Health Promotion in Palliative Care

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1.0 INTRODUCTION

In this book, we discuss experiences of death and dying that may present serious consequences both for the dying and their family members, and for the family members' grief work and health after the death of their loved ones. Factors that emphasise a health promotion perspective of palliative care patients, their families and healthcare workers will be presented and discussed. All approaches to patients and their families must be based on the individual and adjusted to the context and framework. The possibility of following up with the bereaved after a death will be emphasised as an important health promotion intervention. The healthcare workers in palliative care are subject to different stressors, and the priorities are not the same as in other settings. The goal of fulfilling the patient's wishes and needs is essential.

We will look at various aspects that influence healthcare personnel in these settings, and if a health promotive approach may contribute to improving the situation for healthcare workers, patients and their families. We limited this book to dealing with dying adults and the elderly in hospitals, palliative care, hospices, nursing homes and at home. The differences between the health professionals' experiences when children and adults die are too large to be treated as one subject. In addition, there are many questions regarding the organisation of healthcare services and the conditions for healthcare workers related to financing healthcare, public or private healthcare facilities, etc.; these are important, but not a subject of debate in this book.

Much of the research in palliative care is related to patients dying of cancer. This book will provide a broader perspective on palliative care and look at the factors that can contribute to a health promotion approach, regardless of the cause of death. With our focus on healthcare personnel and their experiences, it is natural that the cause of death is not addressed specifically, although different diseases and conditions may require distinct approaches.

Healthcare personnel and healthcare organisations are facing changes due to restructurings and innovations. Little is known about how these changes will influence healthcare personnel and their work situation. This book will contribute to shedding some light on these issues.

2.0 HEALTH PROMOTION

The World Health Organisation’s (WHO) definition of health promotion states that “health promotion is the process that allows the individual and society to improve and maintain their health” and health is defined as “physical, mental, social and spiritual wellbeing” (WHO, 2013). The definition of health promotion includes wellness and preserving health wellness is one of several key concepts for individuals who are dying. They may also have special needs related to health and wellness.

Health promotion in clinical practice has been increasingly viewed as the way forward for healthcare services. This change is described as a paradigm shift (Benson & Latter, 1998). A paradigm is a thought pattern that characterises the people who work within a scientific discipline and may include ideas, values and beliefs that are natural prerequisites for healthcare services (Tannahill, 1984). With a health promotion philosophy as a starting point, new ideas, concepts, values and philosophies may help shape new mindsets about healthcare sciences and clinical practice. The implications of a real paradigm shift in healthcare services can be excessive. Basic values related to the health of both patients and healthcare workers, and the role of health professionals, can be challenged (Benson & Latter, 1998).

Justice is a concept that, in a health promotion approach, must be viewed with increased importance (Kahan & Goodstadt, 2001). Unequal opportunities and abilities to acquire health information and various health challenges throughout various layers of society lead to inequities in health. Research has highlighted information and education as essential to achieving more fairness in terms of health (Benson & Latter, 1998). For healthcare personnel, it is important to facilitate the attainment of information and education for all patients, according to their level of knowledge. This may mean that some patients may need to receive more detailed information than others (Martinsen, 1989). The ability to assess the patient’s condition with regard to the appropriate treatment and the patient’s knowledge level is, therefore, essential. As an example, the use of expensive experimental drugs for cancer patients is a subject that has been much discussed. In this discussion, both healthcare workers and patients have participated. Medications and treatments that are experimental can be both painful and perceived as meaningless for some patients, while signifying a new hope for other patients. Although equality is a fundamental goal, justice will not be given equally to all. Nevertheless, it is important to determine what a caring approach is to each patient (WHO, 2013).

In one model, health promotion is presented as three overlapping spheres of activity: 1) health education, 2) prevention and 3) healthcare (Tannahill, 1984). These three areas together should form a positive and health promotive approach to health attributes. The positive health properties in this model point to concepts such as positive psychology, emotional intelligence and salutogenesis (Tannahill, 2008). There is a growing interest in how patients can be helped to develop new ways to deal with their own illness and health. Promoting coping and resilience to strengthen the individual's health has been seen in this context as a health promotive approach.

Health promotion is positively oriented, including sustainable development of positive health and prevention of ill health (Tannahill, 2008). This also applies to those who work within the health service. Organisation of work, working environment and self-determination in the workplace are of significant importance to facilitate the way healthcare personnel perform their duties. Enjoyment, work and autonomy are of great importance for the quality of care being provided, which also indirectly affect patients' health (André, Sjøvold, Rannestad & Ringdal, 2013).

New research has proposed a new definition of palliative care:

> *Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.* (Radbruch et al., 2020, p. 754)

This definition offers an opening to analyse worldwide advancements in the conceptualisation and practice of palliative care and frames a specific and mutual knowledge of challenges and development in palliative care and research (Radbruch et al., 2020). For a health promotive perspective, this definition points out a new direction which also includes viewpoints from health promotion.

2.1 Health promotion in palliative care

It is a general mistake that health promotion and palliative care are opposing ways of thinking about facilitating care (Kellehear, 1999). Good palliative care has long been regarded as interdisciplinary care, directed at social, psychological and spiritual dimensions of a person, as well as at their physical needs (Saunders, 1977). Treatment for patients who are at the end of their life is palliative, and defined by the WHO (1990) as the active overall care of patients when the disease is no longer responsive to curative treatment. Both healthcare personnel and patients have traditionally taken it to mean that health promotion has no applicability to palliative care, as the conventional view of health promotion is that it concerns encouraging healthy lifestyles (Richardson, 2002).#Implementation of health promotion in palliative care represents a substantial paradigmatic shift. Both the supportive environment and the developing of personal skills are important factors to take into consideration in palliative care (Rosenberg, 2007).

One of the key purposes for health-promoting palliative care is to improve a feeling of self-control and care for palliative patients. It seeks to foster the recognition that the inevitability of death is common for everyone, not special circumstances that someone finds themselves in. In this sense, death is not the main psychological reality of care but instead a day-to-day quality of life issue for all (Kellehear, 1999). Health promotion is intended as a method of end of life care that incorporates the core concerns of palliative care but is responsive to the purpose of health promotion beliefs and practices (Rosenberg & Yates, 2010).

There are a growing number of palliative care facilities that have tried to incorporate health promotion into their routine. One crucial element in the achievement of this has been the perception of these two approaches being similar and a good fit. Health promotion as an approach is more than health education or death education in palliative care facilities (Rosenberg, 2012). Death education is a critical part of a health-promoting palliative care approach. Education about health in its widest social, psychological and spiritual ways is essential for health promotion among palliative patients. There are five important concepts when caring for palliative patients: prevention, harm reduction, community participation, health and death education, and social support (Kellehear, 2008).

In a study by Richardson (2002), the objective was to identify and describe the palliative patients' perceptions of factors and interactions with palliative care nurses that enhanced feelings of health and well-being, and to define health promotion in relation to palliative nursing in primary care. Twelve palliative care patients were interviewed in their own homes. Patients identified two types of therapeutic interactions with the nurses that were instrumental in improving the feeling of health and wellness. Furthermore, psychological well-being was enhanced by humanistic and egalitarian personal interactions with nurses and professional interactions (focused on the disease and physical problems) (Richardson, 2002). With this background, we define health promotion within palliative care as a holistic therapeutic palliative approach based on psychological, physical, social and spiritual perspectives.

3.0 DEATH AND DYING

Nursing care for the dying and their close family members has been a major focus for many years (Henderson, 1997). The hospice movement that developed in England (Saunders, 1977) focused on a “good death”, which involves strengthening both the treatment and the environment surrounding the dying individual. In spite of this philosophy, society has mostly focused on merely avoiding problems and preventing bad treatment of the dying, rather than promoting the positive ideal of the “good death” (Ringdal & André, 2014). Therefore, on the one hand, a growing concern and alienation related to death and dying can be seen, while on the other hand, a tremendous technological development to alleviate symptoms and improve care and treatment has been emerging.

Due to increased life expectancy, lower infant mortality, smaller families and increasing use of supportive and other medical interventions, nowadays, hospice staff are the only health professionals with sufficient experience and knowledge of death and dying (Emanuel & Emanuel, 1998). In many countries, death is “professionalised” in that healthcare staff are the individuals who are responsible for caring for the dying. While health science developments related to death have focused on the symptoms and pain relief, for the patients, the loss of dignity, addiction as well as the loss of control have also been of concern (André & Jacobsen, 2020; Field & Cassel, 1997; Moran, Bailey & Doody, 2021). Many have adopted the definition of a “good death” as “freedom from unnecessary distress and suffering for patients, families and caregivers” (Field & Cassel, 1997). Regardless of culture, religion or other traditions related to death, many individuals have agreed on this basic premise. Four areas have been found to be key resources to achieving a “good death” for all patients: 1) research, 2) training, 3) organisation and 4) financial constraints, as all these factors play a role in forming the standard of care for the dying (Emanuel & Emanuel, 1998). The focus on multicultural concepts of death has also been increasing. What constitutes a “good death” will depend on both society and culture. Research has stated that a “good death” is dependent on the extent of secularisation, individualism and the length of the death process (Walter, 2003). Death and dying have been traditionally linked to religion and cultural traditions.

3.1 The concept of death

So far, there has been limited research around the concept of death. Therefore, our basis is on what people have been reported to think or believe about death. The development of death amongst adults has been represented as three concepts: 1) death as a vehicle to achieve a target or reward, as in a threat of suicide; 2) death as a passage to a new life; and 3) death as a shutdown (Shrut, 1958). Death can also be seen as a deliverance from pain or as peaceful sleep (Feifel, 1955). Furthermore, death may be seen as a punishment, a separation, a reunion or something unreal (Caprio, 1950). The articles referenced here (Emanuel & Emanuel, 1998; Field & Cassel, 1997; Shrut, 1958) are rather old; one may, therefore, wonder whether attitudes and perceptions related to death have changed significantly in the last decade, or whether beliefs about death represent a form of basic understanding. A review article from 1979 (Pollak, 1979) compared several studies and showed that all of them supported the idea of a connection between one's psychological state and death anxiety. For example, one study found that people who have experienced depression experience stronger death anxiety than those who have never been depressed. They also reported that variables such as sex, age, occupation, socioeconomic status, value orientation, and level of consciousness are of importance for people experiencing anxiety about death (Pollak, 1979).

Gesser, Wong and Reker (1987) described four factors that describe respondents' attitudes to death: 1) fear of death/dying, 2) approach-oriented death acceptance, 3) escape-oriented death acceptance and 4) neutral death acceptance. They found that older participants showed less anxiety around death and more acceptance than middle-aged and young respondents. Death anxiety was negatively related to happiness and positively related to hopelessness, while the escape-oriented non-acceptance of death was positively related to hopelessness (Gesser, Wong & Reker, 1987). This is important knowledge when facilitating a "good death", both in terms of factors that may affect the degree of agony and the different perspectives with which people may relate to death.

3.2 Death anxiety

Several studies have shown that death anxiety is a challenge also amongst older dying patients (Cheng et al., 2008; Depaola, Griffin, Young & Neimeyer, 2003; Strömberg & Jaarsma, 2008; Tsai, Wu, Chiu, Hu & Chen, 2005). It can be natural to infer that death anxiety, to a great extent, is seen as a (theoretical) concept, and not as a need or problem area concerning patients to which nurses can relate.

Research as far back as 1955 (Feifel, 1955) and up to 2003 (Depaola et al., 2003) has showed that death anxiety acts as a constant factor. It is, therefore, important to be aware of and take into account the phenomenon of death anxiety that confronts the dying. In the nursing field, the subject of caring for the dying is still a major area of focus. Contributing to a peaceful death is an important goal of nursing care (Henderson, 1997). Nevertheless, the concept of death anxiety has not been of much focus, especially in nursing science. The manner through which this problem can be confronted by elderly dying patients poses a significant challenge. Two of the included articles in this study (Strömberg & Jaarsma, 2008; Tsai et al., 2005) show that many seniors will experience death anxiety to a greater or lesser extent, and that this may increase along with age (Depaola et al., 2003). Overall care in palliative care can help alleviate the anxiety of death (Tsai et al., 2005; Midtbust, Lykkeslet, & Skovdahl, 2011). All the presented articles focused on: 1) what can be done related to older patients dying, 2) comprehensive care, 3) comprehensive documentation, 4) thorough communication and 5) adequate symptom relief (Gjerberg, 2007; Kaarbø, 2008; Lillemoen, 2011; Morita et al., 2014; Paulsen, 2014; Steindal, 2010). Nevertheless, none of the studies linked the concept of death anxiety to their findings.

Healthcare personnel are frequently exposed to dying patients and death in the course of their work. This experience makes individuals conscious of their own mortality and may give rise to anxiety and unease. Nurses who exhibit strong anxiety about death may be less comfortable providing nursing care for patients at the end of their life. An association between nurses' attitudes towards death and their attitudes towards caring for dying patients has been reported (Brockopp, King & Hamilton, 1991). Younger nurses consistently reported a stronger fear of death and more negative attitudes towards end-of-life patient care than older nurses with more experience with caring for dying patients. Healthcare personnel need to be aware of their own beliefs, attitudes and relationship to death. Findings from several countries showed that a worksite death education programme could reduce death anxiety (Deffner & Bell, 2005; Hutchison & Scherman, 1992; Inci & Oz, 2009; Maysui & Braun, 2010), and offer the potential to improve nurses' caretaking skills for patients at the end of their life (Peters et al., 2013).

Another study focused on determining whether a nurse's death anxiety was related to the comfort level of the nurse during communication with patients and families regarding death (Deffner & Bell, 2005). In addition, the study explored whether nurses reported having been exposed to communication education regarding dealing with difficult subjects, such as death and death anxiety. If nurse educators and nurses are involved in staff development, the comfort level of the nurse during communication with dying patients and their families is strengthened**.** Education, training and supervision were found to be negatively affected by an increase in the nurse's own death anxiety and positively affected by exposure to communication education (Deffner & Bell, 2005). Thus, these results indicate a need for education in this area.

The next step is to identify the most effective type, objectives, and content of such education (Deffner & Bell, 2005). The studies described above clearly show that healthcare personnel also may experience agony that may affect their ability to care for dying patients. Various forms of education and training can improve these issues. To provide relief from agony, it is important to know what the phenomenon means for healthcare professionals and for individual patients, and the extent to which individual patients or healthcare personnel experience agony as a challenge.

When studying palliative care nurses who experience death daily, it was reported that they displayed a more positive attitude about death than those who infrequently encountered death. The palliative care nurses also experience less death anxiety than those who do not work with the dying on a continuous basis (Brockopp et al., 1991).

Research focusing on death in maternity units and the ways healthcare personnel cope with perinatal death has shown that such situations may be stressful and challenging. Several serious emotional implications have been reported, such as anxiety, stress, shock, guilt and self-blame. The lack of attention and acknowledgment of these reactions amongst healthcare personnel seem to be one of the greatest challenges, and may lead to the suppression of feelings with serious consequences, such as unresolved grief and low self-esteem (André, Dahlø, Eilertsen & Ringdal, 2016). Studies have shown that when emotional and psychological involvements are recognised, such as in oncological and paediatrician settings, it appears to allow healthcare personnel to find helpful ways to express their emotions (Mander, 2009; Medland, Howard-Ruben & Whitaker, 2004). The concept of emotional labour has emerged in opposition to the view that the expression of emotion is a marginal or even dysfunctional aspect of the work process (McCreight, 2005). Furthermore, nurses may have a longer tradition in focusing on the process in relationships with patients, while physicians strive for more positivistic and product-oriented practices (Steinsbekk & Launsø, 2005).

The universality of death, dying and grieving are endorsed in this book. Similar to other disciplines, including oncology and critical care, healthcare professionals from maternity units experience psychological and physical impacts on their well-being while supporting bereaved parents. Internal (prayer) and external (talking to others) expressions may be used as coping strategies to combat their psychological and physical symptoms (Shorey, André & Lopez, 2016). Culture plays a significant role in the grieving and coping processes of healthcare professionals.

3.3 Death as a multicultural and religious concept

The concept of death and dying cannot be discussed without taking religious and cultural dimensions into consideration. Historically, dying was ruled by religion, and people died in their communities with priests, relatives and others present. Now, in Western society, death is ruled by medicine and technology (Walter, 2003). Death refers to the permanent termination of life-sustaining processes in an organism, i.e., when all biological systems of a human being cease to operate. Death and its spiritual ramifications are debated in every manner all over the world. Most civilisations dispose of their decreased with rituals developed through spiritual traditions. In most cultures, family or friends arrange the ritual disposal of the body, usually either cremation or interment in a tomb. Cremation is a very old and quite common custom. For some people, the act of cremation exemplifies the belief of the Christian concept of “ashes to ashes”. In addition, death has been personified as a figure or fictional character in mythology and popular culture since the earliest days of storytelling. As the reality of death has had a substantial influence on the human psyche and the development of civilisation, the personification of death as a living, sentient entity is a concept that has existed in many societies since before the beginning of recorded history. In Western culture, death has long been shown as a skeletal figure carrying a large scythe, and sometimes wearing a midnight black gown with a hood. This image was widely illustrated during the Middle Ages. In modern-day European-based folklore, examples of death personified are the “Grim Reaper” or the “Grim Spectre of Death”. This form typically wields a scythe and is sometimes portrayed riding a white horse. Death is sometimes portrayed in fiction and occultism as Azrael, the angel of death. Furthermore, a psychopomp is a spirit, deity or other being whose task is to conduct the souls of the recently deceased into the afterlife, as in Greek, Roman and other cultures (Gire, 2002; Harrison, 2006; Holloway, 2006; Robson, Razack & Dublin, 2010).

Religion may contribute to fulfilling basic psychological needs in terms of meaningfulness, control, comfort and social enhancement (Pargament, 2001; Saroglou, 2011). Empirical studies also support a salutary effect of religion on mental health (Ellison & Levin, 1998; Koenig, King & Carson, 2012; Moreira-Almeida, Lotufo Neto & Koenig, 2006; Ringdal, 1996). Positive religious coping expressed by spiritual connection and religious forgiveness is associated with enhanced well-being and quality of life, whereas the inverse relationship is found for negative religious coping expressed by spiritual discontent and pleading (Koenig, Pargament & Nielsen, 1998; Pedersen, Pargament, Pedersen & Zachariae, 2013). Religious and spiritual domains are generally important to people in their daily lives, and not only when they face difficult life situations (Pargament, 2001). Nevertheless, studies have shown religious coping to be especially beneficial for the well-being of people facing long term illness or bereavement (Ai, Park, Huang, Rodgers & Tice, 2007; Gall, Miguez de Renart & Boonstra, 2000).

A number of studies have found that for cancer patients, religious, spiritual and quality of life concerns are paramount (Mytko & Knight, 1999). Mytko & Knight's paper reviews the literature relating religiosity and spirituality to physical and emotional health and quality of life. Variables related to religion – such as religious belief, religious affiliation, religious attendance and perceived religiousness – typically refer to an individual's participation in organised religious institutions and adherence to established guidelines for belief and behaviour. Spirituality on the other hand has been defined as including feelings of connectedness with the self, a community, nature, and the meaning of purpose of life (Bellingham, Cohen, Jones & Spaniol, 1989). Variables related to spirituality, such as spiritual well-being, spiritual maturity and existential concerns, tend to encompass a range of concepts (such as meaning, wholeness, connection, joy and peace) that do not rely on one's participation in an organised religion. Religiosity and spirituality are not mutually exclusive concepts and can exists separately.

Psychological research has found significant relationships between religiosity and spirituality and physical well-being, psychosocial well-being and quality of life (Mytko & Knight, 1999). Cancer patients describe their religious and spiritual beliefs as providing a profound method of coping with the disease and improving their quality of life.

In a study of religiosity, quality of life, and survival in 253 hospitalised cancer patients who filled out a questionnaire including indicators of quality of life and a two-item religiosity scale, it was found that a majority of the cancer patients reported their religious belief had been of support to them after they got cancer (Ringdal, 1996). The poor prognosis patients reported significantly more often than others that their religious beliefs had been of support to them. This study also showed that those who reported high scores on the religiosity scale were more generally satisfied with life and reported lower feelings of hopelessness than those with low scores on the religiosity scale (Ringdal, 1995).

The initial diagnosis of cancer brings with it the possibility of death, and this possibility may continue to be present throughout therapy, remission and even following the pronouncement of it being cured (Martin, 1982). Religious people may find a meaning in life-threatening situations, and even in situations with likely fatal outcomes. Individuals with deep religious faith may not be as threatened by an end of life scenario as someone who does not believe in God, because the fact that one might die in the near future does not, according to religious beliefs, mean the end of existence (Hinton, 1991).

Studies examining the relationship between religiosity on the one hand, and quality of life and survival among cancer patients on the other hand have reported different findings. Some studies have reported negative findings (Cassileth, Walsh & Lusk, 1988; Ringdal, 1995, 1996) while others imply that psychosocial factors may influence the length of survival of cancer patients (Eysenck, 1988; Spiegel, Kraemer, Bloom & Gottheil, 1989). The causal relationship of psychosocial factors to survival is also problematic. If any causal relationship exists, the causal direction may well be in the opposite direction, with the gravity of disease influencing the psychosocial factors (Ringdal, 1996). Although psychosocial characteristics such as hope and hopelessness were not found to contribute to survival in the sample of cancer patients (Ringdal, 1995, 1996), it is still possible that religiosity and psychosocial characteristics may improve the ability to cope with serious illnesses, such as cancer, and that these factors are important for the patient's well-being and quality of life as long as they live.

Terminally ill cancer patients receiving high levels of spiritual support from religious communities are less likely to receive hospice care and are more likely to receive aggressive medical intervention at the end of life and die in an intensive care unit (ICU) setting. End of life discussions by medical teams to patients highly supported by religious communities are associated with reduced medical care intensity near death (Balboni et al., 2013; Balboni et al., 2022).

In a study comparing religious and nonreligious coping strategies, religious coping strategies were found to be stronger predictors of beneficial health outcomes, compared to nonreligious coping strategies (Koenig et al., 1998). Another study has shown that religious coping is related to well-being, and that pessimism was more important than optimism in mediating the relationship between religious coping and existential well-being (Kvande, Klöckner, Moksnes & Espnes, 2015). This study also identified that the mechanisms involving either significant direct effects or significant indirect effects through optimism and pessimism did not change for the whole-sample model, compared to the multiple-group models. This suggests that the nature of the relationships between religious coping, optimism, pessimism and well-being is quite stable and may be generalised across different populations (Kvande et al., 2015).

Though death has historically been clinically defined as the absence of a heartbeat and respiration for centuries, advances in medical technology have led to a modification in this definition to whole brain death (Gire, 2002). Therefore, although all humans will experience death, conceptions about death and how we respond to issues of death and dying vary widely across cultures. It is important for healthcare personnel to understand the complexities that surround the issues of death, and that such an understanding may better prepare healthcare personnel to respect and interact with individuals from other cultures in meaningful ways (Gire, 2002).

3.4 How to achieve a “good death”

Throughout the dying process, many communities within ethnic populations are concerned with the meaning of a “good death”. The good death in different cultural settings means dying while encircled by families, particularly your children, spouses and other close relatives (Haugan & Eriksson, 2021). In a study preformed in Uganda the patients had a negative opinion about extended times of hospitalisation (Kikule, 2003). When staying in hospital for a long period the informants described being negatively affected socially. People in these communities emphasised the importance of being together with the extended family, and not away at a hospice or hospital. The cultural conception of death and the concept of a “good death” was different in this study compared with other studies

(André, 2014; Wachterman et al., 2016). This has implications on the way health promotion and palliative care should be delivered. Searching for meaning in life is part of the salutogenic approach and this makes it important for any health service to focus on the subjective experience of the people targeted (Haugan & Eriksson, 2021).

Several concrete measures have been described that are relevant to facilitating a "good death". A number of articles have identified concrete measures, such as increased expertise, improved and systematic documentation, the introduction of specific models for good care, and better communication and symptom relief (Gjerberg, 2007; Kaarbø, 2008; Lillemoen, 2011; Morita et al., 2014; Paulsen, 2014; Steindal, 2010). All these measures would individually contribute to a "good death". Several of the articles that described the introduction of different care models placed several measures together into a more holistic approach to care (Kaarbø, 2008; Lillemoen, 2011; Paulsen, 2014). Another study highlighted that older dying patients need the same level of palliative care as other age and patient groups (Morita et al., 2014). This is important research because, until now, knowledge development in the field of palliative care has, to a considerable extent, been based on age groups other than the elderly. Although it is also known that death anxiety increases with increased age (Depaola et al., 2003; Tsai et al., 2005), it is now important to focus specifically on this group. Therefore, the concept of a "good death" may be multidimensional by including concrete measures and facilitative methods, in addition to a more theoretical conceptual clarification in relation to what other theoretical concepts can be included to describe a "good death".

In order to offer relief from death anxiety, it is of significant importance to know what the phenomenon means for a patient group, as well as the degree to which the individual patient is experiencing death anxiety as a challenge. When looking at knowledge in this field, a description of death anxiety as experienced by older dying patients is missing. This may indicate that death anxiety may be experienced as difficult for nurses and other health professionals. The overall care of dying elderly patients must be based in a description of how death anxiety is felt by this group, and what can be done to relieve it. In terms of the focus on dignity, it may be assumed that the terms that specify the contents of dignity are of critical importance, even in the context of death anxiety. A holistic approach and care for dying patients include elements such as dignity, thorough documentation, communication, symptom relief and expertise. These items appear to be crucial in facilitating and contributing to a “good death” amongst older dying people (André, 2014).

It is completely natural that palliative care in hospitals, hospices, nursing homes and home care focuses on death. However, it is challenging for healthcare personnel to speak naturally about death and dying (André et al., 2016; Care, 1999; Field & Cassel, 1997; Wachterman et al., 2016).

4.0 PALLIATIVE CARE

All work with dying patients should be based on respect for the patients and close attention to their distress. Furthermore, this work should focus on care for the patients, not solely treating their disease (Saunders, 1965). When palliative medicine was established as a specialty, the goal was to attain as high a quality of life (QoL) as possible both for patients and their families (Stromgren et al., 2001; van Kleffens, Van Baarsen, Hoekman, & Van Leeuwen, 2004).

There are several existing definitions of palliative care, which also include a high quality of life for the patients (Stromgren et al., 2001; van Kleffens et al., 2004). However, the palliative care population is not a well-defined group of patients. A suggestion for a common classification is proposed in Table 1.

Table 1. Patient population in palliative care.

A suggestion for classification

	Expected survival	Karnofsky
Primary palliation	>6 months	70-90
Early palliation	2-3 months	50-60
Late palliation	B 1 month	20-40
Imminently dying	B 1-2 weeks	B 10

(Kaasa & Loge, 2003)

As shown in the table, the palliative care population, as measured by the Karnofsky scale (Karnofsky, Abelmann, Craver & Burchenal, 1948), is heterogeneous with a broad range of needs and desires. The patients' expectations towards the healthcare personnel in meeting needs and desires are part of the special conditions related to palliative care.

4.1 Patient symptoms in palliative care

Patient symptoms in palliative care can be both subjectively and objectively perceived (Kaasa & Loge, 2003). Patients in palliative care display high levels of various subjective symptoms (Coyle, Adelhardt, Foley & Portenoy, 1990). The situation can easily be experienced as overwhelming, and a systemisation of the symptoms might reduce some of the burden on the patients and make the situation more easily understood for the healthcare worker. The most common symptoms amongst palliative patients are displayed in Table 2.

Table 2. Frequency of Symptoms in Advanced Illness (Gutgsell, in Walsh, 2008, p. 815).

Symptom	**Cancer %**	**CAD %**	**Dementia %**	**AIDS %**
Pain	60	60	65	60
Dyspnoea	40	50	-	10
Nausea, vomiting	40	45	-	20
Insomnia	50	-	-	-
Confusion	30	40	60	30
Fatigue, weakness	50	-	80	60
Depression	45	60	60	-
Anorexia	60	40	60	40
Constipation	50	30	-	20
Incontinence	40	-	70	-
Anxiety	40	-	-	-

CAD (coronary artery disease), AIDS (acquired immunodeficiency syndrome) (Walsh, 2008).

As shown in Table 2, fatigue, pain, anorexia, confusion and depression are frequently mentioned symptoms. Furthermore, according to the results presented in this table, almost half of the cancer patients and 60% of the coronary artery disease and dementia patients reported being depressed. Since the terminally ill patients were not asked about their experiences of grief, symptoms of depression may have been expressed as grief reactions, such as sadness and crying due to their deteriorating health condition. However, anxiety was only reported amongst 40% of cancer patients.

In reaching the goal of optimal QoL for the patients receiving palliative care, there is a need for improved assessment and control of symptoms and distress (Kaasa & Loge, 2003). Traditionally, most assessment tools are paper based. The patient completes the questionnaire or forms, or a healthcare worker asks the patient and marks the response. Subsequently, the paper and pen methodology has been brought forward into computerised questionnaires (Bjorner, Kosinski, & Ware 2005; Cella et al., 2005). Palliative care units consist of patients that are frequently frail, with constantly decreasing health and multiple symptoms. Palliative care consists of active, holistic care and treatment for patients with incurable diseases and a short expected time left to live (Faber-Langendoen & Lanken, 2000). Relieving physical pain and other bothersome symptoms is of central importance, together with efforts against psychological, social, spiritual, and existential problems. The aim of palliative care is to improve the quality of life and well-being for the patients and their close family members.

The situation today is that death has moved out of the home and into the institution. It seems that the more developed a country's healthcare system is, the fewer patients die at home.

4.2 Palliative care and aspects of treatment

Palliative or soothing treatment is active, comprehensive treatment and care for patients with incurable diseases and a short life expectancy (WHO, 2011, 2013). Patients with incurable diseases need access to competent treatment and care. Basic palliative care is to be carried out by all clinical hospital departments and in the municipal health services. In addition, the palliative devices used by hospitals and nursing homes, as well as the ambulant multidisciplinary team, assist with building the expertise, advice and treatment in palliative care, both in specialist and primary care services. The regional palliative centres at hospitals play a key role as power centres for research, trade development and competence, as well as taking care of patients with the most complex needs. The family doctor has an important coordinating role, and the ambulant multidisciplinary teams are an important link between the different levels of care (Haugen, Jordhoy, Engstrand, Hessling & Garasen, 2006).

More than three-quarters of those who die each year receive municipal health and human services. The proportion of the service recipients increases with age, and many amongst the oldest receive virtually all services from municipal health and human service providers. Amongst seriously ill cancer patients and their families, factors such as attention, support, continuity of care and treatment, and thorough communication with nurses and doctors have been characterised as critical for improving care and treatment and, thus, increasing the satisfaction with the treatment (Gotay, 1984; Rinck et al., 1997; Ringdal, Jordhøy & Kaasa, 2002; Ringdal, Ringdal, Jordhøy & Kaasa, 2007). During the disease process, the patient and next of kin experience how the municipal services work in practice. Being viewed as stable, several patients remain at home until death. More than half of the patients with severe cancer want to die at home (Doyle, Hanks & MacDonald, 1999). Nearly 90% of all patients with serious illnesses can receive adequate relief by using simple, low technology with medication in the form of tablets, suppositories, medications and/or patches (von Hanno & Spiechowicz, 1998). The nurses' workspace within the palliative care unit is linked to both specialist and municipal healthcare services.

In the nursing field, the goal of "a dignified death" has a long tradition that was first described by Virginia Henderson in the 1960s. She wrote that "the nurse's outstanding feature is to help the person to perform the actions that contribute to ... a peaceful death" (Henderson, 1997). This goal for nursing care is still applicable and shows the direction for the nursing field in relation to the objectives for care and treatment of dying people.

All dying patients do not have the same needs and desires at any given time, but there are some basic assumptions that characterise "good" care for the dying. Patients have expressed the need for the relief of emotional and physical ailments, respect for individual wants and needs and to receive thorough information (Ringdal et al., 2002). Such a process is perceived as therapeutic in itself. Patients also focus on the personal qualities of the nurses at this stage, on what they are doing and how they are acting (Richardson, 2002; Ringdal et al., 2002).

There is a need to create a new cultural expression of the experiences and the community around the death bed and develop employees' ethical judgment in treating people in this vulnerable life stage. To create good care, there is a need to make use of the experience, knowledge and resources of the users, their relatives, and the volunteers, as well as challenge traditional beliefs about what is good care and end-of-life care (Ringdal & André, 2014).

When life is nearing its end, many people prioritise spiritual care. The concept of spiritual care has a long tradition in the nursing profession, and is associated with the goal of a "peaceful death" (Henderson, Deane & Ward, 1995). Spiritual care is also related to the concept of a "good death", which, in turn, contains multiple factors, such as a "dignified death". In an Indian study, the nurses stressed the existential aspects related to the concept of "a dignified death". Nursing actions were aimed at helping the patient to find a spiritual balance in the face of death (Doorenbos, Wilson, Coenen & Borse, 2006). In several cultures, spiritual care is of importance to dying patients. The information that a nurse emphasises will resonate the most with patients, regardless of cultural background and religion. By planning and attending to spiritual needs, one can promote the quality of life of dying patients, regardless of age. According to a description from the North American Nursing Diagnosis Association (NANDA), spiritual unrest (spiritual distress) is described as a disruption in one's belief system (Wallace et al., 2008), while the International Classification for Nursing Practice (ICNP) (Clark, 1998) uses the term "worthy of death" in their nursing diagnosis system. Both these systems emphasise spiritual care in their own way and refer to spiritual care as an essential aspect of nursing as a discipline and in clinical practice, with health promotion connected to a starting point (André & Ringdal, 2015).

The hospice movement has been a driving force to promote the needs of the dying in their last phase of life. In order for profoundly sick and dying individuals to receive appropriate care, holistic thinking and physical, psychological, social and spiritual/existential needs must be emphasised

(Saunders, 1965). There are some common phenomena associated with a “good death”, as well as challenges and best practices related to treating dying patients with a health promotion approach.

4.3 Professionals’ exposure to suffering and death

Healthcare workers are often exposed to the dying process in their work. Work-related exposure to patient death has been linked with several (often contrasting) personal and professional aspects including increased fear of death and death abstention (Linley & Joseph, 2005), a decrease in compassion and death anxiety (McFarland, Malone & Roth, 2017; Quinn-Lee, Olson-McBride & Unterberger, 2014), but also an acceptance attitude toward death (Linley & Joseph, 2005). Personal exposure to death and dying is assumed to cause consciousness of personal death and increase anxiety and discomfort (Depaola et al., 2003). In difference to the general behaviour of most persons who avoid speaking and thinking about death and dying, the palliative care workforce is subjected frequently to the dying process. Research has shown that exposure to death and dying is significantly correlated with professional quality of life among the palliative workforce, with a high exposure to death and dying relating to poor professional quality of life (Samson & Shvartzman, 2018).

Compassion fatigue is described as a state of stress which can increase among healthcare workers in reply to endorsing the distress of patients. It appears with stress and tension build ups due to the continuous need to alleviate patients’ suffering and may lead to reduced personal and professional well-being (Figley, 2002). The occurrence of compassion fatigue is reported among physicians (Panagioti et al., 2018), oncologists (Granek, Nakash, Cohen, Ben-David & Ariad, 2017), nurses (Potter et al., 2010) and social workers (Simon, Pryce, Roff & Klemmack, 2005). The consequences of compassion fatigue for the private and professional well-being of healthcare workers are well documented (Laor-Maayany et al., 2020; Panagioti et al., 2018). The phenomenon of avoiding or retreating from patients as they move closer to death was also reported with respect to compassion fatigue (Granek et al., 2017). Exposure to suffering and death does not inevitably lead to compassion fatigue (Figley, 2002). It appears, that the individual healthcare worker’s internal expressive processes may impact compassion fatigue. Experiencing grief and a feeling of unsuccessful handling regarding their professional work may also lead to compassion fatigue for healthcare workers (Laor-Maayany et al., 2020).

Nurses employed in palliative units are consistently exposed to death, dying and suffering as a core element of their work (Lavoie, Blondeau & Martineau, 2013; Powell, Froggatt & Giga, 2020). The exposure to death was characterised as intense and challenging by nurses, and the two most substantial factors they regarded as traumatic were: 1) when patients endured uncontrolled symptoms (Ingebretsen & Sagbakken, 2016) and 2) patients having underlying mental health challenges (Powell et al., 2020). Because of the work strictly with death and dying some nurses accept death as a normal component in a lifespan (Ingebretsen & Sagbakken, 2016). Some nurses explained in the study that closeness to death provided them with a better perspective of how they would like to live their lives and what was essential (Powell et al., 2020). Nevertheless, some nurses described strategies that are practical or interpersonal, which allow them to express or suppress their emotions (Ingebretsen & Sagbakken, 2016; Powell et al., 2020). One such strategy is where nurses use the 'white coat' or helpful touch as protective structures behind which they can disappear from the reality of the situation (Ingebretsen & Sagbakken, 2016). An additional strategy that nurses employ is the giving and receiving of support; this may be by using clinical supervision, open discussion or emotional debriefing, and sustaining a healthy work/life balance (Balasubramanian & Read, 2012; Boa, Duncan, Haraldsdottir & Wyke, 2018; Ingebretsen & Sagbakken, 2016; Lavoie et al., 2013; Moran et al., 2021; Powell et al., 2020).