DEATH & DYING: WORKING WITH CLIENTS AT THE END OF LIFE

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ABSTRACT

The last century has seen significant changes in how people experience death. There has been a growing discourse about end of life issues and how they affect people. Death and dying are no doubt difficult issues for people to contemplate, including professionals who work in end of life care, however research is beginning to explore how people manage the end of life and what societal issues influence it.

The purpose of this research study is to gain a deeper understanding of the values and beliefs of end of life care social workers regarding death and dying, how their experiences may affect their work with clients who are dying, as well as the supports they have access to in order to manage the challenging work they do. This study explored the experiences of six hospital social workers who work with people who are dying and their families. Qualitative research methods were utilized so that participants could fully share their unique experiences.

The findings highlighted that end of life social work is challenging, complex and fraught with tensions that can lead to frustration and stress. The narratives indicated that high value is placed on a positive dying experience, but due to certain barriers there are struggles in achieving this. Further challenges came from competing demands, such as meeting the needs of staff as well as clients. The value of the social work role was found to be a point of contention for the participants, as they struggled with power imbalances and often fought to have their professional voice heard. Finally, the interviews pointed out that social workers must manage these challenges with few formal supports. This study offers an in-depth exploration of these issues, how they have and effect on social works' involvement with people at the end of life, and what needs to change to ensure social worker's in end of life care are supported.

ACKNOWLEDGEMENTS

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INTRODUCTION

Despite its inevitability, or perhaps because of it, discussing the topic of dying is often difficult, if not taboo. How the end of life is viewed can be influenced by many factors, such as upbringing, personal experiences, and individual beliefs and values; but our perception of these experiences is also influenced significantly by the historical and cultural context in which we live. The dominant discourse on death and dying has changed significantly over the last century as the common circumstances of how people die have shifted over time.

Changes in the dying process have led to an increased interest and involvement in issues related to end of life, such as end of life care, decision making and professional intervention. Specifically, there has been increased concern regarding the quality of life people experience as they die, as well as the quality of their death. The concept of a 'good death' has become prevalent in our society. Our ideas of what constitutes a 'good death' are probably personal and individual and are likely dependent on societal and cultural norms and practices.

The social work profession has gradually come to play a role in end of life care, providing support and guidance to clients who are dying, as well as their families. Given that death and dying are topics that are difficult for many to address openly, social workers likely face many challenges in their daily work. This study considers the experiences of social workers in end of life care within a hospital setting.

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LITERATURE REVIEW

A review of the literature on end of life issues has revealed that there is a considerable amount of information regarding a variety of concerns related to this study, much of it coming from the United States and the UK. Three distinct bodies of literature have been identified as relevant to my research and have informed this study. First, literature on the changing nature of death was explored and provided information about how our society's understanding and management of death has changed over the last century. Second, literature on society's beliefs and values regarding death and dying gave insight into issues such as our fear and denial of death, our ideas of normality, and finally what we consider to be a 'good death', and conversely a 'bad death'. Finally, literature on the role of the social worker was reviewed and provided information on how the values and beliefs of social workers can influence work in end of life care, the need for self-awareness and insight into personal values, as well as the challenges of working on an interdisciplinary team.

Literature on the Changing Nature of Death and Dying

Several studies discuss how until relatively recently, in western society, the end of life was experienced very differently than it is today. It used to be the norm for people to die in their own home, with the involvement of family in the caretaking and dying experience. Dying used to be considered an experience that was inevitable and the focus was on the comfortable transition from life to death and finding a meaning for death. Due to the lack of effective medical treatments, there was little a physician or hospital

could do for a seriously ill person (Bern-Klug, Gessert & Forbes, 2001; Luptak, 2004). However, over the last century the reasons for death have changed considerably, with more deaths in contemporary western nations being due to chronic illness, rather than acute ones. Today, two thirds of all deaths are due to chronic illness such as heart disease, cancer and stroke (Bern-Klug et al., 2001). Luptak (2004) suggests that when the causes of such chronic illnesses and diseases were discovered, hospitals were increasingly utilized to study illness and to treat sick people. Today, more people in developed countries die in hospitals than at home or in hospices. In fact, hospital deaths have been rising steadily. For instance, in 1960 only 50% of people in England and Wales died in hospital compared with 66% for the whole of the UK in 1996 (Seale, 2000). Bern-Klug et al. (2001) concur with this, and suggest that about 60% of deaths occur in hospital today.

Significant advances in medical technology throughout the 20th century have contributed to changes in how, when and where people die. More specifically, the "application of technology to human beings has given society the ability to create life, to improve life, to sustain life and to prolong life" (Miller-Chenier, 1996, p. 1). While it can likely be agreed upon that the increasing use medical technology is advantageous in many circumstances, there has been growing concern regarding the increasing use of medical technology for the purpose of prolonging life, debate about the validity of implementing life prolonging treatments and conjecture about the purpose and value of extending life and what is to be gained by doing so (Kaufman, 2000). Consequently,

Miller-Chenier (1996) suggests that we need to consider the impact of technological

practices on the individual, communities and society in general.

With the shift to increased medical technology and increased reliance on medical

institutions, the dying process itself has become more medicalized, with more complex

medical decisions needing to be made, and those decisions being placed in the hands of

the medical professional rather than the family (Luptak, 2004). Increased medicalization

and institutionalisation has led to interventions, or some might say interference, in the

natural dying process, which in turn has led to criticism and concern about the

dehumanizing emphasis on cure over care (Mackelprang and Mackelprang, 2005; Seale,

2000).

It is clear that there have been many changes in how people die in contemporary

western society, particularly over the last century. Increasingly, death occurred more

from chronic illness, and more often in an institution such as a hospital. The dying

process became more complicated, and it became evident that there was increasing

concern about the cure oriented nature of medicine versus the care of the individual.

Literature on Society's View of Death and Dying

As concern over intrusive and possibly unnecessary medical interventions grew, a

gradual shift in thinking about the way people experience the end of life occurred, and

there was an increased focus on care of the individual. Zilberfein and Hurwitz (2003)

point out that social movements in the 1960's and 1970's, such as civil rights, feminism,

and the autonomy movement in medicine influenced the empowerment of the individual.

Thus, "health care decision making shifted from a model that fostered medical

paternalism to one that supported autonomous decision making, thereby imbedding the right to self-determination in the U.S. health care policy" (Luptak, 2004, p. 9). For instance, in 1990 the U.S. congress implemented the *Patient Self-Determination Act* (PSDA). This legislation necessitates that health care providers, such as hospitals, provide information and facilitate open discussion about end of life decisions (Mackelprang and Mackelprang, 2005). While there is no equivalent legislation in Canada, there is advance directive legislation throughout the Canadian provinces, such as the *Health Care Consent Act (1996)* and the *Substitute Decisions Act (1992)* in Ontario, and the *Health Care (Consent)* and *Care Facility (Admission) Act* (1996) in British Columbia (Carstairs, 2005).

Elligson and Fuller (1998) point out that in contemporary Western society there is an overwhelming focus on individual autonomy and self-determination as a personal value, likely perpetuated by our society's focus on individualism, self-reliance, self-control and independence. Having control over one's life and decisions that affect it is seen as a measure of independence and being independent is considered to be a determinant of success in our society. Indeed, as Seale (2000) suggests, there is a tendency to plan for and control major life events in our modern societies, seen in our use of retirement planning, savings accounts and insurance plans.

This focus on control and self-reliance likely influences not only how we live, but how we die, and "gradually, dying too becomes subject to this wish for control" (Seale, 2000, p.22) With an increased focus on empowerment of the individual and individual autonomy, our society has witnessed an increased concern regarding patient autonomy

and self-determination. In health care, the concept of autonomy pertains to competent patients in addressing their consent to, or refusal of, medical interventions (Osman and Perlin, 1994). It seems that the issue of autonomy has become of fundamental importance in health care in general, and particularly in end of life care.

Given that independence and self-reliance are so important in our society, what are the consequences of losing them as health deteriorates? Lloyd (2004) argues that loss of independence, or an increase of dependency on others, means a loss of autonomy, and in turn means that the individual has failed in some way. In fact, Abel and Nelson, (2001) suggest that because of modern society's focus on independence self-respect itself depends on autonomy and control, causing people who are disabled to be viewed as lesser human beings. Keigher (2000) agrees with this view, and further argues that the same could be said of people who are dying.

Lloyd (2004) posits that "there are inherent tensions between the ideals of autonomy and the physical and social constraints that are generally placed on the dying person" (p. 244) and that the dying have an uncertain position in society due to their decreased status. Lawton (cited in Lloyd, 2004, p. 239) further suggests that we need to consider why decline and deterioration before death are viewed in such a negative light by ourselves and society as a whole. Our society's fear of decline seems to stem from fear of losing the independence and control that is so highly valued. Most people would also agree that fear of death, and the death anxiety that may accompany it, is also prevalent in our society. Some of the literature discussed fear of death and death anxiety as stemming from many aspects of the end of life, including fear about the process of

dying (which often includes decline), death itself and what occurs after death (Lloyd, 2004; Zilberfein and Hurwitz, 2003).

Literature on death denial was explored and it was found that the idea of death denial is prevalent in our society and seems to be expressed in different ways. Denial may be viewed as an individual function, something that a person experiences, generally either someone who has a terminal illness, or a healthy person facing the death of a loved one. Elizabeth Kubler-Ross (1970) wrote about death denial as one phase in a series of stages a person goes through when dying, effectively focusing the experience of death denial on the individual. Even though Kubler-Ross' stages theory has since been widely criticized and the idea that people must pass through stages in progression has been debunked (Goldsworthy, 2005), there remains the fact that people who seem to fail at 'accepting' death, may be labelled as 'in denial'. Planalp and Trost (2008) discuss theories that seem to perpetuate the idea that denial is an individual experience. For example, Problematic Integration theory emphasizes the cognitive work that needs to be done in order to come to terms with impending death. Their study with hospice volunteers also demonstrated that denial was the predominant issue of concern to their participants, who reported that communication about death, between patients and family members, was often difficult. It was noted by the authors that despite society's efforts to enhance communication about death, there continues to be "profound ambivalence and avoidance" (p. 229) in doing so.

Some literature also explored death denial as a social construct that is affected by current social influences. Some suggest that society's death denial comes out of the

changes that have occurred in the way we die. For instance, Luptak (2004) argues that

death denial has become prevalent in society because the experience of dying has

changed and become less visible, i.e. in institutions. Bern-Klug et al. (2001) suggest that

denial occurs because dying is not acknowledged or recognized except in specific

circumstances such as end-stage cancer or irreversible disease, and that "we have also

traded in a dying process that was straightforward and recognizable for a dying process

that is often unrecognizable, invisible, and confounding" (p. 38).

Zimmermann (2004) discusses the various views of death denial, including the

idea that denial is an individual defence mechanism, but ultimately purports that denial is

part of a broader societal view of dying that supports participation in the dying process

and labels anyone who does not comply as 'in denial'. In a later study, Zimmermann

(2007) explores death denial further and suggests that fear and denial of death have likely

always been in existence, but they are now seen as modern problems, reflecting the

dominant discourse of our society, which is that there is a proper way to die. She posits

that in our society there is significant interest in controlling the dying process which

comes from the changes in how we now die. She notes that "out of the necessity for

managing death in modern society, a new narrative on death denial has emerged...the

personal struggle with mortality has become an important instrument in the public

problem of managing the dying process"(p. 310).

Literature on a 'good death' was reviewed and suggests that in our society this

concept has become prevalent. While it is likely that dying well means different things to

different people, the literature notes specific elements that many people believe are

necessary in order to achieve a good death. Both Zilberfein and Hurwitz (2003) and

Bern-Klug et al. (2001) report that an ideal death for many people, including dying

respondents in Zilberfein and Hurwitz's study, would involve pain and symptom control;

being physically and mentally competent; maintaining a sense of control; and having

positive and/or restored relationships with loved ones prior to death.

A study by Seale and van der Geest (2004) also explores what contributes to a

good or bad death, but across several cultures, and found that some common elements in

a good death included: participation and control in the dying process; dying after a long,

successful life; dying peacefully at home; and adequate pain control. They also found

that in developed countries there is an increasing belief that control over the timing and

manner of one's death is an element of a good death. Similarly, Lloyd (2004) suggests

that autonomy and independence are also highly valued as elements that contribute to a

good death. While it seems that there are many common elements of a good death within

our culture, and across cultures, it is important to point out that there are also differences

in what makes an acceptable death between different groups within the same culture

(Seale and van der Geest, 2004).

Dying at home and/or in the presence of family and loved ones seems to be a

common element of a 'good death'. It could be argued that, for many, if this does not

occur a 'good death' has not been achieved. Seale has authored two studies that address

the experience of dying alone. In his 1995 study, Seale explores the experience of dying

alone, whether at home or in hospital, and argued that we consider this as a form of 'bad

death'. Indeed, the majority of respondents in his study reported that it was regrettable

that their loved ones had died alone and they wished they had been with them when death occurred.

While there are clearly elements that individuals believe contribute to a 'good death', it is important to consider broader issues that influence our search for an ideal or good death. For instance, our ideas of normality may play a role in our views of an ideal death. Kaufman (2000) suggests what society considers normal and abnormal (or pathological) is socially constructed and changes over time as scientific and social contexts change. Zilberfein and Hurwitz (2003) also talked about the social construction of death and suggested that in the quest for a 'death with dignity', we need to understand that dignity itself is "socially constructed through belief systems, experiences, and culture" (p. 304). It therefore makes sense that what individuals view as acceptable, or desirable, at the end of life is swayed by what is currently happening in our society.

Freud (1999) also explored the issue of normality. She suggests that we view normality as an ideal, one that is driven by our values about what we consider desirable in life, or we could argue in this case, at the end of life. It is likely that our ideas of normality contribute significantly to what we consider to be acceptable during the dying process. It could also be argued that society's views on independence, autonomy and control, as previously discussed, are seen as normal, while loss of these personal characteristics means that we are somehow abnormal, because we have failed to achieve an ideal way of living.

Earlier, we discussed that dying alone is considered an element of a bad death. Interestingly, in his 2004 study, Seale suggests that the media plays a significant role in

constructing this idea. He puts forth that "dying alone is represented (in the media) as a fearful fate and a moral affair, often being the outcome of an undesirable personal character, either of the deceased or of onlookers, or involving the failings of society at large" (p. 967). It is clear that media portrayals of 'bad death' serve to perpetuate what is considered a 'good death' in our society. It is also evident that there are 'ideals' that contribute to what society considers a good death, and these ideals are based on our ideas of what is normal and acceptable. Seale (2000) proposes that even common end of life experiences such as pain and grief are not considered a normal part of dying and that society views them as "illegitimate disturbances to the normal pain-free existence everyone has a right to expect" (p. 26).

'Ideals' create an image of an experience that likely will not be attained for most people. While some people may achieve what is meaningful for them in their death, society's expectations to achieve an ideal death are often unrealistic and may increase anxiety for people when they cannot be attained successfully. Indeed, Zilberfein and Hurwitz (2003) suggest that anxiety can also occur for people simply because they know that an 'ideal' death seldom occurs.

The way that people view end of life today has evolved. There is more focus on maintaining control, autonomy and independence, with those who lose these more likely to be considered as failing in some way. It is argued in our society that fear of death and death denial is prevalent, and that this leads to a wish for a 'good death'. Elements of a 'good death' seem to be shared by many people and seem to contribute to an ideal way of dying, which in turn is based on our ideas about what is normal. Clearly, how death and

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dying are viewed and understood shapes the experiences people have at the end of life, but also impacts the work of social workers who work with people who are dying. Literature regarding this issue is explored below.

Literature on the Role of Social Work in End of Life Care

Social work has been developing as a legitimate profession for over a century now, with social work in health care gaining steady ground throughout the 20th century. Around 1900, the introduction of medical social work was greatly influenced by the physician and educator Richard Cabot when he put forth that medicine and social factors combine to affect physical well-being (Luptak, 2004). Throughout the middle of the century the prominence of social work in hospitals grew, with an increased demand for social workers in health care in the 1950's and 1960's. In the 1970's, as technological advances improved the efficacy of medical treatments for those with serious illnesses and increased the amount of choice and information available about end of life decisions, there began to be more interest and focus on death and dying in social work practice (Luptak, 2004).

Today, the role of the social worker within health care, and specifically in end of life care, is multi-faceted, with many responsibilities and challenges. The literature demonstrates that there are numerous elements of the social work role, and myriad expectations of a social worker who works with people at the end of life. For instance, Luptak (2004) provides an extensive list of social work activities with dying patients and their families, including "referral, brokering, and generic problem-solving services; emotionally supportive and bereavement counselling; and psychosocial assessment" (p.

11). Consulting with other professionals and supervising volunteers were also noted as responsibilities of a health care social worker. Csikai and Bass (2000) completed a study with end of life social workers and found that one of the most important activities for them was acting as a liaison between clients and other health care providers. Clearly, the role of a social worker in end of life care encompasses numerous responsibilities geared at meeting the unique needs of clients who are dying.

It is clear that the role of social work within health care has transformed and grown and there can be no doubt that it will continue to adapt to our transforming health care system. Regardless of changes in the health care system, social work has consistently strived to position itself as a legitimate profession that has special expertise in addressing the psychosocial wellbeing of clients. As the medicalization of dying increased, social workers began to use their clinical expertise when working with clients at the end of life, which meant there was increasing knowledge available beyond the traditional medical expertise (Seale, 2000; Zilberfein and Hurwitz, 2003).

Social work within a health care setting such as a hospital generally means working with a wide variety of people, and a social worker's values and feelings about death may differ from her colleagues and clients. There seems to be a lack of literature regarding the conflict that can arise when there are competing value systems between social worker and client. However, there is considerably more literature on conflict that can arise within the interprofessional team. Problems including a lack of knowledge about the role of the other professionals, confusion about professional roles and responsibilities, and opposing values can contribute to conflict between professional

members of a health team (Davidson and Foster, 1995; Gregorian, 2005). Interestingly, competition between nurses and social workers has been noted to cause frustration for social workers, who feel that their responsibilities have been appropriated by nursing (Reese and Sontag, 2001). Zilberfein and Hurwitz (2003) suggest that social workers "on interdisciplinary teams must have sufficient self-esteem to thrive in an environment where all team members see themselves as counsellors" (p. 320).

Despite the challenges of working on an interdisciplinary team, acting as a liaison is a necessary part of a hospital practice and must be navigated by many social workers. In their 2000 study, Csikai and Bass noted that "as social work is not the primary profession in health care settings, the liaison and team member roles have long been recognized as vital" (p, 17). They further suggest that social workers can act in a liaison role to foster the communication about end of life decision making that is needed to ensure clients experience a good death.

As in all areas of social work, social worker's levels of awareness of their personal and professional value system are likely to play a significant role in how they work with clients at the end of life. Specifically, various issues such as professional experiences, and personal perspectives and attitudes influence social workers and their work (Mattison, 2000). Engaging in examination of personal values, beliefs, attitudes and fears about end of life is recommended to health care social workers within the literature, suggesting that this is necessary for effective social work practice in end of life care (Mattison, 2000; Zilberfein and Hurwitz, 2003; Csikai and Bass, 2000).

However, there is some concern about the level of preparedness that social workers obtain to work in end of life care, and "in today's death defying society, few may be aware or have confronted their own feelings and values regarding their own mortality" (Csikai and Raymer, 2005, p. 68). Csikai and Bass (2000) recommend that social workers attempt to engage in exploring their own feelings about death, suggesting that "efforts might focus on professionals' comfort level in discussing death and dying and examination of professionals' own issues and values regarding quality of life and care at the end of life" (p. 16).

The literature that was reviewed shows that the role of the social worker in end of life care has grown with the many changes that have occurred in health care over the last century. In the face of significant changes to how social work in implemented in the hospital system, the profession continues to affirm its identity as one that can offer expertise in the area of end of life care and fulfill numerous responsibilities to clients and staff, including acting as a liaison between those two parties. The literature suggests that social workers must be prepared to navigate the conflict that can arise due to professional and personal value differences between themselves, staff and also clients. Awareness of personal feelings and beliefs about death and dying is necessary in order for social worker's to provide effective care to those who are dying.

METHODOLOGY

In this study I utilized qualitative methods in order to explore the experiences of social workers who work with clients at the end of life. Qualitative interviewing allows the researcher to conduct an "open-ended, in-depth exploration of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight" (Charmaz, 2003, p. 312).

Recruitment

Potential participants were recruited through a local network of hospitals. I am not employed in this system, so a colleague provided me with information about a supervisor within the social work department. This supervisor was able to have direct contact with all social workers in this hospital system, so could provide assistance with recruitment of social workers working in a variety of hospital settings. This person was contacted and given information about the study in order to ensure that this was research in which the hospital wished to be involved. When it was clear that this would be suitable research, the contact was then requested to provide a letter of information (Appendix A) to potential participants who worked in the hospital system. It is my understanding that this supervisor did not forward the letter of information to the entire social work staff in the hospital system, but rather sent it by email to a group of workers that she selected. Potential respondents were provided with my contact information, so they could contact me directly if they were interested in participating in the study. This

ensured that the participants' supervisor would not be aware of who chose to participate, and participants would not feel obligated to participate.

The Study Sample

I sought a sample of social workers from a range of hospitals in the area to ensure that a varied population of workers, working with a variety of patient populations, was involved in the study. A convenience sampling approach was used. This approach draws upon pre-determined populations (such as hospital social workers) and uses a period of recruitment that continues until a set number of participants are obtained (Luborsky & Rubinestein, 1995). There was an immediate response to this research by a variety of social workers, which was very encouraging. As I was seeking a convenience sample, and because there were more respondents than could be accommodated for the purposes of this study, the participants were chosen on a first come, first served basis. A total of six respondents participated in the interview process.

The study sample consisted of social workers who work in a variety of departments throughout the hospital system, including intensive care, emergency and oncology. The sample included five women and one man, which reflects the high proportion of women employed in the social work profession. There was a wide range of length of time working in social work, from just a few years to over fifteen years. The sample was racially homogenous as all participants were white. Ages of the participants appeared to range from approximately mid-twenties to early fifties.

Ethics

In order to ensure the confidentiality of the participants, a number of measures were employed. I recruited from several hospitals rather than only one, so as to make it more difficult to identify participants. As discussed above, during the recruitment process, the potential respondents were invited to contact me directly so that their supervisor would not know if they had chosen to participate or not. Contact with the respondents prior to the interviews was limited to brief telephone conversations. Some identifying information was necessary for contact purposes, but was kept in a secure location only accessible by me. Through the information letter, participants were informed that the raw data they provided, recorded on an audio recorder and by hand, would be handled by a minimum of people, limited to me, my research advisor, and a professional transcriber and that no identifying information would be included in the final thesis. At the beginning of each interview, the participants were provided with a copy of the letter of information and a consent form (Appendix B). They were given the opportunity to read it and ask questions. They were then asked to sign the consent form if they wished to continue in the interview. I changed the names of the participants to ensure their confidentiality. Further, I have referred to all participants as female to ensure that particular quotes cannot be linked to the one male participant.

Due to the sensitive nature of the research topic, there was some level of emotional and psychological risk to the participants. All participants were reminded that they could stop the interview at any time or withdraw from the research at any point in the process. A few participants became slightly emotional during their interview,

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particularly when discussing their personal experiences with death; however, when offered, none of them chose to stop the interview due to their discomfort.

The Interviews

Interviews were arranged with each participant when they contacted me by telephone, according to their availability and preferences. Most of the interviews took place at the participant's place of employment during work hours, either in their office or in a private room of their choice. However, one interview occurred at my place of employment in a private interview room, as it was easier for the participant to attend outside of work hours. One interview had to be rescheduled as the participant was busy during her shift. The interview took place later at a time suggested by the participant. A few of the interviews were interrupted either by a colleague of the participant, or by phone calls being received. When this occurred, the interview was paused for the duration of the participants' conversation.

As discussed in the ethics section, all participants were given the opportunity to read the letter of information and sign the consent form before the interview commenced. I then provided some information about myself to the participants, including my educational background, where I currently work, my experience (or lack thereof) in dealing with end of life issues, as well as my interest in the research topic and how this interest had developed. Participants then took part in one semi-structured interview that lasted approximately one hour. The interviews were guided by a pre-arranged set of questions. Participants were asked to share their experiences of their work in end of life care. They were asked questions that focused on their experiences and challenges in their

work, how their personal views and experiences influenced their work, and what kind of support they received in their work environment. The interview guide is included as Appendix C. During the interview I took some field notes; however all interviews were digitally recorded, with the participants permission, to ensure their information was thoroughly captured and could be properly represented in the analysis.

Data Analysis

To analyse the data that was obtained through the six interviews I utilized Grounded Theory techniques. Grounded Theory involves the process of coding the data, which "entails the researcher capturing what he or she sees in the data in categories that simultaneously describe and dissect the data" (Charmaz, 1995, p. 320). Early in the research process I began to search for common ideas and experiences through reviewing the notes that were taken during the individual interviews. This gave me some initial ideas about possible common themes within the data. However, it was when I began to review and code the transcripts of the interviews that I began to see specific ideas and issues that were inherent to all the interviews. Through further analysis of these various issues, several themes emerged that represented the experiences and views of the participants.

Limitations of the Study

There were several limitations to this study. Due to the necessary cap on the number of participants, the chosen participants were the first to contact me. Consequently, several palliative care social workers who wished to participate could not be included in the sample. As palliative care workers work exclusively with people at the

end of life, it is possible that their contributions may have emphasized different issues, and/or provided more richness to the data.

While I was an insider in the sense that I was a fellow social worker, I could also be considered an outsider in that I do not currently work in health care or with people who are dying. Further, I have very limited experience with death in my personal life. While I am fortunate for this, it is possible that my lack of experience and my position as an outsider may have made it more likely for me to miss crucial pieces of information or "clues" that could have led to further exploration of issues of importance to the participant. Indeed, upon review of the data, I have noted some comments that could have been explored more deeply, but instead were left when I asked another, unrelated question.

The size of the sample means that the results of the study cannot be generalized to a wider population, as is typical of qualitative research. However, as it was my intent to get a better understanding of the experiences of social workers who work closely with dying patients, the sample size was manageable and it was possible to get a sense of the rich and complicated experiences that the participants have in their daily work.

FINDINGS

Three themes emerged from the participants' interviews. The first theme explores the idea of positive dying, and looks specifically at dying with dignity, achieving a good death, as well as the role of the social worker in helping with dying. The second theme discusses the competing demands that the participants experience in their work, from balancing their personal views with their professional role, to mediating the needs of both their clients and their colleagues and meeting the needs of those people. The third theme that emerged was in regard to the support for the social work role as the participants experienced it. This area focuses on how the participants feel their role is valued, and on what kinds of support are available for them as they fulfill their role as social worker in end of life care. To illustrate the participants' views on the subject matter, I have included quotes from their interviews. I have replaced their real names with pseudonyms to protect their privacy and to ensure that confidentiality is maintained.

Positive Dying

Dying with Dignity

For most of the respondents, the issue of quality of life and dying with dignity is prevalent in their daily work with patients and families. This was mainly centred on both their own concerns about the quality of life of patients at the end of their lives, as well as the families' concerns about the quality of life of their loved ones. Through our discussions it became evident that people hold different views about what represents an

acceptable quality of life, and that these views are inextricably linked to their personal

beliefs regarding death and dying.

Joanna talked about her work with families who are concerned with the quality of

life of their loved one and who have a good understanding of what measures their loved

one would want taken:

> ...they would see their family member on life support and say 'my family
> member would never want that'.

Catherine discussed how some families need assistance with understanding the

consequences of certain procedures on their loved one's quality of life:

> And really sometimes you really have to work with them, 'what did your loved
> one want?' You know it's not what you want, you want them to stay, you want
> them to live but you know, is this how you want them to live?

Catherine also expressed her concern over prolonging a patient's life when she felt his or

her quality of life would be lacking:

> ...if they're 86 and they're still doing extremely well I'll say yea yea for sure go
> for it, they've good quality care, good quality of life and you know they've got all
> their faculties...but it they don't have good quality what are you bringing them
> back for?

Sheri, who sometimes works with children, recalled the different beliefs and wishes

of families that she works with:

> ...there's some families where the end goal is life regardless of the quality of
> life...and they will say to us we want our child to survive despite you know
> whether they may or may not have a good quality of life. And then there are other
> families who will say no, I only want my child only if they're going to have a
> good quality of life or an acceptable quality of life.

She goes on to discuss her own views on this matter:

> I also am very quality of life focused (but) I don't think I have the right to say
> what's right for them.

For the social workers interviewed, challenges arose when there were differences in perspective such as the ones explored above, particularly when the differences were between families and staff. Several of the respondents discussed their experiences when this would occur. Tamara talked about her personal beliefs about quality of life and how they clashed with one particular family that she had worked with:

> …this woman was not going to live very long. However, her family - and I'll never forget this - her family was life at all cost…and even though we never had the opportunity to ask her, I often wondered would someone you know, being so young, knowing that her outcome was so dire, would she still want to live in this environment this way. And in my mind I thought well if I were her I wouldn't. And that kind of clouded my judgement in terms of assisting this family because there came a point where I thought they were torturing this poor girl.

Joanna spoke about how she sometimes didn't agree with decisions that a family would make and how it affected her personally:

> I definitely see things and I think no, I'll never do that for my family member, I'll never prolong things in a way where the person is so obviously suffering…

She talked about families who are opposed to withdrawing treatment, when the staff believes there is no purpose to treatment:

> …eventually there may be a meeting where the doctor says well, we have done everything we can do…we're prolonging the person's life and their suffering…and sometimes the family tends to say no no and really really struggle with it for a number of reasons…

Catherine also discussed families who had differing views from the staff and the work she did with them around this:

> I had gotten the family to agree to stop [treatment] and they had totally been against it and wanted everything done and I'd gone through it, working for hours… (Catherine)

The interviews with the participants demonstrated that there is a significant focus on quality of life in end of life care, but what constitutes quality of life is challenged in

their day to day work. There was a sense that the social workers had an easier time aligning with families who shared their viewpoint and agreed to 'let go' of their family member, but it was more challenging for them to participate in prolonging a person's life if they believed it compromised quality of life. Further, there seemed to be a need to try to 'convince' families to let go when the individual worker or the hospital staff felt there was a diminished quality of life. This suggests that there is a need to control the dying process in some way.

Achieving a 'Good Death'

As we cope with the growing complexities of end of life care, the goal of achieving, or supporting, a 'good death' or a 'death with dignity' has become increasingly common in our society. The respondents in this study discussed their ideas about what a good death looks like and their role in trying to contribute to a positive dying experience for the patient and the family. Some related positive experiences and discussed what they felt contributed to a good death for a client. Participants also spoke about difficult deaths and what factors contributed to them.

Both Linda and Catherine talked about some very positive experiences with their clients who died:

> It was a good death because I think we did everything we could and we made it a safe death and a death well cared for and we did have an opportunity to get feelings out…we did what we could to make that as good a death as possible. (Linda)

> …we've been sitting here with him and you know he's quiet, he's peaceful…it was a peaceful day. (Catherine)

Janice became emotional when she related a story about helping a family gather with their dying mother in a hospital chapel to sing and pray just before her death:

...and so they sang hymns, they just sang hymns for ten to fifteen minutes and it was powerful and amazing and religious and emotional.

Also discussed were specific elements of a positive death, particularly by Linda (who also has past experience in palliative care). She noted communication and participation as important factors in a good death:

> ... we need to do to make sure that when you have your last days have you done all the things in your life that you feel you can do at this moment or that you've had the chance to say what you need to say to the people in our life you know...We need to start talking about how does one kind of do this (dying)...

Linda also related that she feels that to achieve a good death it is important to provide the option of dying at home:

> ...where you can be in your community, in your community with your friends, surrounded by your stuff, in your bed, watching your TV...

...but that she was concerned that this was not an available option much of the time because of the shortcomings of care in the community:

> ...we're never going to make it what it needs to be (dying at home) if we don't see that as something important.

In their discussions about dying several of the participants also talked about negative dying experiences for the patient and/or the family. For instance, Linda discussed parents who have had extreme difficulty managing their child's death, and alluded to the sense of responsibility she felt about this:

> I know parents who've attempted suicide, become alcoholic; you can tell horror stories happen...I feel like gosh, we should have done something better.

Tamara observed that the people she worked with were too hardened by death and it tends to be a taboo subject, making the dying experience less positive than it could be:

> ...you're faced with this so often that walking with someone, walking that journey with someone doesn't have that same warmth that one would expect in certain environments.

Joanna talked about the people who die in her unit:

> I think that [it] is a difficult place to die...everybody struggles with (it) because you know that this isn't really what people want. If you're dying you want to die in a place where you feel comfortable...

Catherine discussed the negative effects on family members when a death is sudden or

unexpected expected:

> Sudden deaths I think are the hardest because then the family's not expecting it, they've had no time to grieve or to work through this you know and it's much harder for them.

She also noted that:

> Sometimes when family members go home and it ends up that the patient passes in the night then they're guilt ridden to say we shouldn't have gone.

The participant's reflections have given a clearer idea of what comprises a 'good

death' and a 'bad death' for them. Some elements of a 'good death' that the participants

focused on included communicating feelings about dying; promoting a peaceful and

beautiful experience; and dying in comfortable surroundings such as at home. They

discussed negative elements such as not doing enough to make a death positive; lack of

communication about death; dying in an institution; and death occurring suddenly,

without family present. These findings highlight what they consider to be 'ideal' in the

dying experience. It is also evident that, for the participants, there is considerable concern

over the experience of dying, and that high value is placed on achieving a 'good death',

for the patient, but perhaps even more for the family and loved ones. The findings

suggest that achieving a good death will help the survivors cope more effectively with

their loved one's death. The participants' efforts at helping clients to achieve a positive experience are explored below.

Help with Dying Well

Social work has long played a significant role in health care in general, and in end of life care more specifically. The social workers interviewed for this study all reflected on the work they do with patients who are dying in order to assist in the dying process. Several of the participants discussed how difficult their work is and what is needed of them:

> It's actually very complicated work to manage someone's pain and manage all of the symptoms of end of life. (Linda)

> ...you have the skill, you have the knowledge that they (patients) don't so you're able to you know finagle through the system to be able to get what they need. (Tamara)

> ...it was just everything that was in me to make sure that her experience was as comfortable and as beautiful as it can be. (Tamara)

The span of social work tasks is apparent in these quotes, from obtaining services to ensuring a death is a beautiful experience. These quotes also demonstrate the complicated nature of end of life work. It clearly requires great deal of personal fortitude, as well as skill and knowledge to navigate complex bureaucratic systems.

The workers I interviewed spoke further of the ways they could provide assistance to clients and families in the dying experience:

> ...even something as simple and concrete, something with you know a funeral arrangement that they just don't know where to go, can make a big difference to them. (Sheri)

> Many times that's a hard thing for people to get their head around (withdrawing life support). So helping people come to terms with that is sometimes the work. (Joanna)

> ...one of the things I like to do is...ask about the person and invite them (the family) to talk about the person... to give an opportunity to the family to say it's ok you know to talk about this person's life even though that now we're at the point where they've died...I think it's important for the families that they are being supported by someone who hears what they're saying at least... (Janice)

> ...you can actually do a lot of good work to minimize the complexity of people's grief before the death...offer a child or an adult, like the dying person as well as their loved ones some ability to be active in the process so that life ending is a life experience...if you are engaged in your end of life or your child's end of life then your grief will be better. (Linda)

While many clients and families clearly need assistance when dealing with death, some of these tasks also suggest that there is a proper way to die and grieve, and that importance is placed on active engagement in the process.

Some of the participants talked more specifically about particular challenges they have had in helping families deal with the dying process. Sheri reflected on the difficulty of finding a balance between supporting a parent's hope and being realistic about their child's prognosis:

> ...how do you come in day after day if we bash the hope out of you...so that's a terrible balance between being realistic with families and not taking all hope away from them.

Janice discussed her frustration and mixed emotions about a grieving practice (wailing) that she has witnessed in her work:

> Sometimes I find it makes me really angry. Cause my perception of the norm...it that it's not helpful (wailing). It's not a helpful way to grieve and I know that it's probably very helpful for them...so I don't know, that's my kind of 'white person, Western teaching' kind of way that I understand it.

Janice clearly understands that her reaction to wailing comes from her own cultural perspective, yet she struggles with understanding how this practice assists the family in dealing with a death. Through these discussions with the participants, we have gained some insight into the complexities and the challenges of the daily practice in end of life work and it has become evident that considerable value is placed on a positive death and helping to achieve one, even in the face of challenges and frustrations. The themes that have been discussed in this section will be explored more closely in the discussion.

Competing Demands

Balancing the Personal and the Professional

In social work, it is a constant challenge to be aware of how personal values and beliefs influence and impact professional work with clients. The participants were asked if they feel this is a particular concern for them in their work, and if so, how their personal views impact their work in end of life care. The participants all shared their thoughts about this issue, and for all the participants there seemed to be awareness that their personal values, beliefs and experiences have an impact on their work to some degree. For the most part, these social workers seemed aware of the need to balance their personal and professional views, as well as balance their personal beliefs with the beliefs of others. However, it was clear that this was not always easy or straightforward.

Linda talked about needing to make a conscious effort to discern between personal and professional viewpoints:

...and I have to think, is that a professional opinion or a personal opinion?

Both Linda and Tamara suggested that it is challenging to balance personal viewpoints

with professional responsibilities and that they inevitably do intersect:

> So I know when I'm being professional…and I know when I'm in my personal
> world…but your personal informs you professional…I find that challenging
> (Linda)

> I grew up Catholic…I'm sure I can't separate out what part of that shows up in
> this work, what part doesn't… (Linda)

> …it's hard to be able to be outside of yourself to know if what you're really made
> of comes out and who your professional self is, and sometimes they do get kind
> of mixed up. (Tamara)

> …putting my own beliefs aside…was very, very difficult. It was one of the most
> challenging experiences I ever had. But that was for me one of my best lessons
> too, keep the professional and the practice separate you know from the personal.
> (Tamara)

> Several of the participants shared their personal experiences with end of life

issues, from their comfort with the topic to the loss of people close to them. They talked

about how these experiences have shaped them and how they affect their work now:

> I come from a family who talked very openly about it (death) …when I hear that
> someone's elderly parent or grandparent is dying and they have no idea of their
> wishes, personally that's a bit alien to me. I get how people can be uncomfortable
> with talking about it but that wasn't part of our experience. (Sheri)

Sheri further reflected on the influence her upbringing has on her work with clients at the
end of life:

> I think it makes me take a step back when people are more closed…but then I
> remind myself that not everybody's been able to think about these things. They
> need to play a bit of catch-up sometimes because they're a few steps behind…

My discussion with Sheri highlights that people's experiences and viewpoints are often

different. Open communication about death and dying is not common practice for many

people and people have different comfort levels regarding death. Sheri's quote suggests

that it can be challenging to balance personal viewpoints with the needs of clients who have not had the same experience. But there is also an indication that there is judgement placed on those who do not conform to similar viewpoints, as well as a need to bring people 'around' to the dominant discourse of talking about death openly.

Losing a loved one can impact people in various ways, but this experience takes on new meaning for those who work with people at the end of life. The following quotes demonstrate that, for the participants, their direct experiences with death influence how they deliver their practice and meet the needs of their clients, from their ability to work in their department to how their day to day tasks with clients are influenced.

Tamara informed me that her best friend had died recently and she had the opportunity to share in her friend's end of life journey. She discussed her experience with this and questioned how it influenced her choice of work environment:

> ...in a sense I'm grateful for having had that experience. I'm not sure how it would be in this environment, if I would actually be in this environment... had I not had that experience.

Catherine shared a number of examples of how her own experiences with death have had an impact on her work, both positively and negatively. She tries to meet the needs of her clients, and she is aware of how her personal experiences with death help her to advocate for her them or support them. She advocates for clients to see loved ones at soon as possible:

> It could come from my own history, not being allowed to see my step-dad when he died.

She will encourage families to stay with their loved one:

> I tend to encourage people to stay at the bedside. To sing to their loved ones. To rub their feet. To talk to them. To play music. To do whatever makes them more comfortable even if the family member, at that point, isn't even going to really know they're there…probably that's because I stayed with my own mother the night that she passed away…

Catherine also reflected on the death of her best friend and how that has influenced her at work:

> She died two years ago and deaths have been a lot harder since then…the first brain aneurism that we had come in here after that I couldn't deal with…I have since dealt with others and manage it but also know that it affects me later you know because the sights and the smells are very similar to what I remember from [her] death.

Catherine's quotes suggest that personal experiences with death can affect daily practice,

in both positive and negative ways, from how clients are supported to how similar deaths

are managed.

A few of the participants spoke about how certain situations in their work evoke

strong reactions based on their personal beliefs about what is needed by people who

experience a death in their family:

> Well, I personally am a Christian…if I can call someone for them whose going to give them spiritual support I find that that's helpful to me…I feel that then they have some kind of support, they have more support after they leave here…I find it harder after the fact when I know that they've had no faith and they have no supports out there around the spiritual realm and I think it's going to be so much harder on them… (Catherine)

> I very strongly think that if families are going to cope and grieve and heal they need to have some kind of remembrance for this person. But for someone to specify while they're alive that they don't want the family to have a funeral for them is very selfish. I don't shy away from telling people that I think it will be helpful. (Janice)

These two quotes demonstrate that personal beliefs can have a strong influence on how

practice is carried out, but again suggests some degree of judgement that clients are not

conforming to what the participants believe are normal and ideal parts of death and grieving. Through my discussions with all the participants it became evident that it can be challenging for social workers to integrate their personal experiences and viewpoints into their professional practice without their work with clients being affected in some way.

Mediating the Different Needs and Values of Clients and Colleagues

A common component of social work, in any area of the profession, is that of mediation. Most of the participants talked about having this responsibility and acting as mediators in their day to day work with families and colleagues. The situations that called for some form of mediation varied, but mostly pertained to responding to differences between the needs and values of their clients and those of the staff with whom they worked. Below are some examples of some of the struggles that the participants had with their role as a mediator:

> ...just try to be that go between, support the staff and support her (a patient)...It's an uphill battle with family and with staff... (Tamara)

> So a lot of what we do I think is sussing out where they're at and how do we support them in where they're at. And sometimes intervening with the team, when the team don't always get it...I'd hear 'we met with this person and they just don't get it'... (families) do get it, but they're just choosing to be hopeful... (Sheri)

> How do you help them (family) to get to a place where whichever decision they come to is ok? The team is having different feelings, why are we continuing this? What's the point? When parents... actively want to continue care and we don't think it's doing the child any good. There's just so many issues. (Sheri)

> Or then you have a family maybe where some people agree and some people don't and they struggle around that...there are tensions when a family wants to make the decision together but they're at odds with each other. And helping people listen to each other and be able to express their thoughts and feelings in a

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way that...in a way that is helpful to them...in a way that comes to some positive consensus as opposed to you know great conflict around that. (Joanna).

Surprisingly, Joanna was the only participant who spoke of the need to manage the conflict or different needs that can arise within a family. More common in the discussions were differences that occurred between the staff and family members. Tamara's comment reflects these differences and highlights the challenge of supporting both parties without 'taking sides'. In her interview, Sheri discussed a theme common to the participants, where the views of the staff regarding treatment of a dying child differs from the parents views. Her first quote suggested that staff don't always understand or recognize the family's motivations and when assumptions about the family are made it is the social workers responsibility to navigate this tension. While her second quote may refer simply to dealing with opposing viewpoints of families and staff, it also seems to suggest that the social work task may be to bring the family around to the staff's way of thinking.

Working with staff members who hold different opinions and beliefs about how to relate to patients and families can be challenging, particularly if the other professional holds more power than the social worker. Tamara spoke of having this experience, the consequences for the families, as well as her frustrations with navigating this kind of situation:

> ...sometime the line gets blurred...and some staff do that, have at times have their personal values come out and express to families as to what they think they should be doing...that causes conflict and that causes sometimes significant grief for the families...that's a big, big problem...

Interestingly, Tamara is concerned about other staff's values having an impact on families, when we have seen that social workers also struggle with this, and will 'work' with families to 'bring them around' to the staff's opinions on treatment. The main difference may simply be in how this is done.

Tamara continued speaking of her frustration with dealing with power differences:

> So it's trying to play that balance between supporting one's wishes (the patient's)…but to have someone who is the lead who has a different opinion, who has a different mind set…I know he's the doctor in this sense but I have to be the advocate for the patient in this respect. And sometimes it's just difficult because you're just butting heads and there's nothing you can do about it.

In situations such as the ones that Tamara discussed above, the differences in how social workers and their colleagues work with patients and families are highlighted. For Tamara, the work is difficult and frustrating because her colleagues do not work in ways that she feels are helpful to the families. In this kind of situation, social workers must sometimes work alone to advocate for clients and meet their needs (Davidson and Foster, 1995). As Tamara's experience also suggests, social workers must also work against power, which can lead to frustration and a sense of futility.

It seems there are times that social workers must go beyond simply advocating for their clients, when mediating becomes 'fighting'. More energy is spent in meeting the needs of their clients in the face of the barriers created by their colleagues and the hospital system itself. For example, Janice spoke of needing to be more forceful in how she dealt with doctors when she believed more information was needed for her clients:

> And I think too just for families to know that they've got somebody whose acting as a liaison between them and the staff…giving them updates…and bringing in the doctor when appropriate…actually going to the doctor and taking him by the arm and dragging him in to the room to speak with the family… (Janice)

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Catherine spoke at length about 'fighting' to meet her client's needs. She gave several examples of needing to fight with staff in order to get family in to see patients, whether it was just prior to their death or just after:

> ...you sometimes really have to push the nurses and the doctor to get out of there you know...The patient's going to pass away...maybe they can take their last breath with the family...

> I had to fight to provide for this daughter-in-law what she had to have, she had to see her...everybody was fighting against, why are you bringing her, you know she's in a morgue, she can see her at the funeral home. This woman has to see her. And I was the only one that seemed to understand that, other than the daughter-in-law who knew it, but everybody else was like you know don't, don't do it, don't bring her...

Catherine speculated that there is a need for this level of mediating and advocating because the staff's focus is different from hers:

> They're totally focused on the patient and treating that patient and they're not seeing the big picture.

Catherine's quote suggests that social workers have a variety of responsibilities and must navigate the needs of different parties, but also highlights the frustration that can occur when staff members see things differently. This appears to cause tension in Catherine's professional relationships and the need to 'fight'. Interestingly, when a patient was a fellow employee (a nurse), staff's priorities seemed to change. They seemed to see the 'big picture' and want the things that Catherine regularly wants for her other clients, such as family time before the patient died. When Catherine advocated for what the nursing staff wanted for their friend, she had support from then in that battle:

> ...literally having to fight with the coroner which I don't usually have to do either and say you know they want the priest, they want the family to have that last prayer with her...they really need to do this. And he still didn't let all of the

> family but I was able to get the priest and the husband and at least the children in. Again, it was a matter of fighting for what I know they wanted.

It is interesting that Catherine repeatedly used the word 'fight' in her discussion about advocating for her clients. For some, this may be the same thing; however Catherine's use of the word suggests that considerable energy is often needed to meet the needs of clients in the face of opposition from other staff. Catherine's discussion points to the differences in professional priorities and how this can be a struggle to navigate.

Not all conflict that needs managing is related to staff values and priorities. Some of the challenges that workers needed to mediate were related to broader cultural issues, as well as systemic barriers within the hospital. Linda reflected on needing to mediate cultural and racial tensions between a family and a doctor due to the father's traumatic experiences in the Vietnamese war. The family's physician was Vietnamese and he was initially viewed by the father as an 'enemy':

> And then you know navigating the racial tension between the father who was you know, he was physically disfigured because of his experiences as a child in the Vietnamese war and having to deal then with the enemy, who was the physician, and that was pretty difficult.

Janice discussed a time when she needed to mediate between a family, hospital staff and other patients around a grieving practice (wailing) that was occurring in her department:

> ...the social worker's often asked to do something about it and so I find myself trying to explain to other staff and families that this is the way that this family grieves. This is normal and ok.

These quotes highlight that differences can go beyond values and beliefs about end of life decision making, as many of the quotes suggest. Often, the deeply ingrained practices and experiences of clients can present challenges and tensions for the social worker, who must try to balance the clients' needs with the needs of others in the environment.

Janice talked at length about the challenges she faces from the hospital system when trying to allow families to view the body of their deceased family member:

> This is often very challenging from a system perspective...I support (viewing), but the morgue staff doesn't necessarily support it...so working with the folks in the morgue to allow viewing to happen in a respectable manner...that's a challenge.

Janice was asked if she was able to work with the morgue staff to meet the needs of the family. She said yes, but explained that it can be challenging to do this in the face of systemic barriers:

> I'm always able to work with the staff in the morgue or the coroner or the police to make it happen. I might have to go over someone's head or I might have to go a different route but I'm always able to make it happen.

In this, Janice demonstrated that knowing what to do, who to deal with and what works in the system allowed her to manage the institutional barriers that she faces. Indeed, Gregorian (2005) suggests that "despite the frustration of dealing with hierarchical power structures, social workers who can work within the system instead of against it are more likely to achieve success (p. 8).

Meeting Staff Needs

The role of the social worker in managing the challenges of end of life care is varied. The work is not simply directed at providing support to the patient and family, but often focuses on giving support to fellow staff members and meeting their needs as well. Gregorian (2005) states that "successful hospital social workers recognize that the staff is also a client. They understand that by assisting them to deal with stresses related to patient care, they are enhancing their own value to the institution and are more likely to become fully integrated members of the team" (p. 7). This suggests that there is an

expectation that social workers should meet the needs of not only their clients, but also of their colleagues, and the social work profession as a whole.

This idea is reflected in the discussions of some of the participants, who spoke of how they feel the responsibility to go beyond meeting their client's needs, and to support their colleagues' needs as well. Tamara talked about a patient who would signal for a nurse, and then wait a considerable time because they were so busy and her frustration with trying to understand the needs of both sides:

> And so my conflict came in between supporting the staff in their difficult time in the sense that they are stressed out, they are highly overworked but then bringing it back to respecting a dying person's wishes.

When I pointed out to Tamara that she seemed to be doing extra work in order to meet the needs of the client, she agreed and talked about the effects of doing so:

> It's just one of those things where you think to yourself, 'if I don't do it then who will?'...It's very, very draining to co-ordinate everything on top of continuing on with your caseload and your life when you come home from work...You can't split yourself in eight different people...

Catherine remembered a difficult situation when a staff member died and the stress of trying to help the staff in addition to completing all the other necessary work:

> And in the middle of all this (I) was getting calls from her department, from nurses there who were very, very upset, and trying to help them from this distance, you know suggesting what they could do at that point and giving them as much of an update as I could at that point...I'm trying to work with staff I don't know as well and get what they needed...So it was a very hard situation...

The above comments highlight that in addition to the challenges of providing end of life care to their clients, social workers also need to meet the needs of the staff with whom they work in order to be a successful part of the team. This extra role clearly takes a toll on social workers as they struggle to manage their already challenging work.

Support For the Social Work Role

Perceived Value of the Social Work Role

The role of the social worker, and the value placed on that role, has been constantly changing as social work in health care has evolved. Various factors such as "the demands of the healthcare system, the changing nature of medical technology, regulatory requirements, and the societal view and expectations of the medical setting have all shaped the way social workers define their job functions" (Kitchen and Brook, 2005, p. 2). It could be argued that these factors have also swayed how the social work role is understood and defined by other professions within the medical system as well, whether positively or negatively.

Most of the participants talked about how they think the role of the social worker is viewed in their work environment. They reported a mixture of experiences and perspectives about this issue, with some participants experiencing positive feedback about their role, some negative, and some talking about what needs to change. It was clear from several of the participants that social work is viewed quite positively in some departments. Sheri shared that her department is very different from others in which she has previously worked, and that she is fortunate to be part of a team where the social work role is respected:

> I'm really lucky in that the team that I work with, even though they're all different personalities and stuff, I came into a team which already had a highly respected social worker…I don't feel that struggle in this part of the hospital…

She also said that although the nurses with whom she works have wonderful skills in dealing with patients, there are some issues that they do not feel comfortable discussing with families and will call on her to do it for them:

> They don't want to talk about certain issues. They know it's easier in my role to come forward and talk about that.

Joanna commented that there are times when her colleagues do seem to recognize the importance of the social work role:

> You know they see you as a necessary person...I get a lot of support from the team around the social work role. You know they come and appreciate that you've been in with somebody or want you to go in and see their family...a lot of them will say to me 'you know I feel badly that I can't, I don't have time to talk to them...I'm glad you're here to do it'.

These participants both expressed that their role is viewed positively and their work is appreciated, however their comments also highlight that there is a need for the social worker to meet the needs of their colleagues by implementing their role in special situations such as busy times or when the staff are uncomfortable with a certain issue. This suggests that the social work role may only be truly valued and appreciated when the work also meets the needs of the staff, not just the needs of the client.

Despite the positive feedback that some of the participants have experienced in their departments, it is clear that this may not be the norm for social workers who work in end of life care in hospital settings. Social workers may experience frustration when the difficult work they do in not fully understood or acknowledged. "Many workers grappling with loss and grief find few satisfactions and may be jeopardized by lack of recognition of the value and emotional stress of their work" (Davidson and Foster, 1995, p. 5). Several of the participants spoke of how their role is often misunderstood,

confused, and consequently, sometimes devalued by fellow health care professionals.

Tamara, who is a relatively new social worker, spoke about joining a work group and

discussing her concerns about how social work in end of life care is valued:

> ...one thing that I brought to the table as a new member is my difficulty as a
> social worker working with other team members and having them understand the
> vital role of social work within that environment.

She spoke further of the misunderstanding about the role of social work:

> We don't just process unemployment forms and packages. We're there as a key
> support piece, we're there as advocates...

Despite her positive experiences previously discussed, Joanna also reflected on her own

feelings about her role and how she thinks it is viewed by people with whom she works:

> I feel like, oh what am I doing...other kinds of work feels much more you know
> constructive and then I think, ok I sat with someone and listened while she talked
> about her marriage of 60 years or whatever...I know the value in it, but there are
> some days when you know that it's probably not highly valued by other
> people...sometimes you think people are thinking I just visit people.

Misconceptions about the social work role appear to be something which social workers

must deal with, and clearly this issue causes frustration. However, Joanna's comment

suggests that these misconceptions can be internalized and create doubt in how the

worker views her own role and contributions.

In addition to dealing with misunderstood roles, health care social workers often

have to cope with "a loss of control over decisions regarding professional identity and

social work functions" (Sulman, Savage, Vrooman and McGillivray, 2004, p. 289). A

few of the participants spoke of their experience of not having their opinions or expertise

recognized when advocating for their clients at the end of life:

> It's like climbing two walls as opposed to just going through a door sometimes to
> be able to get what you need. Having to explain to a physician or to a team what
> it is you're trying to achieve. Almost having to justify what you're trying to do…
> (Tamara)

> …sometimes we do have a voice in being able to speak up but sometimes we're
> silenced very quickly. It all depends on where you're working. Where the role of
> social worker is appreciated and well known, well established so that does hold
> some water but other places you're just amongst the crowd. Where you're just a
> supportive piece, you're not a key member. (Tamara)

> …not everybody's had the experiences or the expertise that I do either and
> sometimes I just wish I would have a greater say. (Linda)

The above quotes highlight the sense of frustration and futility that comes from these

workers not having their professional voices heard, despite the knowledge and experience

they contribute. Again, it seems that social workers must navigate the power imbalances

that are inherent in the hospital system in order to meet their client's needs.

Two of the participants discussed why they believe social workers are not heard,

and what can be done to change this:

> We are the quiet kind of neighbour to the side that just says yes, hi, I'm here.
> Meanwhile, we need to become more comfortable with the idea of speaking up
> and letting other people know who we are and…the great work that we do…
> (Tamara)

> We need to find ways to articulate how we help people die psychologically well,
> emotionally well. (Linda)

Tamara talked further about the role not being understood, but discussed an educational

programme that is being developed by her and some colleagues:

> We'd like to start with the med students…and create a course or a
> workshop…where we would meet new med students at the beginning of their first
> year to give them an introduction to social work…because sometimes we do
> believe that they really don't understand what it is that we do.

These quotes suggest that while social workers are good at advocating for their clients, they are not as practiced at advocating for their profession, but they are aware of the need to do so. However, the problem of not being recognized as a key member of the staff, or of an interdisciplinary team, goes beyond simply being uncomfortable in speaking up. There are barriers within the health care system that contribute to the view that social work is not on equal footing with other professions, such as the power imbalances discussed above. Educational programmes such as Tamara described are one way to provide information about the social work role, which may be step in beginning to address some of these barriers at the ground level. This idea will be taken up further in the discussion.

Formal Support Opportunities

After exploring how they believed their role in end of life social work is understood and valued, the participants were asked to talk about the formal resources that are available to support them in their challenging work. It is clear that "given the complexity and weight of social work tasks and roles… professional support is crucial" (Sulman et al., 2004, p. 288), and it was acknowledged by several of the participants that professional support is available to some extent:

> I was assigned a mentor when I first started (as a social worker), and having had that individual to go to for day to day social work kind of conflicts or questions, or just case reviews…proved to be very, very helpful. And so when dealing with very difficult situations it's very important to be able to have access to those supports. (Tamara)

Catherine talked about some formal support that was obtained by her department when a difficult death occurred:

> ...we actually ended up at that point having a team come in because everybody was very upset...the full time social worker down here arranged for that to happen...

Sheri also noted that her EAP is available, and recently responded to help the staff of her department when a child they were caring for died:

> They actually just came in, we had very traumatic death recently... (EAP) was able to help all of us who'd been directly involved who wanted to take part in it and talk about things.

Despite these positive indicators of support, it seemed that many of the formal resources discussed by the participants were provided in special circumstances, such as being a new employee or in response to a particularly difficult death of a client. In addition, Sheri made it clear that her hospital's critical incident team is no longer available to respond to such crisis situations, suggesting that factors such as cutbacks and re-organization within the hospital system have led to key support services being eliminated.

While some forms of professional support have been available to the participants, some discussed the shortcomings of their work environment in providing what they believe to be effective support resources. Sheri spoke of the delayed response of her hospital in recognizing the importance of providing formal support to staff to deal with the challenges of the end of life work they do:

> ...I think there's a lot of vicarious trauma that goes on. And only recently has the hospital system really acknowledged that.

Tamara talked about a working group that she considers a formal support, but was not implemented by the hospital. Rather, it was started by her co-workers so there could be a forum for discussion of their work related concerns:

> (it) comes together once a month to talk about practice issues, conflicts, things that they'd like to improve upon, attitudes, those kind of things…(it's) a key piece of support…

Catherine spoke of the need for a mentoring programme in her hospital to increase contact with other workers:

> I think sometimes it might be nice to have a mentoring kind of thing… (and) not be quite as isolated.

And finally, Linda spoke about her belief that implementing a team to specifically deal with end of life issues would provide support to social workers as well:

> …we need a palliative care team…somebody like that who works closely with the social workers… I see that as something that would really help here…they would also be able to do stuff with staff around hey, how are you doing?

These comments suggest social workers have numerous ideas for resources that would support them in their end of life work. However, the sense that these workers conveyed in our discussions was that it is unlikely that such resources could be implemented. Tamara's quote points out that social workers themselves are responsible for creating and seeking out their own support, an issue that will be discussed further below.

When considering why formal support is lacking for hospital social workers, particularly for those who work in end of life care, it is important to recognize that hospital work environments have changed significantly. A study by Globerman, White and McDonald (2002) explored the issue of hospital restructuring in Ontario, and the subsequent effects on social workers in hospital settings. They identified that restructuring included the elimination of traditional social work departments in the institutions they studied. Due to the dismantling of formal social work departments, social workers have been left without their own social work department and with fewer

professional supports, leading workers to "feel a heightened sense of isolation from social work colleagues" (Sulman et al., 2004, p.289). Both Joanna and Catherine spoke of their experience with these issues:

> ...in the unit I'm the only social worker...What I do, I do kind of on my own...there are challenges to that. (Joanna)
>
> ...we're not a department, we're put into departments...you know when we had a social work department you had more close connections. (Catherine)

Sheri was the only participant to report quite a different experience, in that she did not work in isolation in her department:

> I think I'm really lucky in that we don't practice in isolation and that there are three full time social workers...we very much use each other to go through cases, problem solve things also. Even our general office is filled with social workers...we're kind of like our own little group.

Sheri's comment may be the exception to rule, as the elimination of social work departments and placing social workers into other departments and programmes has become commonplace (Auerbach, Mason and LaPorte, 2007).

Seeking Informal Support

For the participants, formal support services to assist them with their end of life work seem to be available to some extent; however it became clear that they did not rely solely on formal resources in order to deal with the challenging nature of their work. It was interesting to see that most of the resources that the participants discussed using on a regular basis were informal. Informal supports can be varied and can include both internal (work) and external (personal) resources. In particular, connecting with fellow staff in unofficial ways was a significant form of support for the participants in managing their daily work stresses. Davidson and Foster (1995) note that "consultation and peer

support help social workers master their reaction to life-threatening illness, death and

grief so patient care can remain priority and the work is more satisfying" (p.11). The

participants talked about such peer support and how it helps them in their work:

> It's important to have those key co-workers, it doesn't have to be a big group, it could just even be that one person (you) can just go to... my source of support is the Chaplain, who is a key part of that environment as well...so I've come to utilize her as a key source of support ... (Tamara)

> I have a whole group of social workers who I eat lunch with...that's helpful...there are days when somebody needs to just talk about what happened with them that morning. I think if we didn't have those lunchtime connections...I don't think that would be good. I don't think that would be healthy...I think you do need that camaraderie and support you know. (Joanna)

> My colleagues are my first sort of go-to people. I get a lot of support from the chaplains and the social workers. Occasionally I will talk to other grief supporters... (Janice)

> I think that the social workers, we just, we support each other...I'm sure there are, you know, counselling services that you can go to, but I think we support each other. (Catherine)

Catherine also talked about how supportive it is to have other staff, such as nurses, ask

her how she is doing with a difficult situation:

> ...because you're constantly there for them and to have somebody come to you after and say 'are you ok with this? Are you doing all right?'

In addition to peer support, it is also important for social workers in end of life care to

have supports and activities separate from their work, including protected vacation time,

work time away from direct client contact, and social and physical activities that

counteract the intensity of their work (Davidson and Foster, 1995). The participants

spoke of the informal supports that they found in their personal lives:

> Outside of work I have a very full life, I have 3 kids…I have a husband…I do yoga, I knit, I have my own faith, I'm Christian…I'm very involved in my church and so, yea, between all of those things…I get support in all of that. (Joanna)
>
> Sometimes I'll just tell her (mother) what my experiences are and it's nice to be heard, someone doesn't even have to say much, just to say well you know I'm here to just listen. (Tamara)
>
> I journal. I go out into the woods and walk. I'm self aware…And you know I take to journaling and praying and doing whatever I have to do to get through it. (Catherine)

The participant's quotes highlight that there is a significant need for informal supports and that these are personal and individual. It seems that informal consultation with colleagues is the most utilized form of support and perhaps the most valued. Because this is a form of support that is available on a regular basis and easily accessible, it may be that it is the most effective form of support in helping social workers manage the difficult work they do with their clients at the end of life. However, this does not negate the fact that formal supports are lacking and could also be beneficial in supporting social workers in end of life care.

DISCUSSION

This study set out to investigate the experiences of hospital social workers who deal with death and dying in their work on a regular basis. The social workers who were interviewed were asked a number of questions in order to gain insight into their professional and personal experiences with death and dying, how their personal views and beliefs about death influence their work, and if they feel they are supported in their work. The participants' discussion of key issues in their practices effectively illustrated that their work is challenging, complex and fraught with tensions that increase frustration and stress in their daily work. The main issues of concern that the participants discussed with me included their views on quality of life; their desire to help clients achieve a 'good death'; the struggles they have with supporting staff as well as clients; how their role as a social worker is viewed; and the support that is, or is not, available to them. These key findings were organized into three main themes: positive dying, competing demands, and support for the social work role. They are explored further below.

Social Work's Involvement with Dying

End of life care is an area of social work that encompasses various tasks and responsibilities in order to meet the needs of clients who are dying. This study demonstrated that the participants engaged in multiple and varied activities with their clients in order to help promote a positive dying experience, from providing help with concrete tasks to providing emotional support. The complex nature of this work was particularly highlighted by the participants' discussion of specific challenges they face

while trying to assist clients with the dying process, such as Janice's difficulty in accepting the custom of wailing as an effective grieving practice.

The participants in this study shared their views on death and dying, what elements contribute to a positive death and their role with clients at the end of life. It became clear that the social workers shared similar views about these issues and that these findings are consistent with the literature. Particular issues were highlighted by the participants. The issue of quality of life was discussed by most of the participants as an important part of positive dying, with much of the discussion centred on their own views of quality of life, when they feel quality of life is compromised, and the impact that this has on them personally and professionally. This was particularly evident in Tamara's struggle to work with a family who, she felt, was prolonging their daughter's life unnecessarily.

Other participants also talked of the struggle to work with families who seemed to have different wishes for their loved one than did the staff. It seemed that it was easier for the social workers to align themselves with clients who shared their views about quality of life. Some of the participants also conveyed a sense that there is a need to try to 'work with' a family to convince them to let go when staff feel there is a diminished quality of life. While the issue of quality of life is widely addressed in the literature, the above findings have not been explored to the same extent. Therefore, further research into social workers' views on quality of life and how they work with clients who hold very different beliefs and goals could be beneficial to the area of end of life care.

While the participants did not speak specifically about death denial in their interviews, some of the views and experiences they shared were consistent with the literature regarding this issue. For instance, Linda spoke of assisting clients in engaging in the experience of dying to help manage their grief better. This highlights that there is an expectation to participate in the dying process and that if a client does not comply there may be negative consequences, but if they do, their experience will be less complicated. Most of the participants spoke of ways they would assist clients in managing death, or of the difficulty they experienced when clients did not have positive experiences at the end of their life, for instance dying alone. The findings suggest a belief that there is a proper way to die and that there is an underlying need to control the experience of death in some way. The participants' views are consistent with Zimmerman's analysis that there is a societal expectation that people participate in their death or they may be labelled in 'denial', and that the dominant discourse in our society is that there is an ideal way to die and a need to control the dying process in order to achieve that ideal.

The idea of a 'good death' is also prevalent in our society today. The elements that contribute to a 'good death' were discussed by the participants and were found to be similar to those explored in the literature. The characteristics the participants believed to be part of a positive death included having a peaceful death; participation in the dying experience; and communication about dying. Two other elements of a positive death that the participants discussed are also investigated in the literature: location of death and dying alone. Location of death is explored by Stajduhar, Allan, Cohen and Heyland who

note that "the idea that home is the ideal location for care and death has taken firm hold in the minds of many health service providers" (p. 87). The participants of this study highlighted this issue and discussed their views on dying in a more comfortable environment than a hospital, ideally at home, surrounding by familiar things and people. Dying alone is portrayed in our society, in particular through the media, as an element of a 'bad death', and is also noted to be a concern for professionals by Seale (1995), who stated there are "associated anxieties about dying alone, outside accompaniment" (p. 379). While Linda talked about it being important for patients to die at home, surrounded by family, Catherine expressed her concern about the negative effects, such as guilt, on family when they are not present at their loved one's death.

The social workers interviewed expressed clear views on what they think comprise a good death. Their personal views on dying well are in keeping with the broader societal view of a 'good death' that is explored in the literature, which suggests that the idea of dying well is constructed around our ideas of what is normal, desirable and 'ideal'. The participants' views seem to perpetuate the idea that there is an ideal way to die and that a good death is desirable and achievable. However, as the literature highlights, it is not always possible to achieve the ideal death. We need to consider that by perpetuating the expectation of a good death, social workers may be contributing to the anxiety level of clients who perhaps are not able to achieve an ideal dying experience. As a contribution to the discourse on end of life care, further research regarding this issue and the role that social work plays in promoting the ideal of a good death would be interesting.

It became evident that there are intricacies involved in navigating the difficult situations that social workers face on a daily basis. While the literature discusses the multiple tasks and responsibilities of social workers who provide end of life care, there appears to be less focus on the personal struggles they experience while trying to do so. Given the challenges to providing help with dying that were noted in this study, it would be interesting to further explore how these kinds of challenges impact their work with clients. Such research may provide more insight into the influence of personal values and beliefs on work with clients at the end of life.

Social Work's Responsibility to Meet Competing Needs

A significant theme that emerged in this study pertained to meeting the needs of both clients and colleagues. The need to mediate tensions that developed between staff and clients was evident in the respondents' stories, and demonstrated the differences in how social workers and other staff work with patients and families. The challenges of trying to meet the needs of clients were particularly evident when dealing with team members who held more power. Despite working on interdisciplinary teams, as is common practice, social workers are considered as ancillary staff. Colleagues, such as doctors and nurses, are considered the primary caregivers in hospital end of life care, which can lead to power differentials within the team. Power struggles can be a result of unequal status, as illustrated by Tamara, who discussed the difficulty of meeting her client's needs when working with staff that have different opinions than her and hold more power. Clearly, it is difficult for social workers to meet the challenges of working with clients at the end of life in the face of power imbalances and "until social workers

can achieve equality of status, a fully holistic approach to patient care is impossible, reducing the quality of services to clients (Reese and Sontag, 2001, p. 174).

As illustrated, the participants need to expend extensive energy in some situations in order to meet the needs of their clients. This was described as "fighting" by one participant and acting forcefully by another. For several of the participants, such action seemed to be needed when staff had competing priorities regarding patient care. Given that social work responsibilities tend to encompass a wide range of tasks, such as meeting family and community needs, it seems understandable that tensions can be present for the workers in their interactions with colleagues who have differing views, or don't see the 'big picture' as Catherine described.

The challenges that are met by social workers in end of life care often go beyond value differences in decision making, and can encompass broader societal issues, such as systemic barriers and cultural differences. The participants illustrated that institutional rules and regulations impact their practice negatively and seem to create additional obstacles for them as they attempt to meet the needs of their clients. Indeed, social workers "experience considerable strain between the client's needs…and the competing needs of the institution" (Davidson and Foster, 1995, p. 6). Clearly, additional skills, perseverance and fortitude are necessary for social workers to effectively navigate the system and meet the needs of their clients. Cultural differences between clients and staff were also identified as an area that needed to be addressed by social workers. Linda and Janice, for instance, both recounted experiences when they were required to attend to cultural expressions that seemed to be negatively affecting others within the institution

(i.e. staff, other patients), suggesting that social workers must endeavour to meet a wide variety of needs beyond those of their clients, perhaps most often the needs of the institution in which they work.

Meeting the needs of fellow staff, as well as clients, also appears to be a common element of end of life work for social workers, as they are "often called upon to address more than one agenda at a time" (Gregorian, 2005, p. 7). Their responsibilities lie beyond meeting the unique needs of their clients, as they may also be expected to attend to struggles or concerns that colleagues are experiencing. As the literature has suggested, this is an important responsibility for social workers, particularly if they wish to integrate themselves successfully into an interdisciplinary team. As Davidson and Foster (1995) note, social workers can "claim their place in health care by demonstrating that they contribute their expertise on dying and bereavement not only to patient's programs, but also to support staff morale across disciplines" (p. 5). The findings of this study speak to this and demonstrate that this issue is one that affects the participants in their daily work.

Most of the participants spoke of needing to assist fellow staff, but some viewed it differently than others. Two of the participants described experiences that required them to offer support to nursing staff, an extra responsibility that clearly caused them stress and frustration, and burdened an already demanding workload. Interestingly, Sheri and Joanna viewed being asked for support by fellow staff positively, and felt appreciated for their supportive role. For instance, they spoke of being asked to manage situations that made their colleagues (i.e. nurses) uncomfortable or they did not have time to

address. For the participants, this was viewed as evidence that they are accepted and valued, which is likely true.

It could be argued that they were also asked for assistance in order to alleviate the discomfort or workload of their colleagues, suggesting that the social worker role is valued to the extent that it can provide support to the primary caregivers on staff, in addition to meeting the needs of the client. However, as primary staff, such as nurses, is often overworked due to limited resources, it is understandable that they ask for assistance from social work. The need for them to do so speaks to the larger issue that there are often not enough resources for staff to do their job effectively, and demonstrates that social workers may be utilized to fill in the gaps in care that fiscal restraints have created. Regardless of the reason that social workers must attend to the needs of other staff, it is clear that additional work is required to do so, which increases the demands on the social work role, can create extra pressure for individual workers and place multiple demands on their time.

Acceptance and Support for the Social Work Role

The issue of the value of the social work role is a common theme in the profession, and is reflected in this study. As illustrated, social work in end of life care within a hospital system is considered a secondary role, and social workers often work with team members who have considerably more power and control. We see that this challenges social workers in their efforts to meet the needs of their clients at the end of life. Because of unequal status in the professions, it is inevitable that there may be a lack

of understanding, or misconceptions, about the social work role. If so, this may lead to the social work role, and the work of social workers, being minimized and devalued.

While several of the participants expressed that they believe their role is a valuable one and they have expertise to offer, one worker seemed to question and try to justify the value of her own work with clients because she believed that others may not highly value the social work role. The findings of this study illustrate that it is possible for workers to internalize the negative feedback they receive and end up questioning the value of their own work. Indeed, O'Donnell et al. (2008) suggest that social workers may experience perceptions of powerlessness since they are in fact less influential and powerful members within the medical hierarchy.

Several of the participants experienced a sense of frustration when their professional voices were not heard and they were not able to offer the expertise they felt they could provide to their team and clients. This again suggests that social workers are facing power imbalances in their work environment and this creates challenges in meeting their client's needs. It is clear that there are barriers within the health care system that facilitate the view that social work is not an essential role. For instance, Reese and Sontag (2001) note barriers such as role blurring, value differences, and as discussed, power differentials. Such barriers can limit a social worker's ability to contribute fully to her team and may impede work with clients at the end of life.

This study highlights the need for the social work profession to advocate for itself, but suggests that individual social workers may find this challenging. However, the findings also illustrate that social workers do recognize the need to promote their role

to other professionals and they have ideas of how to do so. While it is no doubt important for social workers to find ways to advocate for their profession when their role is devalued, it is perhaps more important to further explore the barriers to social work being on an equal footing with other professionals. Only then is it likely that clients who are experiencing the unique challenges of end of life will benefit fully from the specific skills and knowledge that social workers can offer them.

This study has demonstrated that there are many challenges for social workers in end of life care and that supports are needed to help them navigate the complex situations they face with both clients and colleagues. All of the participants described the supports they have access to, both formal and informal. Formal supports to social workers in end of life care were limited, and consisted of services that are available to all hospital employees. There were no services that were specifically geared toward addressing the particular challenges of working with people at the end of life. Some services, such as an EAP, were implemented for staff when especially traumatic deaths occurred in their unit, but this suggests that services were limited to exceptional circumstances. Indeed, the participants described that ongoing assistance to manage daily stress was in the form of informal, personal supports they generally sought out themselves. These supports were mostly described as social affiliations with fellow staff, who would listen and provide support, but the participants also described activities in their personal lives that helped them cope with the challenges of their work.

As discussed, hospital environments have changed significantly and many formal social work departments have been dismantled. The findings show how social workers

are responding to the fact that they are increasingly connected only to the unit in which they work, without the benefit of a connection to a social work department. In addition, they are often the only social worker on their unit. These factors all contribute to workers' sense of isolation from their social work colleagues. Some of the participants discussed their particular experiences of feeling isolated within their work environment as a result of these issues. Only one participant identified that she did not experience this problem, but it seemed that this was an exception and she worked on a unique unit. It has become clear that due to systemic changes in many hospital systems, social workers experience segregation from their colleagues and from their profession as a whole. They often do not have the formal support and backing that a social work department can offer, which can culminate in feelings of isolation, an added stress in a challenging job.

The findings of this study have highlighted that social workers are frequently required to seek out affiliations with other workers in the hospital system in order to gain the support they need and reduce the effects of isolation. While it is touted in the literature that support to social workers in end of life care is vital, the social work profession could benefit from further research into this issue. The need for workers to seek support independently in order to manage their difficult work is concerning, and more knowledge about what social workers need in their work place could be valuable to the profession as a whole, and end of life care specifically.

Implications for Social Work Practice

The findings of this study illustrate that social work with clients at the end of life is complex and challenging, and requires fortitude, personal insight and professional

flexibility. The social workers who participated in this study shared their personal and professional views and experiences with death and dying, which provided insight into what is needed to work in such a challenging area of social work.

Balancing personal values and beliefs with the divergent viewpoints of clients and other staff is challenging. To address this issue, increased education could be a useful venue for social workers to explore their personal beliefs and how they may affect their work with clients who are dying. Education could be provided in undergraduate and graduate programmes to promote increased insight into personal values and beliefs about death and dying. Ongoing education in the workplace could also be helpful to social workers who are currently working with clients at the end of life. Hospital systems need to acknowledge that such educational programmes need to be provided within work hours, so that it is more likely that social workers will attend. Education, perhaps in the form of workshops or 'lunch n' learns', could also be an effective method to integrate more formal support for social workers, to provide information about relevant topics as well as an opportunity to discuss issues of concern about their practice.

Finally, education for other professionals regarding the role of social work is essential to increasing the professional status of social work within the health care system. One study by McIlwaine, Scarlett, Venters and Ker (2007) demonstrated the importance of providing education to the various disciplines in order to increase knowledge about different professional roles. It investigated the effectiveness of an interprofessional workshop for social work and medical student that was geared at exploring their respective professional roles. It was noted that this workshop was

successful in increasing the student's knowledge about each other's role, an important step in developing respect and minimizing power imbalances within interdisciplinary medical teams. Within this study, a similar idea was discussed. As Tamara's example suggests, social workers can attempt to create and implement educational programmes for other professionals, with the hopes of creating increased knowledge and acceptance of the social work role within the health care field.

The participants demonstrated that part of their daily work is addressing the needs of other staff, often the nurses with whom they work directly. This clearly burdens their already heavy caseload, which can lead to frustration and extra stress. While it is natural to want to be supportive of the people with whom we work, due to the nature of their professional role, social workers may be more likely to extend themselves in order to assist their colleagues. It is important for social workers to learn to place boundaries on their role, so the majority of their work focuses on assisting clients not colleagues. This will help reduce the strain that can be created by trying to meet the needs of staff in addition to the needs of clients.

Social workers can advocate within their institution for more formal supports to be implemented on a regular basis. Supervision with a social work manager can increase support to social workers and reduce their isolation. However, it is important to note that within health care supervision can be minimal. In one study, by Bronstein, Kovacs and Vega (2007), it was found that only 36 percent of their sample reported receiving supervision by another social worker, demonstrating that social work does not receive the support it needs in the field.

If formal supervision is not possible, workers themselves can create groups such as the one Tamara spoke of. Such groups may provide an effective forum for workers to discuss issues of concern and to receive extra support. What might begin as an informal venue for a small group of workers may over time transform into an ongoing formal support available to all social workers within an institution. Further, participation in group meetings regarding social work practice, and specifically end of life care, will provide social workers with the opportunity to explore issues of concern, gain insight into their practice and obtain support in their challenging role.

Directions for Future Research

The sample for this study consisted of social workers from a variety of hospital settings. They work with people who are dying, in different capacities and to varying degrees. It would be beneficial to pursue future end of life research with workers who practice exclusively in end of life care, such as palliative care social workers. Doing so could provide different, but equally important insights into end of life care, as their work is geared specifically to this area of social work practice.

The findings of this research study have highlighted that social workers in end of life care are lacking in formal supports to assist them in their work. There is a subsequent need for workers to seek out their own support in most circumstances. Given that workers manage multiple responsibilities on a daily basis, the fact that they need to seek out, and create, support systems within their work environment is concerning. More emphasis needs to be placed on institutions taking responsibility to provide adequate resources to support social workers in their work with clients at the end of life. Further

exploration into this issue in future research initiatives could prove beneficial to social work practitioners in their endeavours to manage the daily stresses in their work.

A final direction for future research that could benefit social work practice in end of life care is exploring the plausibility of implementing educational initiatives with other medical professionals to increase their knowledge about the social work role. It has become clear that social workers are an often undervalued part of the interdisciplinary team, and they face power imbalances generated by their unequal status in the health care field. While one study explored the issue of providing education to students, it would be interesting to investigate if professionals already in practice would be open to such educational efforts. Given that social workers in end of life care must navigate this barrier in addition to managing the particular challenges of their work, providing education to colleagues could generate increased knowledge about, and respect for, the complex work social workers' engage in with people at the end of life. This may be a step toward reducing power differentials and strengthening the status of the social work role.

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APPENDIX A

PARTICIPANT INFORMATION SHEET

Title of Study:　　　Death & Dying: Working with Clients at the End of Life

Locally Responsible Investigator: Dr. Christina Sinding, Department of Social Work, McMaster University
Principal Investigator: Alexandra Vedell: MSW Student, Department of Social Work, McMaster University

You are being invited to participate in a research study conducted by Alexandra Vedell, because you are employed at the Hamilton Health Sciences Corporation and work directly with clients who are dealing with end of life issues. This is a student research project conducted under the supervision of Dr. Christina Sinding. The study will help the student learn more about the topic area and develop skills in research design, collection and analysis of data, and writing a research paper.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family.

Why Is This Research Being Done?
Death and dying is a topic that is, for many people, difficult to think about, much less discuss openly. Given this, social work with clients at the end of life is no doubt challenging, with social workers being required to navigate sensitive and difficult end of life issues that affect their clients. Social workers strive to provide effective service to their clients, a task which can be influenced by their own feelings and experiences regarding death and dying. Exploration into these issues is needed to gain a better understanding of social workers' experiences with clients at the end of life, and what is needed within social work practice to enable social workers to work effectively with their clients.

What is the Purpose of this Study?
The study will explore the experiences, values and beliefs of social workers regarding death and dying; their awareness of their beliefs, how these may impact their work with clients dealing with end of life issues, and finally, what supports are necessary for social workers to explore their own views and to manage the challenging experiences they have

with clients at the end of life. The researcher's goal is to be able to provide information about the results of the study to social workers within the Hamilton Health Sciences Corporation, as well as to the larger social work community. This may be done in one or more ways, such as through publication of the study results or through presenting the findings to hospital social workers.

What Will Be My Responsibilities Be If I Take Part in this Study?
If you volunteer to participate in this study, we will ask you to do the following things:

- Review and sign this consent form;
- Participate in an interview that should be approximately 60-90 minutes in length and will occur at a location that is arranged between you and the researcher;
- If you choose, read and edit a transcript of your interview before the information you provide is analyzed to provide you an opportunity to remove, add or change information you have given.
- Provide contact information of your choosing if you wish to receive a transcript of your interview, or if you wish to be provided information regarding the results of the study.

What are the Possible Risks and Discomforts?
It is possible that you may experience some discomfort discussing issues related to death and dying.

How Many People Will Be In This Study?
4-6 participants will be in this study.

What are the Possible Benefits for me and/or for Society?
You may benefit from the opportunity to reflect on your feelings and experiences regarding death and dying, personally and professionally in a safe environment. You may gain a better understanding of how your views influence your work with clients at the end of life, and your insights may lead to recommendations that will inform clinical practice and social work education.

What Information Will Be Kept Private?
Information regarding your identity will not be recorded within the interview data, i.e. audiotapes/written notes/transcribed data. The only identifying information I will have will be your contact information if you choose to contact me regarding participating in the study. This information will be kept separately from your interview data, and will be destroyed at the completion of the interview. Access to the raw interview data (audiotape and written notes) will be limited to the investigator, Alexandra Vedell, the supervisor, Dr. Christina Sinding, and a professional transcriber, who will not have access to any identifying information. The results of the study will be presented in the investigators' thesis; however no identifying information will be included in this thesis, as pseudonyms will be used. Further, if the results of the study are published, your name will not be used

and no information that discloses your identity will be released or published without your specific consent to the disclosure. The information you provide in the interview will be kept in a locked cabinet in a secure location. It will be destroyed at the end of the study.

Can Participation in the Study End Early?
If you volunteer to be in this study, you may withdraw at any time. You may also refuse to answer any questions you don't want to answer and still remain in the study.

Will I Be Paid to Participate in this Study?
No, however, if you are required to travel out of your home/work area, or pay for parking in order to participate in this study, the researcher will reimburse your travel/parking expenses.

If I Have Any Question or Problems, Whom Can I Call?

If you have any questions about the research now or later, please contact Alexandra Vedell at 905-522-1121, ext. 6203 (day) or 905-308-9741 (evening) or avedell@hotmail.com, or Dr. Christina Sinding at 905-525-9140, ext. 22740 or sinding@mcmaster.ca.
If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100, ext. 42013.

APPENDIX B

CONSENT STATEMENT

SIGNATURE OF RESEARCH PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

_____

Name of Participant

_____   _____

Signature of Participant   Date

Consent form administered and explained in person by:

_____

Name and title

_____   _____

Signature   Date

APPENDIX C

INTERVIEW GUIDE

The interview will begin with the following:

- Introduction of researcher, professional background, interest in the research topic
- Explanation of purpose of research, researcher's position (insider/outsider, experience with the research topic)
- Review of consent form
- Participants will be given a reminder that they are free to answer/not answer any questions in the interview and are free to withdraw from the study at any time.
- Signing of consent form if the participant chooses to proceed with the interview.

The following are possible questions that will be posed to the participant:

- What kinds of end of life issues do you generally address in your work with clients?

- You've mentioned some end of life issues that you typically deal with...I'd like to hear more about those issues...can you give me a specific example from your work with your clients?

- What kind of challenges or tensions did that situation create for you?

- How do you feel this tension influenced your work with your clients?

- I'd like to discuss what kind of views/beliefs you hold about death and dying. For example, cultural/religious beliefs/practices, or moral/ethical beliefs.

- Do you feel that the cultural/religious/moral/ethical etc. views you discussed above, or your feelings about regarding death and dying create any challenges for you when working with clients at the end of life? If so, what kind of challenges?

- You discussed the challenges and tensions that arose in the example you gave, as well as your own beliefs about death and dying...what opportunities do you have to discuss/process your experiences with clients, or your own feelings about death

- and dying while in your work environment (i.e. supervision, discussion with colleagues) ?

- What (additional) kind of supports/resources do you think would assist you in managing any challenges you face in providing service to clients at the end of life?