

## Quality of Patients' Dying and Death Experience in Mansoura University Hospitals: Nurses' Perception

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**ABSTRACT:** Death is fundamental to the nature of being human. Critical care nurses and oncology nurses care for dying patients daily. The process of dying in intensive care units (ICUs) and oncology department is complicated, and research on the quality of end of life care and dying experience is limited in Egypt. The main aim of the current study was to describe the quality of dying and death experience of patients as perceived by nurses working in oncology department and ICUs in Mansoura University Hospitals, and compare nurses' perception in the two clinical settings. The sample involved 90 nurses (45 critical care nurses and 45 oncology nurses). Data were collected using a questionnaire sheet which gathered information about nurses' demographic characteristics, and the modified version of the Quality of Death and Dying questionnaire which elicited nurses' perception of patients' dying experiences in ICUs and oncology department. The majority of nurses reported that their patients were unable to feed themselves and did not spend enough time with their families during the end of life period. Nurses also reported that their dying patients suffered pain, nausea and/or vomiting. More than half of the nurses mentioned that their patients were not fully aware that they were dying and were not afraid of death. The findings of the study showed that cancer dying patients suffered more pain and nausea significantly than ICU patients. The majority of patients in oncology department had their family members with them during dying more than ICU patients. The findings of this study provided a rounded picture of the experience of dying patients in ICUs and oncology department. Such information can be used as a guide to enhance dying patients' experiences and improve end of life care in Egyptian hospitals.

**Key words:** Quality of Patients Dying; Death Experience; End of Life Care; Nurses' perception.

### INTRODUCTION

Death is a fact of life. Conventional medical care does little to open up and address the many sources of suffering in those with life-threatening disease and does little to prepare the patient and family for the process of dying.<sup>(1)</sup> Improving the

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quality of end-of-life care has become a major agenda for patients, families, and the loved ones of persons near death as well as health care professionals, researchers, and policy makers who organize and provide care.<sup>(2)</sup> End-of-life care is defined by the World Health Organization (WHO 1998),<sup>(3)</sup> as “the active, total care of patients whose disease is not responsive to curative treatment”. The philosophy of this care is to attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family.<sup>(4)</sup> The quality of end-of-life care has been receiving an increasing amount of attention in Egypt, in response to an increasing number of deaths occurring in Egyptian hospitals. It also became an important issue for nurses particularly those who work in areas where the death rate is high such as ICUs and oncology department.

What happens at the end of life is receiving the attention of researchers,

policy makers and the public at large, influenced by debates on physician assisted suicide, by scientific and technological advances that can prolong life, and by the challenges of facing death and providing comfort in dying.<sup>(2)</sup> Furthermore, with the recent emphasis on clinical governance, patient centered care and patient choice, coupled with an increase in the number of complaints about issues related to death in hospitals, much has been written about the quality of death and dying.<sup>(5)</sup> In parallel to this has been the recognition of those factors that make for a ‘bad death’ and those important for a ‘good death’. Issues that contribute to the suboptimal care of patients dying in hospital are said to include a lack of open communication, difficulties in accurate prognosis and a lack of planning of end-of-life care.<sup>(6)</sup>

In contrast, common themes contributing to a good death include control, autonomy and independence not

only for issues such as pain and symptom control, but also for the place of death, who should be present at the time of death and the maintenance of privacy. The importance of access is also stressed, not only to information and expertise, but also to spiritual and emotional support.<sup>(7)</sup> Ekiria Kikule, (2003),<sup>(8)</sup> stated that a “good death” in a developing country occurs when the dying person is being cared for at home, is free from pain or other distressing symptoms, feels no stigma, is at peace, and has their basic needs met without feeling dependent on others. The quality of death defined by the Committee on End-of-Life Care of the Institute of Medicine as “a death that is free from avoidable distress and suffering for patients, families, and their caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.”<sup>(9)</sup>

Quality of dying is a term that may be used to describe the quality of life for dying

patients. Patrick and Curtis, (2001), defined quality of dying and death as 'the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others'.<sup>(2)</sup> Dying patients face common and unique challenges that warrant new approaches to measurement of their quality of life at the end of life. Quality of dying is another patient - centered outcome measure that may also be affected by the quality of medical care.<sup>(10)</sup> According to the Institute of Medicine (1997), four basic elements are required for the care of dying patients: understanding the physical, psychological, spiritual, and practical dimensions of care giving; identifying and communicating diagnosis and prognosis; establishing goals and plans; and fitting palliative and other care to these goals. There have been several studies which investigated patients' and their families description of elements of high quality end-of-life care.<sup>(11)</sup>

In a Canadian study of 126 participants from three patient groups [dialysis patients (n=48), patients with HIV infection (n=40), and residents of a long-term care facility (n=38)], the participants identified five domains of quality end-of-life care. These involved adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; and strengthening relationships with loved ones.<sup>(12)</sup> Families praised health care providers who showed concern and compassion; were sensitive and open; took time to listen; treated dying patients and their families as individual human beings; and integrated family members in the patients' care.<sup>(13-15)</sup> Staff members who were perceived as uncaring, unfriendly, insensitive, or disrespectful had a negative influence on families' experiences.<sup>(16)</sup> Dying patients and their families valued open and ongoing communication with health care providers, especially when it

was timed to their needs and allowed them to ask questions and express their feelings and concerns.<sup>(13,14,16)</sup> In other studies, items rated as important were: preparing for death; achieving a sense of completion; being treated as a "whole person"; not being a burden; dying at home; having better communication; having greater access to physicians' time; and being at peace with God.<sup>(17-18)</sup>

Cancer in the developing world, of which the Islamic world is a substantial component, is characterized by far more advanced stages at diagnosis, fewer allocated resources for prevention and treatment, and higher incidence than in countries with more developed health systems. Hence, the development of palliative care services is a more realistic option for most patients who have cancer in Islamic countries.<sup>(19-20)</sup> While too many patients with cancer suffer needlessly at the end of their life. Focus on the cure too often has diverted attention from the care

that patients need. As the National Cancer Policy Board (NCPB) of the Institute of Medicine noted in its 2001 report, improving Palliative Care for Cancer, their families and caregivers all suffer from the inadequate care available to patients in pain and distress.<sup>(21)</sup> In addition, McCarthy et al. (2000) concluded from their study findings that, the last six months of life for patients with cancer is characterized by functional decline and poorly controlled severe pain and confusion. Although patients increasingly prefer comfort care as they near death, many die in severe pain.<sup>(22)</sup>

According to the literature, most hospitalized patients die in ICUs. Most ICU patients are there to take the advantage of advanced technology and frequent monitoring. Sometimes patients die despite the best efforts. Most deaths in the ICU occur in undesirable situations: the patient is comatose, receiving mechanical ventilation, and isolated from family

members. At the same time, family members worry that their loved one is in pain or experiencing personal indignities in a foreign, high technology, impersonal environment.<sup>(23)</sup> Death in the ICU environment can be complicated and is often unnatural.<sup>(24)</sup> Caring for dying patients and their families is considered to be most stressful and painful to the nurses who constantly care for those patients.<sup>(25-26)</sup>

Central to ensuring the quality of care at the end of life is nurses' knowledge and skills in caring for dying patients and their families, and their perception of end of life care. In a study conducted by Asch et al.<sup>(27)</sup> to investigate critical care nurses' perception of end of life care in the United States of America, the results showed that nurses wished they had more say in the care of dying patients. In this study, nurses showed their belief that there was inconsistency in the way dying patients were cared for, and that critical care environment did not adequately foster the

compassion that dying patients need. Similarly, Cartwright et al <sup>(28)</sup> studied end of life care from the Australian critical care nurses' perspectives. In this study, nurses reported the need for better pain control measures for dying patients, emphasized the necessity to improve communication between physicians and patients, and also between physicians and nurses, and thought of themselves as important advocates for patients.

While many health care disciplines are concerned about improving care at the end of life, the nursing profession is particularly well suited to lead these efforts in view of the scope and standards of advanced practice. Nursing's social policy statement indicates that nurses "attend to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation. They integrate objective data with knowledge gained from an understanding of the patient's subjective

experience; apply scientific knowledge to the processes of care; and provide a caring relationship that facilitates health and healing.<sup>(29)</sup>

As elsewhere, it is likely that many patients still die frightened, alone and without dignity, having lost all control, feeling abandoned by health-care professionals.<sup>(5)</sup> Although one would hope that those patients known to a palliative care team are well served, palliative care is relatively under-developed in many parts of our country and is still to be recognized formally as a specialty in its own right. Research on how patients experience the process of dying is scant, and studies on patients' and families' preferences at the end of life are limited in Egypt. From their experience in clinical care settings, the researchers were very interested to look at end of life care provided for dying patients, and how the patients experienced dying and death in hospitals. Therefore, this study aimed firstly to provide a rounded

picture of the current quality of dying and death experience of the patient as perceived by nurses in the oncology department and ICUs, and consequently determine what we need in order to improve the care of dying patients in hospitals. Hence, the current study used the Quality of Death and Dying questionnaire (QODD) to describe and compare the quality of dying and death experience of the patient as perceived by nurses in the oncology department and ICUs. In Mansoura University Hospitals and compare nurses' perception in the two clinical settings.

## **MATERIALS AND METHODS**

### **Materials**

### **Design**

A cross-sectional descriptive comparative research design was used in this study.

### **Setting**

This study was carried out in the Oncology Center and the ICUs (medical ICU, gastroenterology ICU and cardiac

ICU) at Mansoura University Hospitals.

### **Sample**

All critical care nurses and oncology nurses who were involved in caring for dying patients, and who accepted to participate in the study (n = 90) were included. Half of the nurses were working in ICUs and the other half were working in the oncology department at Mansoura University Hospitals. Nurses' ages ranged from 18 to 46 years. More than half of them (62.2 %) had a diploma degree in nursing and the years of their working experience ranged from one year to 20 years with a mean of  $7 \pm 6.4$  (table 1).

### **Tools**

Two tools were used to collect data for the current study:

**Tool I:** is a structured questionnaire which was developed by the researchers, and it consists of two parts:

Part (1) is concerned with nurses' characteristics including the age, educational level, work setting and years

of working experience.

Part (2) includes data related to the distribution of nurses according to number of deaths attended by each nurse and the age group of the deceased patient.

**Tool II:** is the QODD questionnaire which was developed by Curtis, Patrick, Engelberg, et al. in 2002, <sup>(30)</sup> and adapted in the current study after making some modifications. The modified version of the QODD questionnaire was translated into Arabic. In order to ensure the validity of the translation, back translation technique was used, where the questionnaire was translated from English into Arabic, and then from Arabic into English. The final version of translation was reviewed by an assistant professor from the English Department, the Faculty of Education, Mansoura University, and the suggested modifications were made accordingly. The questionnaire consists of 14 questions which addressed different aspects of dying patients' experience. It was used to

describe the quality of dying and death experience of the patients as perceived by nurses in oncology department and ICUs at Mansoura University Hospitals. Then the perception of nurses in the two clinical areas was compared. Nurses were asked to rate their responses to the QODD questions on a four point scale including 'yes', 'uncertain', 'no', and 'not applicable'. A preliminary validation study suggested that this instrument had good reliability and validity characteristics.

### Methods

- An official permission to conduct the study was obtained from the hospitals responsible authorities after explaining the aim of the study.
- Self-administered structured questionnaire sheet was developed by the researchers.
- The QODD questionnaire was modified and translated into Arabic by the researchers. A back translation technique was used to ensure the

validity of the translation. The two versions of the translation were reviewed by an expert in translation.

- A jury of 5 experts in the field of nursing reviewed the tools to ascertain its content validity, and necessary modifications were done accordingly.
- A pilot study was carried out on ten nurses from the ICUs and oncology departments to ensure the clarity and applicability of the tools.
- The QODD questionnaire was tested for its reliability. Test and retest reliability were computed using a small sample of nurses (10 nurse), and it was satisfactory for the current research purposes ( $r=0.87$ ).
- The researchers obtained oral consents from the participants after providing an explanation for the purposes of the study.
- Data were collected during the actual visit to each setting. The

questionnaire took from 5 to 10 minute to be completed.

### **Data Analysis**

Data were analyzed using the statistical Package for Social Sciences Version 15.0 (SPSS15). Descriptive statistics were used to analyze the demographic data. Chi Square was used to compare the quality of patients' dying and death experiences in ICUs and oncology department. Level of statistically significance was less than 0.05.

### **RESULTS**

Table 1 shows the distribution of nurses according to their demographic characteristics. The sample consisted of 90 nurses. The majority (81.1%) of nurses were between the age 18 and 28 years with a mean of  $18.8\pm 4.4$  years. A total of 62.2% of the sample had nursing diploma, and 66.7% had years of experience that ranged from 1 to 5 years with a mean of  $4.1\pm 5.4$  years.

Table 2 illustrates the distribution of

nurses according to the number of deaths attended by each nurse, and the age of the deceased patients. The number of deaths attended by the nurses ranged from 1 to 200 with a mean of  $43.7 \pm 46.6$  while about half of them (50%) reported 1 to 30 deaths and 11.1% reported more than 61 deaths. More than half of the nurses (54.4%) reported that their dying patients were over 55 years of age.

Table 3 illustrates the quality of patients' dying and death experience in ICUs and oncology departments in Mansoura University Hospitals. More than half of the subjects (56.7%) reported that their patients suffered from pain during their dying experience and 43.3% of them stated that their patients suffered nausea or vomiting during this period. The majority of the subjects (91.1%) reported that their patients were unable to feed themselves and 56.7% stated that their patients were not fully aware that they were dying. More than half of the subjects (52.2%)

mentioned that their dying patients were not afraid of death, and about two thirds (66.7%) reported that their dying patients appeared to lose control over what was going on around them. More than half of the subjects (57.8%) reported that their dying patients were not given a choice where to die and their family members were not aware that they were dying. More than three quarters of the subjects (78.9%) reported that their dying patients didn't spend enough time with their families, and 46.7% mentioned that no member of the family was present during the period of dying. Furthermore, 55.6 % of the study subjects believed that their dying patients were not given the opportunity to express their feelings, and the majority of them didn't have any visits from a religious advisor.

Table 4 compares the quality of dying and death experience of dying patient as measured by the QODD questionnaire and reported by ICUs nurses and oncology

nurses. The table shows that oncology dying patients suffered from pain and nausea significantly more than ICUs dying patients ( $P = 0.005$  and  $P = 0.016$ , respectively). With regard to breathing comfortably, self feeding, fear of death and losing control over what is going on around him/her, there were no statistical significant differences between dying patients' experiences in ICUs and oncology department ( $P$  values: 0.940, 0.264, 0.153, 0.968 and 0.388, respectively). Additionally, a considerable percentage (22.2%) of the dying patients in oncology department have significantly more choices to decide where to die, and their family members were fully aware that their patient was dying significantly more than patients dying in ICUs ( $P$  values were 0.049 and 0.013 respectively). The majority of patients in oncology department (86.7%) had their family members with them during dying significantly more than those in ICUs ( $P = 0.001$ ). However, there were no

statistical significant differences between the two settings (ICUs and oncology departments) in relation to patient's end-of-life wishes, having visits from a religious advisor, having a chance to express feelings before dying and spending enough time with the family ( $P$  values were 0.249, 0.352, 0.205 and 0.062 respectively).

## DISCUSSION

The quality of the dying experience is an important outcome for patients, families, and healthcare providers. An understanding of patients' experience of death will help nurses to enhance the quality end of life care and provide good death for our patients. Chao et al (2005) investigated the meaning of good death for terminally ill cancer patients in Taiwan and found that good death meant peace of body, peace of mind, and peace of thought.<sup>(31)</sup> Deaths that are reasonably free of discomfort, in accordance with patients' wishes, and within acceptable professional and ethical standards are high-quality

deaths.<sup>(32)</sup> Physical components of a patient's illness and the care a patient receives in preparation for death affect it.<sup>(10)</sup> Quality measures for end-of-life care include the timely assessment and effective treatment of physical symptoms including pain and dyspnea.<sup>(33)</sup> Dying patients and bereaved family members consider the control of distressing physical symptoms to be an important determinant of a good death, especially in long-term care (LTC) settings.<sup>(34-35)</sup> In addition, the management of physical symptoms is considered a primary indicator of quality of end-of-life care.<sup>(36)</sup>

Unfortunately, during the last month of life, approximately half of nursing home residents experience pain or dyspnea.<sup>(37-38)</sup> Also Tse, *et al*, (2007) reported that pain was documented in 46.8% of all patients, reflecting that pain was still an issue of concern at end-of-life.<sup>(39)</sup> In addition, previous studies demonstrated that many patients dying in the ICU are dying with

significant pain and other symptoms and without adequate communication between families and critical care clinicians.<sup>(40-42)</sup> These findings are in congruent with the results of the current study which illustrated that the majority of dying patients in ICUs and oncology department suffered from pain during their dying experience, but oncology dying patients suffered more from pain and nausea. These findings also supported by the report of National Cancer Policy Board (NCPB) of the Institute of Medicine in 2001 that patients, their families and caregivers suffer from the inadequate care available to patients in pain and distress. The report also emphasized that too many patients with cancer suffer needlessly at the end of their life. Focus on the cure too often has diverted attention from the care that patients actually need.<sup>(21)</sup> Madanagopalan, *et al* (2005) carried out a study to investigate the quality of dying in head and neck cancer patients. They found that

84% of dying patients suffer from pain.<sup>(43)</sup> Other studies have also found that patients experienced moderate to severe pain in the last weeks of their lives.<sup>(44-46)</sup>

Kellehear's (1990) asserted that the conception of good death includes an acknowledgement of the social life of the dying and the creation of an open climate about disclosure with the patient being aware of their impending death.<sup>(47)</sup> There is a need to improve communication with dying patients and families about diagnosis and prognosis in order to ensure that optimal communication takes place and so-called blocking behavior avoided.<sup>(48)</sup> As death approaches, many terminally ill patients want to prepare for the end of their lives. Preparation may involve a discussion of treatment choices, financial planning, psychological acceptance of death, or coming to peace with God.<sup>(10)</sup> In the current study, more than half of the nurses stated that their dying patients were not fully aware that they were dying, and

accordingly they had no choice where they prefer to die, and had no chance to discuss their end of life wishes. This finding was in agreement with Fallowfield, Jenkins, and Beveridge, (2002)<sup>(49)</sup> report that physicians worldwide underestimate the information needs of their patients and the negative impact of non-disclosure practice. This underestimation can lead to withholding relevant information from the patient.<sup>(50)</sup> McCahill, *et al*,(2001).<sup>(51)</sup> stated that health-care professionals have the responsibility of helping individuals prepare for death by facilitating any unfinished business, for example, signing wills, contacting loved ones, appointing a power of attorney. Patients' wishes regarding practical issues such as parenteral feeding, antibiotics and IV fluids should be explored. Each individual should also be given the opportunity for voicing their wishes regarding the desired place of death and who should be present at the time of death. Spiritual and religious

support with an appropriate cultural focus should be offered both to the patient and to the family after death in the context of bereavement support.<sup>(51)</sup>

Achieving a sense of control for persons who are dying, and respecting wishes of patients and their loved ones, are considered from the important goals of high quality end-of-life care. These processes of care are sometimes linked to desirable outcomes such as improved quality of life at the end of life, a notion that has currency for both lay persons and professionals.<sup>(5)</sup> Unfortunately, the finding of current study reported that dying patients appeared to lose control over what was going on around them. This was supported by Emanuel, *et al*, (1999) who believed that one of the major issues in end of life care tends to be the loss of control. Losing of body control, including the inability to feed, bathe, and toilet oneself, is certainly a frequent concern. These losses of control are associated in

many people's mind with indignity and shame.<sup>(52)</sup>

For many people, spirituality plays a very important role in reducing fear and increasing hope. The search for meaning or spiritual comfort in the face of death is often guided by religious and philosophical beliefs. Communication with religious advisors, selected hospice volunteers, or others with special empathy and insight may enhance comfort.<sup>(53)</sup> Clinical chaplains (or religious man) in a palliative care unit provide strength and enlightenment to help patients transcend their death fear and prepare for a good death.<sup>(54)</sup> Research has found that if patients had contacts with clinical chaplains two days before death, the fear of death was lower than that of other patients. A correlation also exists between the degree of death fear experienced, and the duration of contacts with the clinical chaplains.<sup>(55)</sup> The findings of the current study documented that nearly all dying patients in both clinical

settings (oncology department and ICUs) did not have any visits from any religious man. This is very interesting considering the fact that Egypt is an Islamic country where religion and spirituality play a major role in people's daily life.

### **CONCLUSION**

According to the results of the present study, it is concluded that, the increasing institutionalization of death and dying in Egyptian society poses a major challenge to physician and nurses as patients continue to die undignified deaths with uncontrolled symptoms. Efforts should be made to ensure that dying patients receive appropriate end of life care that reduces their suffering and allows good death. The results of the current study shed the light on important aspects related to end of life care such as reducing dying patients' suffering, supporting spirituality, giving the patient the opportunity to express their feelings and wishes, and promoting patient's autonomy. The findings of the

current study provided a baseline information that guides improvements in end-of-life care in oncology departments and ICUs.

### **RECOMMENDATIONS**

1. Practical guidelines for health care team on cancer pain control are recommended and physician' barriers to pain management in hospitals should be further explored.
2. There is a need to improve communication with patients and families about diagnosis and prognosis to ensure that effective communication takes place.
3. Establishing a private setting in the hospital to provide care for dying patients. It must be adequately equipped by medical and nursing staff, well trained in providing palliative care and willing to care for dying patients.
4. Promoting spirituality which has a positive effect on patient's experience

- of dying through involving religious advisors as key persons in communicating with a dying patient.
5. Patients and their families must be given the opportunity to decide where the patient dies, and their decision must be respected from the health care team. Hence, if the patient decides to die at home, there is a need to ensure that he/she will receive the most appropriate care through training his relatives on how to care for the patient.
  6. Preparing and implementing in-service training programs for physicians and nurses related to end of life care.
  7. Including a palliative care module in undergraduate program of medical and nursing students to improve their knowledge in this area.
  8. There is a need for further research on end of life experience and care in Egypt as this subject is considered a virgin area for both medical and nursing researchers.

**Table 1: Distribution of nurses according to their demographic characteristics**

Items	N= (90)	%
<b>Age in years</b>		
18 -28	73	81.1
29 -39	10	11.1
40+	7	7.8
Mean±SD	18.8±4.4	
Range (Minimum-maximum)	(18-46)	
<b>Educational level</b>		
Diploma	56	62.2
Bachelor	34	37.8
<b>Place of work</b>		
ICUs	45	50
Oncology departments	45	50
<b>Years of experience</b>		
1 -5	60	66.7
6 - 10	20	22.2
10+	10	11.1
Mean±SD	4.1±5.4	

**Table 2: Distribution of nurses according to the number of deaths attended by each nurse, and the age group of the deceased patients**

Items	N= (90)	%
<b>Number of deaths attended</b>		
1 -30	45	50
31-60	35	38.9
61+	10	11.1
Mean±SD	43.7± 46.6	
Range (Minimum-maximum)	1- 200	
<b>Age groups of deceased patients</b>		
Less than 30 years	17	18.9
From 30 to 55 years	24	26.7
More than 55 years	49	54.4

**Table 3: Quality of patients' dying and death experience in ICUs and oncology department in Mansoura University Hospitals**

Question	Yes No. (%)	No No. (%)	Uncertain No (%)
Did the patient suffer from pain?	51 (56.7)	22(24.4)	17(18.9)
Was the patient breathing comfortably?	6(6.7)	75(83.3)	9(10)
Did the patient suffer from nausea or vomiting?	39(43.3)	46(51.1)	5(5.6)
Was the patient able to feed him/herself?	6(6.7)	82(91.1)	2(2.2)
Was the patient fully aware that he or she was dying?	17(18.9)	51(56.7)	22(24.4)
Was the patient afraid of death?	23(25.6)	47(52.2)	20(22.2)
Did the patient loose control over what was going on around him/her?	60(66.7)	19(21.1)	11(12.2)
Was the patient given a choice where to die?	13(14.4)	52(57.8)	25(27.8)
Were the patient's family members aware that he or she was dying?	51(56.7)	26(28.9)	13(14.4)
Did the patient spend enough time with his or her family during dying?	12(13.3)	71(78.9)	7(7.8)
Was there a member of his /her family during dying?	45(50)	42(46.7)	3(3.3)
Was the patient given a chance to express his or her feelings?	27(30)	50(55.6)	13(14.4)
Did the patient receive visits from religious advisor?	2(2.2)	75(83.3)	13(14.4)
Did the patient have a specific end-of-life wishes that cannot be achieved before he/she died?	28(31.1)	40(44.4)	22(24.4)

**Table 4 Comparison between the quality of dying and death experience of dying patients as described using the QODD questionnaire and reported by nurses in ICUs and oncology department**

Question	Current area of work		Chi-sq test	P value
	ICU No. (%)	Oncology No. (%)		
Suffering from pain				
yes	18 (40)	33 (73.3)	10.428	0.005 *
no	16 (35.6)	6 (13.3)		
uncertain	11 (24.4)	6 (13.3)		
Breathing comfortably				
yes	3 (6.7)	3 (6.7)	.124	0.940
no	37 (82.2)	38 (84.4)		
uncertain	5 (11.1)	4 (8.9)		
Suffering from nausea or vomiting				
yes	13(28.9)	26(57.8%)	8.307	0.016 *
no	28(62.2)	18(40.0%)		
uncertain	4(8.9%)	1(2.2%)		
Having the ability to feed him/herself				
yes	4(8.9%)	2(4.4%)	2.667	0.264
no	41(91.1%)	41(91.1%)		
uncertain	2(4.4%)	2(4.4%)		
Being fully aware that he or she was dying				
yes	7(15.6%)	10(22.2%)	3.754	0.153
no	30(66.7%)	21(46.7%)		
uncertain	8(17.8%)	14(31.1%)		
Being afraid of death				
yes	11(24.4%)	12(26.7%)	.065	0.968
no	24(53.3%)	23(51.1%)		
uncertain	10(22.2%)	10(22.2%)		
Loosing control over what was going on around him/her				
yes	27 (60%)	33(73.3%)	1.892	0.388
no	11(24.4%)	8(17.8%)		
uncertain	7(15.6%)	4(8.9%)		
Having the opportunity to choose where to die				
yes	3(6.7%)	10(22.2%)	6.052	0.049 *
no	31(68.9%)	21(46.7%)		
uncertain	11(24.4%)	14(31.1%)		
Awareness of the family members that their patient was dying				
yes	31(68.9%)	20(44.4%)	8.757	0.013 *
no	12(26.7%)	14(31.1%)		
uncertain	2(4.4%)	11(24.4%)		
Spending enough time with the family				
yes	17(37.8%)	4(8.9%)	7.333	.062
no	30(66.7%)	40(88.9%)		
uncertain	7(15.5%)	1(2.2%)		

The presence of a member of the family during dying	yes no uncertain	6(13.3%) 38(84.4%) 1(2.2%)	39(86.7%) 4(8.9%) 2(4.4%)	52.05	0.001 **
Having a chance to express feelings	yes no uncertain	10(22.2%) 29(64.4%) 6(13.3%)	17(37.8%) 21(46.7%)	3.172	0.205
Having visits from a religious advisor	yes no uncertain	2(4.4%) 37(82.2%) 6(13.3%)	38(84.4%) 7(15.6%)	2.090	0.352
Having a specific end-of-life wishes that cannot be achieved before he/she died	yes no uncertain	10(22.2%) 22(48.9%) 13(28.9%)	18(40.0%) 18(40.0%) 9(20.0%)	4.114	0.249

\*\* Highly significant at P value < 0.001 \*\* significant at p value 0.05

## REFERENCES

- Support Principal investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*. 1995; 274:1591–8
- Patrick D, Curtis R. Evaluating the Quality of Dying and Death. *Journal of Pain and Symptom Management*. 2001; September 22( 3) :717.
- World Health Organization. Symptom relief in terminal illness. Geneva, Switzerland: World Health Organization;1998.
- Griffin J, Nelson J, Koch K, Niell H, Ackerman T, Thompson M, Cole H. End-of-Life Care in Patients With Lung Cancer. *Chest*. 2003;123:12-31.
- Hardy J R, Vora R. A good death down under. *Internal Medicine Journal*. 2004; 34: 450–2.
- Edmonds P, Rogers A. 'If only someone had told me...' A review of the care of patients dying in hospital. *Clin Med*. 2003; 3:149–52.
- Debate of the Age, Health and Care Study Group. *The Future of Health and Care of Older People: the Best Is Yet to Come*. London: Age Concern; 1999.
- Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ*. 2003;327;192-4
- Cassell MJ, Editors CK. *Approaching death: improving care at the end of life*. Washington, DC: National Academy Press; 1997.
- Steinhauser K, Clipp E, Tulsky J. Evolution in Measuring the Quality of Dying. *Journal Of Palliative Medicine*.2002; 5 (3).
- Institute of Medicine, *Approaching Death: Improving Care at the End of Life*. Washington: National Academy Press; 1997.

12. Singer PA, Martin D K, Kelner M. Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*. 1999; 281 (2): 163-8.
13. Andershed B, Ternestedt B M Involvement of relatives in the care of the dying in different care cultures: Involvement in the dark or the light? *Cancer Nursing*.1998;21:106-16.
14. Andershed B, Ternestedt B M Involvement of relatives in care of the dying in different care cultures: Development of a theoretical understanding. *Nursing Science Quarterly*. 1999;12 (1): 45– 51.
15. Pierce S F. Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum*. 1999;34(2): 5–14.
16. Rogers A, Karlsen S, Addington-Hall J. All the services were excellent. It is when the human element comes in that things go wrong': Dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing*. 2000;31: 768–74.
17. Steinhauer KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476–82.
18. Wilson DM End-of-life care preferences of Canadian senior citizens with care giving experience. *Journal of Advanced Nursing*. 2000; 31(6): 1416–21.
19. Stjernsward J, Teoh N. Current status of the Global Cancer Control Program of the World Health Organization. *J Pain Symptom Manage*. 1993;8: 340-7.
20. Mohammad Al-Shahri. The future of palliative care in the Islamic world *West J Med*. 2002 January; 176(1): 60–1
21. Schapiro R, Byock I, Parker S, Twohig J. Living and Dying Well with Cancer Successfully Integrating Palliative Care and Cancer Treatment. Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation. April 2003.
22. McCarthy EP, Phillips RS, Zhong Z, Drews RE, Lynn J. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. *J Am Geriatr Soc*. 2000 May;48(5 Suppl):S110-21
23. Kirchhoff K, Spuhler V, Walker L, Cole B, Clemmer T. Intensive Care Nurses' Experiences With End-of-Life Care. *American Journal of Critical Care*. 2000 January; 9 - 1.
24. Chapple HS. Changing the game in the intensive care unit: letting nature take its course. *Crit Care Nurse*. 1999June;19:25-34.
25. Anderson CA. Flawed research: is it the design, methods, or the wrong conclusions? *Nurs Outlook*. 1996;44:209-10.
26. Perkin RM, Young T, Freier MC, Allen J, Orr RD. Stress and distress in pediatric nurses: lessons from baby K. *Am J Crit Care*. 1997;6:225-32.
27. Asch DA, Shea JA, Jedziewski MK, Bosk CL. The limits of suffering: critical care nurses' views of hospital care at the end of life. *Soc Sci Med*. 1997; 45:1661-8.
28. Cartwright C, Steinberg M, Williams G, Najman J, Williams G. Issues of death and dying: the perspective of critical care nurses. *Aust Crit Care*. 1997;10:81-7.
29. Curtis JR, Wenrich MD, Carline JD, et al. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. *J Gen Intern Med*. 2001; 16:41-9

30. Curtis JR, Patrick DL, Engelberg R, *et al.* A measure of the quality of dying and death: initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002; 24:17-31
31. Tsai J, *et al.* Fear of Death and Good Death Among the Young and Elderly with Terminal Cancers in Taiwan. *Journal of Pain and Symptom Management.* 2005;29(4).
32. Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. *Ann Intern Med.* 2003;139:410–5.
33. Wenger NS, Rosenfeld K. Quality indicators for end-of-life care in vulnerable elders. *Ann Intern Med.* 2001;135:677–85.
34. Steinhauser KE, Clipp EC, McNeilly M *et al.* In search of a good death: Observations of patients, families, and providers. *Ann Intern Med.* 2000; 132:825–32.
35. Teno JM, Clarridge BR, Casey V *et al.* Family perspectives on end-of-life care at the last place of care. *JAMA.* 2004;291:88–93.
36. Caprio *et al.* Pain, Dyspnea, and the Quality of Dying in Long-Term Care. *JAGS.* 2008 April; 56, (4).
37. Hanson LC, Eckert JK, Dobbs D *et al.* Symptom experience of dying long-term care residents. *J Am Geriatr Soc.* 2008;56:91–98.
38. Hall P, Schroder C, Weaver L. The last 48 hours of life in long-term care: A focused chart audit. *J Am Geriatr Soc.* 2002;50:501–6.
39. Tse D, Chan K, Lam W, Lau K, Lam P. The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths *Palliative Medicine.* 2007; 21: 425–33.
40. Hanson LC, Danis M, Garret JM. What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc.* 1997; 45:1339-344
41. Lynn J, Teno JM, Phillips RS, *et al.* Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med.* 1997; 126:97-106.
42. Levin JR, Wenger NS, Ouslander JG, *et al.* Life-sustaining treatment decisions for nursing home residents: who discusses, who decides and what is decided? *J Am Geriatr Soc.* 1999; 47:82-7.
43. Madanagopalan E, Andrew R, Gary H, Paula M, Peter B. Quality of dying in head and neck cancer patients : A retrospective analysis of potential indicators of care. *Oral surgery.* 2005; 100 (2):147-52.
44. Goodlin S J, Jette A M, Lynn J, Wasson J H. Community physicians describe management issues for patients expected to live less than twelve months. *Journal of Palliative Care.* 1998; 14 (1):30-5.
45. Miettinen T T, Tilvis R S, Karppi P, Arve S, Why is the pain relief of dying patients often unsuccessful? The relatives' perspectives. *Palliative Medicine.* 1998;12 (6): 429-35.
46. Tolle S W, Tilden V P, Hickman S E, Rosenfeld A G. Family reports of pain in dying hospitalized patients: A structured telephone survey. *Western Journal of Medicine.* 2000;172 (6): 374-7.
47. Kellehear A. *Dying of Cancer: The Final Year of Life.* Harwood Academic Publishers, Melbourne. 1990.
48. Costello J. *Dying well: nurses' experiences of 'good and bad' deaths in hospital.* Journal compilation. Blackwell Publishing Ltd 2006.

49. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Med.* 2002; 16: 297–303.
50. Costantini<sup>1</sup> M. et al. Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. *European Society for Medical Oncology.* 2006 may; 17 (5).
51. McCahill L, Ferrell B, Virani R. Improving cancer care at the end of life. *Lancet Oncol.* 2001; 2: 103–8.
52. Emanuel LL, von Gunten CF, Ferris FD. Module 3 Whole Patient Assessment the Education for Physicians on End-of-life Care (EPEC) curriculum; 1999.
53. Emanuel LL, von Gunten CF, Ferris FD. Plenary 3 Elements and Models of End of- life Care. *The Education for Physicians on End-of-life Care (EPEC) curriculum;* 1999.
54. Bhikkhuni TT, Bhikkhuni MS, Chen CY, *et al.* Spiritual care for terminal patients with head and neck cancer [in Chinese]. *Taiwan J Hospice Palliat Care.* 2002;7:269–82.
55. Chen CY, Chiu TY, Bhikkhuni TT, *et al.* Influencing factors of death fear in terminal cancer patients. *Taiwan J Hospipalliat Care* 2003;8(2):134–142.