our volatile and uncertain global environment (Walsh, 2006). Currently, there is growing recognition of the importance of facing death and loss.

In the same time, the quality of life seems to be influenced by cultural values. Fredrikson and Kahneman (1993) argued that when people evaluate an episode, they rely on how the event ends and on the peak moments, bad or good. Retrospective evaluations were best predicted by reports from the peak and ending moment. The authors named this phenomenon *duration neglect*. Diener, Wirtz and Oishi (2001) explored how the ending of a life influences the perceived desirability of that life. They observed that participants neglected duration in judging the global quality of life." Respondents rated a wonderful life that ended abruptly as better than one with additional years of mild happiness (the *James Dean Effect*). Similarly, a terrible life with additional moderately bad years was rated as more

desirable than one ending abruptly without those unpleasant years (the *Alexander Solzhenitsyn Effect*). Finally, embedding moderately intense years in the middle of life did not produce effects as strong as adding those years to the end of life, suggesting that a life's ending is weighted especially heavily in judging quality of life" (Diener et al, 2001). The authors suggested that people perceived life as more positive if it ends on a high note, rather than after a decline.

4.4.b Trauma and PTSD

The death of a close friend or relative or the diagnosis of a chronic illness is a life-threatening event that wound the mind, the body, and the soul. Under conditions of prolonged or otherwise severe trauma, the person's biochemistry (Friedman, 1999) may be permanently altered, as is the ability to give and receive love (Herman, 1992). Just as in novels and the movies, trauma seldom affects the individual alone.

A simple working definition of mental health is the ability to love, work, and play. Yet when a traumatized individual develops more than a 30-day acute stress reaction and goes on to acquire a longer term and more devastating traumatic reaction (such as posttraumatic stress or a dissociative, depressive, or somatic disorder), that person's ability to pursue meaningful work and to develop and maintain safe and loving relationships is severely impaired (Spasojevic, 1994). Unfortunately, at the very time survivors need people the most, their symptoms can lead to alienation, hostilities, and a host of misunderstandings for all involved including coworkers, neighbors, grandparents, and other members of the extended family.

Although not all survivors develop posttraumatic stress disorder (PTSD), the interpersonal repercussions of PTSD are very important. Due to the overlap between the symptoms of PTSD and those of other possible reactions, such as a dissociative, somatic, or depressive disorder, many of the observations made regarding PTSD may also apply to instances where survivors develop a different traumatic reaction. Exceptions include those

interpersonal problems that stem directly from the unique feature of PTSD: the PTSD cycle - states of hyperarousal alternating with states of numbing. Either state can result in mental and emotional disorganization, leaving survivors feeling out-of-control, even terrified, unless they have ways of managing them (Cascardi, 1992).

Extreme states of numbing or hyperarousal can be dangerous. When intrusive thoughts, flashbacks, panic attacks, or other forms of hyperarousal occur while driving, cooking, or working with children or machinery, accidents can result. In addition, the feelings of helplessness and confusion engendered by being unable to modulate the PTSD cycle are reminiscent of the powerlessness and disorientation experienced during the original trauma. Hence the symptoms of PTSD are traumatizing in themselves. Under such circumstances, survivors have difficulty in being present to others. In response, others can feel angered, rejected, or helpless and can easily decide that the survivor is “impossible,” “antisocial,” or “crazy.”

A common way survivor try to circumvent the PTSD cycle is by avoiding interpersonal and other situations that might stimulate it. Abraham Kardiner, who worked with shell-shocked World War I veterans, wrote that traumatization (what we now call PTSD) is similar to schizophrenia in that the person withdraws from the world (Kardiner & Spiegel, 1947). Since the ego cannot handle the anxiety generated by the trauma in addition to the anxieties of normal life, a diminished interest in the world and a decline in personal functioning can follow (Matsakis, 1994). Indeed, it is more often the avoidant symptoms of PTSD, rather than the survivor’s reminiscences, that create negative marital and family interactions.

4.4.c Variables influencing adaptaptation to loss

We can identify a number of variables in the loss situation that influence the traumatic impact of a death (Walsh, 2006). In order to prevent the risk of dysfunction, or to understand and repair long-term consequences, these variables should be always carefully evaluated and integrated in any intervention plan.

(a) Risk Factors and Circumstances around the Loss

Sudden or lingering death. The timing of the death may be more or less appropriate in the course of a person's life. It may be a natural conclusion to a long life, or it may strike a child, a young person, or someone in the prime of life. The way the death occurred and the age of the victim have proved to have great influence upon the grief reactions of the bereaved. Sudden death or death following protracted deterioration are especially stressful for survivors and require different coping processes. When a person dies unexpectedly, family members and friends lack time to anticipate and prepare for the loss, to deal with unfinished business, or in many cases even to say their good-byes. The dominant emotions will be helplessness and fear. In a violent way they are confronted with the fact that the influence and control they have over their own lives is limited. Clinicians need to explore and help family members with painful regrets and guilt over what they wish they had done differently or how they might have prevented the death. When the dying process has been prolonged, family caregiving and financial resources can become depleted, with needs of other members put on hold (Rolland, 1994). Relief of family strain is likely to be guilt-laden. Moreover, families are increasingly faced with anguishing end-of life dilemmas, such as whether, and how long, to maintain life support efforts. Families can be torn apart by opposing positions of members or coalitions.

Ambiguous loss. Ambiguity surrounding a loss interferes with adaptation, often producing conflict and depression (Boss, 1999). A family member may be physically absent but psychologically present, such as a soldier missing in action in wartime or a child who disappears without a trace. The uncertainty about whether a missing loved one is dead or alive can be agonizing. Family members may be consumed by desperate searches and attempts to gain information to confirm the fate of their loved one. In other situations of ambiguous loss, a family member may be physically present but psychologically dead, perhaps unable to recognize loved ones, as in the mental deterioration of Alzheimer's disease (Boss, 1999).

It is important to help family members to deal with the progressive loss of mental functioning and important aspects of their relationship without extruding the person as if he or she were already dead.

Suicide. The suicide of a close relative is one of the most difficult losses to get over (Leick & Davidsen-Nielsen, 1991). The mourner is left with a welter of contradictory emotions: anger, shame, guilt and bereavement. At the same time the mourner often has a feeling of having been rudely cast off by the deceased. The situation is, of course, particularly complicated if the bereaved had a conflict with the dead person when he took his own life.

The rise in adolescent suicide requires attention to peer drug cultures and larger social forces, as well as family influences. Clinicians should also be alert to family patterns, such as threatened abandonment or sexual abuse that may pose heightened risk of suicide. Current life-threatening family situations can trigger catastrophic fears of loss or self-destructive behavior.

When a suicide has occurred, clinicians need to help family members with anger and guilt that can pervade their relationships, particularly when they are blamed, or blame themselves, for the death (Dunne and DunneoMaxim, 2004). The social stigma of suicide can contribute to family shame and cover-up. Such secrecy distorts family communication and can isolate a family from social support, generating its own destructive legacy (Imber-Black, 1995). Clinicians should routinely note family histories of suicide or other traumatic loss that may predict future suicide risk, particularly on significant dates such as an anniversary, birthday, or holiday.

Violent death. The impact of violent death can be devastating, especially for loved ones who witnessed it or narrowly escaped it themselves, as in a plane crash, a mutilating fatal accident, or a murder. Murder, like suicide, brings a sudden loss for which someone is normally quite unprepared. If the mourner has also been present at the murder, there are also both the shocking experience and the feeling of guilt at not having been able to prevent it.

Murders are committed more often by relatives or acquaintances than by strangers. If the murder occurs within the family, there is the complicating factor that the mourner often both hates and at the same time is attached to the murderer. It can be very hard to accommodate this ambivalence. A woman whose husband killed their two children in a fit of jealousy had not only lost her children, but also her husband and companion of fifteen years. It was a great relief for her that we both understood and supported her grief at the loss of the husband, grief which her network was unable to accommodate. Her anger at him did not come till much later.

War and terrorism have a broad impact beyond those immediately affected, now intensified by instantaneous televised broadcast worldwide. Studies of the aftermath of 9/11 have found that posttraumatic stress symptoms nationwide increased exponentially with the amount of television viewing (Siver et al., 2002). Repeated broadcasts of scenes of bombing, death, and destruction are most distressing, especially for children.

Several losses at once. Experience shows that if a person suffers a number of serious losses within a short time, the process always becomes complicated. Each loss requires its grief work. Two concurrent losses trigger off two different kinds of grief work, and the mind finds it hard to contain them at one time. If someone loses both his children in the same accident, it is therefore natural for his feelings to concern themselves particularly with one in one period and with the other in another period. Without help this can become unnecessarily complicated, because the grieving mother or father has guilt feelings towards the child with which they are not concerned at the time in question.

Getting two or more processes of grief work separated out in a useful way is a complicated task. It normally requires professional intervention because the losses together exerted such great pressure that the normal grief work would have been too stressful without the help of the grief group.

(b) Risk Factors and the Mourner's Personality and Attachment to the Lost Person

This is the most difficult factor to assess, because there are so many different aspects present here. The grief work is shaped by the relationship to the deceased and it is useful to understand the difference between love and dependency (Leick & Davidsen-Nielsen, 1991). When there is more dependency than love in the relationship, there is not this flexibility. Bowlby stresses that when a relationship between two people contains love, then they can tolerate separation. The more clear-cut and emotionally satisfying a relationship is, the healthier is the course of the grief work. Also, the grief differs depending upon the stage of life of the person. A conjoint family life review (Walsh, 1999) can help members to share different perspectives, to clarify misunderstandings, to place hurts and disappointments in the context of life challenges, to recover caring aspects of relationships, and to update and renew relationships that have been frozen in past conflict.

Grief work and normal attachment. If we lose someone with whom we have had a good emotional relationship, the pain is naturally very deep. We recall with sorrow all the good times when we enjoyed each other's company. We know that the relationship was mutual. It was a relationship in which problems were faced and solved, which means that the bereaved person does not have a lot of loose ends and unclarified feelings about the deceased. There is a great sense of loss, but complicating emotions like guilt and shame are present to a limited extent. There may be some anger that the deceased has deserted us but is not intense. The mourner will also have a reasonably good network around him and does not have to overcome much reluctance within himself to make use of it. Often the mourner will also have a good and secure feeling of the deceased's presence. This person will rarely be referred to professional help unless some of the other parameters tip the scale. He or she will cope with their grief work with the aid of the network.

Grief work in close and complicate attachment relationships. As a general rule, the more contradictory feelings someone has in relation to the

deceased (consciously or unconsciously), and the less capable someone is of making contact with their emotions, then the greater is the risk of a pathological development of grief. An *imagined example* is offered by Leick & Davidsen-Nielsen (1991): a person with many contradictory feelings, Edna, loosed her husband Geoffrey, which has died of a long-lasting cancerous disease. In their twenty-five years of marriage she was very dependent on George. She did not have outside work, she allowed him to decide everything, and she had his opinions. Edna was the typical 'self-sacrificing' wife. They never quarreled, due to their joint understanding that they 'just had to make a go of things'. Her unconscious anger at having been kept down over many years makes it hard to her to feel his loss thoroughly. Perhaps too Edna has guilt feelings about something which she did not do well enough in connection with his illness and death. It will be even harder if she is also ashamed of becoming a widow at so young an age. The bereavement and the pain are also tinged with guilt, shame and repressed anger. She is now paying the price for her great dependence upon him. Edna's grief work is under threat. She risks either chronic grief or avoided grief, depending upon what she has learnt about expressing feelings in her childhood home. People who have difficulties with the grief process because of contradictory emotions they experience a difficult adjustment process to the new situation.

Grief work in an emotionally distant relationship. It is a typical reversed situation: a dependent women has died and her husband is the mourner (Leick & Davidsen-Nielsen, 1991). He was fond of his wife but was often irritated at her lack of independence. He may regard himself as an exceedingly sensible and realistic person. His friends think he intellectualizes things too much. He did not weep at the funeral and bore up well through the first period. But after the passing of some time, long or short, he may feel emptiness, a sense of loss, and these emotions can confuse him greatly. He has no experience of giving way to these feelings, regarding this as womanly weakness. So, he might resort to alcohol or tranquillizers. Or perhaps he might become physically ill — for example, get heart disease. In widowers we do see a small, but statistically significant, increase in mortality

from heart disease in the first year after the wife's death. Sometimes, this type of man will 'solve' the problem by marrying again quickly.

Grief work in symbiotic relationship. We can think to a couple's relationship in which apparently one is strongly dependent upon the other, but in typical 'symbiotic relationship', the dependency is mutual. In its extreme form the couple live only for each other and have a norm that they never quarrel. In other quarrels do arise, but they are quickly swept under the carpet and rarely lead to a solution of the problem that started the quarrel. Often there are very few or no outside the couple. This type of relationship may exist between spouses, but also between adult children and their parents if they remain living together. It can also be seen in siblings who live together as adults. These are relationships in which one finishes the sentence the other has started saying. They are rarely or never apart. They have almost grown together. In symbiotic relationships there is great dread of separation. It is our experience that this fear can sometimes be traced back to an unprocessed loss in childhood. If one partner in such a close relationship dies, the other is often at risk of a pathological development of grief, because they feel as if they have lost part of themselves.

Grief work in love-hate relationships. A third type of relationship is the ambivalent love-hate relationship. The partners live a 'cat-and-dog life' and the relationship is characterized by constant mutual reproaches and bickering. Outsiders often wonder why they do not divorce. If one of the partners in such a relationship dies, we can often see a brief spell of relief, which is succeeded by feelings of emptiness, anxiety and dreariness. The network is seldom ready to accommodate the grief, the sense of loss and the anger. It can be hard for outsiders to understand the strong attachment there may be between two people who are constantly fighting. It would be too wide-ranging to enter into a deep analysis of the spouses' dynamics. But it is worth noting that in such a relationship there are so many contradictory emotions that the grief work often becomes so complicated that it requires professional help if the bereaved partner is going to get through their grief.

Grief work when a child dies. Losing a child is one of the most traumatizing experiences that any parent should ever go through, regardless of whether it is a stillborn baby, a child who is a minor, or a child who is an adult. Some investigations indicate that it is most stressful to lose infants when the natural symbiosis between mother and child is still great. Other investigations show the contrary: that it is particularly stressful to lose older children. Losing a child entails very difficult grief work, and that age is of minor importance. In our society infant mortality is lower than a century ago so that we do not expect to lose our children. We count on their outliving us, and when they do not, it seems to be a breach of the natural order. This has not always been so. One century ago, the high infant mortality that a couple had conducted to the expectation of losing up to half of their children during their lifetime. This expectation, and the fact that people had more children and were more religious, may explain that a child's death was not nearly such a devastating event as it is today.

Losing a child may result in both avoided and chronic grief. It seems as if it is most often women who end up in a state of chronic grief. They find it hard to let go of the many hopes and dreams that were bound up in the child and thus to complete the fourth task of reinvesting their energy both in other children and in other people. Birthdays and other special anniversaries are particularly difficult. Many parents who have lost a child at birth or during its first year follow this child in their thoughts without this necessarily being pathological grief. They know when it would have started school, when it would have come of age, taken school exams and so on.

A child dying is a great strain on a couple's relationship; the grief either brings the parents closer or it makes them drift apart, often resulting in divorce. One of the problems for a couple who lose a child is that the parents often grieve in different ways. The usual thing is that the husband feels he has to be strong to support his grieving wife. He may postpone his grief or show it elsewhere than when he is with his wife. This can result in criticism from the wife that he is not grieving sufficiently or in the right way. The partners often find it hard to accept that they have not suffered

the same loss, but that they each had their particular relationship with the dead child, and so they have lost something different. It may also be hard for them to accept that they are not working on the same tasks of grief work at the same time, and that may again lead to mutual criticism.

(c) Risk Factors and the Mourner's Psycho-social Circumstances

The extended family and social support. The family loss experience is buffered by the availability of supportive kin and friendship networks. Such resources are especially important during the bereavement and in widowhood (Lopata, 1996). The lack of community for many contemporary families makes loss more difficult to bear. People who are unable to use their network, or have no network, are at risk when grief strikes them. If someone has nobody to share their thoughts and feelings with, they become anxious and ashamed. If someone does not feel that they have family or friends who understand them, they are threatened with pathological grief. When long-standing conflicts, cutoffs, or social stigma have left families disengaged and isolated, clinicians working with loss can be helpful by mobilizing a potentially supportive network and facilitating a healing reconciliation.

Risk of isolation. All grief work entails a risk of isolating oneself. It is not easy to trust or to risk intimacy again after we have experienced the pain of losing a special relationship. When the love-one is dying, we are tempted to give up on all relationships. People may fear that they will, again, suffer, and they are tempted by the illusion that safety and peace can be found in isolation. Even if someone has a good network, the dislike of 'breaking down' in other people's company may mean that the resources of the network are not used. It is a good sign if a mourner is flexible enough in his grief work both to be able to be alone and with others, according to what is needed.

Widows with young children. There is a widespread misconception that it is a support for a young widow or widower if there are young children to be cared for after the death. On the contrary, young children make such a great emotional and practical demands on the parent who is left, that it is

incredibly demanding to have to manage both the children and the grief work. So, the family is at risk. Young children with strong emotional bonds to their parents, showed significant lower levels of cortisol in their brains and high levels of cortisol cause the death of brain cells. Children who are emotionally neglected or abandoned early in life are more likely to have learning difficulties and problems in experiencing empathy, attachment and expression of emotions. (Gunnar et al., 1996) Research shows that the young widows are more at risk than older widows. The young widow's despair can be so great that she is not capable of giving the children more than the most superficial practical care and is unable to support the children in their grief. In other cases, all the widow's energy is put into coping with the practical matters of being alone and having to see to the children's well-being. So her own grief reaction is neglected. Much preventive work can be done by supporting the lone parent during the first period after the death and by ensuring that they get help both with their own grief work and with supporting the children in their grief.

Cultural and religious support. Spiritual beliefs and practices can be wellsprings for resilience with life-threatening illness and loss. Research has found evidence of the positive physiological effects of deep faith, prayer, and congregational support (Wright, 2004). Mourners who are living in an alien cultural or religious setting do of course feel particularly isolated when crisis or grief strikes them. Mobilizing a network that has the right composition is normally an important element of professional crisis help. However, it is not only immigrants who need attention to see if their network contains the necessary religious help for the mourner. Even within the bounds of a country there are cultural differences in regard to the kind of support the mourner is offered. Cultural and religious rites in connection with a death help the mourner to take leave of the departed. It has been said that the basic humanistic attitude of a culture may be measured by the understanding shown to its mourners. On this view, the urban industrialized society must in general be an unhealthy place to be.

Sociopolitical and historical context of loss. The experience of families who suffer war-related deaths is heavily influenced by social attitudes about

the war involvement. The impact of the loss can be assuaged by a common sense of patriotism and heroism for a noble cause and victory. However, highly charged, conflicting positions about a war can complicate family adaptation. Bitter legacies of unresolved political, ethnic, and religious conflict can be passed down from generation to generation.

Cancer and AIDS have become the epidemics of our times, each generating tremendous anxiety and stigma (Sontag, 1988). The social stigma surrounding HIV–AIDS has contributed to secrecy and estrangement, impairing family and social support, as well as critical health care. The epidemic of AIDS in the gay community — and, increasingly, for men, women, and children in poor communities — is all the more devastating because of the multiple losses and anticipated losses of partners, parents, children, and other loved ones in relationship networks (Landau-Stanton, 1993).

Gender-based constraints. Although gender roles and relationships have been changing in recent decades, expectations for men and women in dealing with loss are still influenced strongly by gender-based socialization and role constraints (Stroebe, Stroebe, & Schut, 2001). With a death in the family, mothers are particularly vulnerable to blame and guilt because of expectations that they bear primary responsibility for the wellbeing of their husbands, children, and elders. Women have been socialized to assume the major role in handling the social and emotional tasks of bereavement, from the expression of grief to caregiving for the terminally ill and surviving family members, including their husband’s extended family. Now that most women are combining job and family responsibilities, they are increasingly overburdened in times of loss. Men, who have been socialized traditionally to manage instrumental tasks, tend to take charge of funeral, burial, financial, and property arrangements. They are more likely to become emotionally constrained and withdrawn around times of loss. Cultural sanctions against revealing vulnerability or dependency block emotional expressiveness and ability to seek and give comfort. These constraints undoubtedly contribute to high rates of serious illness and suicide for men following the death of a spouse (Lopata, 1996).

4.4.d Resilience and Growth

There is large evidence that traumatic experiences can change a person's life. Extensive clinical research has documented the deleterious effects of such experiences on adaptation efforts in the short and longer term (Kessler, 1995), and clinical interventions have been developed to reduce symptoms and facilitate recovery (Foa, 2006). In the present, the study of posttraumatic adjustment includes also resilience and thriving. To understand the ingredients of adaptation to traumatic events, it is necessary to examine the process of that adaptation, not just its final cross-sectional result.

Resilience

Resilience is the resistance to psychosocial risk experiences (Rutter, 1999), the process of coping with adversity that contributes to the development and enrichment of protective factors (Richardson, 2002). Foa and colleagues (2005) have defined resilience as one end of a continuum of vulnerability to emotional dysfunction and psychopathology when exposed to a stressful experience. As we have argued resilience have two components: resistance against destruction and the ability to construct a positive life in spite of adversity (Turliuc & Măirean, 2011). In this way, resilience can be identified in the initial reaction to a traumatic event, in features of the recovery path associated with achieving a return to baseline functioning, and in the final product of the adaptation (Butler *et al.*, 2007).

Lepore and Revenson (2006), cited by Morland, Butler and Leskin (2008), “have highlighted different aspects of resilience by delineating the ideas of recovery, resistance, and reconfiguration”. In *recovery*, the elasticity of response is emphasized; people bend but do not break in the grip of the stressor and ultimately return to their original state. This is probably the most commonplace understanding and usage of the term resilience. Recovery is an elusive term when it is applied to bereavement. The therapists specialize in bereavement counseling usually sustain that we can talk about recovery “when the bereaved can finally think of the dead

person without overwhelming sadness and invest energy in other thoughts and activities.”

In the case of *resistance*, the person’s functioning is not seriously affected by the stressor or, if it is, the effect is minor and short-lived (Afuape, 1985), and has been found in a large proportion to people experiencing typical bereavement, reviewed in Bonanno (2004).

The *reconfiguration* suggests the permanent adaptation to or alteration as a consequence of the trauma. The occurred changes accommodate the demands of the traumatic situation. This latter type of resilient functioning shares much with adversarial or posttraumatic growth (Joseph & Linley, 2004), especially its consequences for future adaptation.

Growth

For more than ten years, researchers documented the benefits and positive changes that some individuals reported following adversity (Joseph et al., 1993). There are suggestions that positive changes in outlook can accompany negative changes following disasters (Joseph et al., 1993) and terrorism (Butler, 2004), and that positive changes can be construed in the context of a wide range of challenges. As Tedeschi and Calhoun (2004) have noted, “reports of growth experiences in the aftermath of traumatic events far outnumber reports of psychiatric disorders”. The idea of positive adaptation — labeled as posttraumatic growth, adversarial growth, and thriving, among other appellations – signifies post event adaptation that exceeds pre-event levels of functioning.

Traumatic experiences severely disrupt, and sometimes shatter, the individual’s usual modes of belief about self and the world, overwhelm adaptive resources and typical means of coping, and in many cases negate previously valued goals and strivings. ”The psychological upheaval that ensues is marked by significant distress, at times incredulousness or conscious denial, and the struggle to come to terms with the new reality of the individual’s posttraumatic existence and the world. The struggle is evidenced in cognitive efforts, in the form of unbidden ruminations, to adapt to the experience and its aftermath. By disclosing and examining the

experience (through talking, writing, praying), accepting what cannot be changed, disengaging from previous goals and beliefs where necessary, and eliciting the emotional scaffolding and means of disclosure provided by social contact, clients may alter schemas and develop a new narrative understanding of the experience and its meaning” (Tedeschi & Clahoun, 2004).

4.4.e Belief System

Making meaning. A critical aspect of growth is the search for meaning in the experience, which is generally viewed as central to posttraumatic adaptation (Janoff-Bulman, 1992), and the perception or construal of positive aspects or benefits to the experience (Affleck & Tennen, 1993). A family’s shared belief system significantly influences adaptation to loss (Nadeau, 1998). Beliefs about death and the meanings surrounding a particular loss are rooted in multigenerational family legacies, in ethnic and religious beliefs, and in the dominant societal values and practices (Walsh, 2004). In a study of posttraumatic growth following the September 11, 2001, terrorist attacks in the United States (Walsh, 2004), the single greatest predictor of posttraumatic growth across all domains, both in the short term and 6 to 9 months after the attacks, was the level of positive changes in existential outlook initially reported. Clinicians need to appreciate the power of belief systems in healing the pain of loss as well as the destructive impact of blame, shame, and guilt surrounding a death (Rolland, 1994).

Mastering the possible. Western values of mastery and control can hinder acceptance of a death. Family members may despair that, despite their best efforts, optimism, or medical care, they cannot conquer death or bring back a loved one. Studies find that resilience involves mastery of the possible: engaging fully with loved ones in the dying and mourning processes, alleviating suffering, making the most of precious time, and healing relational wounds.

Transcendence and spirituality. Meaningful memorial rituals foster healing bonds and the transformation of relationships with the deceased from a living presence to an ongoing spiritual connection. Death ends a life, but not a relationship, which is sustained through memories, stories, and deeds. In traumatic loss, some survivors become blocked from healing, and may perpetuate suffering through self-destructive behavior or revenge and harm toward others. Studies of resilience find that healing is fostered by efforts to tap into the best aspects of the deceased person and the relationship. As one mother stated after a driver took the life of her daughter, “My daughter wouldn’t want me to become consumed by grief or rage; she would want me to honor her life by taking up some meaningful pursuit in her memory.” Personal suffering may be transcended in sparks of creative expression, as in poetry or music, or in community social action to spare other families a similar tragic loss. In some cases, religious beliefs can be sources of distress (¹ Domino & Miller, 1999). One mother in an interfaith marriage believed that the stillbirth of her second child was God’s punishment for not having baptized her first child. It is important for clinicians not to exclude the spiritual dimension of the experience of death, dying, and loss from their assessment and therapeutic work and to consult with, or refer to, pastoral counselors as appropriate (Walsh, 1999).

In the course of our life we all will experience the pain of losing our most beloved relationships. Love may be the most powerful force of life but it cannot stop death. Furthermore, the degree to which our own mortality affects our living is incontestable. Confronted with death and dying we are confronted also with our mortality. While every cell in our being desperately wants to live, the one of inevitable events is that one day we shall all die. Terror Management Theory (TMT) (Solomon et al., 1991) addressed the psychodynamic processes underlying people’s coping with awareness of death. TMT suggests that concerns about mortality play a pervasive role in human affairs, and sustained that people construct cultural worldviews in order to manage the terror engendered by the human awareness of death. Although biological influences, such as increased life expectancy, have modified the experience of death and dying, there are

other factors at play. A global way of thinking about these factors is the concept of a death system (Kastenbaum & Aisenberg, 1972) and is the sum total of the social, psychological, and cultural influences that frame ways in which death is viewed. Death systems are culturally based and shaped by two types of factors: factual factors (i.e., one's personal exposure to death, life expectancy) and theoretical factors (i.e., perceived control over nature, perceptions of what it means to be human). One way to study the death system is by its death attitudes. For example, death attitudes are pervasive concerns for many older adults. From a death system perspective, as individuals age, they have a greater likelihood of death and often face the loss of close friends and family members, which in turn increases their exposure to death. However the association between age, death attitude and fear of death, in older adults remains inconsistent.

4.5: Religious attitudes towards dying and death

Judaism:

Traditional criteria for death are cessation of breathing and heartbeat. Conservative rabbis accept brain death as fulfilling these criteria.

Advance instructions for health care are permitted according to Jewish law.

The views on artificial nutrition and hydration vary based on the sect/movement in Judaism.

Most rabbis permit that Jewish patients may enroll in the hospice.

Islam:

Everyone will face death at one point or another, the manner in which a person dies is of great personal importance. Death can only happen by God's permission, although it is recognized that disease or trauma may cause death. There is a belief that health care providers must do all to prevent premature death. Pain is God's way of purifying man and that pain has an educational purpose i.e. pain may compensate for sin.

Euthanasia is an act against God's authority, however, pain relief and cessation of life support of a patient whose illness causes him to suffer in agony is permitted as long as there is formal agreement between all concerned parties.

Christianity:

Do not cause death either by act or omission.

It is acceptable to use painkillers and sedation to avoid a terminal suffering and despair if it does not cloud consciousness and take away the final opportunity to repent later.

There is no obligation to postpone death, but an attempt to save life at any price is forbidden. However, medical technology may be used to obtain yet another opportunity for repentance.

The approaching death is a last chance for the Christians to reconcile with those who have been hurt by them and seek God's forgiveness. Christians who view religion as a culture may exhibit a secular approach to end-of-life decisions.

Advance directives allow the dying patients to appoint decision makers who will provide instructions that their wishes are followed (Hinkle and Cheever, 2014).

4.6: Conclusions and recommendations

Conclusions:

Of the four issues presented in the discussion, the following conclusions emerged:

The first issue - the more years a nurse has studied, has more experience and done research on the subject, the more positive are her opinions about euthanasia, the importance of balancing symptoms, the dignity of the patient and his wishes. The most positive opinions were of nurses with a doctorate, followed by nurses with master's degree and finally nurses with BA. 70% of all the nurses responded that they had undergone

training or attended professional education on palliative care and euthanasia, thus corroborating this conclusion. Another conclusion that emerges, despite the fact that there is a direct connection between the number of years of study and attitude of the nurse, is that 77.3% of the nurses agree that they lack sufficient training and knowledge in the field of euthanasia and palliative care, and that they would like to receive additional training in these areas to provide optimal care. 71.6% stated that if such a course were to be conducted, they would ask to participate. This leads to the conclusion that the nurses in Israel desire vocational training and courses in palliative care and the dying patient, and that the team, working with these patients, feels that it is important to keep up-to-date professionally.

The second issue - religion and the degree of religiosity does affect the position of the nurses regarding euthanasia and the end-of-life decisions. A significant difference was found between Jews and Muslims regarding the importance of dignity of the dying patient and family, which was of high importance among Jews, while the knowledge and awareness index of euthanasia, was lower among Muslims compared to Jews and Christians. According to the statement, "*the terminal patient may decide on his life at any stage of the illness before agony and suffering*" it was found that 58% of the Muslims strongly agree with this statement, compared to 70% of the Jews who strongly agree with this statement. These figures suggest that Jews are more likely to discuss end-of-life and euthanasia in a dying patient. A significant bond exists of euthanasia with religiosity between traditional and secular, between secular and religious, and between traditional and religious. In other words, the attitude of secular nurses is more positive towards euthanasia than traditional and religious nurses, and the attitude of traditional nurses is more positive than religious nurses.

The third issue - patient dignity and the principle of autonomy are factors influencing the decision-making process of nurses. The study shows that 66.3% of the nurses agree with the statement "The role of the treating staff to offer the patient the possibility of euthanasia" and raise the issue of euthanasia and the end-of-life to the dying patient and his family. In

addition, it was found that the dignity of the patient and family was viewed as one of the most important factors affecting the caregiver, since 90.2% of the nurses believe in the statement "The right to die with dignity is as important as the right to live with dignity". 96.6% of the nurses agree with the statement that "the possibility of dying with dignity means emotional well-being for the patient," and that 95.7% of the nurses agree with the statement that "dying in dignity provides physical comfort for the patient". This data emphasizes that the dignity of the patient is one of the most important factors influencing the decision making of the nurses in conjunction with the understanding that the physical and mental well-being of the dying patient and family is critical in end-of-life decisions. For example, if the dying patient asks the staff not to perform resuscitation if necessary, the staff will be willing to honor the patient's request even if they do not agree with this request because patient dignity and autonomy are important factors influencing their decision.

The fourth issue – involvement of interdisciplinary teams has a positive effect on nurse's decisions regarding euthanasia and end-of-life, and enables the nurse, as part of the interdisciplinary team, to propose to the patient optimal solutions and decision-making as a result of being affiliated to this forum. This data indicates that the team, caring for the dying patient and family, feel that the most suitable decision for the patient is reached by an appropriately trained interdisciplinary team that plays a significant role. Indeed, 62% of the nurses noted that the decision was made by the patient in cooperation with the interdisciplinary team, that includes a physician, a nurse and a social worker. Another finding that strengthens this conclusion shows that in the statement "There is a need to invest more resources and staff training for a variety of different professionals in order to promote a dignified death" 99.8% of the nurses agreed, with 81.4% agree strongly, indicating a growing desire of teams to deal with dying patients and discuss the question of end-of-life training of dedicated interdisciplinary teams in order to provide the most appropriate treatment in an individual way to the dying patient.

Recommendations

- *Opening vocational training and specialized courses on euthanasia and palliative care for nurses who work in the various wards and not just for those working in hospices and in the oncology wards.* According to the findings of the study, the nurses in Israel who treat dying patients in many different wards feel that there is a gap between the knowledge they acquired during nursing studies and their work in the ward, and the knowledge they feel they are expected to follow. This gap makes it difficult for nurses to treat the patient and family optimally. The opening of vocational courses and training on the subject will help nurses bridge the knowledge gap, regarding treatment of dying patients and families, and provide professional and efficient treatment. In addition, the training will provide nurses with a sense of security in the complex and sensitive care provided to the patient. Expanding the horizons and imparting necessary skills to the nurses to treat dying patients will have a positive impact on the nurses' experience and opinions and the enhance treatment of the dying patient.

- *Establishing the interdisciplinary team, including a physician, nurse and social worker, in the wards that deal with the dying patient.* It was found that the opinions of nurses in Israel in making decisions, the interdisciplinary team provides a professional and higher quality response to the dying patient while raising the confidence of the nurses who provide treatment. The interdisciplinary team adjusts for comprehensive decisions much more than if decision-making is performed by one staff member. In many cases, in addition to the medical, nursing and social responses, extra intervention of a dietitian, psychologist and other staff members who are relevant to the patient's condition, and all help to provide a professional, correct and comprehensive response to the problems and wishes of the dying patient and family, thus alleviating the suffering of the dying patient in various ways.

- *Furthering new research on the psychological and ethical aspects of nurses' opinions about euthanasia.* This study examines the influence of religion and education on the views of the nurses in Israel regarding a

palliative care and euthanasia for the dying patient, which contributes to raising awareness of the dire need of nurses training and professional courses in the area. These influences also contribute to understanding the differences between the various religions regarding euthanasia and the role the staff plays in a situation when questions are asked regarding the end of the patient's life and the option of euthanasia. Further research on psychological and ethical aspects, for example, can contribute greatly to a deeper understanding of the motivations of nurses in the field of euthanasia and their effects on end-of-life decision-making. It is possible to get first-hand information from nurses who have experienced or are currently experiencing a condition in which their family member was dying and treated with palliative care and how this affects their opinions in comparison with their personal exposure to the subject.

In the world of modern medicine, the use of euthanasia has existed for many years but still constitutes a major and central point of contention in medical ethics. Today, many places in the world understand the great importance of euthanasia and palliative care in patients who have been defined as terminally ill and their illness accompanied by great agony and suffering. There is an understanding that a person's right to his body and life, but on the other hand arises the question of the sanctity of life and whether it is possible to find a balance between these in order to alleviate the suffering of a patient who is dying and lives a life of pain and agony. With the main goal being to improve quality of life by balancing pain control symptoms and mental support in order to provide maximum mental and physical comfort to the dying patient.

In many cases, end-of-life decisions are rejected again when a deterioration occurs in the patient's condition, and then there is no way of knowing whether he or she would prefer to shorten his suffering or prolong his life. The law of the dying patient allows a person to express his or her desire in advance for future written treatment when he is healthy (pre-medical guidelines) if he is a dying patient who will not be able to make decisions in real time. Another way that the law allows is to grant a special power of attorney to another person.

In 2005, the Steinberg Committee was established to discuss these issues in order to assist complex patients who wish to end their lives in order to alleviate their suffering.

Many nurses, from different religions in Israel and around the world, face daily situations of this type and report that there are many factors that influence and assist the patient with the decision-making process.

They also note that this sensitive issue raises many halachic, moral and medical dilemmas that sometimes stop them from providing the optimal treatment they can provide.

For example, religion and the degree of religiosity of nurses influence the tendency to prolong life together or in opposition to the patient's requests. The level of education of nurses, when they studied for more years and were exposed to more complex subjects, tended to help patients with their requests despite their personal beliefs. In addition, the presence of the interdisciplinary team also affects the way nurses and decision makers relate to the end-of-life. When the decision is made on the interdisciplinary team's forum, the opinion of the nurses about euthanasia is more positive because they are exposed to additional aspects of the patient's terminal illness, for example, a psychological aspect that would not have been exposed to him had there not been the interdisciplinary team.

In addition, it seems that many nurses are willing to take part in enrichment courses and modules in order to acquire sufficient tools to deal with complex patients and thus feel more confident that the decisions they make about end-of-life and euthanasia are both informed and beneficial to the patient.

It is important to raise the sensitive issue that deals with the life and death of patients who are dying, and the high importance attached to the care staff, including nurses who are committed to preserving their dignity, faith and desires, especially during the process of dying. Mentally and physically to the patient. And therefore, it is very important to deepen the knowledge and broaden the horizons of the nurses in everything related to the physical and mental state of a patient who is dying and in a very sensitive situation.

Chapter 5:

PALLIATIVE CARE AND EUTHANASIA OF JUDAISM

5.1: Cultural and Religious Aspects of Palliative care

The consideration of institution of end-of-life care is an emotionally charged issue for the patient, their families and caregivers. Attitudes and approaches to palliative care vary widely amongst religions and cultures. Decisions are influenced by the beliefs of the caregivers, patients and their families. Given the heterogeneity of many societies including our own, it is worthwhile to examine the differences in approaches to palliative care and end-of-life issues in different cultures and religions. Even within individual countries, the manner in which palliative care is delivered varies by culture and religion. Examples of the differences in attitudes on the part of both the caregivers and patients will be presented.

Among the world of medicine, heated debates regarding the use of active euthanasia as a means to shorten the pain and suffering of a terminally ill patient, has become one of the most controversial ethical topics in health care. Interestingly, another form of euthanasia that is commonly used in practice today is passive euthanasia, the withholding of a medical treatment intended primarily to prolong a patient's life and not treat their illness. Furthermore, euthanasia must be separately identified by patients who willfully requested it and of those who are unconscious. An unconscious patient can obtain approval, provided a family member or legal guardian can represent Advanced Directives (AD) signed when the patient was mentally competent.

Moral arguments on the subject continuously arise. Supporters argue for a person's right over their own body, the right to choose to live pain-free and the right to prefer death over a life without dignity. Opposers maintain the argument of preserving the sanctity of life. They warn that

with the granting permission to take a life, even in extreme circumstances, may lead to the decrease in requirements to qualify for active euthanasia allowing for unjustified circumstances to be approved.

Religion and spirituality take a leading role in a person's life and health. The development of an individual's autonomy and process needed to make medical decisions, religious affiliation constitutes an important factor. This point is made clear especially in EOL decisions: stopping treatment or avoiding it, ineffectiveness of the medical treatment given, nutritional support and advanced directives (AD) for a patient that is not interested in a life-prolonging treatment (Kassim, 2016).

Mercy killing is mentioned in the Jewish *Halacha* “*This day, I call upon the heaven and the earth as witnesses [that I have warned] you: I have set before you life and death, the blessing and the curse. You shall choose life, so that you and your offspring will live; (Deuteronomy, 30:19)*”, this verse means to choose life and not death since it's the natural and immediate choice. Even for terminally ill patients, or those suffering from extreme emotional distress, the bible commands to choose life and not succumb to death.

There are three main principles in Jewish medical ethics. The First: The sanctity of life, The Second: aging, illness, and death are a natural part of life and The Third: improvement of the patients' quality of life is a never-ending commitment (Padela, 2006). As a rule, the arbitrators allow avoiding actions that will prolong the suffering of a dying man, and some even say that that prolonging is forbidden, if that person is not interested in it.

Regarding EOL decisions, the law also plays an interventive role in resolving conflicts that arise between the *sanctity of life* and the *quality of life* within the health system. Medical communities handle ethical and constitutional dilemmas but must also be sensitive to patients holding different beliefs and values, while implementing advancement of standards and laws.

Up until 2005, the Israeli law considered an individual responsible for the death of another if “by his deed or by omission he hastened the death of a person who suffered from a disease or injury, which would have caused death even without that deed or omission” (Penal Law 5737-1977, p.93). The

courts in Israel never gave the permission to perform active euthanasia, but in many cases allowed avoiding life prolonging treatments such as; disconnecting a respirator, avoiding dialysis, discontinuing nutrients and fluids.

In 2005, a law was enacted in Israel to put to order medical treatment of a dying patient while properly balancing the sanctity of life, value of a person's autonomy, and the importance of quality of life.

This book was conducted to examine the influential impact of local cultures and laws on the perception and standpoint of a Jewish population. The specified topic addresses one's opinions on Euthanasia and End of Life (EOL) care. The targeted demographic are Jews living in Israel, where euthanasia is not permitted by law, and Jews living in the United States, where euthanasia is permitted by law in certain states. A qualitative research done by Schweda in 2017, "Beyond cultural stereotyping: views on end-of-life decision making among religious and secular persons in the USA, Germany, and Israel," found no definitive correlation between nationality, culture or religion. A conflicting issue manifested an interest on the subject particularly as a result of two opposing arguments. The physicians Hippocratic Oath utterly forbids "mercy killing" and includes pledge: "I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly, I will not give to a woman an abortive remedy. In purity and holiness, I will guard my life and my art" (Edelstein, 1943). Contrarily, present day medical equipment and care preserves life far beyond its natural course and timeline of death. These contradictions are evident for the need of an extensive theoretical and practical research on cultural differences.

Another element being studied is the influential affect of a community on an individual's opinion. Taking into account one's culture, ethical beliefs, religious community, laws and regulations, and place of residence in relation to their perception regarding EOL care and euthanasia. The main focus was on Jews residing in Israel and the United States as well as the different sects within the countries themselves.

The premise is based on the wide variety of beliefs and perceptions amongst the different sects and cultural backgrounds of Judaism. Each

community should have the right to receive treatment that complies with their beliefs and values. If one disassociates themselves from a specific community and turns to public political policy, the subject of legal regulations regarding EOL decision still stirs conflicted disagreements. (Schweda et al, 2017).

Analysis of this study was compiled using the quantitative research method comparing perceptions of Jews, within different sects of Judaism in Israel and the United States, regarding EOL care, while taking into account socio-political influence and opportunities available to them by law.

It is hypothesized discrepancies will be found between the Judaism sects (Ashkenazi, Sephardic, Eastern, Mixed) with regards to perceptions and stands on matters associated with euthanasia. Stands on euthanasia are depended on the level of religiosity: religious, traditional or secular. Perceptual differences addressing euthanasia will also be found between the Jews residing in Israel and the United States.

The independent variable in this essay is the legal, religious, cultural and political environment associated with an individual. The dependent variable is the perception and stand of the individual regarding euthanasia and EOL decisions.

5.2: Literary Review

EOL decisions are based first and foremost on an individual's basic perception of life and death, their values and desire to live an honorable life. Combining it all, consider the following questions: can the autonomy of a patient be kept, as well as his right to end his life with dignity, in an environment controlled by paternalistic professionals and medical bureaucracy? Is it moral to stop or withhold life-extending treatment from a patient? Is it moral to aid a terminally ill patient in ending his life, an act defined as "assisted suicide", or even execute euthanasia? How much influence does medical principles and political regulations have on the individual concerning sensitive personal and family matters? (Schweda et al, 2017).

Approaches in decision-making regarding EOL are rooted and highly influenced by the culture an individual belongs to, especially their religious and spiritual affinity. One's personal background and past experiences is taken into account as well. (Schweda et al, 2017). Here forth, a demand arises in public discussion, to take into consideration cultural and religious differences on matters of medical ethics as a multi-cultural environment. The limitations of treatments for "dying patients" on their deathbed created a severe moral dilemma with medical, social and religious repercussions. In opposition, it is morally argued that euthanasia is assisting a person who voiced their wish to end their life, as a means to better the situation when suffering from an incurable disease to end prolonged suffering. Supporters emphasize a person's right over his own body, a person's right not to suffer and his right to prefer death to a life without dignity. Opposer's maintain the argument of preserving the sanctity of life with warning that granting permission to take a life, even in extreme circumstances, may lead to the decrease in requirements to qualify for active euthanasia allowing for unjustified circumstances to be approved. In the 20th century, Germans were the first to perform active euthanasia on thousands of mentally ill and physically disabled people, using deadly gas. At the end of the 20th century the health system in Holland solved the problem of patients suffering from incurable diseases. They allowed active euthanasia for thousands of patients resulting not only in the ease of the patients' suffering but also ending their medical and financial burden.

5.3: Euthanasia in Judaism and the *Halachic* basis for the dying patient bill

The approach towards the "terminally ill" subject has always been sensitive and conflicted morally within medical health care. The Hippocratic oath states "I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect". *Halachic* law consistently address moral issues, even more so with the progression of medical

treatment and technology. On one hand, doctors today have access to diagnostic tools and advanced treatments. Means to prolong life far beyond what was possible in the past. On the other hand, prolonging a life does not necessarily improve a patient's quality of life. Occasionally it may lead to the prolongation of pain and suffering (Steinberg, 2003)

Halacha states the sanctity of life outweighs the individuals' autonomy completely forbidding *active euthanasia*. Stopping medical treatment that may lead to the shortening of a life is considered an active intervention making it unacceptable. Withholding medical treatment is considered *passive euthanasia*, and as such, allowed in certain circumstances (Schweda et al, 2017). If a patient is not suffering but is unconscious and incurable, obligations to continue treatment are questionable. Arbitrators such as Rabbi Yosef Shalom Eliashiv claims "if a terminally ill patient is suffering in agony, or even extreme mental distress, and asks not to continue life-prolonging treatments that just adds to the suffering- withholding treatment is allowed, but there is no prohibiting it if it prolonged his life under those conditions." Rabbi Shlomo Zalman Auerbach states, "if a terminally ill patient is suffering it's a *mitzvah* and a duty to avoid prolonging his life of agony, and it's prohibited to take actions that will extend his dying misery" (2003, שטיינברג).

Prohibition of active euthanasia is not only towards killing itself but includes any slight movement of the patient that may hasten death; "One must not pry his jaw, anoint him, wash him, plug his orifices, remove the pillow from underneath him, or place him on the ground" (Hurwitz, 2006).

Prolonging sufferance in patients by attaching life-support or performing CPR according to popular beliefs is unnecessary. Medications provided in such cases should also be withheld except for fluids and nutrients. A patient already hooked up to a respiratory machine, the dilemma arises on how to disconnect them. Most arbitrators pray for a peaceful and quick death for a terminally ill patient in hopes to save them from unnecessary misery. Steinberg emphasizes specific EOL situations involving great suffering in which according to *halichic* principles, prolonging life can be avoided. A balance by which the sanctity of life is preserved as well as other values such as the prevention of suffering are respected.

5.4: Steinberg Committee Report – summary of principle from reports

1. It is utterly forbidden to perform active euthanasia.
2. Withholding death preventing medical treatment is permitted under three basic conditions: a) the patient is dying b) the patient is in great agony and c) the patient does not wish to postpone his death. This also applies to not being connected to a ventilator as long as the above conditions are met.
3. For the first time, Israel has legal obligations to administer palliative treatments (to ease suffering) to terminally ill patients and their family members.
4. It is mandatory to discuss transparently procedures in the presence of the patient or his/her representatives.
5. Advanced directives (“living will”) will be respected if in accordance with the above conditions.

Special points mentioned at the Steinberg committee:

- Not renewing a treatment can be defined as withholding treatments.
- As a rule, a patient shall not be dehydrated or starve to death even with approval of withholding life-prolonging treatment.
- A patient shall not be disconnected from a pacemaker or ventilator. A patient can be connected temporarily to a ventilator with a predetermined date to shut down and not to reconnect, if the above conditions apply.

5.5: “Israeli Dying Patient Act” in Israel vs. “Death with Dignity Laws” in the USA

In 2005, Israel enacted the Israeli Dying Patient Act (IDPA). This Law regulates the medical treatment of terminally ill patients based on an appropriate balance between the sanctity of life, the individual's autonomous will and the importance of quality of life. This Law is based upon

the values of the State of Israel as a Jewish and democratic state on fundamental principles in the realm of morality, ethics and religion. In prescribing the medical treatment of the terminally ill patient, his or her medical condition and the degree of suffering are the primary considerations. (IDPA, 2005). This law offers guidelines for a responsible physician to assess a patient and the necessary requirement to determine a patient is terminally ill; "...if satisfied that the patient is suffering from an incurable medical problem and that his life expectancy, even if receiving medical treatment, does not exceed six months. "A responsible physician can determine a terminally ill patient as end-stage when a number of vital systems in his body have failed and his life expectancy, even if receiving medical treatment, does not exceed two weeks.

5.5.a Preliminary medical instructions (Advanced Directives) to future medical treatment of a dying patient

The Advance Directives form is intended for any individual interested in documenting any preliminary medical instructions. The patient in detail addresses future medical treatments in case they are diagnosed with a terminal illness, become unfit, or are dying. Two key points are referred to: First, withholding life-prolonging medical treatments and second, receiving life-prolonging medical treatments, even if caregivers do not think them necessary. Any individual older than 17, able to voice their will, deemed fit, is fully conscious and in sound mind, whether healthy or ill, is permitted to leave advanced directives voicing their wishes for future end of life treatment.

The "Death with Dignity Law" was first passed in 1998 in the state of Oregon in the United States. Its basis was on the notion that a terminally ill patient should be the one making his or her own EOL decisions. They are to determine themselves how much pain and suffering they are willing to endure (Schweda, 2017). "Death with Dignity Laws" in Oregon, Washington and Vermont, permits adults over the age of 18, diagnosed with an incurable disease and dying, to request a "Lethal Prescription" from their

physician. They must be resident of one of these states for a minimum of 5 years to be eligible to make a request. The request must be executed verbally twice as well as in writing. Two witnesses must be present during the request with a 15 day span between each request. Two physicians must confirm the patient is indeed terminal with an incurable illness, that the patient is in physical or mental agony and that his life span will not exceed six months. Physicians are also required to determine if the request was given in sound mind and the patient is not suffering from depression. The physicians have a duty to explain all the patients' options, including palliative care. Once all the criteria's are met, the attending physician is permitted to prescribe the patient a lethal dosage of sedatives. The law also obligates the physician to report to the health care authorities on every "lethal prescription" written. After the patient is deceased, an inspection of the process is carried out by the state. The law protects physicians acting within these rules and the patient's death is not considered "suicide" but a natural death, caused by his original illness. It's important to state, the law obligates the patient to administer the medication themselves and forbids the physician to give it to the patient in any way (Ganzini, 2016).

5.6: Repercussions of an illness on a terminally ill patient and their family

Handling the harsh news is an ongoing process for the patient and their family. Time and support are important tools needed to acclimate and accept what is to come with a terminal illness and impending death. The patient and family encounter uncontrollable fear of the unknown future. In families with a history of bad communication or serious issues tend to experience more difficulties when a person close to them is nearing death. Nonetheless, an opportunity is opened for family members to resolve existing conflicts allowing for a renewed closeness (Brunner & Suddarth, 2014).

5.7: Characteristics of a terminal illness

Although every person experiences terminal illness differently, the process in which the disease manifests is also affected by the social and cultural attributes of the patient. Some believe the notion of a potentially lethal disease, making decisions regarding life-preserving treatment, dying and death often as dichotomic, meaning, the result will be winning or losing. For instance, a terminally ill patient after failed medical treatments might lose faith in the medical system and treating staff (Brunner & Suddarth, 2014). The symptoms of a terminally ill patients are similar regardless of the originated disease. They can be caused as a result of the disease itself (like difficulties breathing due to obstructive lung diseases), indirectly (like vomiting and nausea cause by pressure on the abdominal area), the medical treatment or an associated disorder not related to the disease. Examples of such symptoms include pain, difficulty breathing, nausea, weakness and anxiety (Brunner & Suddarth, 2014).

5.8: The process of decision making at EOL

In Western Medicine, the process of decision-making is based on the patient's autonomy, honesty and consideration of the patient's will to stop treatment or withholding life-prolonging treatments.

According to Jewish tradition, the process of decision-making regarding EOL care acknowledges the difference between active and passive euthanasia. Under the IPDA (2005), when a patient wishes to avoid treatment, their wish is usually honored. When a patient is deemed unfit his wish can be verified in a number of ways such as: medical AD given in writing by the patient, a decision made by a legal guardian, or a combination of both. An institutional/national committee derived of medical and health care professionals, religious, ethical and legal figures, can make a final decision in case of a dispute or if there is a doubt regarding the patient's will. The national committee handles appeal of decisions made by institutional

committees. In addition, handle other social and family matters as well as religious and ethical aspects. It should be noted, the IPDA does not give complete freedom to act as one pleases: it is absolutely forbidden to stop an ongoing medical treatment if it may cause a patient's death. This law can prevent the renewal of medical treatment that ended independently, not premeditated or against the law. A compromise is offered through this law by allowing medical treatments to be stopped without contradicting religious and cultural beliefs (Glick, 2015).

5.9: Ethical issues regarding EOL

In the last three decades, technological developments have advanced allowing life to be prolonged longer than ever before. Arising challenges of improving the quality of life for a dying patient are constantly addressed. There are more options today in assisting a patient to end his life painlessly. Unfortunately, the access to new technological therapeutic equipment often ends up causing dying patients' pain and suffering. Prolonging life beyond a certain point where people consider valuable brings up troublesome ethical dilemmas (Brunner & Suddarth, 2014). It is important to inform patients all of their options regarding EOL decisions and care. Discussing openly with the patient is a crucial element in supporting them during the process of decision-making as well as their acceptance of the end being near. Caregivers involved can evaluate the patients understanding of their new reality and how they are dealing with the diagnosis, allowing them to adjust accordingly their means of care to the individual, fitting to their perception and values.

Prior to handling difficulties associated with EOL decision-making, the medical community should aim to act according to ethical obligations, legal requirements and a patient's religious beliefs. Addressing ethical issues between the medical staff and patient may possibly become an obstacle resulting in a delay of deciding treatment. Responsibilities of a caregiver always includes considering the patient's autonomy throughout the

process, which can contradict with their ethical responsibility to better the patient and avoid harm. Ethical challenges increase when the patient is not fit enough to make his or her own decisions. In such cases, the patient's family can decide based on their wishes.

5.9.a Palliative care of a dying patient

Palliative care has developed in recent years allowing a holistic and humane approach in treatment for dying patients. Palliative care considers the patients' needs individually, adjusting to their personal needs and preferences. Its principles include:

- Respecting patients' goals, preferences, and choices;
- Attending to the medical, emotional, social and spiritual needs of the dying person;
- Using strengths of interdisciplinary resources;
- Acknowledging and addressing caregiver concerns;
- Building mechanisms and systems of support (Brunner & Suddarth).

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.” — Dame Cicely Saunders, nurse, physician, writer, and founder of hospice movement (1918 – 2005).”

Spirituality for patients is directly influenced by their beliefs on the meaning of life, goals they must achieve, and values they hold dear. All these qualities grow together, becoming a source of hope to their approach with death. For most patients, facing death brings up many questions such as; “What is the meaning of life?” “What is the point of suffering and the existence of an afterlife?” In a study held by the American Association of Retired Persons (AARP) in 2009 regarding EOL issues it was discovered patients' expressed needing honest answers from their physicians (74%), and to understand medical treatment options (64%). In addition, religious and spiritual comfort (37%), giving to others (33%) and the fulfillment of personal goals (27%). (Brunner & Suddarth, 2014).

5.9.b Stands on death

Coming to terms with ones' own death, or of a loved one, has its challenges and for some constitutes as a threat and creates anxiety. These feelings increase among dying patients fearing the unknown, pain, loneliness, losing control over their body and the inability to communicate with their surroundings. Spiritual support provides guidance for people questioning the meaning of life; "spiritual support is a holistic therapeutic approach, that puts the individual in the center of it and compliments other treatments that are provided in other ways, while giving special attention to the spiritual aspect. The spiritual support is focused on healing, guiding, strengthening, freeing and empowering people, in any situation they are in (Rumbold, 2003)."

5.9.c Rejected in preliminary hearing: physician assisted death for dying patients, July 13th, 2016

In 2015, the Knesset, Israel's national legislature, rejected an additional proposal of the Dying Patient Act, Physicians Assisted Suicide, in preliminary hearing. It was proposed that a dying adult patient, fit of sound and mind, who has been an Israeli citizen for the past 5 years, is permitted to request a prescription from their primary physician of a lethal dosage of sedative to administer themselves. The draft stated: "the dying patient act acknowledged the fact that it is possible to preserve the life of terminally ill patients in an artificial way beyond the natural limits of its disease. This technical ability condemns patients to continuous physical and mental suffering as it prolongs the dying process without hope or purpose. The law respects the patients right over his or her own body and thus allows physicians to accept a dying patient's request not to prolong his life using artificial means. It permits physicians not to connect or renew a treatment of a patient to a respiratory machine if they are diagnosed with an incurable disease, dying, and have given consent in sound mind."

The health minister, Yakob Litzman, replied on behalf of the government: “If a patient is given two days to live by physicians and someone comes up to him in the street and kills him. Can we not accuse the killer with murder? As long as a person is alive and breathing it is forbidden. I’ve seen cases of people who thought they were dying and physicians said it was a lost cause and suddenly they got up. According to *Halacha* killing a dying person is murder and it is forbidden to do so.” (M.knesset.gov.il, 13 July 2013).

5.10: Conclusions and Recommendations

Conclusions: The perceptions and stands regarding euthanasia are influenced by historic values, religion, socio-economic status and cultural aspects. The discussion on euthanasia increases awareness of the options available via palliative care and important bio-ethical considerations such as a person’s right to end his own life. This allows one the maximum autonomy, sanctity of life, patient-physician relationship on matters regarding regulations and the actual process of EOL care. Managing the treatment of a patient with a Jewish religious affinity is based on beliefs and values of the individual. The EOL decision-making process refers to the patient’s autonomy and the authority of the Rabbis dealing in human-life laws, *dinei nefashot*. Most arbitrators believe that a dying patient suffering in agony from an incurable disease fully has the right to avoid certain treatments that will only prolong his suffering.

The findings show complex differences with regards to cultural and religious aspects of EOL decisions among Jews in Israel and the United States. In Israel a greater openness and awareness can be seen, their involvement on the matter especially when making decisions. The influential impact a religious affinity has on ones stands of euthanasia are profound within the religious groups.

Secular populations support the autonomy of a dying patient and their right to be involved in the decisions of his or her own treatment. They have

the right to die with dignity, to end their days in a familiar environment and allow relatives to be involved in the treatment management process. Having said this, there is a correlation between religious and orthodox populations in Israel and the Jews residing in the United States. Specifically stands on the sanctity of life as well as the approach of a patients' life being in the hands of professionals.

Additionally, the role of a physician has been questioned on how to approach the treatment of a mentally unfit individual or a patient not interested in receiving treatment. The great debate arises between ones who believe a person has complete ownership of his or her own body, and others who believe a person cannot forsake his body including no right to harm him or herself by avoiding treatment. This dilemma continues with the arising question about the treatment itself and if continuing it will only prolong suffering. Rabbi Feinstein's believes (Ganzini, 2001) a dying patient can avoid treatment since it doesn't constitute self-harm but should be seen as the best decision for that individual at that point. There are cases where a physician will be permitted to fulfill a patient's request of avoiding certain treatments. Even so, Ganzini makes a point to mention this is not a general allowance but on a case-by-case basis.

This study examined the affect geographic location and culture has on an individual perception regarding EOL decisions and euthanasia. Demographic characteristics were addressed, and stands were questioned in connections to ethical, legal, political, religious and social attributes. The questionnaire did not include analysis of one's personal experience and if ever had faced EOL decision-making personally or with a loved one. An individual's personal experience may have a deep impact on one's perception, resulting in completely opposing or supporting their cultural-religious-spiritual-local influences. Further investigation on this subject is highly recommended.

With the increase in population and life expectancy, people today are suffering from chronic diseases more than ever before. Multiculturalism in the health system along with the advancements of modern medicine must work hand in hand to continuously consider and respect patients'

autonomy. Western medicines acknowledge patients having complete control and rights over their body. A dying patient not interested in prolonging his or her life has the right not to. However, a religious practicing Jew view thing differently when making decisions on the subject. The process is not based only on cultural norms, but by Jewish law and its rabbinical representatives regarding the subject of EOL. Many traditional beliefs are influenced by old-fashioned perceptions and understandings of physiological processes an individual experience at the end of one's life. With the advance of modern technology, spiritual leaders have begun to reconsider certain beliefs. Nevertheless, many cases involving Rabbis in making medical decisions challenges the conventional notions on matters of patients' autonomy. Decision-making to treat a dying patient entails awareness of the Jewish religion, involvement of the patient's family, legitimizing autonomy of the patient and relying on Rabbinical advocates of the Jewish Law, *Halacha*.

Arbitrators of *Halacha* teach that one must not hastens a man's death intentionally, even if specifically requested since it is one of the ten commandments "thou shall not kill". On the other hand, arbitrators also believe there is no obligation prolonging a meaningless painful life if a patient requests it too. The value of life is supreme but not an absolute one. *Halacha* and its fundamentals are based on *mesir hamonea*. A principle in which *halacha* has the authority to permit, prevent and stop any action considered life-prolonging a dying patient which does not quicken death. It seems unquestionable with life being of supreme value, any life prolonging action must be taken and continued no matter what the cost. *Mesir hamonea* provides a balance between preserving the sanctity of life and other values such as preventing suffering, under well-defined conditions.

The IPDA created a bridge linking opinions of many arbitrators on this issue. A patient with a life expectancy of less than year is considered a patient with an incurable disease. According to *Halacha*, any patient under this category must have their wishes respected including treatments causing suffrage. In the United States, "Death with Dignity" allows a dying patient to hasten their inevitable death. It offers opportunity to contemplate the most

important question: “What is the meaning of life?” The process has steps necessary to make the right decisions regarding care while advocating autonomy on the right to die with dignity specified in the law.

This study examined the cultural and local legislations influence on the standpoint of Jews regarding Euthanasia and EOL care along with comparing the Jewish populations of Israel, where euthanasia is against the law, with the United States, where euthanasia is legal in a number of states in America.

The findings show approach towards euthanasia in Israel to be more positive and liberal, despite it not being permitted by law. That positive approach was also more prominent among the secular population in Israel, holding opinions and support of dying patients’ autonomy as well as the right to die with dignity.

Findings from the United States projected a more negative approach even though euthanasia is permitted in a number of states. The law also permits advanced directives allowing a dying patient to choose how to end their life. It is believed as a result, Jews living in the diaspora, outside of Israel, tend to become active members in local Jewish communities. Parents send their children to Jewish schools, attend organizational events, and practice Judaism, integrating Jewish traditions with the local cultural norms. Leaders of these Jewish communities have a significant role by giving guidance. The making of medical decisions must coincide with *halacha*. A common factor was found between the Jewish population living in the United States and Orthodox Jews living in Israel. Rabbinic leaders and *halachic* arbitrators are their main source of guidance when in need to make a decision especially regarding medical care.

5.10.a Key points: Judaism and the end of life

- Jewish law is specific, and may appear inflexible; however, rabbinic interpretations and an improved understanding of modern medicine demonstrate that there is flexibility when approaching end-of-life care

- Rabbinic involvement in medical decision making is common and may challenge conventional patient autonomy, particularly at the end of life where the threshold for withholding life sustaining treatments in view of ‘futility’ may be higher than western trained physicians. However, this is not universal and careful explanation of treatments and prognosis is vital in allowing the family to make decisions together with rabbis
- Patients may request medical interventions which the medical team may be uncomfortable with, as the Halacha requires a physician to do everything in their power to prolong life, but prohibits actions which prolong the act of dying or hasten death
- Healthcare professionals should explore and establish the importance of prayer needs, Shabbat observance and the degree of involvement of the rabbi and family in decision making
- Jews refrain from actions considered work on the Shabbat, such as writing, carrying, use of electrical devices or business transactions. Be mindful of this when treating patients observing Shabbat, for example when prescribing patient controlled analgesia (PCA)
- A dying patient should not be left alone and Jews will wish to fulfil their obligation of ‘Biqqur Cholim’ (visiting the sick)
- Judaism prohibits prayer in the presence of bodily fluids. The dying patient can be incontinent, so if the patient cannot be continually cleansed the family/clinical team should seek rabbinical guidance to determine the correct course of action

Chapter 6: **PALLIATIVE CARE AND EUTHANASIA OF CHRISTIANITY**

6.1: Christianity's Positions and Perspectives on End of Life Decision-making and Euthanasia

The Dialogue between Medicine and Religion:

Euthanasia (which comes from the Greek words for “good death”) may be defined as action which accelerates the death of patient with an incurable, terminal illness in order to alleviate the patient’s suffering and pain. The decision-making process pertaining to terminally ill patients is among the most prominent and long-standing problems in medicine. It is influenced by religious, ethical, and cultural values. The issue concerns not only the patient, but also the patient’s family and the medical staff. Unsurprisingly, there have been extensive ongoing discussions about this subject between medical staff, lawyers, religious figures, and other involved parties.

The treatment of terminally ill patients is one of the most enduring and prominent problems in the field of medicine. The prolongation of the life of a patient, especially a patient suffering severe anguish, raises serious medical, moral, legal, and economic questions. These questions concern not only the patient, but also the patient’s family and friends, as well as the physicians and medical staff. Unsurprisingly, there are extensive ongoing discussions on this issue among medical staff, religious leaders, lawyers, and the media, who often express their opinions, especially following dramatic events related to this issue (Aviv & Galili-Schachter, 1999).

The concept of euthanasia originated in the classical period of ancient Greece. The term comes from the words εὐ (eu) meaning “good” and θάνατος (thanatos), meaning “death”. Some define it as the accelerated death of a patient by the patient or by caretakers. Others define euthanasia

as a merciful desire to end the life of person who has a terminal illness in order to end the person's suffering and pain (Steinberg, 1982).

According to Steinberg (1982) here are several types of euthanasia. Active euthanasia is a deliberate action, such as injection of a drug, which will end the person's life. Passive euthanasia involves withholding treatment that keeps a patient alive. Voluntary euthanasia refers to a patient's choice to die. The patient must be mentally capable of making such a choice. Involuntary euthanasia refers to killing a patient without the patient's consent.

Over the years, euthanasia has assumed a large and significant place in the field of health, making it impossible to ignore. Discussion of this issue covers various factors and areas. Two main areas pertaining to this dilemma are ethical and religious values. It should be noted we may distinguish between the religious values associated with the three main branches of Islam, Judaism, and Christianity. This chapter will briefly present the perspective of each of these three religions, then focus on perceptions of euthanasia within various denominations of the Christian religion in Israel.

According to the religious worldview of Judaism, a person does not have the authority to choose to die. Life is a gift given by God, and only God can take it away (Steinberg, 1982). People do not own their bodies and cannot end their lives. God gives people their bodies "on deposit" so that they can fulfil the tasks and commandments given in the Torah (Hebrew Bible) and carry out acts of morality. People have no right to harm this deposit in any way.

"Your blood be on your head, for your own mouth has testified against you, saying, 'I have killed the LORD's anointed.'" (Samuel 1:16).

From this it is understood that killing is murder in all cases.

Islam categorically prohibits all forms of suicide or any action that might help people kill themselves. Islam forbids Muslims from planning or determining the date of their death in advance.

"Whoever killed a soul, except for a soul slain, or for sedition in the earth, it should be considered as though he had killed all mankind." (Table-Al Ma'ida - 5.32).

“The recompense for he who kills a believer deliberately is Hell, he is eternally there. Allah will be angry with him and will curse him and prepare for him a great punishment.” (Women-An Nisa’ – 4.93).

The Christian religion agrees with the position that life is a divine gift and no one has the right to dispose of it. Therefore, euthanasia is unacceptable in the Christian view, as shown in the following quotes.

“Prosperity and adversity, life and death, poverty and riches, come of the Lord.” (Sirach 11:14)

“For whether we live, we live unto the Lord; and whether we die, we die unto the Lord: whether we live therefore, or die, we are the Lord’s.”

“Why, you do not even know what will happen tomorrow. What is your life? You are a mist that appears for a little while and then vanishes.” (James 4:14)

6.2: Literature Review: Euthanasia

Euthanasia is primarily a problem of contemporary society. It has attracted attention around the world. Due to the progress of medical science, life expectancy has increased. Additionally, lifestyle changes have altered patterns of common diseases. Today, many incurable diseases, such as cancer, are still common and cause great pain and suffering. Euthanasia is an important concept associated with this problem (Mousavi et al., 2011).

According to Mousavi et al. (2011) there are four types of euthanasia.

1. Active euthanasia: an intentional action causing death, such as a fatal injection of a drug.
2. Passive euthanasia: Withholding treatment that keeps a patient alive.
3. Voluntary euthanasia: Ending the life of a patient who voluntarily chooses to die. The patient must be mentally capable of making this choice or have the ability to undertake the action him or herself.
4. Involuntary euthanasia: Killing a patient without that person’s knowledge or consent.

6.3: Christian Position on Euthanasia

Christianity is the most widespread religion in the world. Like Islam and Judaism, it is a monotheistic religion. These three religions have similar characteristics and are interrelated historically. It cannot be said that there is consensus regarding end-of-life decisions in the Christian context. Christianity, as a religion, consists of a diversity of denominations including Jehovah's Witnesses, Lutheranism, Catholicism, the Orthodox Church, and others.

The sacred text of Christianity is the Bible, which includes the Old Testament (Hebrew Bible), together with the New Testament which, according to Christian tradition, renews the previous covenant with God. The place of worship for Christians is the church, where most religious ceremonies are conducted, including prayer, baptism, and marriage ceremonies. The clergy person in charge of church services is the priest, who leads a community of believers. Other clerics on the hierarchy are bishops and cardinals. There are numerous Christian holy sites in Israel such as Bethlehem, Nazareth, Jerusalem, the Church of the Holy Sepulcher where Jesus was buried, the Via Dolorosa (the path Jesus walked to his death), the Jordan River, the Sea of Galilee and other places where Jesus performed miracles according to Christian tradition (Kovaľová, 2016).

The sanctity of human life, as described in the Hebrew Bible, is a central belief of Christianity. Although the Bible teaches that humans should have respect for all God's creations, including plants and animals, it clearly expresses the special honor people should have for human life. This respect is granted to all people, regardless of sex, race, status, age, sexual orientation, appearance, or mental ability. It is not earned through admirable characteristics or one's contribution to society, as this would justify attributing greater value to some lives and less to people deemed less worthy. The Bible teaches that God grants each person special respect and sanctity (de Villiers, 2016). In making decisions regarding medically assisted suicide or euthanasia, a Christian response will necessarily consider ethical implications in light of the Bible's message and the sanctity granted to each

person by God. These decisions will also need to take into account the prevailing moral views held by the Christian Church, the society in which the patient lives, the patient's family, and other Christians (de Villiers, 2016).

6.4: Catholic Position on Euthanasia

Catholic ethics are rooted in the long Christian tradition and theological and ideological sources including the Bible, teachings of philosophers and theologians, and other religious texts, such as papal encyclicals. Saint Thomas Aquinas first outlined the duties of physicians, which he called the "natural law". This established a broad moral framework for Catholicism. Since St. Aquinas' time, confession manuals and theological summaries have asserted that physicians must carry out their duties and activities according to the "natural law". However, this is no longer interpreted as a series of demands and prohibitions, but rather as a recommendation for physicians to do everything possible in order to behave in a way that shows understanding and respect for the purpose of human life (Kovaľová, 2016).

The most important principles of physicians' behavior are considered to be those based on the divine privilege accorded to human life, holism, freedom, responsibility, community relations, and mutual assistance. Pope John Paul II expressed the official position of the Catholic Church on these issues in 1995 in the Encyclical letter *Evangelium Vitae* which was published in the Catechism of the Catholic Church in an abbreviated form. Among other issues, this document expresses a papal opinion that, "Euthanasia must be distinguished from the decision to forego so-called "aggressive medical treatment", in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family." Euthanasia is discussed in this document as a worrisome phenomenon indicative of a "culture of death" which is spreading in societies characterized by a mentality, according to which society is "burdened" with too many old and incapacitated people.

Other documents issued by the Vatican, for example, the *Declaration on Euthanasia* (1980), state that it is permissible to end treatment of a dying patient who is suffering and in great pain even if this poses the risk of shortening the person's life as an unintended secondary effect. The document also notes the role of suffering and the pain of death in the Christian symbol of Jesus on the cross. Active euthanasia is prohibited. Palliative care is required for terminally ill patients with incurable diseases (as cited in Koval'ová, 2016).

The Magistrates of the Catholic Church condemn euthanasia as a type of murder. Their philosophical basis for this is the value and autonomy of life. The values of the sanctity and dignity of human life are necessary condition for goodness. The Magistrates add a theological argument to this philosophical worldview, namely that God is the Creator and master of all life and therefore life is a gift which people cannot choose to reject. Further, the fifth of the Ten Commandments, "Thou shalt not kill," forbids ending anyone's life. The Magistrates argue that medicine should be practiced in the service of life not death. They make a strong appeal for palliative care instead of euthanasia in response to unbearable suffering and suggest that palliative care should be available to all terminally ill patients (Liégeois, 2013). According to Preiss and Beazer (2015), Christianity in general and the Roman Catholic Church in particular completely oppose all types of voluntary euthanasia.

The Latin (Western Catholic) Church is one of the streams within the Catholic Church, and so the perspectives of Catholic Church on all issues including euthanasia apply to the Latin Church as well.

6.5: Position of the Orthodox Church on Euthanasia

The Orthodox Church is a branch of the Christian Church which is similar to Catholicism in many matters of religion and morality. The identity of this Church is rooted in the Christian Church established in the first millennium, especially with regard to theology. Issues of ethics in general

and bioethics in specific are understood in the framework of the personal relationship between believers and God. This ethical position is based on the assumption that God the Creator is incomprehensible and unknowable to humans and that God's presence can be felt only through a personal mystical experience. This mystical role of God is religious principle, according to which all people, including physicians and other health care workers, are connected to God through their personal moral responsibility for every action. Death is interpreted by the Orthodox Church not only as a biological process, but as a mystery full of hidden religious purpose and blessings. From this, it follows that any death resulting from a human decision is seen as a challenge to God's authority. Any medical action that is not focused on extending and preserving life is considered immoral. The Bioethics Committee of the Church of Greece points out that there is always a possibility that a diagnosis was made in error or that a disease may take an unexpected course and there is always hope for a miracle. Therefore, the Orthodox Church forbids refusal of treatment, even when a fully conscious patient wishes to stop treatment (this includes treatment that could save the patient's life). The doctor has a moral duty to persuade patients to agree to treatment. The Orthodox Church permits the use of painkillers, but only to the extent that they will not cause the death of the patient. They forbid the cessation of artificial nutrition even when there is no hope for recovery. Although the term "good death" is a literal translation of the Greek word for euthanasia (as explained above), according to the Orthodox Church, a good death is calm and painless. The contemporary interpretation of active euthanasia as a merciful end of life is totally rejected by the Orthodox Church (Koval'ová, 2016).

According to the theology of the sacred, life and death are communal events. Any discussion of death and life, from the perspective of Christianity as a whole and the Orthodox Church in particular, necessarily includes the concepts of the Holy and of the church. In the Orthodox view, death or a "good death" must be discussed in terms of the theology of the sacred. In this context any death could be a "good death" even if it entails suffering, pain, or loneliness. A good death is not just dying in the hospital

numbed by painkillers. One might ask: Did Jesus die a good death? Did the saints and martyrs die good deaths? Of course, most people are not expected to suffer the kind of death endured by Jesus and the saints, but their deaths, despite their pain and suffering, can still be considered “good” since their martyrdom was an expression of their faith, and the value they placed on their Christian communities.

Funeral services and early liturgical traditions in the Orthodox Church clearly show the communal dimension of death. People participate in various ways in the death of a member of their community. The various liturgical formulas and the overall formula of a funeral service presuppose a moral understanding of death (this of course applies to other denominations as well). In the Orthodox theology of the sacred, a human is not only a biological entity, but is a member of a community. A good life, in fact life itself, is not more than just biological material or a living body, and should be considered as such (Ježek, 2014).

On one level, this perspective proposes that human life cannot be separated from the biological being. If we understand human life from the perspective of the Orthodox theology of the sacred, a person is not an autonomous being who can make decisions about his or her existence. A person is always connected to the divine source of existence. Man as an entity is created in the image and likeness of God, and God exists in the community. A person does not have the autonomy to choose to end his or her life without affecting the community. However, having said this, one does not have to fall into unrealistic idealism. The collapse of an individual’s ability or desire to live is not only the responsibility of the individual. It is a sign that the community has failed. This failure is implied in multiple ways. For example, I find it hypocritical that many Orthodox theologians repeatedly argue against euthanasia for theological reasons (such as that humans being created in the image of God) but fail to acknowledge that their arguments do not alleviate the suffering of a dying patient in any practical way if the community does not follow these principles. In theology, one must say A, but also B. A person can be created in the image and likeness of God, and also represent the image and likeness of the

community. A person's ability and will to live reflects the life of the community and its ability to take care of members. If the community fails in this aspect, it is not morally justified to blame the individual for failure (Ježek, 2014).

6.6: Protestant Position on Euthanasia

Protestantism is the youngest Christian movement. This movement has raised significant moral questions, which each of the denominations (Lutheran, Baptist, Methodist, Presbyterian, etc.) relates to differently. Unlike Catholicism, Protestantism emphasizes personal knowledge and interpretation of the Bible. Given the diversity of denominations and communities, there can be no clear and simple definition of Protestant bioethics and medical ethics or a single set of established principles for dealing with end-of-life questions. Most Protestants make use of modern methods treatments for extending life. Some religious communities support the cessation of treatment when hope for healing no longer exists. There are different opinions on the issue of euthanasia. For example, the German Protestant Church issued detailed principles regarding end-of-life decisions which clearly rejected euthanasia. In contrast, there are members of the Reform tradition in the Netherlands who defend euthanasia (Koval'ová, 2016).

6.7: Ethical View of Euthanasia

Increasingly, ethical positions enter debates of controversial issues such as euthanasia. The ethical view takes into consideration the idea that a terminally ill patient should make the decisions regarding the final stage of life. Since euthanasia is so controversial, it is fitting to bring into the discussion ethical aspects of making a decision to die in a dignified manner (Terec-Vlad & Terek-Vlad, 2013).

Christian ethics praise the advent of hospice services and palliative care for terminally ill patients. While the goal of medical care and treatment is curing the patient, the goal of palliative care is providing effective relief of physical, psychological and spiritual pain and suffering. It has been suggested that palliative care can now effectively relieve the suffering of 95% of terminally ill patients (de Villiers, 2016).

Ethical advice is based on an assessment of basic values: the privilege of life, autonomy of the patient, and the relationship between caregiver and patient. To incorporate these values, caregivers must clarify that life is a privilege, respect the autonomy of the patient, and provide the best possible care, including counseling on existential questions (Liégeois, 2013).

Who Supports and Opposes Euthanasia?

Christians who support voluntary euthanasia have said that choosing a painless death is a “demonstration of love and compassion”. They argue that voluntary euthanasia for terminally ill people will increase their quality of life by removing the stress of facing a painful death. They also argue that witnessing a patient die slowly or in a medically-induced coma can be extremely difficult for family members and for the medical staff (Preiss & Beazer, 2015).

In Belgium, the debate is over. A perfectly healthy person can sign an agreement to end his or her life following a diagnosis of Alzheimer’s or dementia. Children can be killed if they are seriously disabled “in order to alleviate the suffering of the parents” or the children. The current situation there shows how the practice and procedures of euthanasia can become blurred in complex legal proceedings (Ježek, 2014). Euthanasia, under certain conditions, was legalized in Belgium in 2002 for adults. Euthanasia is legal in at least six other localities: the countries of Holland, Luxembourg, Switzerland, and, within the USA, the states of Oregon, Washington and Montana. The rules and conditions require that the patient must be terminally ill and in constant and unbearable physical or mental suffering, as a consequence of an incurable disease or a serious accident (Shah & Mushtaq, 2014).

6.8: Euthanasia Around the World

Previous surveys indicate that there is a high level of unregulated euthanasia in Belgium and Holland. In Belgium, euthanasia represents close to 32% of all deaths (Richmond, 2014). This indicates that some healthcare professionals are willing to take responsibility for making a judgment regarding whether a person's quality of life is so poor that death is preferable. Euthanizing people without their request or consent involves mutual reciprocity of the legal "means of defense" in their legislation (Richmond, 2014).

Romania has not yet legally regulated euthanasia. Switzerland grants an individual the right to a dignified death as part of a framework of personal freedoms. Also, in Belgium and the Netherlands euthanasia has been legalized. It is believed that if death is inevitable, alleviating suffering is the humane course of action (Terec-Vlad & Terec-Vlad, 2013).

The pro-euthanasia position adopted in some developed countries arises from the belief that a person suffering from an incurable and fatal illness should be able to make the decision to end his or her life. However, controversy arises in Third World countries and in countries where religious beliefs have a greater impact on the consciousness of the individual. For medical practitioners in this social context, euthanasia is contrary to religious values, and may be viewed as the same as suicide or murder (Terec-Vlad & Terec-Vlad, 2013).

In Western liberal democracies, the right to autonomy plays a central role in discussions of the legalization of medically assisted suicide and euthanasia. The moral value of autonomy is seen as being at the core of the right to human dignity, which in turn is perceived as a fundamental human right. Although they are in the minority, it is possible to note there are several Christian ethicists who argue in favor of practices enabled by turning autonomy into a central value (de Villiers, 2016).

The importance of patient autonomy as a moral principle in the Western (Christian) world is not accepted in other ethnic or religious environments. Current medical recommendations and guidelines may be

contrary to certain religious views. It is clear that in certain cases, aspects other than religious ones should be taken into account, for example, the existing laws of a society (Kovařová, 2016).

6.9: Conclusions and Recommendation

We make the following recommendations:

1. Establishment of advisory groups in hospital departments that deal with terminally ill patients, which will be composed of clerics and medical staff, in order to increase awareness of cultural and religious issues related to euthanasia and end-of-life decisions. There is a wide spectrum of populations in Israel, each characterized by blood relations, traditions, social norms, and more. In addition, there are also sub-populations that differ in their beliefs and ways of thinking. Advisory groups in hospital departments that deal with terminally ill patients, which include clerics and medical staff belonging to the same religion and population as the patient and who understand the social environment and values of patients and their family would raise awareness among the professional staff about religious and cultural aspects of end-of-life decision-making. These groups may help offer solutions for terminally ill patients and their families, thus facilitating end-of-life decisions.
2. Establishment of workshops and lectures in the Christian community to explain the options available to terminally ill patients. These workshops could be led by doctors, social workers, monks, and nuns. These would contribute to raising awareness among the population about various treatment options, such as hospices and palliative care for patients with terminal diseases in order to alleviate their suffering and support them during critical stages of the illness.
3. Passage of bill that allows terminally ill patients to choose the way in which they want to end their lives. Israeli law does not allow active euthanasia. However, the *Terminally Ill Patient Law* allows, under

certain circumstances, cessation of life-prolonging treatment. For example, in some cases a patient may be taken off a respirator, not given medication, or not given an artificially assisted supply of food and liquids.

There exists a relatively large number of terminally ill patients who wish to undergo voluntary euthanasia in order to end their own pain and suffering. This decision is based on knowledge and understanding of their medical condition. It is therefore necessary to consider this and to implement a law that allows passive or active euthanasia under certain and specific conditions, in order to give patients all possible autonomy regarding the end of their lives.

The treatment of a terminally ill patient is one of the most prominent ongoing problems in medicine around the world and in Israel. The prolongation of the life of a patient, especially a patient suffering severe anguish, raises serious medical, moral, legal and economic problems. The problem concerns not only the patient, but also the patient's family, friends and acquaintances, physicians and medical staff. The topic of euthanasia is the topic of wide-ranging discussions on ethical and religious values. When euthanasia is defined as the acceleration of death by the caregivers then any passive or active action with the intention of causing a painless death to a patient can be considered euthanasia.

The findings of this study seem distinctive to the Christian population in Israel. On the one hand, we learned that the attitudes and perceptions of the religious Christian groups in Israel indicate they are totally opposed to all types of voluntary euthanasia. They believe that life is a gift from God, people are not autonomous and cannot decide to die, and medicine is in the service of life and not of death. In contrast, the secular Christian group was more likely to support autonomy, allowing patients to express their wishes and make decisions regarding end of life and euthanasia.

Finally, it is important to note that this study to some extent helps us understand certain points more clearly and effectively. It could serve as the basis for further research on the subject of euthanasia and religion. It is reasonable to assume that eventually Israel will follow the path of other

countries in the West and will enact a law that permits active voluntary euthanasia. Currently, any person who helps a relative die may be charged with murder. This often leads to heartrending tragic deaths and suicide. Therefore, it seems inevitable that there will be a need for such a law to prevent partisan actions of inappropriate euthanasia that are still considered murder.

The subject of euthanasia or the “easy death” is described as the cessation of pain and suffering which derives from a terminal illness with no cure. Since the subject includes decisions regarding the end of life, the decision-making is significantly tied to the value of the patient’s autonomy, religion, religious movement, and the religious propensity to which s/he belongs. That is why decisions regarding the end of life create difficult dilemmas in the world of medicine.

6.9.a Key points: Christianity and the end of life

- Christians believe in the resurrection of the dead and everlasting communion with God and that a good death is part of this process
- Clinicians should recognise that the cluster of traditions and denominations making up the Christian faith have some theologically grounded variations that may influence end-of life decisions
- Christians believe that life is a sacred gift from God and as such do not allow assisted suicide or euthanasia
- Both Roman Catholics and Protestants who are dying may wish to be visited by a person from their church. Roman Catholics may wish to receive the Sacrament of the Sick with anointing (Last rites)
- Christians recognise the medical benefits of organ donation (although for many, this should only follow full cardiorespiratory death not merely brainstem death) and do not regard their beliefs as being in opposition to post-mortem
- Funerals themselves vary between the different churches and traditions; they typically involve readings from scripture, hymns and eulogies. They are, religiously speaking, celebrations of a person’s life, with thankfulness for the person’s faith and

Chapter 7:

PALLIATIVE CARE AND EUTHANASIA OF ISLAM

7.1: Euthanasia is one of the most difficult and complicated dilemmas with which medical ethics is dealing.

The subject of euthanasia is one of the most difficult and complicated dilemmas with which medical ethics is dealing. The stand of Jewish law on the matter of euthanasia is complex; the Halacha completely rejects taking a stand to bring a person to his/her death actively, but it is more forgiving about more passive actions. Most of the passages do not support actions to pointlessly lengthen life with suffering. Thus, this approach is similar to the ethical-medical approach which is legally carried out in most of the western countries.

Israeli society, being a society of immigrants, is heterogeneous which amalgamates within it various nations, ethnic groups, religions and cultures. The differences in each of the groups – Jews and Arabs, religious and secular, Mizrahi and Ashkenazi, is what influences the choice of medical treatment for each person, and it also affects how one treats the patient and his/her family. Therefore, it is very important to know the central religious principles in Israel.

Knowing the culture assists the medical team and the paramedical team to know how the patient and his/her family view the illness and help them in dealing with it. This is especially true in specific situations in terminal patients which according to all opinions are suffering incredibly and every day and every hour they have more pain and suffering.

This is about patients suffering an illness without a cure, in the terminal stages, where large quantities of pain killers are not helping anymore, and the doctors have no real way of helping. Here there is great importance in getting to know up close the wishes and beliefs of the

patient in order to relieve his/her suffering. The terminal patient tends to die from the pain and the ongoing suffering and from the terrible quality of life, and in this case death is a mercy to the patient.

That is why there are countries like Switzerland and Holland where a physician is allowed, by special rules, to cause a patient to end his/her life where the physician is the one who actively takes the life via a “Mercy Killing” or euthanasia. Euthanasia, Mercy Killing or the Good Death is a medical term that is expressed by causing the death of another in very specific situations which call for euthanasia. The purpose of this act is mercy, compassion and relief from pain and suffering.

In Israel there is the Patient who is About to Die (Act 2005), according to which can be fulfilled the person’s right to die with dignity, but not actively since Israel does not offer the option of euthanasia. This controversial topic is creating quite a public storm in Israeli society: the argument is around moral and ethical considerations like maintaining individual rights and the patient’s autonomy, anchored in the Law of the Basic Dignity of Man and his Freedom, and to assist the right of the person to die with dignity and prevent agony to him/her on the one hand, and opposed aspects of the religions, Judaism, Islam and Christianity, on the other hand.

The rationale behind our work is to examine the topic under the glasses of Islam and its movements. In Islam, the sanctity of life is above all else, and suicide or physician-assisted death are most definitely forbidden. According to the Koran, life is given by God, and He is the One who can take it, and Man has no right to interfere. “And do not kill the soul which Allah has forbidden, except by right” (Koran: Al-Israa, Aya:32, p.285).

According to the Druze, which is a movement of Islam that believes in the Koran and believes in the passage written in the Koran אלקרים: “And for every nation is a [specified] term. So when their time has come, they will not remain behind an hour, nor will they precede [it]” (Koran: Al-A’raaf, Aya:34, p. 154), they believed that the destiny of Man is what God determined and we do not have the right to interfere with fate that is determined by God.

Thus, according to Islam, even when there is no point in continuing the medical treatment, when the patient is terminal or in a vegetative state,

the patient should continue to be nurtured, given liquids and nursing, relief of pain and suffering as much as is possible, and the patient will live the life God had determined for him/her.

Our purpose in this project is to examine the positions and perceptions of Islam in decisions tied to end of life and euthanasia. That is, when is euthanasia required, active and passive euthanasia, the right to life vs. the right to die with dignity, study the principles of Islam and its movements, study the beliefs of the Moslem patient – how s/he treats the disease and perceives death.

And thus we ask the research question: What are the positions of Islam and its movements regarding making decisions tied to end of life and performing Mercy Killings in Israel? And are there cases that allow for euthanasia?

Research Hypotheses:

1. No differences will be found in the positions towards euthanasia according to the different movements in Islam.
2. Differences will be found in the positions towards euthanasia according to level of religiosity.
3. Differences will be found in the positions towards euthanasia according to gender.

7.2: Euthanasia and its Principles

The biotechnical development advanced many possibilities to extend life in terminal stages, what was in the past impossible (Mehran, 2014). Oftentimes, the novel treatment extends the lives of these patients but also burdens them and adds pain and suffering and leaves them with an inferior existence (Teller, 2006), a matter which has created new issues about decisions that take place at the end of life like euthanasia. Now physicians must deal with such issues as Mercy Killing, not only ethically and professionally but also in a manner that is also accepted philosophically and in terms of religion (Narimisa, 2014).

The term euthanasia means “The Good Death” or “The Easy Death” (Ayuba, 2016) and the literal definition of the term is: “Putting to death a patient suffering from a cureless disease in order to prevent him/her hard or unbearable suffering” (Shiran, 2015). That is, the ending of a patient’s life according to particular principles and under particular circumstances, when medicine cannot cure or provide a proper quality of life (Narimisa, 2014). This term relates to three criteria: firstly, that the patient is suffering from an incurable disease in a terminal stage; secondly, the patient needs to be in a state of difficult or insufferable suffering which is individual to each person; and lastly, the action that the term refers to is active and done to the patient: “the killing of a person” (Shiran, 2015).

Euthanasia can be expressed in two ways – active or passive euthanasia. In active euthanasia the demonstration of the process of death is via artificial means, medicine or treatment, either through the physician or through the patient as assisted by the physician. That is, the doctor is the one who provides the means of death and manages it like giving a fatal dose of medicine (Pirani & Badruddin, 2015). By contrast, passive euthanasia will take place in two ways: withholding life-prolonging treatments like not connecting to a life support machine or withdrawing from life-prolonging actions like disconnecting from a life support machine. The action can be voluntary from the patient where s/he asks and freely chooses to free him/herself from the suffering or it could be the physician’s decision without the patient’s consent (Habad, 2001).

7.2.a The Ethical Position which Supports Euthanasia

Regarding the issue of end of life decisions there are difficulties in making a decision between the sanctity of life and the autonomy of the patient. Ethically, euthanasia is a serious ethical issue in bioethics (Rayan, Alzayyat & Khalil, 2016). The ethics, the public policy and the law were very much in support of the need to control pain, to maintain dignity and to avoid useless and difficult treatments for people (Abu-Rakia, 2016). Thus the claims in support of euthanasia focus on dignity, autonomy and

lessening the patient's pain, in addition to arguments concerning the emotional burden of making a decision (Rayan, Alzayyat & Khalil, 2016).

One of the ethical issues supporting euthanasia is the dignity of the patient, where the term "Death with Dignity" takes a respectful place in strengthening support for euthanasia. The idea is that death in medical surroundings is neither natural nor dignified, and that euthanasia allows terminal patients to die a dignified death instead of continuing to rely on life support machines and medical equipment. This idea claims that these patients receive medicines which may influence them so much that they may dose into a deep sleep out of consciousness besides the tubes stuck in their bodies which degrade them (Rayan, Alzayyat & Khalil, 2016).

Similarly, people supporting euthanasia believe in giving priority to the value of respecting the rights and the principle of autonomy of the patient according to which the patient can judge the situation and decide for him/herself. Moreso, believers in euthanasia claim that the cessation of life according to a person's request is moral because it is based on the individual's decision. There are those who claim that if a person is certified as autonomous and chooses to end his/her life or has someone else assisting him/her in doing so, this is an autonomous decision that must be honored (Rayan, Alzayyat & Khalil, 2016). The purpose of this is to lessen the uncontrollable pain and suffering.

Another theory that supports euthanasia is the Utilitarian Theory. This theory determined that when medical resources are limited, it is not proper to waste the resources to maintain the life of a terminal patient when these resources could be utilized to help other patients who may have a better prognosis. Furthermore, it is not fair for the family members to use up their savings in a treatment for a terminal patient, and to remain without proper resources to live their lives properly (Rayan, Alzayyat & Khalil, 2016).

7.2.b The Ethical Viewpoint Opposed to Euthanasia

The “Slippery Slope” is one of the biggest fears for people opposed to euthanasia. They claim that if you allow a certain behavior that looks right, like euthanasia of a terminally ill patient, there is a fear that this allowance will lead to different behavior, which is quite unworthy ethically due to similarities between them or social pressure. Otherwise, absolute borders will be crossed and allow euthanasia also in cases where in the beginning there was no intention to allow it (Haber, 2001). In addition, the main moral objection to the involvement of medicine in euthanasia claims that it harms the moral duty of the physician which is to do no harm, as the physician’s job is to do all in his/her power in order to treat the patient (Haber, 2001).

7.2.c The Islamic Perception of Euthanasia

The idea of euthanasia is very much influenced by religion which is considered an important factor in determining the measure with which a particular population accepts the idea of euthanasia. In Islam the spirit of Man is described as an electric current or as an energy which seeps into the lamp which is the body and the light that is created which is the human soul (Badarana, 2008). According to Islam, the strongest and most accepted opinions are against euthanasia and can be summarized into two main reasons: First, the holy life and euthanasia and suicide are not included among the reasons allowing killing in Islam; secondly, Allah decides how long each one of us lives. According to Islam the sanctity of life is above all else (Nikookar & Sooteh, 2014) and it must be guarded like in cases of preventing abortion or euthanasia or suicide which are considered great sins in Islam and will prevent entry into heaven (Badarana, 2008). So, killing someone out of pity and in order to ease pain and suffering is not just a sin, but a threat on the moral fabric of society (Nikookar & Sooteh, 2014).

Thus Islam forbids euthanasia, mainly active euthanasia. This viewpoint is strongly supported by ethical laws and principles in the Islamic communities (Rayan, Alzayyat & Khalil, 2016) since the concept of suicide converges within euthanasia because the historic description of the debate regarding end of

life stays focused on the issue of suicide, and euthanasia is considered a part of it (Ayuba, 2016), and it is forbidden to hasten death via suicide or to ask to end one's life with the help of another.

In addition, a few leading Moslem jurists compared euthanasia to murder and therefore concluded that in actual fact it is Haram (forbidden). For example, el-Kardawi put out a ruling which equates euthanasia to murder (Ayuba, 2016). The great Mufti of Saudi Arabia, Abed el-Aziz Ben Abdallah Ben-Baaz, declared that anyone who decides on the death of another before s/he is dead is not a Moslem (Ayuba, 2016). And the Islamic court, which is based on interpretation of the Koran, does not recognize a person's right to die voluntarily. So a suicide attempt, alone or assisted by a physician or someone else, is completely forbidden. The Koran notes this in a number of chapters: "Do not kill yourself for Allah is most merciful" (Koran 4:29); "Do not take the life that Allah has created as saintly" (Koran 6:151) (Baradana, 2008).

The moment of death is under Allah's control and Man cannot intervene at all in this matter, Man does not need to try to hasten or delay the moral death (Alagal) (Narimisa, 2014) according to the Holy Koran – "Indeed Allah [alone] has knowledge of the Hour and sends down the rain and knows what is in the wombs. And no soul perceives what it will earn tomorrow, and no soul perceives in what land it will die. Indeed, Allah is Knowing and Acquainted" (Koran: Luqman, Aya: 29, p. 414). And let us also remember: "And it is not possible for Man to die without the approval of Allah and with a permanent injunction" (Koran 3:145).

Dr. Mohammad Sayid Tantawi said in Noef Alshmari's study from 2016: "Euthanasia is not a possible decision religiously neither for the physician nor for the family members and even for the patient him/herself. Human life is a gift which must be maintained and Man should not throw him/herself to death." Therefore, when people take it upon themselves to shorten their lives themselves or via assistance like with a physician, they are fulfilling Allah's task of interfering with the Divine Plan (Rayan, Alzayyat & Khalil, 2016).

7.3: The principles of medical ethics in treating a Moslem patient are according to known principles:

- Avoid doing harm
- Provide just and legal treatment
- Maintain the patient's independence and sovereignty
- Provide the patient with efficient treatment

According to Islam, any injury to the body, soul or society is forbidden, and anything that is helpful is permitted (Baradana, 2008).

On the other hand, according to Islamic Law, there are two instances of passive assistance that allow a terminal patient to die:

1. The use of pain killers in order to ease physical pain or mental distress.
2. The cessation of useless treatment if the family members all agree. This enables death to take its natural course (Ayuba, 2016).

It was cited in Ahmad et al.'s 2016 article that Dr. Muzamil Tzidiki, former President of the Islamic Union of North America, said: "If the patient is hooked up to life support machines, it is possible that it will be permitted to disconnect him/her, with proper treatment and consideration, and let nature take its course." This sort of thing is common in Iran and in other Moslem countries. In addition, if medically life cannot be restored, then there is no point to maintain the patient in a vegetative state or in a deep freeze; the doctor's job is to preserve the process of life and not that of dying (Rayan, Alzayyat & Khalil, 2016).

Furthermore, in a few meetings held in Mecca, Jedda and Amman, a Moslem jurist ruled that it is not permitted to unplug a patient from life support or life-saving equipment unless the physician is certain that the death is inevitable, and the patient will remain alive only via a life support machine – s/he is considered dead biologically although legal death can only occur when the breathing stops completely after turning off the life-saving equipment.

7.3.a The Palliative Treatment vs. Faith

Doctors oftentimes deal with discussions about changing aims of treatment, and especially about transferring the patient to a palliative treatment. The patients may also respond negatively to such a change, with denial, anger or sadness. All of these are normal reactions to loss of control, fear of the immediate future, or fear of death. For the most part, patients and their families will have their own timetable and a way of processing this information. The physicians must be patient and put an emphasis on support and promising an aggressive treatment of symptoms (Abu-Rakia, 2016).

Palliative medicine sanctifies the quality of life and easing of suffering, and the physician must be well-versed in the topic of suffering and to know the ways to prevent it. The physician must see suffering as an enemy to be destroyed and for this s/he has at her/his disposal many powerful medicines. Therefore, the palliative treatment is required, among others, in cases of terminal cancer, neurological diseased without a cure, advanced dementia, and extreme heart insufficiency.

On the other hand, Baradana said in his 2008 article that: “Many Moslems view palliative treatment as an escape from conventional treatment after it was given up and are certain the treatment does not preserve life but rather delays death and postpones the verdict.” There are those who will feel deprived by them being a minority or with an inferior health insurance, or that they believe the decision was reached in order to clear a bed for another patient. The use of prayer and begging Allah to cure diseases has existed in Islam for many years, and current studies found the contribution of faith to Allah in curing and easing distress from diseases. The Moslem prayer causes mental and physiological relaxation. Also, charitable activity and supporting the needy have a positive influence on overall feeling and health. Likewise, fasting was found to influence health and feeling. The spiritual aspect of the Moslem patient is very important in maintaining balance and an overall good feeling. Breaking the balance can cause diseases or worsen the condition of existing ones.

Abu-Bakar el-Razi was among the first to present the subject in his book “Spiritual Medicine” Reading special passages from the Koran constitutes the cornerstone of spiritual healing. Contrary to el-Razi, the first to present the topic was Abu-Zayid Elphalchy (lived in 850-934 A.D.) who wrote the book “The Efficiencies of the Body and Soul” (In Sallah el-Badan and el-Anaphs), where he emphasized the importance of combining the treatment of the body and the soul. The last one criticizes the doctors he feels are interested in the findings of the body alone while treating diseases and neglect the mental and the spiritual aspects of the patient. Elphalchy stressed the importance of healing by looking at pretty pictures (guided imagery) and listening to pleasant music (Badarana, 2008).

7.3.b The Shi’ite and Sunni Islam Movements in Making End of Life Decisions

The issue of euthanasia is clear and unified in all branches of Islam. In a Moslem framework, euthanasia is rejected as illegal for religious reasons (Nikookar & Sooteh, 2014).

There are many important differences between Moslem countries. There are those countries ruled by Islamic rules that accept Sharia legal and administrative rule, like Iran and Saudi Arabia. What differentiates between them is that in Iran the rule is by Moslem Shi’ites and in Saudi Arabia by Sunni Moslems.

The Shi’ites, as the official religion of the Islamic Republic of Iran, had many fatwas regarding studies on various bio-ethical issues such as organ transplants, abortions and genetic research, some of which were implemented by the Iranian Parliament in recent years. But regarding euthanasia, the latollah Humeini, the superior leader of the Islamic Republic of Iran, a known and respected Shi’ite Moslem researcher, and other Shi’ite religious men such as the latollah Safy Gulpigany, Navari Hamdani, Makaram Shirzi, Puzzle Lenkarni Wabajet, agreed that all types of euthanasia, including fatal drug injections and physician assisted suicide, are haram (forbidden) and a type of murder (Nikookar & Sooteh, 2014).

The Sunnis, including the Druzes, Ahmadis, Sufis and Circassian movements that act according to the Sunni movement, also join the Shi'ites according to el-Shich Diab Mahdawi who said in an interview with him by IDB in 2012: "The issue of euthanasia is a matter that has been recently raised, and thus it was not possible to see it in earlier periods, but it should be assumed that it is not possible to kill someone without any connection to his/her difficult disease in the hope that Allah will cure him/her." He added and said: "We are not supposed to kill someone for claiming that s/he is suffering and in pain. Today medicine has become a measure of development. The patient may receive a few drugs to ease the pain, but it is not permitted to kill him/her." He further says: "Scientists differ regarding brain death, and there are those who claim that brain death is actual death, since even today there is no medical information that says the patient can come back to life, and the legal commission that took place in Amman says that brain death is real death, and there is no point that the patient's parents waste their money on treatment or leave him/her dependent on life support." On the other hand, "others say that the patient is brain dead but the heart is beating, the lungs are functioning so the person is not considered dead. Thus in the case of brain death there is a dilemma. But everyone agrees that euthanasia is not permitted, even if the patient him/herself asked to be released from his/her punishment it is not allowed, so s/he needs to be patient."

All the sages of the Islamic religion treat active euthanasia as forbidden and there is no difference between the Sunni and Shi'ite schools. Life is sacred and thus active euthanasia is forbidden in any of its shapes and forms. The Koran emphasizes: "We give life and cause death, and you shall return to us" (Koran:43). Passive euthanasia is permitted when there is no chance of healing and ease of suffering. At any rate, the patient must be given nourishment, liquids and ease from pain and suffering until death.

It is permitted to prevent or cease treatment of the terminal patient if the following conditions have been met:

- Brain death: according to known international medical criteria.

- Vegetative state: with irreversible damage when the patient is unaware and cannot communicate with his/her surroundings.
- State of helplessness: the treatment being given preserves life and delays death without any help in lessening the patient's pain and suffering.
- Situation without purpose: the patient can continue to live with the treatment, but the mental and physical damage grow, and one cannot expect the family or the patient to continue to suffer.
- Unbearable situation: the disease is terminal; advanced and irreversible and continued treatment is unbearable to the patient.
- Treatment can be stopped under two conditions: diagnosis of brain death, and the treatment given does not heal or ease the patient's suffering, but rather lengthens the natural and unavoidable process of death (Badarana, 2008).

7.3.c The Patient who is About to Die Act 2005 and the Patient's Rights

Until 2005, there was not a law that dealt with avoidance of life prolonging treatment or euthanasia, but decisions on the topic were brought before the courts so as to provide physicians with a declarative step not to prolong the life of a patient. The rulings were not consistent and stemmed from the personal considerations of the judges. The first request to cut off life support and thereby commit euthanasia was presented by Gideon Nekesh by petition to the High Court in 1987. Nekesh, 53 years old, came down with muscular dystrophy and claimed that he wished to end his life by unplugging the life support machines after these had been connected to him without his consent – this was considered an attack. The hospital replied that the surgery was done with consent, so the petition was denied. Nekesh died during the trial (Noar Shoher the Hebrew Court, 2017).

According to the law the difference between a patient who is about to die and a terminal patient is that the physician is certifiably responsible to

determine that the patient is about to die: if it is determined that the patient suffers from an incurable medical condition and a lousy quality of life, even if s/he is given medical treatment, is not over six months long, despite the fact that this is a terminal patient, if it is determined that s/he is in a medical state where a number of essential systems in his/her body failed, but if given medical treatment is not over two weeks long.

According to the Patient who is About to Die Act 2005, it is the right of the patient to demand to avoid receiving medical treatment. It is meant to set straight medical treatment in a patient who is about to die while properly balancing between the value of the sanctity of life, and the person's autonomy and the importance of quality of life. This law is based on the values of the State of Israel as a Jewish and democratic state and on basic principles of morality, ethics and religion. According to the law, the Patient who is About to Die Act 2005, the patient has the right to decide and request to avoid providing him/her with medical treatment to prolong his/her life.

The law also allows a person to predetermine his/her will about future treatment if it is determined that s/he is about to die. The law does not allow a complete free hand: one cannot purposely do something to kill the patient, or that its results most probably can cause death, whether done with mercy and compassion or not, and whether at the request of the one about to die or another person or whether not, one cannot assist in a suicide, one cannot avoid giving an unfit patient about to die food and liquids, palliative treatment and accompanying treatment, even if s/he requested in advance, and one cannot cease continual medical treatment since this may bring about the patient's death.

When the patient about to die refuses life prolonging medical treatment, against the autonomous wishes of the physician who is obligated to protect human life, the right to life on the other hand, so Israeli law does not permit euthanasia except in very specific circumstances, and most of these cases reach the courts for discussion (Drory, 2006).

Additionally, the patient about to die who does not wish his/her life prolonged, and s/he is of sound mind, these wishes must be honored, and medical treatment should be avoided. A patient about to die who is not of

sound mind and is suffering significantly, and does not wish his/her life to be prolonged, medical treatment should be avoided when tied to his/her incurable illness including lab tests, surgery, revival, connecting to life support, chemotherapy treatments, radiation or dialysis, and all according to his/her wishes as determined.

Similarly, the patient's autonomy was defined in the Patient's Rights Law. According to the law, the patient is the one making the decisions over his/her body. In the law are defined the patient's rights and obligations of the medical system to him/her with all that concerns receiving information, exams and treatments. The law enables the patient to include family members in the decision-making process regarding his/her medical condition or to prevent their intervention. The patient is defined by law as having autonomy. Thus, the medical condition and the patient's wishes are the only considerations which must be considered in setting treatment. Nonetheless, the bio-psycho-social viewpoint presents a different view that the treatment of the patient be given in different frameworks, including family and community. In this view, the family's stands and considerations should be taken into account, and it should be included in decisions (Herzberger & Rubinov, 2009).

The decisions made in many hospitals are usually done at the patient's bedside. A very large number of the patients are in a serious mental or physical crisis, and their decision-making ability is in doubt. It is possible to evaluate such ability by giving out psychological tests. Various researchers (5-7) believe that it is possible to determine, via a number of simple questions, whether a patient understands the treatment offered him/her and whether s/he can make a clear decision. If the patient is not sound to make decisions, but there are medical orders that were given by the patient or his/her proxy, the doctors must act according to the patient's wishes. In the Patient who is About to Die Act it is emphasized that when there are no preliminary wishes, then a "close person" – with continuous and prolonged ties to the patient, who knows him/her and their values – can make the decision in his/her place (Herzberger & Rubinov, 2009).

In 2014, the Israeli Knesset put forth a proposal for the law “Physician Prescribed Death.” The explanation was that the “Patient About to Die” gave only a partial answer to the problems of terminal patients who all they have to look forward to in the short time left them is “continual mental and physical torture.” It solved the problem of those whose remainder of life depended on artificial measures like advanced medical medicines and technologies. It did not solve the problem of terminal patients who continue to suffer without relying on advanced medical technologies. The proposal stated: “Patients like these cannot fulfill their basic human and civilian right for an early and freeing death, and under the law they are destined to continue and suffer” (Ben Dov, 2014).

The response to the law proposal wavered between supporters and opponents. Prof. Avinoam Reches, former Chairman of the Medical Histadrut Ethics Bureau, said: “We need to provide those same people humane tools, so they will not have to commit suicide in a terrible and horrible way.” He added that: “the new law allows them to end their worthless lives full of suffering humanely.” Dr. Leonid Idleman, Chairman of the Medical Histadrut, was a strong opponent to the proposed law: “We feel empathy towards the harsh suffering of the terminally ill and their families, but it is not a doctor’s job to assist a terminally ill patient to end his/her life in an unnatural manner. We were not taught this, and we do not teach this to the future generation of the medical community. Euthanasia and physician assisted suicide are unethical acts” (Ben Dov, 2014).

7.4: Dilemma between the Perception of the Treating Team, the Family, and the Terminal Patient and the Need to Make Decisions

There are three parties in euthanasia: the dying patient, the patient’s family and the treating physician (Narimisa, 2014). On the topic of end of life decisions there is a difficulty in making a decision based on the sanctity of life and the autonomy according to which a patient of sound mind is the

one to decide about him/herself. This principle is very different from the paternalistic approach that was accepted in the not so distant past and is still accepted in many hospitals, according to which only the physician decides what s/he sees as best for the patient. The growing trend today in the Western world is to report openly to the patient about medical diagnoses, even when they are about terminal states, and to include him/her in his/her treatment decisions (Teller, 2006).

Physicians avoid discussing death with their patients and even avoid touching their terminal patients. Also, there are differences between the wants of the physicians and those of the patients regarding end of life treatments. In most cases, the doctors tend to treat more than the patients would have wanted in similar situations (Teller, 2006).

Treating a dying patient constitutes an important challenge to the treating team, enabling death with dignity which gives great satisfaction to those treating the patient. Treating a religious believer requires special skills and knowledge from the person treating him/her (Badarana, 2008).

Most of the physicians recognize the patient's right to be the main influence about life prolonging treatment at the end of life. But a lack of conversations with the patients about these topics has been reported due to difficulties with the medical staff, both on the part of the doctors and the patients. In one US study, testing attitudes of internists regarding withholding of end of life treatment in various hypothetical situations, it seems that a large percentage of the doctors would not have withheld treatment of the patient, even if s/he her/himself asked for it, which brings about the lengthening of the dying process. One of the reasons for this is lack of understanding and knowledge of the ethical and legal issues regarding end of life decisions. In the same study it was mentioned that the doctors had an easier time withholding breathing and dialysis than withholding artificial nourishment and hydration.

There is also a big influence on the manner in which the physician presents information on the patient to the family on the family's decision about continuing or withholding treatment to the patient (Teller, 2006). An important part of the discussion on euthanasia regards the families of the

patients about to die. The families suffer a double crisis: firstly, the trauma of the family is not losing a loved one, but rather losing the image of the person they knew and loved who is also changing under the circumstances; it is this loss which is oftentimes much more difficult, their loved one is changing before their eyes from an independent person to one who requires assistance and support, especially when the patient's mental state deteriorates (Shiran, 2015).

In a study from 2006 in the internist departments of Hadassa Hospital, a team from the internist department of Haifa's Rambam Hospital and in Tel-Aviv's Ichilov Hospital, and based on qualitative interviews: described that a DNR procedure had been put in place, not acting to intervene and lengthen the life of a patient who has stopped breathing and whose heart has stopped beating, that is written on a form and whose purpose is to document discussion between the family and the medical team about the family's wishes and the medical vision of the team. From a discussion with the family one tries to get information about the desire of the patient and his/her family. The family is explained that the optimal treatment of the patient will continue, and if there is a need for invasive actions whose benefit is completely temporary and does not improve the state of the patient, they will act in accordance with the conclusions of the discussion between them.

The study shows that 95% of the interviewed physicians said that a DNR procedure exists in their department while 5% said no such procedure exists in their department. 91% of those interviewed acts in accordance with the existing procedure, while 9% do not act in accordance with the existing procedure. A number of physicians said that since the DNR procedure has been in place, the number of "as if" revivals has narrowed greatly. 59% of those interviewed said that sometimes the team does an "as if" revival. 23% said that they would feel comfortable with this, 68% said they would not feel comfortable with this. According to most of the doctors interviewed, the desire of the patient and his/her well-being are at the top of the list of priorities. If the case is one of a clear-headed terminal

patient who is well aware of his/her medical condition, and does not want to suffer, his/her desire before all else, and s/he has a full right to regret.

The patient's final wishes are what determine. Oftentimes a patient, following painful treatment, changes his/her mind and is not interested anymore in prolonging the suffering. When asked if to give morphine to ease shortness of breath to a patient who has been decided not to hook up to life support, 82% of those interviewed are willing to give, 18% are not. 73% of those interviewed are willing to give morphine to ease the pain of a patient also suffering from lung disease and who has been decided will not be hooked up to life support, while 17% are not willing. Most of the doctors who would have given morphine said they would have given it in order to ease pain, and not to euthanize, and they would have tried very much to give a dosage that does not suppress the center of breathing, and gradually (Teller, 2006).

Sometimes the family has its own interests in making a decision for itself, and not always is the family decision for the benefit of the patient alone, sometimes there is a financial burden in this matter and sometimes an emotional burden. "If the patient is brain dead and the family has huge financial expenses to leave him/her on life support and if there is no hope after removing the devices, the family can ask to be disconnected from the devices, this does not sit well with euthanasia, but it should be emphasized that support devices like breathing apparatus, can be removed when a patient is biologically dead" (Rayan, Alzayyat & Khalil, 2016).

"Furthermore, it is not fair that family members use up their savings in the process of treating their loved ones suffering from terminal illnesses and be left without important resources for their pursuit of happiness" (Rayan, Alzayyat & Khalil, 2016). There are those who view the taking of a life as causing damage to the family and to society in general, the individual's freedom to choose is limited by the damage s/he causes others (Narimisa, 2014).

We shall summarize with Shteinberg: "It is impossible to reach a universal decision, agreed upon by all, to the medical problems tied to end of life. The moral dilemmas on this topic are many and complex, and it is

possible to find philosophical, legal and religious justifications in almost every direction of thought and action.” People differ in their opinions and customs, and these differences should be considered in the medical field (Herzberger & Rubinov, 2009).

7.5: Conclusions and Recommendations

The findings of the research show that Moslem religious men should intervene regarding making end of life and euthanasia decisions, since according to the literature, Moslems, mainly the religious among them, base their decisions on the Koran which is considered the guide to Moslem behavior. So terminal patients should be enabled access to religious Men to help and support and explain the options that could be taken. Similarly, if a law will be passed in the future, the religion and its positions should be taken into consideration, in which cases it is allowed and when it is forbidden to commit euthanasia.

In addition, by religious Men and the professional team of physicians through organized and professional workshops it is possible to raise the awareness of the Moslem people regarding end of life decisions, existing options and their rules and rights. Such workshops can take place with the help of the Ministries of Health and Education, they can be held at universities, nursing homes, a day of education and enrichment from the Arab cities in Israel. And the hospitals can provide Moslem patients or their families with escorts regarding acceptable treatments today for the terminally ill, and in parallel to work with the medical and welfare team on techniques and personal skills to deal with cases of terminal patients and euthanasia if any future laws will be passed.

After doing our study we see that it is worthwhile to implement an additional wider study in the area of decision-making tied to end of life and euthanasia that investigates a broader Moslem Israeli sample, in Arabic countries and around the world. In addition, the unique influences of extent of religiosity among Moslems on positions tied to end of life decision-

making and euthanasia should be investigated. It would also be interesting to study in depth the streams of the Islamic religion and the demographic influence on their way of thinking concerning these positions, with an emphasis on the streams of Islam in Israeli society that are influenced by procedures and laws in the country. And as further research, it is possible to carry out the study with a monologue sample to investigate in depth what are the perceptions and positions regarding euthanasia by gender.

The issue of euthanasia is one of the most difficult and complicated dilemmas with which medical ethics is dealing. The point of the present research is to examine the dilemma between medicine and religion and examine the perceptions and attitudes of the Moslem population (Sunnis, Sufis, Ahmadayyas, Circassians and Druzes) in Israel regarding euthanasia of terminal patients. The terminal patients, with an incurable disease, tend to give in to the endless pain, the endless pain and suffering that does not cease, and get rid of it through death, which in this case is for them and act of mercy and redemption.

On the matter of end of life decisions there is a battle between the sanctity of life and the autonomy of the patient. Putting an end to life or causing death to terminal patients actively or passively goes against the perceptions and attitudes of Islamic law. In Islam, the sanctity of life is of the utmost importance, suicide or physician assisted death are definitely forbidden, which is why the idea of euthanasia is very much influenced by religion. According to the Koran, life is given by Allah, and He is the one Who can take it, and no Man has the right to interfere. "Do not take the life that Allah has determined to be Sacred," " *وَلَا تَقْتُلُوا النَّفْسَ الَّتِي حَرَّمَ اللَّهُ إِلَّا بِالْحَقِّ* " (The Koran 29:4).

And as to the principle of the autonomy of the patient, the patient's independence, this is when the patient is controlled by and decides by him/herself. Furthermore, supporters of euthanasia claim that the cessation of life according to a person's wishes is moral because this is a decision for an individual. The point of the research: our goal is to examine the attitudes and perceptions of Islam regarding euthanasia – are there differences between the different movements, does the extent of religiosity influence

end of life decisions of the terminal patient, when is euthanasia required, what is active and passive euthanasia, the right to life vs. the right to death with dignity, and how do the beliefs of a Moslem patient affect how s/he looks at the disease and perceives death.

The research hypotheses tested in the current study are as follows:

1. No differences will be found in attitudes towards euthanasia according to the different movements in Islam.
2. Differences will be found in attitudes towards euthanasia according to extent of religiosity “religious, traditional, secular.”
3. Differences will be found in attitudes towards euthanasia according to gender.

The study was held among the population of all Israeli citizens, over the age of 18, Moslem (Sunni, Druze, Circassian, Ahmadi, and Sufi). The first hypothesis in the study, which states that differences will not be found in attitudes towards euthanasia according to the different movements in Islam, was rejected. According to the study’s findings, the Circassians were the biggest supporters in the patient’s autonomy and most supportive of his/her right to die with dignity as opposed to the other movements of Islam. This is in contrast to the literature where we would expect not to be a difference in the streams – it is clear that all branches of Islam have a unified outlook on euthanasia. In the Islamic context, euthanasia is rejected as illegal religiously.

The Sunnis, including the Druzes, Ahmads, Sufi and Circassian branches who act according to Sunni customs, also join the Shi’ites who said that “the issue of euthanasia has been raised recently, and therefore it cannot be seen in earlier periods, but one can assume that a person cannot be killed without his/her hard disease in the hopes that Allah will cure him/her.” In Islam, active euthanasia is viewed as forbidden and there is no difference between Sunni and Shi’ite schools of thought.

Life is sacred and worth above all else, and to aid someone and make him/her die is completely forbidden, no matter what s/he is going through. Allah created him/her and mankind cannot decide and determine his/her death. The Koran emphasizes: “We give life and cause death, and to us you

shall return” (The Koran: 43). Additionally: “And it is not possible for Man to die without Allah’s approval and with a permanent injunction” (The Koran 3:145). It also turned out that according to the results, the knowledge on euthanasia is the lowest with the Sunnis compared to the other streams of Islam.

The second hypothesis was found to be significant for differences in perceptions and opinions about end of life decisions as depending on religious extent.

According to the literature, the sick person must be patient with his/her suffering, euthanasia is completely forbidden, even if the patient him/herself asked to be released of his/her suffering. In addition, it turned out that the religious person is the most supportive of a known environment for the terminal patient as compared to the secular and traditional people. This was also supported in the literature that with the coming death, many visitors surround the patient to support him/her even if s/he is unconscious, even if s/he is not aware of his/her surroundings. It was found that knowledge about euthanasia is highest with the religious people, afterwards the traditional people and finally the seculars.

The religious person who is close to God and the scriptures has the highest awareness of its limits – s/he knows what is allowed and what is permitted and in which cases is euthanasia allowed and when it is not. It is permitted to cease treatment of a terminal patient under two conditions: brain death and also if the treatment given does not heal or lessen the pain but rather lengthens the life and amplifies the patient’s suffering.

An additional finding that came up in the present study, a difference was found in the perceptions and positions about euthanasia by gender. The men support a known environment for the terminal patient more than the women. In addition, the men are more supportive than the women in the patient’s right to die with dignity. Moreover, the men are more supportive than the women in the autonomy of the terminal patient, and also men have a wider knowledge than women regarding euthanasia.

Conclusions: The research findings show that Moslem religious people should intervene in end of life decision-making, awareness of the Moslem

people in Israel should be raised about acceptable treatments today for terminal patients.

Recommendations: As a continued research, perform an additional study regarding end of life and euthanasia decision-making according to demographic variables, and how the extent of religiosity of the individual influences his/her thinking on the subject, it is possible to carry out the study with a wide sample and the monologue from Israeli Moslems, in Arab countries and around the world.

The issue of euthanasia and decision-making tied to end of life are influenced by religion. As mentioned earlier it is definitely forbidden. But there is still a part of the Moslem community in Israel which supports active euthanasia, indeed that sees it as mercy and redemption to the terminal patient, and which also supports the autonomy of the patient and his/her right to die with dignity.

7.5.a Key points: Islam and the end of life

- Muslims pray only when ritually clean, and are not able to pray among bodily fluids or waste
- Muslims will often wish to bury their dead as soon as possible. Therefore, timely release of the death certificate is vital
- The Shariah does not recognise suicide; the right to die is not voluntary and it is forbidden to terminate life prematurely either actively or passively
- Islam is not a monolithic religion or set of beliefs and due to a sociocultural variation, some patients will choose to defer to their own scholarly views

Chapter 8: CONCLUSIONS AND CONTRIBUTIONS

This book has investigated and identified the obstacles to the implementation of the palliative care provisions written into Israel's Terminally-Ill Patients Act, 2005. The better we understand where these obstacles come from the more likely we shall be able to improve patients' quality of life, allow them a dignified death and respect their last wishes. How to die and where to die are topics that people can be prepared for and the professional caregiver has a great impact on the decision-making process of terminally-ill patients and their families.

Providing full and honest information can empower the patient and their family, providing patients and the guidance they need in order to obtain palliative care and a "good death" is an invaluable last gift to them, no death is evil but a shameful death. Palliative care has much to offer in easing our passage at the end-of-life and it has the potential to do this for many millions of people around the world. The authors of this book would wish to see a big rise in the numbers of patients receiving palliative care in Israel and around the world.

8.1: Conclusions

(a) *National provision and awareness of palliative care*

It is evident from the findings presented and discussed in the present book that the application of palliative care in Israel is still limited by a general failure to implement the 2005 Act. In many countries, access to palliative care is insufficient for the population in need. As it was already mentioned in this book, the Shvartzman Committee suggested that Israel aim for the lower of the two higher ratios, that is, an increase from 76 to

370 beds, and that it achieves this by, among other strategies, converting existing beds in oncology, internal medicine, neurology, geriatric and pediatric wards and complex case beds. Yet general hospitals already suffer from an overall shortage of beds so that this strategy would only worsen that shortage (Meyers-JDC-Brookdale Institute, 2005; Report of the Palliative Care Guidelines Committee, 2005). Nor is it possible to develop a palliative care system separate from the existing health care system and social support network - there is simply not the resources and capacity to do this.

The World Health Organization (WHO) has developed a Public Health Model for integrating palliative care into society. This model requires a 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 (Leon, Florez, De Lima, & Ryan, 2011). In Israel all this is the responsibility of the regulator of PC, the Israel Ministry of Health. The Ministry has two relevant roles in this regard: it supervises and controls the working of Israel's national healthcare system and the health management organizations who are the chief service providers in that system, and it is the body responsible for the implementation of the 2005 Act. It is also the body best equipped to engage in a campaign of public education for the purpose of changing negative attitudes to palliative care and hospice care.

Thus, the first major conclusion of the present study is that little will improve in the provision of palliative care in Israel if the Ministry of Health does not commit itself actively to that goal.

(b) *Medical training and education*

Once it is decided how much new healthcare worker training needs to be supplied, the content and teaching methods of current palliative care training programs need to be reviewed. Frontal lectures impart facts and increase knowledge but understanding requires bedside or at least simulation experience, so that knowledge is applied appropriately. Continuing medical education, consisting of lecture-style presentations, consistently fails to change physician behavior (Davis et al, 1999). National

data in many countries show that the medical teaching faculty themselves feel unprepared to teach many of the competencies required for PC. Faculty members say they lack several resources, including proficiency in a variety of didactic and interactive teaching methods (e.g., facility with small and large groups as well as one-on-one teaching), skills in assessing learners' needs and providing appropriate feedback, and ability to promote self-reflection and self-directed learning. In addition, the particular emotional and communication demands of end-of-life care pose further challenges for the clinician-educator (Sullivan et al., 2005).

Nor will learning communication skills be enough on its own to change the attitudes learnt by doctors in clinical training. For these to change 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. It is vital that trainees be active participants in their training, which will include role play, exercises in reflectivity, case analyses, maintaining a personal journal, lectures, and the analysis of video clips and films. Training will optimally cover the following elements:

- Knowledge and understanding;
- Skills and competencies;
- Attitudes and professional behavior;
- Personal and professional development.

This training will also discuss how transcultural palliative care deals with the understanding and evaluation of cultural factors in advanced disease and end-of-life care. It will take into account the different cultural, religious, ethnic, and ethical value systems, and it bridges the gap between different cultural contexts by a more fulfilling communication between the care providers and patients and their families (Bell et al., 2010).

(c) 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 end-of-life conversation. In that conversation they must be equipped to, if necessary, persuade/inform patient and family that treatment goals have to change from cure to palliation and preparation for death.

For this trust and open communication to exist truth-telling is a *sine qua non*. The principles of patient autonomy and dignity require that patients be given all the information necessary to understand their condition and the range of available approaches to their care and treatment. Drawing up Advance Medical Directives is one key component of this autonomy. The findings of the present study make it abundantly clear that if the oncologist does not take the initiative to broach the issue of Advance Medical Directives they will in most cases not be drawn up and registered.

Lastly, the critical sensitivities involved in handling end-of-life care in a manner that supports the patient's dignity and autonomy make it likely that certain personality traits are needed in the oncologist. The national regulator has to give thought to how these traits can be encouraged and sustained.

(d) *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. This team should hold team meetings to take end-of-life and other key decisions. Shared decision-making will be of higher quality than lone decision-making by the oncologist, as well as being supported by a wide range of inputs with respect to the patient's and family's needs. It also allows a holistic approach. Such combined decision-making relieves the "personal physician" of the burden of sole responsibility.

Effective interdisciplinary collaboration and teamwork are important components of high-quality patient care, especially in complex clinical areas such as palliative care. However, medical education provides little to no preparation for interdisciplinary practice. Oncologists need to understand the roles of other disciplines and the advantages of the interdisciplinary

approach in health care (Fineberg et al., 2004) and training programs need to be designed and applied, teaching both the principles and skills of palliative care and the provisions and requirements of the 2005 Act.

(e) Continuity of care

Operational methods need to be devised to ensure the continuity of care between hospital and community-sited facilities, including hospice home care. These methods must include computerized medical records and a computerized information system that is available to both hospital and community care doctors, which will both give them ready access to key data and improve communication between them. A good information system also helps patients and their families take well-founded end-of-life decisions.

8.2: The contributions made by this study

We would first make the point that the contributions to knowledge made by this study are universal because the issues are similar all over the world. Second, despite the current low rate of referrals to palliative care in Israel (and other countries), an expansion of the utilization of palliative care is to be expected for a number of reasons—more patients and families will demand it, especially as oncologists come to realize that patient autonomy is more than words to pay lip-service to; hospitals will be anxious to avoid lawsuits over non-consultation, etc.; and lastly palliative care will be seen as a means of reducing the costs of end-of-life care. This increased anticipated demand for palliative care requires formal carers and their national regulator to be equipped with the knowledge and skills to handle these referrals sensitively, skillfully and accurately. We would place this work in that context.

(a) Doctors' attitudes:

The World Health Organization's Public Health Model for integrating palliative care into society emphasizes clear national policy, adequate drug

availability and the education and training of health workers. In Israel the relevant legislation has been passed, drug availability is not a problem, palliative care facilities and services are also widely available and a component of the national 'basket' of drugs and services which are provided free at the point of service. Yet, despite all this, no more than 8-15% of oncology patients receive PC, and that without looking into patients dying from causes other than cancer. The present study has thus demonstrated that the negative attitudes of doctors (and the general public) and their cure-oriented training is as big a barrier to the expansion of palliative care as any other.

(b) *Oncologist as 'commander':*

The present study has demonstrated that leaving the oncologist in sole charge of hospital-sited end-of-life 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. Shared decision-making by all members of the multidisciplinary team will ensure a higher quality of decision-making. This widening of the 'circle of responsibility' would also take in family doctors and hospice home care specialists, both of whom have demonstrated in the present study a universe of attitudes far more PC-sympathetic than oncologists display.

(c) *Medical training:*

It was hoped that the findings of this study would reveal the training/educational needs of doctors - and oncologists in particular - with respect to the ethical issues raised by the care and treatment of dying patients. Did they need, for example, communication skills, skills in dealing with loss and grief, the capacity for self-knowledge on the issue of their own death? The research findings, it was hoped, could be used to develop training programs for formal caregivers, designed to raise their awareness and knowledge of this subject, to give them the skills and authority and readiness to discuss end-of-life issues with their patients, etc. To some degree this has been achieved but the present study has also 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 is untested and unproven. Additional research is therefore urgently required as to how this modification can be achieved.

(d) *The effectiveness of the 2005 Act:*

Many of the proponents of palliative care and hospice care laid up great hopes in the 2005 legislation: they expected that the Act would empower patient autonomy, legitimate shared decision-making and the patient's choice of place and mode of death, and so on. But the findings of the present study show convincingly that passing legislation is one thing and that 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 disappointed. 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 (e.g. the transition point from curative to palliative care; who is the patient's "personal physician", etc.). But then, secondly, we know that the doctors admit to not having familiarized themselves with the Act in any depth. And 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. By the latter adjective, I mean that the weight of prejudice against hospice care, both in the medical profession and the general public, has not been actively countered. (Even where the patient and their family are not so prejudiced their oncologist usually does not broach end-of-life issues because he/she expects them to be opposed.) These societal attitudes and how they might be educated are another key topic for further research.

8.3: Recommendations submitted to the Israel Ministry of Health

With the aim of having the findings of the present study applied to current practice a multidisciplinary panel was appointed 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. One instance of the problem is the division of responsibility between the 'attending physician' in the community and the 'attending physician' in the hospital. In most cases, the discovery/determination that a patient is to be defined as "terminally-ill" within the meaning of the Act is made in a hospital setting. Despite the "personal physician" being duty-bound by the 2005 Act to inform the patient of his/her having entered this category and of their right to draw up Advance Medical Directives, attending hospital physicians do not see it as their job to do these two things, and in practice they are not done until the patient is transferred to a community care setting (if even then).
2. The 2005 Act charges the "attending physician" with the duty to inform the patient that he/she is terminally-ill within the meaning of the Act. The breaking of this bad news is an extremely painful task and one which requires relations of trust between doctor and patient. Imposing this task on a stranger - and attending physicians in the community are strangers to hospital-treated patients at this stage - is most inappropriate and unreasonable, from the point of view of both physician 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. He/she would inform the attending physician that he/she intends to do break the news and cooperate with the attending physician in the community as necessary. It would

be the latter's responsibility to verify that the bad news has been broken but not to break it himself/herself.

3. According to doctors the 2005 Act's definition of a 'terminally-ill patient' is insufficiently clear. Indeed, to determine that a person is definitely a "terminally-ill patient' is extremely problematic. Medicine is not mathematics and this determination cannot be made with the required certainty. The Ministry of Health must therefore revisit and review the current definition a 'terminally-ill patient'.

The present research study has provided an identification and evaluation in practical terms of the barriers currently impeding the referral of patients to hospice care. In order to improve conditions for the implementation of the Act and the referral of patients to palliative care we propose that emphases and modifications be introduced into the Act so as to eliminate uncertainties in its interpretation.

8.3.a Ensuring continuity of care and information between hospital and community

The maintenance of medical records and full documentation is an important strand in the implementation of the 2005 Act. We propose two improvements:

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.

The present research study has added insights into problematic aspects of current information flows and doctor-doctor and doctor-patient communication. 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.

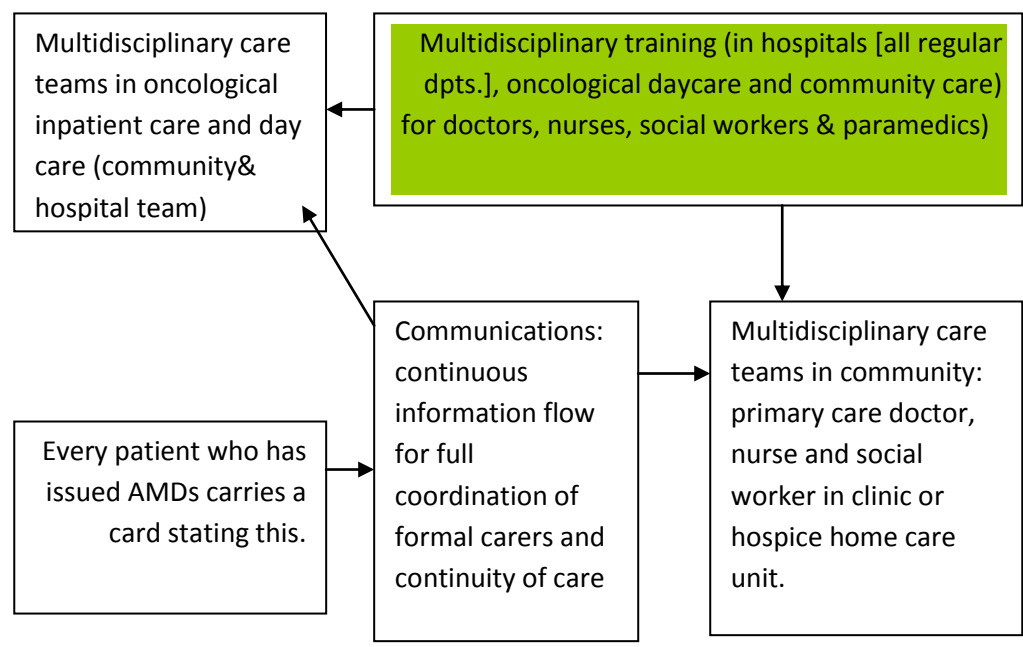
8.3.b Training for doctors in the 2005 Act

1. The Ministry of Health has a commitment to setting standards for the study and mastery of the provision of the 2005 Act. It should require doctors to take periodic short study courses and/or longer training programs in the implementation of the Act. This study and familiarization requirement has to be regularly enforced: doctors should be given positive and negative feedback and penalized if necessary.
2. The Ministry of Health and institutes of higher education will introduce changes into the core medical training program which will make palliative care an integral element of medical education and raise doctors' awareness and knowledge of it at an early stage in their career. The Ministry and the institutes will also promote multidisciplinary instruction/teaching sessions on core topics, such as doctor-patient communication, ethical issues, and so on.

In practical terms doctors' mastery of the 2005 Act is currently mediocre and their attitudes to it and to the principles of palliative care embodied in it even more negative. There are many doctors, the present study discovered, who have not made even a basic study of the Act and these are doctors selected by this study to represent those who work in almost daily contact with the issues of the care and treatment of dying patients. In light of this, the Ministry of Health, as the maker of national policy, must make efforts to enforce its declared policy, and the institutes of higher education must make changes to basic medical training. Together, these two initiatives can expand the acknowledgement and utilization of palliative care in Israel.

Below (*Fig. 5*) is set out a model which combines training programs with a computerization process designed to provide the continuous information flow needed to serve as the back-up to continuity of care.

Fig. 5: Training and communication for continuity of care



8.4: The follow-on from this study
Further research required

- The PC-related behavior and beliefs of the categories of doctors' not selected to participate in the present study needs to be investigated in the same way as the doctor-respondents of this study have been.
- The effectiveness of even the modified training approaches cited above (10.2.3) is unproven. Additional research is required as to how attitude modification in the medical profession can be achieved.
- The negative attitudes of patients and families (actual and anticipated) and how these attitudes might be educated needs to be researched. A particular population which needs research is the families of patients who have ended their lives in hospice care or palliative care settings. Were they happy that they had made the right choice? Especially, were they at peace with the decision to end curative, life-prolonging efforts? What was the process that led up to their decision? What helped and

what hindered? What did they expect from members of the treatment team?

- An outstanding finding of the present study was that when doctors were asked *in principle* what they felt about referring patients to palliative care many expressed support for palliative care but *in practice* felt strongly constrained by a number of obstacles, of which the chief one was a lack of communication skills with patients and their families. This obstacle needs further exploration: What communication skills do doctors have? What would be the effect on palliative care referrals of improving/expanding these skills?
- Doctors attitudes to and fears and beliefs about death - of patients and their own - need to be widely explored, particularly as regards their effect on the implementation of the 2005 Act.
- Another useful area of research would be how oncologists' colleagues - nurses, social workers, dieticians, etc. - experience the care and treatment of terminally-ill patients, and in other that hospital contexts, such as oncological day care. To what extent do these 'colleagues' agree/disagree with the oncologist's decisions? What do they think about truth-telling, shared decision-making, etc.? What are their attitudes to hospice care?
- The economics of hospice care are another important strand in the debate. Many doctors stated for the present study that it was their understanding that hospice care could save many of the financial resources spent on life-prolonging efforts. This understanding needs to be researched and corroborated, or not. If proved true, it could increase the transfer of patients to palliative care at the correct point in time.
- Until now the published literature has emphasized clear national pro-palliative care policy as the key requisite for a strong palliative care sector. The circumstances now demonstrated in Israel indicate that a clear policy is not enough. It is evident that we need an addition to the existing literature which deals with the obstacles and barriers which the present study has disclosed. It is our hope that this work will prove the first swallow of that summer.

8.5: Methodological limitations of the present study

- The first limitation is that death and dying are taboo subjects in Israeli society. Sensitivity to these issues is aggravated by the popular emphasis on the power of medicine to heal, or at least ensure survival. This makes it very hard for doctors to talk about death. It does not figure in their basic training, during which they are taught that their role is to save life rather than to think of palliation and providing the setting for death with dignity. And this, even when palliative care is an integral element of modern medical practice. Even in Premature Baby units the issue of the consensus (non-)treatment of babies with severe birth defects is suppressed from open discussion.
- Sample size and composition: the sensitivity and complexity of the research topics made it hard to recruit research participants. A major topic was the non-implementation of the 2005 Act and doctors are not interested in seeing themselves as law-breakers. Further, we restricted our sample recruitment to doctors in daily contact with dying patients, but this does not mean that there are no other doctors who should be familiar with the legislation on the care of terminally-ill patients.
- Another source of difficulty in the research topic is that 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. This is hardly accepted research territory.
- A fourth source of difficulty is the issue of national medical policy - who makes it? The literature stresses the importance of clear national policy, adequate training and drug availability. 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.

- A fifth problem area is the attempt to apply the Theory of Planned Behavior to the reality of physician behavior in the field of PC. One of the critical variables of the Theory is what the authors term 'subjective norms', that is, in the case before us, what doctors perceive to be the behavior expected of them by society, colleagues, patients and their families in relation to the approaching death of a terminally-ill patient. The problem for the researcher is that it is not very clear what these expectations are. There is wide variation, not to speak of contradictoriness, on the issue.

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