Palliative care

The role of Counsellors
Abstract

The following article is a study about counsellors working with terminally ill patients receiving Palliative care. In an effort to understand their role in the Palliative team and how they participate in the care of dying individuals, four counsellors working in four different Palliative hospices in Stockholm were interviewed by using structured interviews. The key questions concern the methods and interventions counsellors use, the risk factors that the job entails, the support they receive and finally their reflections about life and death. The literature on the topic was accessed via Ersta Sköndal Högskola College library and Internet database. The results of the study reveal that Palliative Care Approach takes into consideration all aspects of an individual (physical, psychological, social and spiritual). Counsellors are part of a multidisciplinary team and their role is to focus on the social and psychological aspects. They undertake comprehensive assessments of the patient’s context and their coping strategies through the use of psychosocial theories such as Sense of Coherence and Logo therapy. Via their skilled use of core counselling skills they establish close relationships with patients and families. At the same time they are always mindful of keeping the right distance. Counsellors are the receivers of a lot of emotional pain and suffering of patients and families and as such this transference can lead to emotional exhaustion. Access to good support is an essential prerequisite for avoiding burnout. Close encounters with death leads to reflections of life and death. Counsellors need to be well developed and experienced in order to provide good quality palliative care.

Keywords: Palliative care, Counsellors, Counselling in palliative care, psychosocial support, existential anxiety, death, bereavement,
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Introduction

Background

Death is a fact of life that will happen to all of us. Sooner or later we will die. But how and where we die is a whole different story. Most of us never think of our death but for some people who happen to have incurable diseases, the fact of their impending death becomes difficult to ignore. Accidents can transform a healthy person’s life in an instant and the person has to be on life supporting systems, sometimes for the rest of their lives. People who suffer from chronic disease or disability are confronted by problems that are as much psychological as physical, and involve all members of their family and the wider social network (Parkes, Relf & Couldrick (1996, preface). Such situations can bring about changes in a patient’s life that requires them to deal with psychological, existential and social problems that comes to the forefront beside the medical needs (Lundin, 2009). The care that patients receive towards the end of their life when there is no hope left for cure is known as Palliative care.

Palliative encompasses a wide range of specialist services, but began in the UK in the late 1960s with the development of the modern hospice movement by Dame Cicely Saunders when she founded St. Christopher’s Hospice in Sydenham, London. The number of hospices and specialist palliative services has increased rapidly since that time. An Interdisciplinary Team (IDT) usually delivers services to this group of patients. The team includes several individuals with expertise in various areas and who work in a holistic fashion to serve the interest of the patient and the family (Fine & Kestenbaum, 2008, p.7). “In palliative care units, the professional team is constituted before the patient is encountered, and guidelines state that doctors, nurses, social workers, physiotherapists, chaplains, and so on are all essential members. Over the course of time, the group becomes tightly bonded as well as clearly defined” (Randall & Downie, 1999, p. 80). The following study focuses on one of these experts on the Interdisciplinary Palliative team, i.e. the Social worker/Counsellor.

Problem statement

Irene J. Higginson (2012), states that, “From a public health perspective it is important to understand and map the circumstances in which people die, including symptoms, physical, psychological, social and spiritual concerns, the quality of life and dying and the experiences of caregivers. Such information is critical for planning interventions and services to improve palliative and end - of- life care” (Cohen & Deliens, (eds), 2012, p. 35). Social work is multifaceted and can be applied in any kind of setting. It could be social workers working in
the slums caring for people dying of Aids or it could be social workers caring for dying patients in high-tech hospitals with all the latest medical equipment and service available round the clock. Whatever the context, the study of the circumstances of dying and the symptoms that it entails are crucial for the development of healthcare and to provide services that are effective. Since we are all mortal, we will all benefit from scientific studies that are undertaken to find out the concerns of death and the process of dying. When we know better, we can always do better!

**Purpose**

The purpose of this study is to gain an understanding of the counsellor’s role and to how they contribute towards giving patients good quality palliative care. It also aims to highlight their own reflections about the meaning and purpose of life and death and lessons learnt due to their constant exposure to death.

**Research Questions**

The study aims to answer the following questions:

- What methods and interventions do counsellors use to support patients and their families through the crisis that they encounter in the face of impending death?
- What challenges and risk factors do the counsellors face in their work and what support do they receive?
- What are their views on life, death and dying and what lessons have they learnt?

**Literature Review (Earlier studies)**

Studies in the field of Palliative care are truly staggering. However, the bulk of studies highlight the doctors and nurses role in helping patients whose lives have been thrown into chaos. There are few articles that specify the counsellor’s role in Palliative care. I found one very interesting study in the Journal of Palliative Medicine, titled, *A novel Approach to Hospital Palliative Care: An Expanded Role for Counselors* (2011) written by Carol W. Babcock, M.F.T. and Larry E. Robinson. The study was about a hospital in Central Georgia, USA, which had adopted a model of having the Counsellor at the heart of the team. They had built up a strong counselling base in palliative service with masters prepared counsellors rather than the major reliance on advance practice nurses or palliative physicians. The model used was *The Transitions and Palliative Care Therapy Model*, which had become the standard of practice in the hospital. It continues to be a successful means of managing the most complex cases in the hospital. The study showed that having the counsellor at the heart
of the Palliative team diminished “potential for conflict, communication deficits, time constraints and knowledge gaps”.

Lisa Sand is a Social Worker in Sweden. She has extensive experience of working with people dying from Aids in USA. When she moved to Sweden she continued her work with terminally ill patients in the Palliative care. Her PhD titled *Existential challenges and coping in palliative cancer care: Experiences of patients and family members on the existential crisis that patients and family members faced by incurable cancer and how the crisis is managed* (2008), illuminate the profound and inevitable impact of death-threat in a palliative context. Primarily it exerts influence on the patient but it affects family members as well. Recently, she also wrote a book together with Peter Strand titled, *När döden utmanar livet- Om existential kris och coping i palliative vård* (2013).

**Definitions and Theory**

**Palliative care Approach**

The Palliative care approach was an effort by pioneers such as Cicely Saunders, Elisabeth Kübler-Ross, Jeanne Quint Benoliel, Florence Wald, Balfour Mount, Ida Martionson and Colin Murray Parkes (Papadatou 2009). The principles of this holistic model were implemented and further developed over the years by inspirational health professionals who cared for people at the end of life. “This approach was based on a new set of values that humanized the care of dying individuals, who were invited to actively participate in their care, and of families who were supported before and after the patient’s death. The message of these pioneers was loud and clear: individuals have the right to have a say in their experiences and the care they receive in the face of death (Papadatou, 2009, p. 7).

The World Health Organisation (WHO) defines Palliative Care as follows: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

“Modern palliative care services, whether delivered through hospice units or community-based teams, use the capabilities of many different professionals. These might include nurses, doctors, counsellors and complementary therapists, psychologists, occupational and physiotherapists, clergy, managers, volunteers administration staff and social workers” (Davy & Ellis, 2000, p. 8). Peter Strang, says that good quality palliative care can relieve suffering
and create quality in the remaining days of the patients life by explaining, informing, and making the process comprehensible even if one cannot correct all the problems. Palliative care can help the patients to find meaning even in their last days (Beck-Friss & Strang, (eds) 1999, p. 87).

Palliative care in Sweden is called *Vård i livets slutskede*. According to The Stockholm Health Care Guide (*Vårdguiden*), palliative care should be based on a holistic approach of the patient and family. It should provide care for the patient’s physical, social, and existential problems. It should also provide support to the family. In Sweden, Palliative care came about through a number of health and law reforms based on the *offentliga utredningar*. An important one, *Vårdens svåra val* (SOU:1995) gives clear guidelines on the subject. All over the world, especially in the western world, there has been an increasing focus provide quality patient-centred care through emphasis on guiding patients and families through the illness continuum (Babcock, M.F.T. & Robinson, 2011).

**Counsellor**

Counsellors are “highly skilled professionals who have completed a lengthy training course, including the theory of psychological and social functioning, and a period of supervised practice. They may be skilled in group work as well as working one to one. In Palliative care they may work directly with patients or families focusing on those people who have complex relationship problems or psychological needs” (Parkes et al., 1996, p. 55).

“The social worker or chaplain can listen in a unique way, for they are not involved with physical therapy and are experienced as the recipients of unacceptable feelings and projected angers. Negative feelings in this situation may be frighteningly strong and these are better expressed than buried only to appear in a different guise, often affecting both family and staff” (Saunders, Baines & Dunlop, 1998, p. 49).

“Communication in psychosocial care and spiritual care is directed towards the expression of the patient's thoughts and emotions, and patients should feel appropriately assured that the carers have a professional concern for their welfare, and so are genuinely listening and trying to understand” (Randall & Downie, 1995, p. 225). Linda Emanuel, stresses the importance of being very careful in the exchange of communication. She writes, “Because the information in terminal illness is often of grave significance, communication at the end of life needs to be conducted with sensitivity to and a deep understanding of the psychological processes entailed in taking in, adapting to, and making use of difficult, usually highly undesirable, information”(Cohen & Deliens, (eds), 2012 p. 99). Counsellors can offer support at a deep
level, providing time with the patient in order to minimise mental pain. “Isolation adds to suffering, particularly to the feeling of failure and the sense of guilt suffered by many dying patients. Sensitive honesty engenders trust and can be supportive to both patient and family. The question of truth, of how to break bad news, is frequently discussed. However, no report can take the place of attentive listening and response to the questions an individual is asking at a particular time” (Saunders, Baines & Dunlop, 1998, p. 46).

**Counselling**

According to Parkes et al., (1996) they define the word counselling, to mean that the helper is listening to and communicating with the other person in a purposeful way - in a way that is enabling, whether it involves helping other people make decisions about their care or whether it is focused on exploring how they are reacting to their predicament.

**Counselling skills**

In a study titled *Support and caring: exploring the concepts* (1992), O’Berle and Davies explored the key dimensions of counselling skills. The authors used a grounded-theory approach based on the actual experiences of an expert nurse in supportive care. In this article, the authors relate their concepts of support to existing nursing theory and to previous clinical research in both support and caring. Justification for the dimensions of the model was found in the nursing literature. However, distinguishing support and caring as concepts was difficult.

“Research into supportive roles in palliative care has identified six key dimensions in relation to clients which may help guide our use of core counselling skills. These supportive roles are: Valuing, connecting, empowering, doing for, finding meaning, preserving one’s own integrity” (Davy & Ellis, 2000, p. 16). These six dimensions that were identified by O’Berle and Davies overlap significantly with the common factors which research suggest underpin effective counselling of any kind.

**The Counselling relationship**

“All counselling skills are offered through the intentional use of a supportive relationship between the self of the helper and the self of the client, involving two whole people whatever their roles and whatever the disease process involved” (Davy & Ellis, 2000, p.16). Since the relationships involve interaction between people it is important to know the right distance as a professional towards the patient or family. “In every human interaction there is a ‘right distance’. Move in too close and the other person will feel intruded upon; back away too far and they will feel alienated or rejected. ‘The right distance’ varies with the nature of the
relationship and the circumstances, and it is constantly changing so that a distance that feels right at one time may be uncomfortable at another” (Parkes et al., 1996, p. 28).

**Burnout**
“Burnout is a very popular concept in healthcare that describes the cumulative effects of caring for people in need” (Papadatou, 2009, p. 122). Papadatou quotes Maslach (1982) who describes burnout as “a syndrome that involves an increased sense of emotional exhaustion, the loss of compassion that results in a depersonalised approach to people and a reduced sense of personal accomplishments that lead to impaired job performance” (a.a.). The work of a counsellor is tough and can be emotionally distressing. “Many patients have a great deal of adversity in their lives and so may transfer that adversity into the team (a.a.).

**Support**
“Support must be given to help staff to deal with the griefs that are a normal part of their work. It needs to be multidimensional and no one strategy will suit all members. Diversity ensures that people will feel safe enough to use and develop their skills and recognize when they need to seek additional help” (Parkes et al., 1996, p. 34).

**Death and dying**
According to Linda Emmanuel, “People with serious illness are often in unknown territory. Not only have they not experienced these current illness circumstances before, nor faced their imminent mortality but, in present day western culture, many people have not witnessed another person’s death” (Cohen & Deliens (eds), 2012, p. 104). Clark and Seymour (1999) refer to Bauman (1992), who says that contemporary society has organized itself on the basis of trying to avoid death. The media image of death is distorted from reality. “Most patients lose consciousness well before the moment of death. For them the last experience of life is a quiet slipping away, which is a far cry from the dramatic image of death conveyed by the mass media” (Parkes et al., 1996, p. 92).

**The social workers essence**
All, of us strive to make sense of the services we provide. We attach various appraisal meanings to them by seeking to answer questions such as ”Were my services effective, meaningful, and worthwhile? ” How do I know I did a good job?” (Papadatou, 2009, p.153). In his book, *Förstå Socialt Arbete* (2010, p. 386), Bengt Börjesson writes that the first step towards professional introspection means that one asks the question “ Is there any meaning
to do what I do? Do I attain positive results with the client I work with right now? Is my job meaningful?"

**Logotherapy**

Viktor E. Frankl was an Austrian neurologist and psychiatrist as well as a Holocaust survivor. His experiences as a concentration camp inmate led him to study the reasons why some people were better enabled to cope even in the most difficult of environments. His work led him to establish *logotherapy*, which is a form of existential analysis. In his best-selling book *Man's Search for Meaning* (1995), he chronicles the reasons that help people discover the importance of finding meaning in all forms of existence, even the most wretched ones, and thus a reason to continue living. Frankl became one of the key figures in existential therapy and a prominent source of inspiration for humanistic psychologists. The question of the meaning of life arises naturally during adolescence but can also become very prominent when fate intervenes in one’s life through some unexpected trauma such as an accident, death of loved ones, or being faced with a debilitating disease etc. Our relationships take on a new meaning and through them we find the strength to face the situation (Frankl 1990). A human being, Frankl says, is primarily a historical being; his life has a historical context and cannot be isolated from this coordination system. This system is a system of relationships and it determines the meaning an individual attaches to his or her life, even though it may be implicit or unpredictable (Frankl, 1990, p. 63). The first step towards helping a patient is to understand the context of his or her life. All information is vital, demographics (age, occupation, education, religion ethnic background, geographical location of the family etc.), functional (medical, emotional, behavioural) and critical family events (Rolland, 1994, p.78).

**Sense of Coherence**

This term was coined by Aaron Antonovsky and is also known as *Sense of coherence*. In his book, *Unraveling the mysteries of health* (1991), explains what it is that made some individuals more resilient to the stressors they encountered in daily life compared to others. Antonovsky identified these characteristics, which he claimed helped a person to be better equipped to cope with life and its challenges and remain healthy. He said that these traits provided a person with a “sense of coherence”. He developed a scale (Orientation to Life Questionnaire) to measure these various characteristics in people. The main features of the theory are:

*Comprehensible:* to which extent the events in life are seen as ordered, correlated, structured and coherent rather than chaotic, unordered, random, unexpected and inexplicable. A person
with a high sense of KASAM feels that he or she can plan ahead and as such future events can be predictable. Even when unexpected events change their plans they find a way of finding coherence.

**Manageable:** The degree to which one feels that one has the resources at one's disposal and that with its help one can meet the requirements of the stimuli, which one is constantly bombarded with. “Stands at one's disposal” can refer to resources that are under one's control or monitored by loved ones such as the husband, or wife, friends, colleagues, God, history, party leader or doctor, people you know you can count on and whom you can trust. If you have a high sense that things are manageable then you will not feel like a victim of circumstances or think that life treats you unfairly. Unfortunately, stuff happens in life, but when it occurs, one is able to get along and not mourn forever over the unfairness of it all.

**Meaningful:** People, who have a very strong sense of coherence, always have some goals in their lives that are important to them. This gives them a sense of purpose in life. Sometimes these goals are challenging but they are certainly worth investing the time and effort.

**Coping strategies.**

Davy and Ellis (2000), explain the coping strategies identified by Stroebe and Stroebe (1995). These strategies include the following:

- **Confrontive coping:** letting feelings “out”, fighting for what you want- fighting spirit
- **Distancing:** trying not to think of the situation.
- **Self-controlling:** trying to keep your feelings to yourself and trying to act normal.
- **Seeking social support:** asking others for advice, sharing feelings.
- **Accepting responsibility:** self-criticism, promising to do things differently, ‘next time’.
- **Escape-avoidance:** hoping for miracles, fantasizing, comfort eating, smoking.
- **Planful problem solving:** making plans, changing lifestyle.
- **Positive reappraisal:** considering ‘what really matters’, finding faith, growing as a person.

“These coping strategies are potentially some of the major psychological resources that people have to draw on in times of stress. However, they may or may not be successful in helping someone to mange or live with a stressful situation or an illness” (Davy & Ellis 2000, p. 38). “If a condition involves crisis, the family’s history of coping with crisis in general, especially unanticipated ones should be explored” (Rolland, 1994, p.82). “In situations of illness and disability, we must be cautious about judging the relative usefulness of positive illusions and minimization of, versus direct confrontation with and acceptance of, painful realities. Often both are needed and the skilled clinician must thread the needle supporting
both the usefulness of exaggerated hope and the need for treatment to control the illness or a new complication” (a.a.).

“A terminal illness can make families feel as if everything is out of control, and clinicians can help them regain a sense of mastery over this painful process. Involvement of all family members, including children, in some aspect of caregiving normalizes the process of dying, provides a sense of coherence through participation, and counteracts anxiety and feelings of helplessness” (Rolland, 1994, p.180).

**Method**

**Design**
The study is qualitative and uses an inductive approach. According to Neuman (2003, p.172), “Qualitative researchers primarily follow an inductive route. They begin with empirical data, follow with abstract ideas, relate ideas and data, and end with a mixture of ideas and data”. According to Backman (2008), when following a qualitative approach, the focus is on meaning, context and process. *Meaning* refers to the researchers interest in understanding how individuals experience their reality in relation to their earlier experiences and how life and the world derives its meaning. *Context* refers to the study of people in real life situations and *Process* refers to how meaning is created via interaction with other people. For the purpose of this study, I used structured interviews. “The interview is a short term, secondary social interaction between two strangers with the explicit purpose of one person’s obtaining specific information from the other. The social roles are those of the interviewer and the interviewee or respondent. Information is obtained in a structured conversation in which the interviewer asks prearranged questions and records answers, and the respondent answers (Neuman, 2003, p. 292).

**Participants**
The interviews were held at four different hospices in Stockholm with four counsellors. The names of the hospices are:

- Ersta Hospice, Folkungagatan 121
- Stockholms Sjukhem Mariabergrsgatan 22
- Praktikertjänst, Dalarövägen 6 Handen
- Nacka LångbroPark Bergtallsvägen 12
Limitations

The sampling method I used was based on Convenience factor. According to Bryman (2002), the participants that happen to be available for the researcher are called Convenience Sample. Palliative sections are not in the university hospitals like Karolinska and Södersjukhuset. Instead they are in special hospices scattered around the city. Due to time restraints and personal reasons of difficulty to travel to locations outside Stockholm for conducting the interviews, I limited my interviews to the hospitals in Stockholm.

Data collection

The first step in conducting the study was to find out the scientific literature available on the topic. I used Ersta Sköndal’s college library Internet database using the search engines such as DIVA, Academic Search Premier, Libris, MedLine, Nursing and Allied Health Source, SocIndex, PubMed, SwePub etc. As soon as I typed in the words Palliative care I came up with thousands of articles on the subject. I did a general sorting of articles that were relevant to my essay by quickly reading the Abstracts of each article. I then refined my search by using the words counsellor, counselling in terminal care, counselling skills, death and dying, spirituality etc. After I found the relevant articles, I printed them out. I also borrowed books from the college library at Ersta and Norra Sköndal. The first two weeks were spent on reading up on the literature that I had found and deepening my knowledge on the subject. This also allowed me to come up with the questions that I would later formulate for the interviews.

The next step was to find the participants. I checked Stockholm’s health guide (Vårdguiden) via the Internet and searched for the hospices closest to my address. This was done to make the travelling time for conducting the interview as short as possible. My aim was to interview around five or six counsellors. I called around ten hospices. I managed to get interviews with four counsellors without any problem. However, it became difficult after that. One hospice, Lilla Erstagården in Nacka, which I called, had a counsellor who had recently joined the palliative team as a substitute for the main counsellor who was on leave. She had only worked there for ten days. This made it irrelevant to my study. The other hospices, which I called, did not answer or return my calls even though I left many messages.

Personal Bias

“Understanding of varying phenomena, such as understanding a text, or coping with practical situations often takes place through an emotional background. As people are historical beings who live in different realities, they understand the world from different living conditions and perspectives. People's preconceptions become the basis for the interpretation of the world”
(Sohlberg & Sohlberg, 2009). My personal bias is that due to my personal background and exposure to the death of a close relative that succumbed to cancer, as well as acquaintances who have been diagnosed and are living with Aids, I feel drawn towards the subject of death and the struggle and pain that people encounter in the face of impending death. It has made me consciously reflect on the subject of not only dying but living with dying. I am also fascinated by the enormous efforts that are undertaken here in Sweden and other developed countries to make the end of life as good as possible unlike the place I come from, i.e. India.

Despite the efforts of the Indian government and co-operation of international agencies like United Nations, Amnesty, and Red Cross etc. to improve the lot of those affected with Cancer and Aids, there is a lot left to be done due to the large scale of interventions required and the lack of infrastructure. There is still a tremendous amount of stigma attached to having Aids and this leads many to commit suicide or face social isolation. Spurred on my personal experiences and natural curiosity about the meaning of life and death I wanted to learn more on this subject by undertaking a qualitative research on this topic. I wish to gain a deeper understanding of how to help people live the remaining days of their life in the best possible way. My personal bias is that although there are many theories about the human experience one can still learn a lot from the shared experiences of those who are actively working in the professions.

**Interview Analysis method**

The approach of analysing the contents of the interview is hermeneutic. According to Bryman (2002), the critical aspect of hermeneutic interpretation is the connection that is made between the understanding of a text from the author’s perspective and from the historical and social context in which the text was created. The hermeneutic approach puts focus on the author’s understanding and a sensitivity regarding the context. The method of analysing is Bricolage. According to Kvale (1997, p. 251), Bricolage means the individual chooses the tools that happen to be available even though they were not designed for the task in question. The Bricolage interpreter adapts various technical discourses to each other, moving freely between different analytical techniques and concepts. Such a way of creating meaning through a variety of ad hoc methods and theoretical approaches is a common form of interview analysis and stands in contrast to more systematised analytical forms and techniques, as categorization and conversation analysis.

The 4 interviews that I conducted with the counsellors were taped using my IPhone. Each interview lasted for approximately an hour with the exception of one that lasted for one and a
half hour. After I conducted the interviews, I replayed the recording and transcribed it verbatim. After that I translated the interviews to English. This naturally took a few days since the interviews were very long.

In the days following the interview I immersed myself in reading the transcripts many times. After a while I got a general impression and then began the first step of analysing by identifying qualities and themes. They were then put under broad headings. I found out that the participant’s answers were all quite similar. The interviews with the counsellors resulted in detailed and rich descriptions and I have chosen to cite a lot of their answers in the analysis because I feel that it clearly reveals the nature of the counsellor’s work and the reflections they have on life and death. Their answers describe in-depth how they help to care for patients who are terminally ill and not including the major portion of them would not do justice to the study as a whole. I then discussed the study, trying to sum up the main themes of the analysis and then ended with a conclusion.

**Reliability**

Reliability means dependability or consistency. Qualitative researches want to be consistent (i.e. not vacillating and erratic) in how, over time, they make observations, similar to the idea of stability reliability. One difficulty is that they often study processes that are not stable over time. Moreover they emphasize the value of a changing or developing interaction between the researcher and what he or she studies. Qualitative researchers believe that the subject matter and a researchers relationship to it should be a growing, evolving process (Neuman 2003, p. 184). The reliability of the following study has low chances of reliability because the results will not be consistent if another researcher attempts to apply the same method. The result is dependant on the researchers own interpretation and that in turn differs from individual to individual. It is also dependant on the researchers relationship to the subject matter, which can change over time.

**Validity**

“Validity means truthful. It refers to the bridge between a construct and the data. Qualitative researchers are more interested in authenticity than validity. Authenticity means giving a fair, honest and balanced account of social life from the viewpoint of someone who lives it everyday” (Neuman 2003, p. 185). “Most qualitative researchers concentrate on ways to capture an inside view and to provide a detailed account of how those being studied feel about and understand events” (a.a.). The following study is a truthful account of the counsellor and their experiences as told to me. It also attempts to give an inside view of the counsellors
world, their feelings and how they understand dying patients and their families. I have also
done my best to translate the transcribed interviews as carefully as possible. However, I am
aware that there is always the chance of a meaning here or there to get lost in translation. It is
my strong belief however, that the chances of that occurring in the following study are
minimal.

**Interviewer Bias**

Interview expectations can create significant bias. Neuman (2003), says that interviewers who
expect difficult interviews have them, and those who expect certain answers have them. In
addition interviewer bias can arise from expectations based on a respondent’s age and race.
An interviewer’s visible characteristics, including race and gender can affect interviews. The
counsellors were used to being interviewed and as such had no problems in answering my
questions. I think that their relaxed manner helped to put me at ease and we were able to
establish a good connection right from the start. The counsellors were very willing to talk
and this generated in detailed answers to the questions complete with real life examples. I also
think that my own interest in the subject material about relationships, life and death also led
me to ask more questions on that topic. My age and gender made no difference to the
interview. Most of the Counsellors had a great deal of experience having worked for almost
ten or fifteen years in the profession, with the exception of one counsellor who had worked
for three years. As such the age of the respondents could have affected the outcome slightly.

**Ethical Concerns**

“The ethical issues are the concerns, dilemmas and conflicts that arise over the proper way to
conduct research” (Neuman, 2003, p. 116). Since Palliative care is a deeply private and
sensitive topic for patients and relatives, I was aware that the counsellors were bound by a
confidentiality contract. I was thus careful in my approach and intended to respect that by not
asking any questions that would make them feel compromised in any way. I understood my
responsibility as a researcher to follow the Research ethical guidelines.

**Information Requirement** - The researcher must ensure that the interviewees are informed
about purpose of the study, that participation is voluntary and that they have the right to
cancel at any time (Bryman, 2002). When I called the reception of the hospices, I explained
the reason for my call, stating that I was a student at Ersta Sköndal Högskola and was writing
my student theses on the topic of Counsellor in the Palliative team and needed to interview
counsellors. They connected me to the counsellor in charge and I could then speak directly to
them. Once again, I explained the reason for my call and elicited the purpose of my study. I
also made it clear that it was completely voluntary to participate and that they could at any
time decide to withdraw their participation without adverse consequences. I also mentioned
how I would proceed and how long the interview was supposed to be.

Consent Requirement - All participants in a study should be free to decide on their
participation (Bryman, 2002). The counsellors that I spoke to agreed to my request but
mentioned that it would take a while before I could come over to the hospice since many
students had already called them up from other colleges and their schedule was quite busy. I
managed to get their consent for the interview without any problem.

Confidentiality requirement - all members of the study will be treated with utmost
confidentiality (Bryman, 2002). Before conducting the interview, I went through the ethical
issues of the study with the counsellors. I explained to them that they would be kept
anonymous. I also made it clear that they could always stop or refuse to answer any question
whenever they felt that it was inappropriate. I have in my study of the counsellors guaranteed
anonymity by not using their names. I have stored personal data and interview material in
such a way that no unauthorized person can access them.

The usage requirement - All collected data on individuals may only be used in the study it
refers to, and for no other purpose (Bryman, 2002). I was careful to inform that our material
would only be used for the purpose of the study. I mentioned that the interview would first be
recorded, transcribed and later deleted after receiving my grades for the study.

Result and Analysis

Palliative Care Approach
Each counsellor mentioned the holistic aspects of Palliative care and the guidelines clearly
stated by WHO, relating to palliative care, which is applicable for all the countries in the
world. They said it was a very stable foundation. Teamwork, they said makes it possible to
fulfil the aims of Palliative care. The doctor, nurse and the counsellor meet once a week but
also on the day of enrolment of the patient in the hospital. They all try to look at the situation
with different perspectives identifying different needs (Davy & Ellis, 2000). Together with
the team the counsellor assesses what’s important for the patient and set goals to improve the
quality of life for both the patient and the family.

So we use the WHO guidelines and work together as a team and recognise the importance
of the team. We also have a process kind of thinking. It is a kind of structure that we use, a
form of graphic description of what to do and how to do it. It means that there is a main
palliative process, secondary process, existential process and so on. Then how one does
that and fills that function, that is where everyone differs in his or her profession.

Teamwork can always be improved.

The counsellors did their best to follow the holistic approach to people, taking in all aspects mental, physical and spiritual. It also included the support and care for relatives as well.

The Palliative care model has a holistic view of man, that we are not just a body. We have relationships. We become who we are through our interactions. We are a part of society. We have a story to tell. We wrestle with existential challenges. What is it that makes sense when I have so little time left to live? Is there anything that I want to do to put things right before I die? Is there anything that I need to sort out, practical or financial before I die? How can I get contact with people I have not had in a long time? These are the common types of issues that people have. The Palliative Care philosophy says that we should consider these types of issues.

The Palliative care approach sees each individual as unique.

We have a Care philosophy that is based on each individual. We use different key words to identify the character of the person we encounter and how we can respond to his uniqueness in the best possible way.

Joining the Palliative team and finding out their role was not as clear-cut in the beginning for many of the counsellors. It was the team who helped them in the process.

The first time felt like I was re-inventing the wheel! I had no other counsellors to talk to, but I did have friendly and supportive nurses and doctors and clinic manager for that part. I noticed the importance of the team, right from the very beginning, but what exactly I would do as a counsellor there, I had to pretty much figure it out for myself!

I got no introduction when I started! I had to find my own way at work in consultation with the manager of course and others in the team but there were no other counsellors whom I could turn to and ask for advice or a second opinion. I had to take my own initiative but the manager and the team supported me very well. There was no requirement for me to perform in a certain way at once. I got a lot of time and space to get acquainted with the organization. I was of course nervous!

Methods and Interventions used by the Counsellor

Understanding the context of a patient

When the patient arrives in the Palliative department, the doctor, nurse and the counsellor have a meeting together with the patient and family. They go through the process of explaining, informing and making the current situation comprehensible (Beck-Friss & Strang (eds), 1999). The patient may also choose which family member he or she wants to be present in the meeting. It is vital to map out the interaction patterns of the family members and
identify problematic and healthy relationships. The counsellors stressed the importance of understanding the patient’s background and relationships (Frankl, 1990).

*It becomes obvious to see that a patient always has a context, belongs to a group of people and that you have to take that into consideration. We always have conversations with the family and we try to listen a lot to what the family has to convey. Thus, families have their own stories and we need to listen to them in order to understand them better. In doing so we can help both the patient and the family.*

A detailed study is done on the patients network, social situation and a care plan is made on the basis of the above information (Rolland, 1994). Each plan can be adjusted according to the changes that occur with the progress of the situation.

*My guiding principle is always to do what Søren Kierkegaard, has formulated so nicely, that if you want to give another person the support he or she needs, then you have to meet that person where he or she is at the moment, not where I think he or she should be. My entry point is always, “How does it look for the patient right now?” It may be different depending on how old a person is, whether they are nearing the completion of their life, has family, friends and is stable or not. Some people are very prone to crisis despite their old age. Everyone needs support. Some need aid that nurses can provide, some need more, such as families with children, people who are frail or have mental problems or drug or alcohol abuse problems, financial problems, etc.*

*Families have their own stories about what has happened before in life, relationships, conflicts, past losses and trauma and even what has happened previously in hospitals and the care which the patient received and if they had complaints about it or not. During the family sessions we try to listen very carefully to what the family tells us. It is extremely important.*

Some patients and families are particularly vulnerable and are more prone to going through a difficult time during the illness trajectory compared to others. According to the counsellors, it is important to identify the stressors (Antonovsky, 1991).

*We do not ask straight out about such things but there are families who tell us about it especially families who have complicated backgrounds, experienced previous losses, or if they come from countries where there is war or have been wars and if they have experienced problems with the healthcare system, if they have been mistreated or have not been sufficiently well looked after. Sometimes families are worried about how the hospital stay will be, if the dying will become prolonged or sudden. Some of them have worries about the hospitalization process but sometimes this can even be extended to how complex or complicated grief becomes after the patient dies. The model that we have, our approach, can be said, that we make extra efforts to reach out to such families.*
One of the counsellors mentioned an important aspect of the counsellor’s role i.e. being competent in a broad range of subjects such as having knowledge on law as well as having some medical knowledge.

*The counsellor must work with all kinds of situations. It is very important that as a counsellor you have good legal knowledge. For example, a man died here last night. He had no immediate relatives. What do you then do? Who takes responsibility for him? Who is going to take his belongings etc.? Who manages his contacts? You cannot hand out the patient’s things to his best friend or someone else before first getting legal permission. As a counsellor, you must have extensive knowledge and understanding of different networks and government organisations and even some medical knowledge. It is good to have some idea about it. E.g. brain tumour can give personality disorders. Then it’s good to know how it affects the patient and his reaction to his own illness.*

Oftentimes many patients might not expect to meet up with a counsellor or may not know what a counsellor does, so initially it means informing them that counselling is available and that a counsellor has knowledge of many issues like insurance, economic issues, practical things, community support and other resources etc.

*My experience is that it is important for both the patient and relatives to have someone outside the family to talk to. But if the patient says no, it’s quite ok. But almost always most of them want to have someone to talk to. Some do not want to talk to me, they might want to talk to the nurse instead and that is all right because we work in a team and help each other.*

**Assessment of Coping strategies**

If a condition involves crisis, the family’s history of coping with crisis in general, especially unanticipated ones should be explored (Rolland, 1994). The counsellors are aware that there is much that spins inside the head of both the patient as well as the patient’s family when faced with a debilitating disease or faced with the thought of dying. For some it is really difficult to handle and for some it isn’t. Some can handle difficult circumstances better than others. The extent to which they could be better equipped to cope had a lot to do with the strength or weakness of a person’s sense of coherence (Antonovsky, 1991).

*Some are simply more secure than others. Some have grown up with a basic security, stable childhood, family, parents, and strong relationships and feel that they have the support of near and dear ones. Some can handle the fact of their own death, while some not. Some old people may feel that they have lived their life and have come to the realization that it is time to say goodbye and yet some older people are terribly afraid to let go.*
One of the things that the counsellors mentioned in the interviews was that in order to help the patient and give them good service it was crucial to recognise and assess their needs. The counsellors describe the kinds of patients they encounter and how they manage to identify their coping strategies (Davy & Ellis, 2000). Almost all the counsellors described one or two aspects of the coping strategies and how they intervened, elucidating it with real life examples.

**Fighting Spirit:** A counsellor must be very careful to not dash the hopes of patients and families but sometimes they need to intervene and help families acknowledge the possibility of loss. It is more common for families not to accept the impending death of their loved ones. But sometimes it was also mutual and both parties maintained the status quo. Sometimes it could be so severe when it was reciprocal that neither party could confront the topic of death at all.

"I feel that in the beginning many patients as well as relatives have a fighter attitude, they will fight on. This is fine in the beginning but it can become a struggle if they become obsessive about it for too long. Sometimes a family member may express something like this to me; "I know he will not be around long and I would love to ask him about how he wants his funeral to be, how we should do with summer house etc., but I dare not say it". It becomes apparent that the more energy you put into maintaining this outward appearance of a fighter spirit, the harder it becomes and eventually it becomes so hard that it robs energy from other more important things. I think that as a counsellor, I then need to intervene and talk to both patients and family members so I can help them to communicate with each other and bridge the gap between hope and the possibility of death. I can ask them, "What's the worst thing that could happen if you were to ask about the funeral?" and then they usually answer, "that the patient (he or she) may feel hurt and start to cry" And then I ask "Isn't it not quite relevant to cry at this stage"? I may then suggest that perhaps they can cry together. And very often they do it, they cry together and when it is over they can then focus on the important issues and it can feel like a huge relief.

**Maintaining hope:** One of the counsellors gave an example of how one can understand and have respect for the need of patients and families to maintain hope.

"I remember a patient I had last year. He was an amazing young guy, born in 1982. He had cancer. He could talk openly about his illness and was very clear. "I know my chances of surviving are minimal and the likelihood that I'll die soon is quite certain, but I want to do everything I can do to survive. It is quite important for me to think I might belong to the few percentage of people who actually survive. Why should I not be one of them? I love my life and my job. Why should I not be able to do things in life as everyone else? I like to think that I will do so." It was amazing, I think, that this guy was able to think like that and at the same time say, “but if it doesn’t work out like I think, it might be very interesting to see..."
what will happen when I die”. He died a few days later. He was not denying his death in any way.

**Planful problem solving:** One counsellor felt that the fighting spirit is probably more characteristic of the younger generation and it was understandable that they made plans for the future.

I think that young patients struggle really hard. Here I can generalize a little bit and say that what characterizes young patients is that they want to be in control. Usually they are very updated about the latest treatments and know a lot about their medications in detail and read so much about their disease online. They are on special diets and treatments. It becomes very important for them to be in control. Perhaps, they are able to have a more open dialogue with their doctor compared to the older generation. However we usually tend to think that the elderly are more accepting of dying because they are old, but many of them do have a hard time too.

**Escape-Avoidance:** Most of the counsellor’s experience said that it was unusual for patients to truly deny the fact that they are dying even though it may appear that they are in denial. Some of them might be doing that to protect their loved ones and as such try to maintain a cheerful attitude and a brave spirit.

Even though I know he or she will die I can go along with the patient who thinks “I may live for a while longer if I create the illusion of it for myself, otherwise I might not be able to live through this day if I continuously think about death. I can create the illusion that I’m going to have weeks and months ahead of me to live. I can dream of different things I want to do in the fall or next summer even though I know it will not be the case”. I think that as a counsellor, there is no need to break or crush that illusion. This is to show respect for the patient’s coping strategy.

**Positive Reappraisal:** The counsellors mentioned that there is much grief for both the person who is dying and their family. However some patients gradually transformed over the course of the illness and became positive instead of simply letting life slip away. They looked foreword to simple things that gave them joy and added a sense of meaning. Such individuals have learnt to let go of the fighting spirit.

They look forward to someone coming to visit them, to go home if possible on a short leave; they look forward to midsummer and meeting grandchildren etc. In the end we all learn that eventually what is important in life is what I have before me and how I get to set the tone.

**Core counselling skills**
The counsellors all used the core counselling skills identified by O’Berle and Davies (1992). They described vividly the manner of how they implemented these skills in their work. The
successful use of these skills led to forming good relationships, which was crucial for palliative care (Davy & Ellis, 2000).

**Valuing:** Every person is worthy of respect and we should see him or her as unique individuals, regardless of their background.

> I have a deep respect for every human being. I think in a way that our unique nature becomes very clear when we are nearing death. I can almost feel something religious in the existential part, that there is something amazing in that every person is unique. It is a miracle!

What is it that is unique in us as humans beyond the conception of the disease? One of the counsellors put it like this:

> A person, is their collective experience, their own story, a story about me, from the time I was born until now, the genes I inherited of course, but also my relationships, my experiences, my life, what has shaped me, my environment, what I’ve been through, joy and sorrow, and everything that I have gone through in life.

> As a counsellor, my role is to come empty handed and listen to your problems. Every person is unique. Each person has his or her own agenda. It’s not me who decides on what to talk about. Someone said, that if you come with full hands, you couldn’t take anything with you. The fact is that I can never know what is going to play out when we meet.

**Active listening:** All the counsellors whom I interviewed described that a major portion of their work in the hospice involved actively listening to patients talk about their situation. They described how they saw themselves as a recipient of all kinds of feelings, grief, despair and crisis of other people and how they partook of the information shared by patients.

> I see myself as an instrument, a kind of vessel or a carrier of something. Use me! I want to make myself useful to you. Come to me with your crisis, grief, despair, questions, your strength, and your survival strategies, whatever, tell me all about it! Let’s have a dialogue. I have all the time to listen to you. However that does not mean I’m totally passive. I’m pretty active with the way on how to handle the situation and ask lots of questions and make suggestions.

A key counselling skill is the capacity to listen attentively without interrupting clients. This includes ‘listening’ to non-verbal messages such as tears, as well as words.

> It is something you learn along the way. It is important to be able to relax and not be worried that you have all the answers. I simply listen to you. I’m interested in what you have to say. It is important. I have no agenda. It’s like adjusting a radio frequency and tuning in to what you have to say to me.

> Listening actively helps you to meet the real person, completely stripped of the trappings of context. It becomes a meeting on many levels. Sometimes, listening can also take place
when no words are exchanged. Silence can be very powerful and sometimes even helps me to reach out and connect with the patient in a special way.

All the counsellors said that they were very close to their patients. They had a strong desire to really reach out to them, to give individual support, focusing on what was most important to the patient and how they could help them and give them what they needed. They also felt a lot of respect for them.

*I feel a lot of affection for my patients. I can understand and feel a very strong affinity with them. I even use the word love sometimes.*

**Connecting:** The counsellors explained that in order to help the patients in the best possible way it is very crucial to build a relationship with the patient. The first step is to establish a connection and then use that connection to create a relationship. Patients have to obviously get pain relief for their illness and but it is very important to build a relationship first because then everything else became so much easier. Even though patients sometimes have a very short period of time the counsellor can still make the effort to form a relationship with their relatives. It is applicable to the entire Palliative care team.

*Building a relationship means to create trust and confidence in the patient for what we do.*

*If we succeed in that, everything becomes much easier compared to a patient who is distrustful or becomes aggressive or guarded. Then the work takes on a much challenging course.*

**Informing:** When a patient arrives in the hospital the doctor, nurse and the social worker meet him or her with their family. They are given general information. It also depends how seriously ill the patient is and if the patient is in a condition to listen and talk. In that case the families are the ones to meet with the specialists.

*A lot of patients are so sick when they come here that they die quickly in a couple of days and then we might be not able talk at all with them. It can be difficult to build a relationship with the patient if they are seriously ill. In that case we talk to the relatives and we try to build a relationship with related parties as best we can. We put a lot of focus on the patients, but sometimes they can be asleep or unconscious most of the time. We invest all our efforts on making the last days as good as possible. We do everything we can, the whole team by working intensively. Sometimes death is expected quickly and sometimes there are longer hospital stays if death comes gradually. The duration of the hospital stay is difficult to measure. There are those who have been here for months and those who are here for just one day.*

**Being courageous:** One of the counsellors mentioned that the essence of forming relationship with a dying patient was to have the courage to listen.
Relationships, they’re very much about having the courage to listen. I am here to listen to you first instead of presenting ready-made solutions. Sometimes patients may not have much time left to live, and then it is extra vital that we have to be very quick to get in touch with them. Being fully present and alert in the meeting and having the courage to listen to their difficult stories are very important.

Being present: Presence is the most important aspect in building a good relationship.

Being present means that you try and target your attention 100% on the person in front of you and more importantly when the person in front of you is a dying patient because they may not be able to talk and then it’s the little nuances and the body language that you have to pay attention to. I try to show them that I have all the time in the world to be there, just for them and everything else is unimportant. Because unlike other patients, these are dying patients and it could be so that this might be the only meeting I will be able to get with them and then it might have devastating consequences if I am busy checking my watch! Who knows, maybe the patient will die tomorrow! It is of course difficult to talk when there is limited time and I know that I have to go or be somewhere else or something unexpected comes up or happens. It is frustrating at the same time to be aware that we will probably never see each other again and that unlike other meetings this is perhaps the only meeting I will ever get, like, Once in a lifetime. I’ve talked to many people who know that this is perhaps the last time we will be having a conversation and on such occasions it is very important to listen to what they have to say. Perhaps something important or unique needs to be said. And I need to do is to be here to listen and receive it, and then it’s important to focus. I’m pretty good at putting things aside.

The counsellors all emphasised that the most important aspect of building a successful relationship was achieved by being present for the patient. It is important to have to have the right attitude and approach towards patients. It was very important that they do not appear impatient in front of the patient by checking the clock etc.

It is a kind of mental preparation. I always try to find this presence inside me. I gather myself for a moment and think that now I’ll meet this person or this family or Gannar and then as I step into the room I open myself both body and soul for that meeting. Sometimes things may happen unexpectedly, things that I had not anticipated but you always have five seconds to step back and think about the next course of action. You can do a lot in those five seconds. I choose to use them in a good way. I stop and take a step back and then I collect myself and then do what is required. I try to be absolutely present during a conversation. Even when I finish a conversation or a phone call I always make sure that I end it well. So how one starts and ends a conversation, I think is very important.

Presence for me means that during a conversation, I do not have my cell phone on and disturb the patient. It’s about showing them respect. When I sit with patients I do not look at my watch, even if I have ten other patients who may be waiting for me. It’s easier to have
conversations with the relatives here in the hospital but if are unable to come I do my best to be present when I have phone calls with them. I then try to be present in my thoughts with them.

It is important to be present. When I go to meet the patient either at home or here in the hospital, I focus on what I should do. I am very careful and prepare myself fully for the meeting. I do not like to rush in at the last minute. It is important how you sit, where you sit and to think all the time from the patients perspective and ask the patient how he or she wants it. And then I try to really focus and be mentally and physically present. I also like to think about what I communicate with my body language especially eye contact. It is important to adapt to each patient since they are all different. One must be very responsive to their requests and empathetic and focused.

The sharing of anxieties and views is an acceptable part of the treatment process. Many times it makes a difference on how things are said.

One doesn’t always need to be completely explicit when it comes to talking about death. You can talk about death in a kind of meta-language. It can be very interesting. We use a kind of meta-communication. We talk “as if” life would go on, as if it was about this or that even though we both know that in a few days or weeks you’ll be dead.

Existential conversations: The majority of conversations are all about life issues that do have an apparent religious content, but are about life in general. What is it that gives meaning to our lives? (Frankl, 1990). Patients talk about their lives and think about it, why was it the way it was, and what could they have done differently? Why did I make the choices that I made? Many are afraid of dying. We as human beings want to live on and see what’s going on.

I was with my group and we had a question about “what is an existential conversation”? Yes, according to me, you never know it in advance. I just had a deep existential conversation with a man but we did not talk about anything that was about the big questions about life and death and yet it was very existential in its nature. This man was originally from Spain. He was a very angry and bitter man. Yes, there were a lot of things, he said, that had contributed to making him angry. When I met him that day, he was very keen to talk about food and wine. He described different types of Rioja wines, all varieties of Spanish food and how to cook them; he described in minute detail how to cook pig’s feet, which wines were the best etc. Then he talked about politics and politicians both here in Sweden and in Spain, he thought they were all idiots! He talked for a long time. And then, at the end of our conversation, he sighed very deeply and said, “And now, it is all over! This is the end and I cannot do anything about it”. Life for him had been about all the things he’d told me. It had given him his sense of purpose and meaning. Later on, I met his daughter who shared her side of the story and described her father. She said that he had been quite a grumpy and angry person, which in turn had to do with who his parents had been. He had grown up with an angry mother who was not emotionally close and that he
had faced tough circumstances growing up. Even though he had a wife and children who loved him, it was still very dark inside his mind. He was quite bitter having had experienced war and so on. He moved here to Sweden but it had involved a lot of struggle. Meeting him and his family was like watching a very dramatic Spanish film. It also felt very sad. It doesn’t happen often that I cry in front of the patient. Sometimes I cry in private to myself but if tears do come up in the presence of the patient or family as it sometimes does, I do not try and hide it. I think it doesn’t matter. It is human to have compassion.

Communication and Support: Mental suffering is likely to be enhanced by any physical distress; the doctor can do much to relieve the one as the other is tackled. Discussion of palliative treatments and competent symptom control can open up communication and bring support at a deep level, demanding time with the patient and the close contact often denied at this stage (Saunders, Baines & Dunlop, 1995). The patient may be very afraid of both kinds of pain and may also be concerned about how long it will last what happens when they die. They may also be worried due to their religion and worry about going to hell and question whether they have lived a good life or done the right thing.

Sometimes, I feel inadequate if the patient suffers a lot and there isn’t much I can do. Medically, you can relieve the symptoms of pain. There are doctors who are there for that. But existential anxiety, that is different. One must dare to go into the depths of suffering with the patient. It would be an incredible denial on my part if I didn’t help to ease their existential pain.

This morning for example I had a conversation with a man who has been undergoing treatment to keep his incurable disease at bay. His situation was not progressing well despite the treatments. He was very upset. “You know M”, he said to me, “now I’m surely doomed.” Then we had a conversation about how he wanted the remaining days to be. We talked about both the emotional stuff and legal things.

Challenges and risks
Investing Time to build close contacts: The counsellors said that building relationships take time and yet sometimes a connection can be made despite time constraints. In purely quantitative terms counsellor sometimes have time and sometimes they don’t and yet there can be a high quality to the relationship at all times. Some had a lot of flexibility on the amount of time they choose to spend with a patient.

I met a patient, a young guy only two times and yet we managed to have really long conversations and we got pretty close to the deep stuff. If you know that there isn’t much time left, then it becomes more intense. I think that there is no time to waste on small talk. You become aware of what’s really important.
We do have a time set beforehand but it is not too rigid. I can always adjust it in case the conversation touches on important things and it becomes inappropriate to interrupt. It also depends on how long the patient is able to talk or not. Sometimes they may be so seriously ill that the conversation is over within an incredibly short and obviously you have no time to build a relationship. Sometimes people die within a few days after being enrolled here and then it’s really hard.

Counselling cannot take place without establishing a relationship (Davy & Ellis 2000). One of the greatest challenges that counsellors faced in their job was to maintain the right amount of distance (Parkes et al., 1996). They explained the dangers of becoming too emotionally attached with a patient and what it meant to know their own limits. They emphasised their professional role but said that everyone is different regarding how he or she carries out that role because of his or her personality and the amount of experience one had. It was very important to reflect about it.

Being a Professional, I must leave my private life outside. It is very important to distinguish between being a friend and professional. It’s very important to know where to draw the line. It is very dangerous to walk across the border. I have had so many patients over the years who have said to me, “M, you’re such an amazing support for me,” and I can understand them, but sometimes the patient or their relative can say “Can I invite you to dinner, or can we go out and have a drink?” It’s very easy to feel that one has becomes a part of their network. If I have a patient, I try to figure out the network, family, friends, etc. that they have. I’m just a small part in that network and only for a short while. I should not be the one to whom they say, “M, you understand me better than my husband,” In such a situation I have to be the one to help the patient and her husband to come closer together. I should definitely not take the role of her husband! I have to help the person to communicate with their network. All therapists and social workers will have patients who really like them and become fond of them. It is always the therapist who must remember not to cross the line. It is very important to ponder over that. It is horrific to read in the newspaper or watch on TV about priests who had sex with catechist or a social worker working in a prison having a relationship with an intern. There are many who will fall in love with you but I think that it is very important to know where to stop.

It is easy to get emotionally affected.

It is clear that one encounters patients in extremely difficult situations, such as a dying parent who has to say goodbye to his or her child/children and then it is obvious that one is affected by such a meeting. I must be careful to maintain my professional role despite being emotional. If my private emotions take over in a meeting then I stop being a professional. I am then unable to help and support the patient or the family. I think that they would notice it. At the same time, one must be extremely empathetic in this line of work in order to do a good job but I have to maintain a certain distance, while being empathetic and responsive.
The level of emotional attachment is not black and white. It was difficult for the counsellors to define the exact amount of involvement saying it was a fine line. The right distance varies according to the nature of the relationship and circumstances (Parkes et al., 1996).

There are situations where staff can sometimes become very emotionally involved and emotionally affected but we must do our best to not let that reflect in our interactions with patients. We need to deal with it in the staff group. It shouldn’t be the case that I sit and cry during a session and the patient has to comfort me. Then one is too emotional and unprofessional. On the other hand, nurses have told us that when someone has died and the family situation is very touching they started crying a little softly even though relatives could see them. I think it is alright in such situations to show how you feel for family members because they can see that the staff are concerned or that it is a sign that the patient meant something to them.

I am very engaged. There are always some patients that you really like but then you need to think, Why is it so? Sometimes, everyone likes a particular patient. Then one can also wonder what is it that she does that makes all of us like her? Some people are so easy to like. As a counsellor one can become very close. In a worst-case scenario, patients may end up believing that we are their friend and not their counsellor!

Over the years, the counsellors learnt and developed a certain way of working that allowed them to be true to themselves. Even though they were close to their feelings, they learnt to deal with them in a professional manner. Most of them were always touched by their patients, but not in a way so that it hurt them.

For me it’s constantly reminding myself that I am here for them and that they are not here for me. Our conversation should not be a sharing of my experiences. Patients should not have to listen to my experience of grief of how my mother died or so, nothing of that sort. I’m here for you and your needs. Your story touches me, and it concerns me, but at the same time, only up to here. It does not go all the way in, how shall I say? I’m here for you and you may take what you need out of me in the form of care, protection, some sort of courage or hope but not everything that I am.

Some of the patients are very curious and ask a lot of questions. They do their best to become friends with the staff. One counsellor mentioned that it was a way of coping for the patient.

I think that it is the patient’s coping strategy to try and become friends with the staff. By doing so, death becomes less threatening. In a way it takes the edge off death. I’m very clear about where to draw the line. I never involve my personal life. It is important both for my sake and partly for the patient’s sake that I’m here for the patient and not the other way around.

All counsellors mentioned that one couldn’t know all this from the start. Maybe theoretically, but it required experience to know where to draw the line (Parkes et al., 1996). There is a
difference between being overtly emotional and being concerned for a patient and it is very important to reflect on it and ask oneself, why am I getting so involved? A Counsellor cannot do a good job if they get too close with the patients because then they lose the ability to look at the situation with distance and may miss out on what the patients really need.

Sometimes you can form an instant connection with a patient. Everything matches so well. But I think that one should be careful and not get entangled emotionally. If you go in as friends then you are vulnerable. It is important to take a step back and rise and get a bird’s eye view of the situation. However, I’m not cold or detached. I know how close you should go with a patient. One should not take over their family or what family members should do.

Sometimes counsellors can feel emotionally fatigued especially if they listen to patients who have had a lot of problems such as difficult childhoods or a difficult life in general. Too much of involvement can lead to emotional exhaustion and this in turn can lead to loss of compassion and a depersonalised approach to people and a reduced sense of personal accomplishments that lead to impaired job performance (Papadatou, 2009). This applies to all types of people in the caring professions and even more so if you work with death.

There are a lot of emotions involved. There may be major conflicts, for example, a man who has just died and his children and his new wife do not agree, and all these relationships come to the forefront. There may be a lot of anger, which is transferred to us. It is easy to get tired after such a day and it can feel very heavy. It is then important to find support, talk to friends and colleagues or others in the group.

Counsellors have to train this ability of being empathetic and at the same time not get emotionally overburdened. That is why it was so vital to have good supervisors who could support them.

Not everyone wants to work in a place that has to do with death! All our patients are dying and eventually die. Yes it can be tiring and that’s usually when I am careless about my rituals of filling myself up with energy and setting aside time for reflection. I derive strength from being in stillness. If I get careless about my meditation and Qi gong, I become fragile and drained of energy. Too much of emotional overload can deplete you of the vital energy to listen and be empathetic. It is important to work on yourself, do your best to replenish your energy, otherwise you risk becoming cold and hard and you cannot be bothered to know. It’s horrible and it’s a high price to pay. Actually it is not possible to have such a job without good supervision and not being able to confide in your team. You cannot be a “lone wolf” in this job. You have to work together with the team, with your colleagues. My team has been together a long time so it’s a good thing.

Some meetings make the counsellors uncomfortable and sometimes it can be difficult. If someone is suffering very much they can feel a kind of frustration when they cannot relieve
the symptoms of the patient is any way. There is a lot of anxiety when patients have difficult
symptoms to put up with.

Sometimes I wish I had a magic wand that I could simply wave and say “Abracadabra!”
and everything would be all right. It is very difficult sometimes. I feel inadequate and ask
myself what can I do for this person who is suffering so much, who is so sad and longing
for something or is very afraid and anxious of dying? I usually try to think like this, that
now I’ll meet someone who wants to meet me and that person is very scared and is in a lot
of pain, perhaps has vomited throughout the night and is feeling very sick, lonely and
frightened. Now I must be the one who is least fearful and least worried. I am not sick, I
will not die, I do not have a cancer and thus I must be the one who is the most courageous
person in this room. It does not mean I do not feel sad for the patient but I have to be the
one who shows it the least. It helps me sometimes to think like this.

Organisational changes can also cause stress. There have been many sudden changes in
Swedish social insurance system and new laws have come up and this is not a good
combination. It becomes stressful.

We have new ways to document; you have to be sure that what you say is legally relevant in
the current context. You have to constantly keep yourself updated. Sometimes it can be
confusing with all the changes. I feel that Sweden is spinning faster and faster. When I was
a newly qualified social worker, I thought I knew everything about laws and social
insurance, but nowadays I am not sure at all.

Support must be given to staff to deal with the griefs that are a normal part of their work
(Parkes et al., 1996). Formal support was attained via supervision, mentoring as well as
regular meeting with the team and clinic managers. The counsellors used informal support such
as finding someone in the team with whom they can openly share their feelings as well as
support through their private network of family and friends and activities that kept them
engaged and increased their well-being.

I talk to colleagues or someone in the team, with the doctor or someone you feel confident
with. How do I learn to be emotionally strong? Well, the older you get, the tougher you
become in some way. You’ve heard it all, seen it all. It’s good that you get older. You
become less afraid at work. I am not afraid of anything, but that does not mean I will not be
affected at all. I need the support of my colleagues and to know that we are there for each
other. Sometimes my colleagues call me because I have pretty extensive experience and that
makes me happy. I am not afraid and I do have the courage to talk to people at the end of
their life.

Personally I do not get so emotionally affected, but sometimes it can be difficult supporting
families. I talk with my colleagues, friends, psychotherapist, and supervisor. We always
have different supervisors after three or four years so that we can gain new perspectives and be able to think differently.

A lot of work can be delegated to the nurses since there are far more resources for the nurses as compared to the counsellor. It is important to take the help of the rest of the team. The thing that helps me a lot is the mentoring that I receive from my mentor. We have individual meetings once a month and I get to really talk about how I feel and the emotions that arise in certain situations and how I can handle it. We also have team coaching. I’m the only counsellor here, but I will soon get a colleague after the summer, which I’m looking forward to. I’m sure it will be great fun!”

The counsellor is an active member in the Palliative team and offers a range of counselling services to both the patient as well as the family members. In many cases he or she may even refer the family members to other relevant organizations such as Försäkringskassan etc. that may help them in practical matters so that they receive the appropriate support and help. Sometimes this can even involve getting in contact with government authorities and charity organisations outside the borders of Sweden. A counsellor gives a detailed example of how they helped to bring a patient’s mother from Calcutta. She explains that for something like this to take place it takes a lot of organizational support and cooperation in the team as well as between relatives and volunteer organizations. It is a great feeling when they succeed and know that they did their very best.

We had a patient, an Indian woman from Kolkata who was very sick. She had lived illegally in Sweden for a long time. It had been very tough for her. Many things had happened in her life. Her last wish was that her mother could come from India and meet her. She had not seen her in the last 10 years. Her mother was illiterate and very poor. So, we made a plan on how to bring her here. It was a monumental task and at first we were not even sure if it would work, but we decided to make an effort. The whole team was involved in the process. Somebody managed to contact her brother in India. He in turn had to contact a lot of people in India who could help to arrange for his mother’s passport. We then needed money for the air tickets. Some collected donations from voluntary organisations. We collected around 15 000 – 20 000 kronors from the Salvation Army. We had to fix her visa and I had to personally promise the Swedish embassy authorities in India to take responsibility for her stay. We fixed everything! Somebody went to pick her up at the airport. And then finally, she was here to see her daughter. It was such an incredible moment when she and her daughter met. She was a very strong woman. Her brother had told her not to cry and she did her best to hold back her tears. She had a very strong faith and truly believed that it would be better for her daughter in the next life. Her daughter died a week later.
Reflections on Life, Death and dying

The moment of death was a solemn moment for most of the counsellors. Death was also quite peaceful and led to moments of reflection. All the counsellors mentioned that death was usually very peaceful and not dramatic (Parkes et al., 1996).

Usually it is peaceful and quiet. It is a significant moment similar to the moment when one is born. I think if I had worked as a midwife, I would feel the same, on an existential level. I like to think that, life is like walking on a beach. There are footprints on the sand for a while and then the waves come and wash them away and the footprints disappear forever as if you had never walked there. It’s like blowing out candlelight. But one can also wonder, what? Is that all? Should it be like this? But on the whole, I think death is pretty un-dramatic.

Some patients may have difficult symptoms or have difficulty overcoming anxiety as they near death. But on the whole, hospital death is usually very peaceful. So when someone dies, it feels serene.

Every time I’m with someone who dies, I think that it becomes very quiet in the room. It is so definite. One minute there is a living human being there, even if he or she is asleep or unconscious and the next minute he or she is dead. There is such a huge difference when life vanishes; the body really is just a shell. I always think of the stillness that accompanies death. It gets so quiet when life in the body stops, the eyes close, the body becomes still, breathing stops. None of us know what happens to a person after death. Death is a single one-way trip. It’s about having respect for it.

It also depends on the age and if children are involved. Some people and families are more vulnerable in moments of death.

Of course, there is a huge difference between the deaths of a young guy who has a serious accident driving a motorcycle compared to elderly people who have been ill for quite a while. With children whose parent die, it is extra emotional. You need to prepare them before you go in and see the dead body. It may seem hard to do that, but it somehow it also feels good to help them. Some are crying, some screaming, some children might draw a drawing and put it on the bed beside their parent. So it can be really difficult to witness such scenes.

Sometimes the death of a patient spurred the counsellors to deeper reflections and write about their experiences.

Sometimes I write poems. It was a long time since I did that. I wrote a poem about a woman who had been here with us for some time and she died. She was a researcher from China. She was divorced with a teenage son and had struggled really hard. She wondered what would happen to her son, who would take care of him after she died? There was much that had happened in their lives. Luckily, there was an old professor who became his legal
guardian after her death. Her death was very special. The professor and his wife were here. She had struggled so much in her life but when she died it was very peaceful.

Most counsellors reflected on their role of caregiver and if their services were useful or made a difference to the patients (Papadatou, 2009). Bengt Börjesson (2009) says that the first step towards a professional introspection is to ask the question “Is there any meaning to what I do?”

When I feel that with my knowledge I have been able to contribute to a good death for a patient, that it has become less difficult for the patient and family and that I have helped their last days to be good while they have been here, then I feel happy and satisfied. The most difficult thing is when I do not know if I’ve managed to understand the patient’s needs or if I that feel that I might have missed out on something. Sometimes it is difficult to meet families where there is much hardship, violence, abuse, and so on.

I feel that I do a meaningful job. It is clear that it is extremely painful for a parent to say goodbye to his or her child but again it’s my job to support them in the best way. The kind of support that we give varies. E.g. it may be about a single parent who does not have a family network and then the question arises with whom the kids should grow up with afterwards. I do my best to help them. I get in touch with Social Services and see what we can do. Or could it be to inform and support the healthy parent on how to cope after the death of the other partner and how to be there for the child. These are difficult issues but if I can make a difference, it feels that I did a good job.

All the counsellors mentioned that although death is a universal fact, we, in Sweden are not very good at talking about death. Death is hidden away in the hospitals and it becomes unnatural (Clark & Seymour, 1999). We are not good at dealing with death and grief. The counsellors mentioned that through the years that they had worked as a counsellor they had found out that many people were terribly lonely and afraid of death. Perhaps it had to do with the fact that Sweden was a very individualistic society. Most felt that there had been a community in the old days due to the church. This had both its good and bad sides. The bad side was that people were forced to follow the church rules and it was very dogmatic but on the other hand a community existed because of the church. But today, in Sweden, the community has almost disappeared. People are very lonely here and this becomes especially more noticeable during the end of life unlike patients who come from other countries who often have a different culture and a wider network of friends and family. Sometimes, all of them are here much to the irritation of the caregivers sometimes! In Sweden we have a high standard of living but there is a longing for community and ritual.

With the advent of the hospital culture in Sweden, I believe that sick people were transferred to the hospital department and death and disease were hidden form the public.
So it ceased to be a natural phenomenon in the same way as it was earlier on. I think that the mindset that prevailed during the 70s was that we should protect ourselves from all painful experiences. So if death was hidden from view, one did not have to deal with the pain. But I think it gave the opposite effect. It became unnatural. Then came the reforms in Sweden, and people could finally choose where they wanted to die. Slowly but surely it will get better but we have a long way to go. I think people in general have too little experience of facing death and grief and crisis especially in relation to terminal illness. I also notice that many relatives do not really know if it is possible for the patient to die at home. I help them with information concerning the regulations. I grew up in the countryside and my mom’s sister died at home. They had her body in the coffin and everyone could come and pay their respects. Everybody was there, relatives and neighbours and many stayed for a few days. It was beautiful.

Firstly, the counsellors said that it is easy to get into this profession having high ideals. However, the constant exposure to death, they said could lead one to become emotionally exhausted (Papadatou, 2009). It is thus very important to take care of oneself because if you feel good, you can give a lot. One reflects a lot about life and death in this job. Death had become meaningful in the life of the counsellors as it taught them to become more aware of life and reminded them that there is no guarantee for anyone of us. They were grateful for their health and appreciated the little things in life everyday. So it was important to prioritize the important stuff in life and appreciate the moments that exist.

When you’re young it is easy to think you have all the time in the world but with increasing age and also when you’re working with terminally ill patients, you get reminded to live life well with your near and dear ones. You learn to be present and not postpone life. In this job you get reminded of your mortality. You never know how long time you have left.

This job involves a lot of interaction with public authorities, other government bodies, so it was very useful to have some experience working in those fields before starting here.

“I used to work as a “Biståndshandläggare” before I started here. “Myndighetsutövning” i.e. being a bureaucrat was not my thing, but I can still feel that the experience helped me greatly in this job. There have been countless times when I have been able to help patients get what they need by contacting Social Services and other organisations. That’s because I understand their working methods and know what help patients are entitled to. I think it is crucial to understand how the system works because then you know what issues you should lift and how to raise them”.

Relationships are the most important part of living a satisfying life. At the end of one’s life it was important to forgive yourself for all the all the things one has not done. There are things
that one will regret but there is nothing one can do except to forgive. Death is a sort of closure of your life. It involves a sort of acceptance.

I think that relationships are the most important in this life. I have seen so much of pain and loneliness among men who have invested everything in their careers and never took time to be with their family. They neglected their children and did a hundred different things and missed out on what's most important. There is much sadness there and they have a very strong need to be forgiven. We cannot expect everyone to be able to forgive, certainly not! One must talk privately about it, how did it happen, why did it happen etc. so that one can forgive oneself... Life is difficult and people are complicated beings!

**Discussion**

From the interview analysis, it has become clear that the counsellors saw themselves as an important member of an Interdisciplinary team of specialists that deliver Palliative care to terminally ill patients (Fine & Kestanbaum, (eds), 2008). They followed the Palliative approach, which is a holistic model that humanizes the care of dying individuals (Papadatou, 2009). The counsellor focuses in helping patients manage a wide array of psychosocial matters as well as alleviating anxiety in the process of facing death. The counsellor is skilled in assessing the contexts and coping strategies of the patients and families (Parkes et al., 1996). Through detailed assessment of a patient’s context using psychosocial methods such as KASAM, developed by Aaron Antonovsky and Logotherapy by Viktor Frankl they are able to recognize the mechanisms of the patients coping strategies as well as their meaning systems. Armed with that knowledge, they can navigate through the complex systems of meanings people attach to their relationships (Frankl 1990). They can then come up with relevant interventions matching the needs of the patient and their families.

The Counsellor is a vital link between different instances and provides assistance to the family members and relatives, both during the time of illness and after the death. Good communication skills are vital in assessing the patient’s emotional state and in elucidating their needs. Communication in psychosocial care is directed towards the expression of the patient’s thoughts and emotions and patients should feel that carers have a genuine professional concern for their welfare and also are genuinely trying to listen and to understand (Randall & Downie, 1995). Counsellors offer support at a deep level and take time to be with patient to minimise mental pain (Saunders, et al., 1998). They focus on building good relationships with the patient and families (Parkes et al., 1996). Through the use of effective communication skills identified by O’Berle & Davies they helped patients to alleviate pain
and cope through the crisis that people faced at the end of their lives (Davy & Ellis 2000). These skills take time to be honed to perfection and are acquired through experience.

The relationship between the patient and the counsellor take on a heightened significance. As such the counsellors mentioned that they needed to be aware at all times of the emotional costs of becoming too close to patients or their families and that appropriate boundaries are to be maintained for the best interests of everyone involved. The right distance varies with the nature of the relationship and the circumstances and as such counsellors tread a fine line of finding balance in relationships with patients and families (Parkes et al., 1996). One can become easily stressed owing to the highly emotional nature of the job and may lead to burnout (Papadatou, 2009). It is vital that they have adequate support via the team, supervisors, mentors as well as family and friends and find ways to replenish their energy so that they can be a true source of comfort for those facing their last days of life (Parkes, et al., 1996). Efficient teamwork and organisational support can help counsellors achieve results that give them a deep sense of satisfaction of being able to help patients and families. Counsellors understand the existential anxiety associated with dying. Due to the vast amount of experience they had, they felt that that many people in western society are lonely and fear death due to their lack of exposure to the death of others (Cohen & Deliens (eds), 2012). They also reflected on their role as caregivers (Bengt Börjesson, 2010). This introspection in turn enabled them to have meaningful existential conversations about life and death with patients.

**Conclusion**

Counsellors enter a dying person’s life at a most intimate time in his or her life cycle. They serve as the recipients for a lot of sensitive information. As such communication at the end of life needs to be conducted with sensitivity to and a deep understanding of the psychological processes entailed. Through their expertise of psychosocial methods and efficient use of counselling skills they assist patients and families through the often difficult and frightening journey towards death. Palliative care needs counsellors who are compassionate, wise, well developed and who have common sense combined with professional knowledge. In this way, they can contribute in giving good quality palliative care and be a true source of comfort for patients and families.
References


Appendix 1

Interview questions

1. General:
2. How long have you worked in Palliative Care? Why did you start working in Palliative Care? Is it motivated by personal experience or by other or something else?
3. Can you describe how it was the first time when you started and became part of the palliative care team?
4. Do you remember anything in particular that was good and something that you thought was not so good in the initial period of joining?

What methods or intervention do the counsellors have at hand for enabling them in this line of work that brings life and death into sharp focus? What is the nature of the partnership/relationship-role of the counsellor?

5. How do you accompany someone through a process to face death? Is there a clinical or theoretical model that you work from?
6. How do you create relationships between dying patients and caregivers?
7. Being present: What does this mean for you? How are you present, both physically and mentally, with patients?
8. Have you had any experiences that you never forget when you felt really present?
9. What does involvement with a dying patient mean? What is a good level of participation?

10. What does a professional relationship to you? Is there anything personal in a professional relationship? What does it mean in this case?
11. Do you have time to build close relationship to the patients?
12. Have you had any patients that you became especially close with? Can you tell a little more about what it was that made you became close to each other?
13. What does it mean to be emotionally involved with a patient?
14. What does it mean to be either too emotional or aloof?
15. What advantages and disadvantages are there with their respective approaches?

What challenges do the counsellors face due to their work where one is constantly reminded of the fragility of our human lives and our purpose in it?
16. Do you feel discomfort and anxiety for patients suffering very much? Can you tell us about both how it feels for you physically and mentally?

17. Have you experienced death many times?

18. How do you handle it?

19. Is it emotionally stressful working so close to death?

20. How do you manage it?

21. What is a healthy approach to death, do you think?

22. Have you been present when a patient has passed away? What did you experience in the moment? Feelings, thoughts?

23. Is death different in different contexts? Children, adults, close contact?

24. Are there specific patterns in yourself that you can tell us about? Some examples of what you usually do?

25. How do you feel afterwards when a patient has passed away?

What risk factors does the work entail for their mental health?

26. How do you handle the heavy work in your workplace? What risk factors exist at work? Mentally and physically?

27. Do you talk about it with the others in the group?

28. Can you show your feelings to others in the group? Do you suppress emotions?

29. What support is available in the workplace? Managers? Specific support people?
   Specific discussion groups / forms of support? Health?

What has changed in Their Own view as to the meaning of life and death? How do they make sense of the system?

30. What is the belief system do you have? Are you Spiritual? Religious? Multi Dimensional?

31. How do you relate to patients who are atheists and do not believe in god?

32. How do you relate to patients who are faithful and believe in a god?

33. What have you learned in your job about the meaning of life?

34. What are your thoughts on death?

35. How do you view your identity as a caregiver? Has it changed since you started?

36. Have you developed since you started? In what way?

37. What feels good and what is it that you think could be better? Have you been able to influence the system?
38. Do you think you are doing a meaningful job? What feels most satisfying? What is difficult?

39. What would you say to social workers who want to work in palliative care

40. What can they contribute to the on-going palliative care debate through their own experiences? Do they actually contributed to the debate - how in that case? Are there situations where they can be / are involved in discussing / debating approach in palliative care? Conferences, journals, etc.?