THE AMERICAN ACADEMY OF CLINICAL SEXOLOGISTS

SEX, DEATH AND DYING: AN EXAMINATION OF SEXUALITY AND TERMINAL ILLNESS AMONG HOSPICE WORKERS, PALLIATIVE CARE PROFESSIONALS, TERMINALLY ILL PATIENTS AND THEIR FAMILY CAREGIVERS

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DISSERTATION APPROVAL

This dissertation submitted by Michael Ian Rothenberg has been read and approved by three committee members of the American Academy of Clinical Sexologists.

The final copies have been examined by the Dissertation Committee and the signatures which appear here verify the fact that any necessary changes have been incorporated and that the dissertation is now given the final approval with reference to content, form and mechanical accuracy.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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Abstract

Sexuality, death and dying are topics that examine, what appears to be for many, two of the greatest taboos in American society. Sex and death, we are taught from an early age, are not topics for polite conversation. As one who has provided emotional support for hundreds of terminally ill patients and their families, I've experienced, first hand, how the very topic of death can oftentimes make people quite uncomfortable. More than once, at social gatherings, hands were actually withdrawn in greeting when I was introduced, in whispered tones, as Mike, the hospice worker, as if death could be passed along for guests to catch like the common cold. Once I began my education in clinical sexology and began to also include the topic human sexuality in my dialogue on death and dying, I found that conversations sometimes came to abrupt and awkward conclusions. Though, invariably, in whatever circles I traveled, there were always those who appeared to be intrigued by the topic of sexuality and death and who would actively seek my company and conversation. I began to believe that by discussing the topic, I was providing a type of legitimacy that made it acceptable for people to ask questions.

But as a hospice social worker, I was troubled by the lack of attention paid to human sexuality by those in the field whose professional goal was to facilitate the dying process for patients and their families. As sexuality is such an integral part of the lives of most people, it was curious, to me, how palliative care professionals, the physicians, nurses, social workers, chaplains and home health aids, who comprise the interdisciplinary hospice team, could be so reticent, or absent, when it came to the subject of human sexuality. Realizing that very little attention was being provided to patients and families regarding sexuality and the dying

process, I began to regularly include human sexuality as part of my psychosocial assessment. Not to my surprise, patients and families were thankful for the chance to ask questions and express feelings.

This paper uses both qualitative and quantitative measurements to examine sexuality, death and dying among hospice and other palliative care professionals, patients and their family caregivers. Sexual issues are examined from the perspective of the patient, the spousal or partner caregiver, the adult child caregiver and the professional staff. This paper looks at the dying process and the reasons to include discourse on human sexuality as part of the dying process when providing psycho-educational support to patients and families. This paper examines the five stages of death, popularized by Elisabeth Kubler-Ross, and explores these stages from a unique sexological perspective through the use of case studies. Finally, this paper examines the results of a survey on sexuality, death and dying that was provided to hospice and palliative care workers and examines the researcher's conclusions.

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I would like to thank Dr. Jakob Pastoetter and Dr. Sherry Leib for lending their valuable time, consideration and support.

I would also like to thank Dr. William Granzig for having the vision, the desire and the foresight to provide the world a forum from which to educate, illuminate and eradicate prejudice and harm.

And finally, to the sexologists who have come before us to lead the way and clear the path on a sometimes dark and oftentimes hard to travel road, I wish to acknowledge with a quote that somehow seems to capture, for me, the very essence of our work.

“To transform the spirit of love into light
That shall illuminate the night of life
For those who pass darkly through it”

Havelock Ellis
June 10, 1925

Table of Contents

Table of Contents
(Continued)

Page

Table of Contents
(Continued)

Page

List of Figures

Page

Figure

Vita

Michael Ian Rothenberg is a psychotherapist in private practice in Winter Park, Florida. Michael is also a full time faculty member at the University of Central Florida, School of Social Work where he teaches courses in Clinical Social Work Practice, Child Abuse: Treatment and Prevention, Children's Services and Human Sexuality and is Coordinator of the Title IV-E Child Welfare Education Program.

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Michael is a former hospice social worker and has provided both psychosocial and psychosexual support to many patients and families experiencing terminal illness, death and dying. Michael has served as a guest lecturer, conference speaker and invited panelist. Michael is a Diplomate of the American Board of Sexology, Board Certified Clinical Sexologist, Certified Sex Therapist, Licensed Clinical Social Worker and member of the National Association of Social Workers.

Michael lives in Orlando, Florida with his wife and two sons.

Chapter One

Methodology

This research on death, dying and sexuality among terminally ill patients, family caregivers and palliative care professionals utilizes both qualitative and quantitative methodology and is comprised of several sections.

The research first examines, through a review of the literature, sexuality as it is related to the dying process and explores, specifically, the relationship between terminally patients and sexuality, family caregivers and sexuality and palliative care professionals and sexuality.

An examination of Elisabeth Kubler-Ross' five stages of grief is then explored from a sexological perspective and, utilizing qualitative methodology, an examination of the author's personal experience in working with terminally ill patients, their family caregivers and other palliative care professionals is explored through the presentation of case studies that examine denial and isolation and sexuality, anger and sexuality, bargaining and sexuality, depression and sexuality and acceptance and sexuality.

Finally, using quantitative methodology, the results of a survey that examine the attitudes of palliative care professionals regarding sexuality and terminal illness are presented. The survey examines demographic data and presents findings specific to sex, religiosity and profession.

Chapter Two

Sexuality and the Dying Process

Why conduct an examination of death, dying, sexuality and intimacy among terminally ill patients, their family caregivers and palliative care professionals?

For many terminally ill patients and caregivers, sexuality was, and still is, a vitally important aspect of life. The ability, for these individuals, to openly discuss sexuality and communicate sexual needs and concerns, at the end of life, with the palliative care practitioners whose professional role is, in part, to address the physical, spiritual and emotional needs of terminally ill patients and their caregivers is a topic that requires further examination and exploration.

Hospice, the primary system providing physical, spiritual and emotional support for terminally ill patients and their families in the United States, "recognizes dying as part of the normal process of living, so hospice care focuses on maintaining the quality of remaining life" (Lattanzi-Licht, Mahoney and Miller 1998, 48). Psychiatrist and thanatologist, Elisabeth Kubler-Ross, who spent over three decades in researching death and dying, and who was, probably, the world's foremost expert on the subject, once stated simply that "the only incontrovertible fact of my work is the importance of life" (Kubler-Ross 1997, 15). Hospice workers, myself included, are often fond of stating that hospice is not about dying but that hospice is, in fact, about living. One could make the argument that having a sex life would be, by most definitions and for many individuals, part of a normal process of living and an important factor in assessing quality of life. If this is so, one must

wonder why there is then such a scarcity of information related to death, dying and sexuality.

Dr. Ira Byock, considered by many to be one of the world's foremost living authorities in the field of death and dying, does not, in his written work, provide very much discussion regarding sexuality and the dying patient though he does write that there is "human potential to grow-as individuals and as members of families- through the process of dying. Being with people who are dying in conscious and caring ways is of value to them" (Byock, 1997). My own anecdotal experience as a hospice social worker, who has provided emotional support to hundreds of patients and families, has shown that when it comes to sexuality and dying, there is a lack of communication and openness that often stifles this potential for growth and connection among individuals and families and prohibits professionals from providing conscious and caring service regarding sexuality and the dying process.

Though there are very many books written that address the topics of death and dying and those that discuss sexuality and chronic illness, very few, comparatively, ever touch upon the topic of sexuality as being an integral part of the dying process for patients and their family caregivers. There are a few exceptions in the literature on death and dying though sexuality is sometimes addressed, even then, as a taboo subject (Fitzgerald 1994, 155).

One notable example reports on the results of a study that examines sexuality and terminally ill patients where one third of couples will continue to have intercourse up until a few weeks before the death of the patient (Sankar 1999, 207). According to this author, the need for couples to continue to their sexual relationship should be "respected by other

family members and caregivers and that couples will need quiet uninterrupted time" (p.207). This author recognizes the importance of sexuality to the terminally patient's self worth as "respecting sexual needs is part of sustaining the autonomy and the dignity of the dying person" (p.208). This is one of very few professional works that seek to validate the notion that sexuality and sexual contact are important for terminally ill individuals and their partners.

Another example in the literature discusses the importance of sexual contact for the terminally ill patient and partner. This author writes that it is important to "let your loved one know that it is still all right to cuddle under the covers and to enjoy each other's bodies" (Kolf 1999, 38). The author offers suggestions for the patient who notices a "marked change in libido, sexual response or functioning" and offers that the patient should check with a "medical professional" and provides that "illness, treatment and medication can have a direct effect on these responses" (p.38). The author also states that it is important for the terminally ill patient to "find someone you feel comfortable discussing personal matters with and do not assume you have to set your sex life aside" (p.38). This argument, to seek outside assistance when questions arise related to sexuality, would also lend support to the notion that, perhaps, terminally ill patients and their family caregivers would be better served by clinical sexologists who were specifically trained to provide services for this population.

In discussing intimacy and sexuality among terminally ill patients, caregivers and palliative care professionals it is important to provide definitions of intimacy and sexuality. Intimacy, as opposed to sexuality, is more often discussed in the literature on death and dying. Intimacy, in death and dying literature is often seen as a type of closeness or a

bonding between individuals rather than anything that has to do with sexual activity or sexual behavior. Often intimacy is seen as an emotional congruence, between patients, families and caregivers, achieved during the dying process and before death. When discussing intimacy and the terminally patient and family, they are often described as being better able to express their feelings toward one another and especially express feelings of love "as a family we had never been more intimate, more open, more openly loving" (Byock 1997, 25). Intimacy is not described in the literature on death and dying as related to touching, caressing, or of being of a physical or sexual nature.

Sexuality can be defined in different ways. One author, writing about the subject, in regard to aspects of death and dying, defines sexuality as "being more than having sex with someone". Sexuality is "the way you feel about yourself as a man or a woman"

(Fitzgerald 1994, 260). In this respect, sexuality has a subjective definition. The American Heritage Stedman's Medical Dictionary (2004) defines sexuality as the condition of being characterized and distinguished by sex, concern with interest in sexual activity and sexual character or potency. Merriam Webster's Online Dictionary (2006) defines sexuality as the quality or state of being sexual, the condition of having sex, sexual activity and expression of sexual activity or interest. Sexuality also can "be more broadly defined to include intercourse, noncoital partnered activities and masturbation" (Willis and Arnold 2002, 4).

For this paper, reflecting the current literature on death and dying, intimacy will be defined as a state of emotional closeness or congruence but will also refer to the closeness shared through both sexual and non-sexual touch. Utilizing the aforementioned definitions of sexuality, this paper seeks to define sexuality as any aspect of human sexuality, sexual

expression or sexual behavior as it relates to patients, family caregivers and professional palliative care workers.

Hospice care, available to terminally ill patients who have generally been given a prognosis of six months or less, is provided through Medicare and private insurance. Hospice care is palliative, rather than curative, in that the primary objective is to alleviate the terminally ill patient's pain but not to cure the patient. The patient, along with their family, is served by the hospice interdisciplinary team which is comprised of attending physicians, nurses, social workers, chaplains, therapists, home health aides and volunteers. On occasion a bereavement counselor is also available to provide support to family members before the patient's death. The goal of the hospice interdisciplinary team is to attend to the medical, spiritual and emotional needs of the patient and family. "What's different about the hospice approach is its comprehensiveness, its specialization to the unique needs of the terminally ill and the commitment to humane care for the dying that underlies everything a hospice does" (Beresford 1993, 9). The aim of such comprehensive care is to "enhance the quality of life at the end of life by alleviating physical pain and emotional distress" (Baird and Rosenbaum 2003, 17). Sometimes emotional distress for the dying patient can also, very often, include issues that are directly related to the sexual needs and concerns of both the patient and the family caregiver. Though the goal of hospice is to provide for the specialized needs of the patient and caregiver, as related to the dying process, it appears though that, in actuality, very little professional attention is paid to sexuality, death and dying.

Chapter Three

Terminally Ill Patients and Sexuality

In working with terminally ill patients, I found that many of my patients and their family members did, in fact, have questions and concerns that were related to sexuality but they were sometimes too shy or too embarrassed to bring up these concerns to the hospice staff. Some patients, who were able to express themselves, regarding sexual needs and concerns related to their terminal illness, reported that they were led to believe that their feelings were not valued by staff members when their questions were either left unanswered or when the subject was quickly changed by the practitioner. Other patients reported being aware of both verbal and non-verbal messages provided by the staff regarding sexuality such as practitioners asking why they would ever ask about such things, nervous giggling or both avoiding eye contact and eye rolling.

For some hospice patients, changes in their appearance, both actual and perceived, have a negative affect on their sexuality. This notion is often reinforced by the portrayal of sexuality in the media. “There is a deep seated belief, promoted heavily by advertising, that the only people who can have sex are those who are young and physically perfect. The aging, the physically unattractive, the handicapped and those who are ill are excluded from the club” (Kahane 1995, 199). For a great many terminally ill patients, these thoughts have been internalized. Even for those patients who have once enjoyed an active sex life before illness, a common notion is that they must now subscribe to the role of a sick person and society dictates that those who are ill or aged must not have any interest in sexual contact.

Because the palliative care professionals, who provide physical, spiritual and emotional support, often never broach the subject of sexuality with the patient and family caregiver, this also helps to reinforce the message that sexuality is not a topic that is to be openly discussed.

For patients who suffer from chronic illness, sexual concerns are not uncommon. “Many chronic illnesses, from cancer to heart disease, as well as many of the drugs used in the treatment of these conditions, can either temporarily or chronically impair sexual interest” (Leiblum and Rosen 1989, 23). Those patients whose chronic illness has now been characterized as being terminal are experiencing the same sexual concerns as before only now many of the palliative care practitioners, who are providing care for these patients and who might be biased or simply uncomfortable with the subject matter, believe that their focus should be on the dying process, making amends, coming to terms with end of life issues and not sexuality, sexual needs and concerns.

Some terminally patients that I have worked with, who have had a diagnosis of end stage cancer, have also experienced disfigurements such as those caused by head and neck cancer, testicular cancer, cancer of the tongue or mouth. Several female patients have undergone mastectomies, sometimes several years prior, but have received no counseling before joining the hospice program. As one author writes in discussing human sexuality in health and illness “Great apprehension may be associated with dysfunction of any part of the body, particularly those parts linked to gender identity and sexual functioning” (Woods 1984, 285). There is an important need for palliative care professionals to assist those patients experiencing such difficulties.

Other hospice patients, whose cases I have been assigned, have been diagnosed with end stage COPD or chronic obstructive pulmonary disorder "For any patient with COPD, the exertion of sexual activity can promote breathlessness and fatigue" (Schover and Jensen 1988, 252). This does not necessarily mean that the patient is no longer interested in sexual activity but sometimes the fear of being unable to breathe can cause sever anxiety for the patient who will then avoid sexual contact to prevent an anxiety attack from occurring. For the terminally ill patient "progressive disability and chronic fatigue also can lead to clinical depression, further decreasing sexual desire" (p.252).

For some of my male terminally ill patients, the loss of their ability to have erections has caused them to question their identity as husbands, as men and as sexual partners. For many patients "negative thoughts about being unable to get or keep an erection generate negative feelings, such as anxiety and shame" (Schover and Thomas 2000, 211). Loss of erection very often will lead to depression for these patients. As might be expected, most of these terminally ill men are reluctant to bring up these topics with their hospice interdisciplinary team members. A trained professional could counsel these patients and their partners to "switch to other kinds of touching, such as mutual caressing of the genitals or a sensual body massage, and enjoy feelings of pleasure" (Schover 1984, 80). Partners can be taught even when unable to have an erection "the man or woman can rub the head of the penis across the clitoris" and that "the penis can be moved slowly across the clitoris, pressed against it (just barely touching or more firmly) or held in position against the clitoris and the penile shaft moved up or down or sideways" (Alterowitz and Alterowitz 2004, 76). Instead of offering information on sexual variety or techniques, it has been my experience that most members of the hospice team will attribute the patient's depression to

being an expected part of the dying process without ever exploring the possibility of the patient having sexual concerns.

There have been some patients who have reported having fear and anxiety because they were afraid that, at some point, they could pass their illness to their partner through sexual contact. These were not patients who had a communicable disease, like AIDS, but were patients who were afraid that they could pass lung or stomach cancer on to their partners. Other popular myths believed by patients that are related to sexuality include the belief that "sex saps one's strength and thus is harmful to anyone not in the best of health, too much sex is unhealthy and causes illness, having sex weakens the potency of medical treatments like medication"(Schover and Jensen 1988, 75). When these myths are not explored, they can cause the terminally ill patient undue fear and anxiety.

Terminally ill patients have often expressed concerns about getting into heaven or going to hell because of what they, or their church, have perceived to be unacceptable, bad or immoral prior sexual activity. Along with the physicians and nurses who provide for the patients medical needs and the social workers who, primarily, provide for the patients emotional needs, the hospice team also includes a chaplain who provides spiritual support for the patient and family. Part of the hospice philosophy is that "spiritual care is essential for dying patients and their families" (Beresford 1993, 39). Sometimes, though, the patient and or family caregiver will not want to discuss these sexual concerns with the chaplain because of either real or perceived judgmental behavior. As I approach patients openly to discuss sexuality as part of the dying process, many patients will, after establishing rapport, share these sexual concerns. Most of my female patients who have discussed fear of death related to sexual behavior have attributed this fear to having had abortions, premarital sex

or sex outside of marriage. The male patients who have expressed fear of death due to sexual activity have attributed their fear to having had, sex outside of marriage, same sex activity, impure thoughts and fantasies, cross dressing and sex with animals. In order to help patients alleviate their emotional pain, it is inherent that the palliative care professionals become comfortable discussing topics related to sexuality or refer patients and families to someone who is knowledgeable in human sexuality and comfortable in discussing these topics.

Chapter Four

Family Caregivers and Sexuality

For this paper, family caregivers are distinguished from professional caregivers in that they are not employed by the terminally ill patient to provide care in a professional capacity as are professional caregivers who work for home health agencies, nursing homes, assisted living facilities and hospitals.

Partner or spousal caregivers as well as the adult child caregivers of terminally ill patients report specific needs related to sexuality. Sometimes, the partner or spousal caregivers report having guilty feelings because, even though their partner is ill, they continue to have feelings of sexual desire and arousal. Often these caregivers can experience, guilt shame and depression. One author who writes about learning to live with chronic illness states that “the lack of a sexual partner can be ameliorated by self stimulation or masturbation” (Pitzele 1986, 188). Some caregivers feel guilty about masturbation because of religious or societal norms. Some partners or caregivers will seek sexual contact outside of the marriage or relationship which can often lead to further feelings of guilt.

Caregivers of terminally ill patients have also expressed feelings of anger related to sexuality as “anger can interfere with sexuality, no matter whether the anger is directed at fate, at oneself, or at one’s partner” (Schover and Jensen 1988, 68). Some caregivers are angry that their partners are ill and are now unable to enjoy sex as they once did before their illness. If the partner had been a smoker and was now diagnosed with a terminal

illness such as end stage lung cancer, some caregivers have been known to blame the patient for having the illness. Oftentimes the partner or spousal caregiver has a need to direct their anger at someone, or something, and the easiest target is, most often, the patient. Many caregivers have difficulty in directly discussing angry feelings that are related to sexuality.

Often the caregivers simply need direction and counseling regarding sexuality and how to communicate their needs to their partners as caregivers "might be confused as to how to reach out and communicate" (Wheeler and Lombard 1989, 74). Many caregivers are reluctant to discuss these needs with their palliative care professionals and the palliative care team is often just as hesitant to discuss concerns with the patient and caregiver. If these sexual needs are not explored, they can't be treated.

Sometimes partner or spousal caregivers will report a fear that by initiating or resuming sexual activity, the partner can endanger or shorten the patient's life. This is a common misconception. Palliative care professionals who are comfortable with the subject area and able to provide education about sexuality as related to common terminal illnesses such as cardiovascular disease, cancer and end stage renal failure can readily discuss "safety of sex for cardiac patients" along with "effects of therapy on sexual function" for cancer patients and "effects of medication and disease related factors on sexual function" for those with end stage renal disease (Schover and Jensen 1988, 213).

Though not specific to the adult child caregivers, lack of desire attributed to the caregiving role and physical exhaustion is the primary complaint made by this group regarding sexuality and terminal illness. Adult child caregivers refer to men and women whose primary responsibility is to care for a terminally ill parent. Often the alteration in

familial role tends to diminish sexual desire especially if the adult child caregiver is caring for the patient at home. This leads to sexual difficulties for the caregivers and the spouses and partners of these caregivers as well. Again, these caregivers are not likely to broach the subject of sexuality without prompting from the staff. The trained palliative care professional could provide the adult child caregiver with information such as ways to "add variety to lovemaking" in order to "make the experience more exciting" (Laken and Laken 2002, 129). In an attempt to change the mood the caregiver could "use candles, music, scented oils and lotions" or "stage sex to occur in various locations both inside and outside the house" (p.129). The goal would be to increase desire for the caregiver by offering a change in the setting, location, time or sexual fantasy.

Chapter Five

Palliative Care Professionals and Sexuality

It has been written that “all of us are sexual beings. Our sexuality is an integral part of us, it is there before birth and until our death.” (Wells 2000, 15). Death and dying expert Elisabeth Kubler –Ross once wrote that “dying is an integral part of life, as natural and predictable as being born” (Kubler-Ross 1986, 5). Our sexuality is just another natural component of who we are as human beings. For many terminally ill patients, “expressing oneself within intimate relationships is important to quality of life” (www.palliativecarevictoria. com).

There is an important need for palliative care professionals, those individuals who have been entrusted to ensure that the emotional, spiritual and physical pain of patients and families are alleviated and ameliorated, to become proficient at discussing sexuality and providing psycho-educational and psycho-sexual support.

Our sexuality is ever present and “under normal conditions, a person’s sex life ends only in death” (Haeberle 1983, 471). There are many, though, who would wish to believe that people stop thinking about sex and sexual matters as soon as they are diagnosed with an illness or, for those who are aged, many years before.

Sometimes the professionals themselves, along with some older patients believe that sexual activity is reserved for the young. “Even when their physical and mental health is excellent, men and women in their fifties, sixties and seventies sometimes

exhibit an old-man or old woman act" (Butler and Lewis 2002, 222). It's as if the older person must now subscribe to a certain preconceived role that dictates how a person of a certain age should act. I have worked with many palliative care professionals who fully embraced this notion or who have turned a blind eye to those patients for whom sexual activity was still an important part of their lives.

"Sex negative myths and attitudes add up to policies or attitudes that prohibit sexual expression among the aged and nowhere is this more evident than in nursing homes and other institutions that provide care for older men and women" (Kelly 1992, 188). Though most hospice patients are provided services in their homes, there are those who reside in nursing homes as well. In these institutional settings the notion that a terminally ill elderly man or woman could have any interest in discussing sexual concerns is considered, by staff and administration, to be utterly preposterous yet as a hospice social worker I, personally, have had interactions with residents who were grateful to have someone with whom they could openly discuss their sexual issues and concerns.

As many terminally ill patients are, indeed, though by no means exclusively, older people, there tends to be a bias, among palliative care professionals, and among society as a whole, that older people are not, or should not, be interested in sexual matters.

"In the western world older and even middle-aged persons are often discouraged from sexual activity. They are reprimanded or ridiculed for their sexual interests according to the general assumption that sex in old age is abnormal, indecent and disgusting" (Haeberle 1983, 471).

Though it appears that this notion regarding sexuality and the aged is pervasive there is an imperative that "the health care professional caring for patient's sexuality has a role in recognizing the presence of sexuality in every part of their work, to look for it in both health and illness" (Wells 2000, 15). Palliative care professionals have a responsibility to their patients and to the families of the patients to attempt to put aside their judgments surrounding sexuality. "Every life is different from any that has gone before it, and so is every death" (Nuland 1993, 1). In understanding that every life and death is, in fact, unique, palliative care professionals need to better accept that, for many, sexuality is an important factor in their lives.

Terminally ill patients and caregivers who are in a same sex relationship can experience additional hardship in regard to the attitudes of some palliative care professionals and death, dying and sexuality. Some palliative care professionals, due to religious convictions, that proclaim same sex activity as sinful, will serve these individuals but will distance themselves, emotionally, and sometimes physically too, from patients and caregivers who are in same sex relationships. These practitioners will be professional but clinical and cold with limited physical contact. Others will be friendly and accommodating to the patient and caregiver but will talk about the lifestyle of the patients and caregivers in disparaging terms outside of the patient's home. Still others believe that it is their moral responsibility, as part of end of life care, to help these patients and caregivers to renounce their beliefs in an attempt to achieve eternal salvation and they actively devise methods to save the patients from their, perceived, sins such as initiating discussion regarding accepting Jesus Christ and the afterlife.

For some palliative care practitioners, it is the patient's religion and ignorance about religious practices and sexuality that impact the relationship between the patient, caregiver and the hospice team member. On occasion I've personally had to educate staff members about non-mainstream religious beliefs, such as Wicca or other nature based religions, when team members believed, erroneously, that the patient and caregiver were involved in devil worship, sexual rituals and sexual sacrifice. Some of these palliative care professionals, out of ignorance and fear, have refused to serve these patients and families and their requests were granted by supervisors. As one who believes that part of the role of the hospice social worker is to advocate for the patients and families, I've often educated the palliative care staff about the patient's and caregiver's right to sexual self determination and sexual expression of any kind. I've attempted to assist palliative care practitioners to become more aware of their judgments and how judgmental behavior can create barriers that affect the families that they serve. I've been successful with some but those who subscribe to a fundamentalist perspective believe that they are working with a mandate from God regarding what is right and what is wrong in terms of sexuality and sexual behavior.

"Sexual dysfunction and dissatisfaction in chronically ill patients are underdetected and undertreated because of barriers to discussion about sex and lack of medical training in human sexuality" (www.mja.com). Palliative care professionals must realize that by not speaking openly about sexuality or by not facilitating conversation with patients and caregivers they are doing a disservice to their patients. "It can be argued that the professional responsibility is to try to be aware that feelings about sexuality, often unspoken, can influence health" (Wells 2000, 13).

Health refers, not only to physical health, but to emotional health as well. A written work published by a hospice volunteer successfully captures an exchange by a hospice volunteer and a hospice nurse regarding sexuality and a spousal caregiver (Andreae 2000, 134).

> "She confided that as a Hospice nurse, she found sexual issues the hardest to deal with. "I have one patient whose husband keeps telling me that he hasn't had sex in two years" So what do you tell him? I wonder.
>
> Lee shrugged. "I say, well, there are other outlets…"
>
> I can't imagine telling Ray it's OK to masturbate! I exclaimed, my mind thoroughly boggled.
>
> Jeanette snorted in disgust.

This is an all too common scenario. The patient's spouse, who is obviously seeking support and guidance from those who have pledged support is effectively brushed aside, and discussed with shock and indignation, rather than recognized as person, with questions about sexuality, who is obviously in need of assistance.

This lack of forthcoming information is experienced at many levels, even before the patient has been given a terminal diagnosis. "At a breast cancer forum in Philadelphia, a social worker asked a room packed with dozens of women (and a few devoted husbands) if their cancer docs had ever mentioned sex to them. By my count only three people raised their hands" (Silver 2004, 171). By the time patients and their families are accepted to a hospice program, they have, most likely, been on a long journey, interacting with many health care professionals who have, probably, not ever discussed sexuality.

"Patients are likely to discuss sexual concerns only if their professional carers routinely take a sexual history and are comfortable doing so" (www.hospiceworld.org). It can be argued that the members of the hospice interdisciplinary team, but especially the hospice social workers who are mental health professionals providing emotional support during the dying process, should be required to have some training in sex therapy. "Mental health professionals trained in sex therapy can help you improve your sexual communication, adjust to changes in your sex life…or resolve sexual problems that are related to anxiety" (Schover 1997, 63). If a palliative care practitioner is not comfortable in discussing sexuality, a referral should be made to a sex therapist or clinical sexologist who is trained in working with terminally ill patients and their caregivers.

The PLISSIT model developed by Jack Annon (Annon and Robinson 1978, 35-36) could be successfully utilized by hospice and other palliative care practitioners to provide quality counseling service to terminally ill patients and families regarding sexual issues. Using this model, "clinicians treating a sexual problem can intervene on several levels of therapeutic intensity. Annon's PLISSIT model of sexual counseling identifies four levels of intervention" (Schover and Jensen 1988, 150). These four levels of graded intervention include permission, limited information, specific suggestions and intensive therapy.

Permission

As hospice patients and caregivers are unlikely to initiate questions relating to sexuality, by giving permission the palliative care practitioner encourages patients and families to discuss sexual problems and concerns without fear of judgment or ridicule. It is

therefore imperative that the palliative care practitioner initiate this discussion by asking the family or caregiver if they have concerns or questions related to sexuality, illness and the caregiving role. In asking these questions, the palliative care professional is letting the patient and caregiver know that questions about sexuality are commonplace and acceptable.

The hospice team member can also share that many families have questions related to sexuality and acknowledge that, sometimes, patients and families might feel shy or awkward in asking questions of a sexual nature. It's important for the team member to assure the patient and caregiver that the team member will always be glad to answer questions about sexuality.

Limited Information

The hospice practitioner can provide patients and families with needed psycho-educational and psycho-sexual support. Hospice practitioners regularly provide the terminally ill patients and their family caregivers with limited information on the changes associated with the dying process such as decrease in food or fluid intake and increased sleep patterns. General information can also be regularly provided by palliative care practitioners regarding the effect of pain medications on sexual desire and arousal or how changes in the body, like a decrease in energy or in activity level, that are a natural part of the dying process, can affect sexuality.

Specific Suggestions

When needed, specific suggestions can be provided to terminally ill patients and their caregivers regarding techniques like sensate focus, use of different sexual positions to alleviate pain and discomfort, the use of lotions and oils, vibrators, varying times for sexual activity to coincide with the effects of pain medications, enlisting fantasy and using oral sex or masturbation to address sexual needs. The hospice team members can offer specific suggestions such as engaging in sexual activity in the early morning hours when the patient has more energy. Palliative care professionals can also provide suggestions for the patient and caregiver on speaking with other family members and caregivers to ensure that they have privacy to engage in sexual activity.

Intensive therapy

Sometimes intensive therapy might be recommended for pre-existing sexual problems experienced by the terminally ill patient or the by the spousal or partner caregiver such as a sexual dysfunction that is pre-existing and is not related to the patient's terminal illness. In this case, as in the case of a palliative care practitioner who is either unable or uncomfortable in discussing sexuality with patients and caregivers, the patient and caregiver should be referred for counseling and for treatment to be provided by a trained sex therapist or clinical sexologist.

Chapter Six

The Five Stages of Grief and Sexuality

Psychiatrist Elisabeth Kubler –Ross first developed the five stages of grief in her groundbreaking book titled On Death and Dying (1969). Kubler-Ross, after interviewing hundreds of dying patients and listening to them share their stories about the dying process, realized that there were, in fact, distinct experiences that all terminally ill patients experienced. The five stages of grief, first applied only to the terminally ill patient, were later used to describe reactions experienced by both the patient and their family members and caregivers.

According to Kubler-Ross, the five stages of grief are denial and isolation, anger, bargaining, depression and acceptance. Though there is no substantive discussion of sexuality, sexual issues or sexual concerns noted in Kubler-Ross' initial work, these five stages of grief can also be examined from a sexological perspective to include sexuality as an important component of the dying process.

Sexuality and grief play a significant role in the dying process for both terminally ill patients and their family caregivers. As the stages often do not progress in order and patients and caregivers can revisit stages throughout the dying process, grief stages and sexuality can be especially problematic when the terminally ill patients and their caregivers experience different stages of grief at different times.

For example, we might see a family caregiver who has come to terms with their

spouse or partner's illness and the subsequent limitations on sexual functioning and, at the same time, we find a terminally ill patient who is in denial as to how the illness has affected sexual functioning, desire and arousal and who is experiencing denial and isolation. Conversely, we might find a patient who has accepted their illness and the affect that the dying process or medication usage has on their sexuality while, at the same time, the spousal caregiver is angry over the loss of sexual contact.

As palliative care professionals are responsible for attending to the physical, spiritual and emotional needs of patients and families, it can be argued that by not attending to their sexual concerns as well, which impact the aforementioned needs, they are doing their patients and families a disservice. In order to better meet these needs, palliative care professionals must become better aware of sexuality, grief and the dying process and the resulting implications for terminally ill patients and their spousal and partner caregivers.

Chapter Seven

Stage One: Denial and Isolation and Sexuality

According to Kubler-Ross “Among the over two hundred dying patients we have interviewed, most have reacted to the awareness of a terminal illness at first with the statement, No not me, it cannot be true” (p. 38). Kubler-Ross believed that denial and isolation went hand in hand and purposefully grouped the two experiences as one single stage. It is often seen that the patient and caregiver will also experience denial and isolation in relation to sexuality and the dying process.

Some terminally ill patients will deny that they are experiencing any sexual problems related to desire or arousal or having sexual performance difficulties but will, in fact, distance themselves sexually from their partners. Their partners, in turn, will sometimes report experiencing a decrease in, or lack of, sexual activity. Depending upon the extent and the severity of the terminal illness, the partners sometimes report not wishing to engage in sexual intercourse but will report missing intimacy and closeness that was once shared through sexual and non-sexual touch. As the patient is in denial and because there has been little, or no, communication regarding the impact of the terminal illness on sexuality, the patient and caregiver become increasingly isolated as the illness progresses.

On occasion a patient will report having the belief that the caregiver no longer finds the patient sexually attractive any longer. Sometimes this is seen when a patient has experienced a change in their appearance due to weight loss, hair loss, or surgery, such as a mastectomy, that can affect how terminally ill patients view themselves as sexual partners.

These patients might still have interest in sexual activity but, due to their cognitions, isolate themselves sexually from their partners.

Some caregivers deny the extent of their partner's terminal illness and have unrealistic expectations of the terminally patient's sexual capability either due to progression of the terminal illness or effects from medication. The terminally ill patient's decrease in sexual desire and arousal can sometimes be perceived by the caregiver as rejection and can lead to increased isolation. This is another reason why psycho-sexual support and open and honest communication is important for both the terminally patient and caregiver.

Chapter Eight

Stage Two: Anger and Sexuality

Kubler-Ross reports that for the terminally ill patient, “when the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment” (p.50). The grief stage of anger is a very common experience seen in both patients and caregivers when examining sexuality and the stages of grief.

Often when a terminally patient can admit to himself, or to herself, that due to the terminal illness they no longer engage sexually in the same way that they once did, feelings of anger can develop. This anger is often directed at the spouse or partner simply because they are perceived to be a safer target for the patient’s anger. The patient is usually more reluctant to direct their anger at the physicians, nurses, and counselors who are providing services because the terminally ill patient has the fear that the palliative care professional might leave them if anger is directed towards them. Patients, instead, feel safer in attacking those closest to them because they understand that, most likely, their partner will not abandon them due to their expressions of anger.

This often leads to significant problems within the relationship since the partner who is being verbally assaulted often does not understand the source of the patient’s anger and, instead of being able to help the patient discuss sexual concerns, is driven further from the patient. Because the patient’s expression of anger is directed at the caregiver, the caregiver, sometimes, then becomes emotionally distant and less interested in sexual activity with the patient. As the caregiver is less interested in sexual activity with the patient, this reinforces

the patient's cognition that the caregiver is no longer interested in sexual activity because of the changes that the patient is experiencing as part of the dying process and serves to increase the dysfunctional pattern of engagement between the patient and the caregiver.

Other patients have reported that the progression of the terminal illness has affected their ability to perform sexually and, subsequently, led them to question their sense of being real men or women. Some male terminally ill patients, who are no longer able to achieve or maintain erections, have described having sexual feelings but having no choice but to avoid sexual contact of any kind since they cannot perform sexually in the way they once did. Other female patients who report not feeling like real women because of surgeries, cognitions or the effects of medications also report wishing to avoid all sexual contact with their partners. These cognitions that lead to a decrease and then cessation in sexual activity often cause terminally ill patients and partners to exhibit anger at each other and those around them.

There are those terminally ill patients whose anger is directed at the nature of the disease itself or how they have come to acquire the terminal illness. Some patients with a terminal illness such as AIDS have been known to experience anger at themselves for contracting the illness or anger at a partner for infecting them. This is especially true of some patients who had been infected with HIV, through unprotected sex, by partners who had been unfaithful or who, knowingly, had the virus but did not disclose this fact to them. There are also cases of spousal and partner caregivers who are angry at their spouses for having been smokers and who, subsequently, have been diagnosed with a terminal illness such as end stage lung cancer. The anger directed at these patients makes it difficult for the

patient and caregiver, who might have once enjoyed sexual activity, to now have the desire to engage sexually with each other.

There are times that patients, who have anger related to their terminal illness and changes to their sexual activity and ability, will be so angry that they will direct their anger to not only their partner but also to everyone around them. These patients, and caregivers, who are angry and express their anger vocally, are sometimes quite difficult for the palliative care practitioners to properly establish rapport with and serve professionally. As these are the terminally ill patients and caregivers who may need extensive psycho-sexual support, it's imperative that the palliative care team is able address their sexual needs or refer the patients to sex therapists who can provide needed support.

Chapter Nine

Stage Three: Bargaining and Sexuality

Kubler- Ross wrote that the terminally ill patient "knows, from past experiences, that there is a slim chance that he might be rewarded for good behavior and be granted a wish for special services. His wish is almost always an extension of life, followed by the wish for a few days without pain or physical discomfort" (p.82). Bargaining, as related to sexuality and dying, is seen very often by the palliative care professional providing support to terminally ill patients and families.

Very often the terminally ill patient will bargain with God for more time and the bargaining often includes the patient asking forgiveness and promising to cease to ever again engage in a sexual behavior that is often not accepted by the patient's religion or perceived the patient to not be accepted by society as a whole.

Sometimes the bargain is specific such as when a terminally ill male fundamentalist Christian patient asked to live to see one more Christmas in exchange for giving up the recurring fantasies of same sex activity that the patient reported had plagued him since childhood. Other examples of terminally ill patients who have bargained with God for more time include a patient who promised to never masturbate again to pornography and who sought assistance in destroying his pornography collection, a male patient who promised to confess to his family preacher that he had sex with animals when he was a thirteen year old boy living on a farm and a woman who offered to confess to her family that she conceived a child out of wedlock and had received an illegal abortion more than fifty years ago. All of

these patients were bargaining, not to live indefinitely, but for a little more time in exchange for changing, or making amends for, some aspect of their sexuality.

Many terminally ill patients express a belief that their terminal illness is directly related to a perceived punishment from God. More often than not this punishment is perceived as God's disapproval of their sexual behavior. Some patients have expressed that paraphilic activity, such as the patient who reported having sexual contact with a farm animal, has now caused the patient to have liver cancer seventy years later. This patient does not have the insight to understand that the two are not medically correlated but a trained palliative care professional, who was comfortable in discussing sexuality, could offer validation and help this patient to explore his emerging feelings before his death.

Sometimes it is the spousal or partner caregivers who do the bargaining as is the case when they are the ones who disapprove of the patient's sexual behavior. An example is the spousal caregiver who reported that her husband's cancer of the tongue was God's punishment for his affairs with other women throughout their marriage and that she would forgive him if God would make him better. Another example involves a young woman of nineteen who was the caregiver for her mother who was diagnosed with AIDS and was given a prognosis of only days to live when admitted to the hospice program. The caregiver, a young woman with strong religious convictions, reported that her mother, a former IV drug user and prostitute, was dying because she had angered God because of her sexual behavior. The caregiver prayed that she would continue to give her life to Jesus and help her mother every day to seek his forgiveness in exchange for sparing her mother's life.

Patients and caregivers who are experiencing the bargaining stage of the grief process are often in a great deal of emotional pain. The pain of grieving for the end one's life or the

life of a loved one is compounded when sexuality is perceived, by the patient or the caregiver, to be the cause of the terminally ill patient's illness. Palliative care professionals who are able to discuss sexuality and sexual issues and who are willing to bring up the subject with patients and caregivers can greatly assist these patients and caregivers with their sexual concerns and alleviate emotional distress related to sexuality.

Chapter Ten

Stage Four: Depression and Sexuality

Kubler –Ross wrote “When the terminally ill patient can no longer deny his illness, when he is forced to undergo more surgery or hospitalization, when he begins to have more symptoms or becomes weaker and thinner, he cannot smile it off anymore…his anger and rage will soon be replaced by a great loss” (p.85).

Many terminally ill patients will grieve things lost to them as part of the dying process such as sexual activity. Most people want and need to be close to other people. We want to touch and be touched both physically and emotionally (www.helpguide.org). This is especially true for younger, sexually active patients and caregivers but it can also be true for older patients as well.

Often sexuality is a concern for patients who are in their seventies, eighties and even in their nineties. Sometimes, older patients are prescribed, by societal standards, to portray the role of an older person. This role dictates what an older man or woman is supposed to be like and older people, according to social norms, are not to have an interest in sexuality. There are times when the older terminally ill patient, himself or herself, believes this to be true and will not discuss sexual issues because they believe that having a conversation about sexuality is not a proper topic for a person of their age. The fact that discussions about sexuality are rarely entered into by the hospice staff reinforces this notion. Often, though, older men and women grieve the loss of sexuality, sexual contact and sexual touch as any other terminally ill patient would.

Very often, the older terminally ill patient is seen as experiencing depression. This depression is dismissed, by families and by palliative care practitioners as well, as being just a part of the dying process or being one of the stages of grief that all terminally ill patients experience.

Sometimes, though, this depression is related to changes in sexuality for the older patient and when the terminally ill patient or partner or spousal caregiver is afforded the opportunity to address questions about sexuality the patient can begin to move from depression regarding their sexuality to acceptance. Many older terminally patients are often thankful when presented with the opportunity to discuss sexuality as related to the dying process and grief.

Kubler –Ross also writes that "the second type of depression is one which does not occur as a result of a past loss but is taking into account impending losses" (p.86). In this respect, the terminally ill patient and caregiver grieve not what has been lost to them in the past but what is lost to them in the future. This specific type of grief is known as anticipatory grief and is "the grief work we do as we try to prepare ourselves ahead of time for a loss" (Schoenberg and Carr 1974, 347). Often terminally ill patients and their spousal or partner caregivers will grieve the loss of future sexual contact and activity with their partners. This grief stage can be particularly difficult when either the patient or the caregiver reported enjoying mutually satisfying sex with their partner before the diagnosis of terminal illness.

An example would be the caregiver who had presented with depression that the hospice staff had originally attributed to being a normal part of the grieving process. The patient and caregiver, a couple in their early fifties, reported twenty years of happy marriage and

the caregiver was simply told that depression was to be expected. After providing the caregiver with the opportunity to discuss sexual issues and concerns, she disclosed that she and the patient had enjoyed having sexual contact often and that she was grieving that an important and special part of her life was going to change forever. By offering validation and normalization for her feelings, the caregiver was able to express her feelings about sexuality and the dying process and begin to work through the depression stage of her grief.

Chapter Eleven

Stage Five: Acceptance and Sexuality

According to Kubler-Ross “if a patient has had enough time (i.e., not a sudden, unexpected death, and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his fate” (p. 112). For the terminally ill patient and family caregiver experiencing grief, many do, in fact, reach the stage of acceptance and sexuality.

Though difficult, at first, once the patient and caregiver accept that death will, in fact, occur and that there are going to be changes related to sexuality and the dying process, these individuals then become ready to explore other avenues and are amenable to suggestions to help them to express their sexuality.

It is the sexually accepting patient and caregiver who understand that the dying process affects desire and arousal and sexual functioning. These individuals are aware of the affect of pain medication on sexuality and are agreeable to discuss alternating the time and location of sexual activity to compensate for these changes. The sexually accepting terminally ill patient and caregiver are willing to discuss alternative sexual positions that make it easier for the patient to engage in sexual activity. These individuals are also agreeable to discuss options for sexual contact besides coitus such as oral sex, the use of vibrators and various other types of sexual touch.

Kubler-Ross states that it is the patient “who has been given some help” (p. 112)

in working through the stages of grief who is able to reach the acceptance stage. The same is true for the patient who reaches the stage of acceptance and sexuality. In order for the terminally ill patient and spousal or partner caregiver to reach this point, it is important that competent help be provided by the palliative care staff to assist with sexuality, sexual needs and concerns.

Often the professional staff has their own biases, judgments, opinions and beliefs that prevent them from fully offering the patient and family much needed psychosexual support. Palliative care practitioners must become aware of their own sexual issues, learn to speak openly with patients and caregivers about sexuality and provide patients and caregivers with the right to sexual self determination. This begins with the understanding that all patients are sexual beings, sexual activity is a natural part of life and that, like each death, each life is different and each patient has their own unique sense of what is sexually important to them as individuals.

Because most terminally ill patients and their spousal or partner caregivers do not openly discuss how physiological changes related to sexuality and the dying process, chronic pain or exhaustion can affect sexuality and sexual functioning, it is up to the palliative care professionals to raise the issue for them. By relating to the terminally ill patient and their spousal or partner caregiver that, very often, individuals, like themselves, have concerns about sexuality, the palliative care workers normalize the sexual concerns of the patient and caregiver. By simply then asking if they have any questions, the physicians, nurses, chaplains, social workers and counselors who serve these patients and caregivers will facilitate an environment of non-judgmental acceptance regarding sexuality and terminal illness.

The following chapters highlight five case studies from the researcher's practice that examine Kubler-Ross' five stages of grief from a sexological perspective. These stages include denial and isolation and sexuality, anger and sexuality, bargaining and sexuality, depression and sexuality and acceptance and sexuality. The names, diagnoses, and locations have been changed to protect and conceal the identity of the patients and caregivers discussed.

Chapter Twelve

Case Study: Denial and Isolation and Sexuality

Elisabeth Kubler-Ross combined denial and isolation as one single stage in the grief cycle. As the following case study illustrates, denial and isolation, when applied to sexuality, can also lead to difficulties for patients diagnosed with a terminal illness.

John was a handsome, well built, six foot tall, twenty-seven year old Hispanic male diagnosed with end stage lung cancer. John was not working and had recently relocated to Florida to live with his mother and stepfather. During our initial visit John minimized the seriousness of his illness and his doctor's recent prognosis of six months or less that precipitated John's admittance to the hospice program. John reported feeling fine and having no health problems besides feeling a little tired once in a while. Our early conversations consisted mostly about the differences between Central Florida and the northeastern city where John had lived after moving from the Dominican Republic at age 12. As I had once lived in the same area, we shared a similar background and rapport building came easy. During our initial visits, John denied having any problems at all related to his health and reported enjoying an active social life that included visits to local dance clubs and frequent sexual activity that consisted of one night stands with women whom he met at the clubs.

John was an unusual hospice patient in that he first initiated conversations related to sexual activity and spoke openly about sexual behavior. In my experience, most hospice patients and caregivers are reticent when it comes to discussing issues related to sexuality but are eager to ask and to answer questions when presented with the opportunity. I

suspected that this had to do with his sense of machismo (John later told me that Hispanic men do not talk about their feelings with other men) as well as an attempt to normalize his illness. John spoke often about his girlfriend, Gloria, who lived up north and whom he believed was going to move to Florida. It was John's hope that this girlfriend would move in with him and that they could, according to John, start a new life together.

John's primary focus became Gloria's pending visit and the long weekend trip to Miami that he had planned for the two of them. John, initially, continued to remain upbeat and during our visits, I provided emotional support through active listening and through the therapeutic use of physical presence. We had now developed a good rapport and while John continued to deny his illness, I did not attempt to confront his denial. Denial is, for some patients, a protective factor that facilitates the dying process for the patient and in hospice work there is often little reason to strip a patient of this defense. As a few weeks passed, John's health began to decline and he reported having less energy to go out to the clubs. John's Mother reported a change in John's attitude and behavior and stated that he rarely left his room anymore and had isolated himself from his family. When asked a how he was feeling or if he was experiencing any pain, John continued to insist that there was really nothing wrong with him and that the doctors had gotten his diagnosis all wrong.

During one visit with John, a few weeks after our first meeting, in response to a general inquiry as to how he was feeling, John responded angrily "Damn it, I'm OK. There's nothing wrong with me. Leave me alone. I don't want to talk about the shit that's happening to me". John turned away from me and broke into tears. This was the first time that John made reference to experiencing changes. John turned to me and stated that it was "all over between me and Gloria. She wouldn't want me now. I'm not a man anymore". In

sensing that John was alluding to a sexual concern, I asked John if anyone had ever spoken to him about the effects that cancer could have on sexual performance. Though John spoke openly about sex with me, he had never asked specific questions nor had he spoken with his physician or nurse about changes and they had also never broached the subject with him.

Though I attempted to bring up the topic of cancer and sexuality once before, John had abruptly changed the subject, indicating that he was not yet ready to discus these issues. By bringing up the subject, though, I indicated to John that this was a topic that was acceptable to talk about, if and when the time came, when John was amenable to discussing the affects of cancer on sexuality. By denying that there was a sexual problem, John had effectively, if temporarily, isolated himself both emotionally and sexually.

John reported that because he could no longer maintain an erection as he once did, he was afraid that Gloria would no longer be interested in his companionship as a sexual partner. Fearful that she would spurn him, John broke up with Gloria over the telephone immediately before her scheduled visit to Florida.

As John was now ready to discuss sexuality and because I had previously normalized the subject, I provided John with psycho-educational and psycho-sexual support regarding fatigue, effects of medication and changes in libido. We discussed other sexual options for John and Gloria such as erotic and non-erotic touch, and massage. As John was still able to achieve and maintain morning erections we discussed varying the time of sexual contact to coincide with John's current level of sexual functioning.

Though reluctant at first, because we had established a good rapport and level of comfort in discussing sexual issues, when Gloria finally did come to visit, John asked that

she be included in our meetings. John died approximately two months after Gloria's visit but they did, in fact, make their trip to Miami where John and Gloria both reported utilizing the techniques and methods that we had discussed and sharing a mutually satisfying sexual experience.

Chapter Thirteen

Case Study: Anger and Sexuality

For some terminally ill patients and their family caregivers anger is related to sexual concerns. Brad and Laura were both fifty four years old, without children, and had been married for more than thirty years. Brad, a psychotherapist, was recently admitted to Hospice with end stage stomach cancer and had been given a prognosis of six months or less. When assigned to their case I found both Brad and Laura were experiencing the anger stage of grief. Because of their extreme anger and hostility, I was unable to establish rapport and I had some difficulty in obtaining information during my initial psychosocial assessment.

Brad and Laura, his primary caregiver, had both reported having a good and happy marriage. Brad and Laura had a beautiful beachfront home, boats, expensive cars and they reported having enjoyed outdoor activities. Both reported taking care of their bodies, eating right, not smoking and, until the cancer diagnosis several months ago, enjoying a healthy and active lifestyle.

The couple reported that they were shocked by the diagnosis and that they were the last people in the world to expect to have to deal with something like terminal cancer. Brad and Laura both reported feeling cheated by life. Neither the patient nor caregiver were tearful during my initial and subsequent visit, but would often yell and curse at each other, myself, their nurse and other members of the hospice team. Brad and Laura both appeared to be consumed by their anger and they had a hard time expressing any other emotion.

Subsequently, the entire hospice staff had a hard time establishing rapport and providing services.

On my second visit with this apparently hurting yet outwardly hostile couple, after attempting to establish rapport, I mentioned that some couples who have recently been through an experience like theirs, find that they sometimes have questions about sex and sexuality that are related to their diagnosis and treatment. I explained that I was available to answer questions for them if they had any or if any arose. I was on a dual visit with a newer hospice nurse whose eyes grew wide and whose mouth dropped in apparent horror as I began to discuss sexuality with this very angry patient and caregiver.

Much to the nurse's surprise, we began what was to be an intensive dialogue regarding sexuality and terminal illness. Laura reported that they once had a very good sex life but now they were barely having any physical contact at all and it was adding to her anger. Brad reported missing sex, intimacy and closeness but that he couldn't perform sexually like he used to before the cancer. Brad stated that sex was an important part of their lives and the fact the cancer had changed that too made him even angrier. Being an insightful person, Brad reported that he realized that he was driving Laura away with his anger when he really wanted and needed sexual contact. Laura, who was sitting across the room, moved next to Brad and put her hand on his leg. For the first time, I was able to notice the anger dissolve and, as if on cue, Brad and Laura held hands and smiled at each other.

During our sessions, Brad shared that much of his anger was related to the decrease in his libido and Laura reported that she was sure that Brad just wasn't interested in sex any more which caused her to become angrier at "this damn cancer that's ruined our lives". Brad and Laura both reported that they had sexual concerns and knew that they had to

discuss the impact of the cancer on their sexuality but that no one had ever brought it up to them before and, even though Brad was himself a therapist, they didn't know how to initiate the conversation with their doctor or, later on, with the hospice staff.

In helping Brad and Laura talk about their sexual concerns along with regular psycho-sexual and psycho-educational support that addressed techniques, positions and sexual changes related to the dying process, I was soon able to help them to more readily express their feelings about their sexual needs. In time, the couple moved from the anger and sexuality stage towards the acceptance and sexuality stage in the grief process. This very angry couple soon presented as genuinely warm and caring. Brad lived for several months more than his initial prognosis and both he, and Laura, reported having mutually satisfying sex until shortly before Brad's death.

Chapter Fourteen

Case Study: Bargaining and Sexuality

Most of the patients I've worked with who are experiencing the stage of grief that includes bargaining very often offer to change an aspect of their sexual behavior that they believe is in some way responsible for their terminal illness. Larry was an example of such a patient.

Larry was a married, seventy-two year old, non-practicing Catholic, retired traveling salesman who was recently diagnosed with a glioblastoma or what is more commonly known as a brain tumor. Larry, whose cognitive functioning had not yet been severely impaired was given a prognosis of six months or less. Though he complained, at times, of dizziness, tiredness and headaches, he presented, during our first meeting, with normal mood and broad affect.

During the psychosocial assessment when I began to discuss illness and sexuality, Larry abruptly confided that he had been an unfaithful husband and that he had cheated on his wife Marian more times than he could count. Larry believed that his illness was a punishment from God for his sexual indiscretions. Larry stated "I need to talk about this with someone but Marian is always here and I can't let her know about what I've done because it would kill her".

Marian happened to be at the drugstore picking up a prescription when I arrived and I explained to Larry that people often have questions or concerns related to sexuality and I was glad to listen or to try to answer his questions. Larry stated "listen, I love my wife but she was always dead in the bed. I needed someone to make me feel alive and now,

as punishment, God is killing me". Larry continued, "I promised God that I would never cheat again, if only he would let me live, but this tumor keeps getting bigger and bigger. I swear I'll be a good husband from now on if he lets me live. I'm not ready. I want more time"

Larry appeared genuinely fearful and spoke with urgency as he feared that Marian would return home at any minute. I provided Larry with emotional support and offered validation and normalization for his emerging feelings. Larry also spoke of his fear of going to hell for his sexual behavior and for displeasing God. As Larry had spiritual concerns, I offered to have the hospice chaplain contact Larry as well but, as is often the case with patients with sexual concerns, Larry stated that he could "never discuss this with a priest" and wanted no contact with clergy. Larry thanked me profusely for speaking with him and stated that this had been building inside of him for years. He was thankful for the opportunity to discuss his feelings with someone and declared that I was a blessing sent straight from God.

Marian returned home after a short while, concerned about leaving Larry home alone. I offered to stay longer during my next visit so that Marian could take her time at the store knowing that someone would be at home with Larry. I also knew that this would allow Larry an opportunity to further discuss his feelings of guilt related to prior sexual behavior. Marian stated that it would be wonderful to be able to spend an hour at the store knowing that Larry's needs would be attended to by a member of the hospice staff. I left Larry and Marian at the end of the day pleased that I was able to help Larry in addressing his sexual needs and concerns.

When I returned to work the next day, I was told by my clinical supervisor that Larry had requested a different social worker. He called the office shortly after my visit and reported that he did not like me and asked that I never return to his home. I suspected that Larry had probably disclosed too much information during our initial visit and now felt uncomfortable.

Like Larry, very many of my terminally ill patients in the bargaining stage of the grief process have promised that, if allowed to live, they would change or make amends for their sexual behaviors. These behaviors most often include infidelity, same sex activity, unprotected sex, oral sex, pregnancy outside of marriage and, on occasion, paraphilic activity such as bestiality. Patients often report that these behaviors have resulted in their receiving a terminal illness inflicted by a vengeful God and this can often result in much distress for patients during the bargaining and sexuality stage of the grieving process.

Chapter Fifteen

Case Study: Depression and Sexuality

Thomas was a forty year old man whose wife, Annabeth, was diagnosed with end stage liver cancer. She had been on the hospice program for almost two years when I was transferred their case. Thomas and Annabeth were the parents of an eight year old son named Alexander. Thomas was self employed and was the primary caregiver for both Annabeth and Alexander. After a very long struggle with her disease Annabeth had reached a level of acceptance. She reported being very strong in her faith and stated that she "knew that her time here was almost done" and that she was "ready to go home to the Lord". While Annabeth was experiencing acceptance, Thomas was experiencing the grief stage of depression. Terminally ill patients and family caregivers often experience different stages of grief at different times and this can lead to both emotional conflict as well as sexual difficulties.

When I met with Thomas for the first time, he was working in his home office. Thomas worked from home as a computer programmer. As Annabeth had been on the hospice program for a considerable amount of time, Thomas was knowledgeable about the role of the social worker. "I already know what you do for Annabeth" he said. I let Thomas know that I was available to support him just as much as I was there to provide support for Annabeth and that I'd be glad to meet with him separately if he liked. Thomas said that in all the time that Annabeth had been ill, no one had ever made that offer before.

As I regularly brought up the topic of sexuality with patients and families, I had expressed to Thomas that many times couples experiencing terminal illness have questions regarding sexuality. I explained that I understood that some patients and their caregivers had difficulty in discussing this topic but I was amenable to answer any questions at all. I assured Thomas that there were few topics that I had not discussed before with other caregivers and I asked Thomas if there was anything that he'd like to discuss with me today, thereby, offering permission for Thomas to ask questions about sexuality, sexual problems and concerns while at the same time offering recognition and validation for Thomas and his feelings. "It's so hard" Thomas stated with tears in his eyes. "I feel like I'm all alone in this and no one seems to understand how hard this is for me, as a man".

Thomas stated that he had been very depressed because as Annabeth grew weaker and sicker over the four years since her initial diagnosis, he still had sexual needs. "I feel guilty about it and then I feel more depressed. I tried to bring it up with Annabeth's hospice nurse years ago and she yelled at me and told me I was being selfish". I haven't talked about it since. For more than one year Thomas and Annabeth had no sexual contact at all. "What's wrong with me?" I'm a terrible person. My wife is dying and all I can think about are my own needs. I make myself sick". Thomas shared that he had, several months ago, thought about taking his own life and that if it weren't for his young son needing a father, he would have killed himself a long time ago. "I cry every night".

I explained to Thomas that I didn't believe that he was being selfish and that his desire for sexual contact with Annabeth was a natural response and experienced by other caregivers in similar circumstances.

Thomas reported that he and Annabeth had enjoyed an active sex life before her illness and I explained that the loss of a sexual partner was just cause for sadness and grief. We discussed masturbation and Thomas, who was raised as a fundamentalist Christian, reported having deeply ingrained beliefs, from childhood, that masturbation was dirty and sinful. Thomas explained that his mother had caught him masturbating as a boy and he was severely beaten by his father for his ungodly act.

Though Thomas offered that he knew, on an intellectual level, that masturbation wasn't really wrong he was still conflicted about his feelings and was overcome with guilt that led to increased feelings of depression . Thomas reported that he also knew that he would never cheat on his wife and break his marital vows so masturbation was his only outlet. Thomas reported that he had succumbed to his urges and was now masturbating nearly every day. Thomas shared that he didn't know if it was wrong or not but that he continued to satisfy his needs in the only way he knew how.

Thomas appeared to want someone to give him permission and to let him know that it was acceptable to satisfy his sexual needs through masturbation. I offered validation and explained that for many caregivers of terminally ill patients masturbation provided an acceptable form of sexual expression. The psycho-sexual information provided to Thomas appeared to provide him with the impetus he needed to move from the depression stage of the grief process to the acceptance stage.

In the next few weeks, as Thomas was able to satisfy his sexual needs without guilt, he reported that his depression had, to a great extent, subsided. As Thomas began to feel better about himself, and more accepting of the role that masturbation plays in regard to

caregivers, sexuality and the dying process, he became more open to the idea of initiating some limited sexual contact with Annabeth with a goal of coitus sometime in the future.

Though Thomas did not wish for Annabeth to join in our discussions about masturbation, she had reported, separately, that she also expressed a desire for a greater level of intimacy with Thomas that would include both sexual and non-sexual touch.

Beginning with sensate focus exercises, Annabeth and Thomas began the process of slowly, once again, experiencing each other's physical touch. These exercises progressed over several weeks with positive results. Though now too weak for coitus, Thomas was happy to report that he spent the night next to Annabeth in her hospital bed. Thomas reported that he and Annabeth enjoyed satisfying sexual contact for the first time in years as she stroked his penis and brought him to orgasm. Annabeth reported feeling closer to Thomas than she had in a very long time and enjoyed his holding her in bed until morning. Thomas had reported that his depression had finally lifted and he was now able to reach, along with Annabeth, the grief stage of acceptance and sexuality.

Chapter Sixteen

Case Study: Acceptance and Sexuality

Sometimes the acceptance stage of the grief process, as it relates to sexuality, can affect the terminally ill patient and the family caregiver in equally important ways.

Mary, a seventy six year old patient, was diagnosed with end stage stomach cancer. She had been given a prognosis of six months or less eighteen months prior to my involvement in her case. She and Sam, her eighty year old husband, were sexually active and, until recently, had enjoyed coitus at least twice a week. They lived with their middle aged daughter Roz and her husband Mark.

I found this family to be remarkably open regarding issues of sexuality. Mary and Sam spoke freely with their daughter about their sexual needs and concerns. Roz reported that because of her increasing responsibility as Mary's primary caregiver, she had begun to lose interest in sex with her husband. From almost my initial encounter with this family, most of our work involved sexual issues. Mary's hospice nurse reported, during our interdisciplinary team conference, that this family was "sick and disturbed and obsessed with sex". As a hospice social worker, part of my role was to educate and, often, I did educate other staff members about tolerance and respect for the patients and families that we served.

Mary, a self described "tough old broad" had, in the beginning stages of her cancer, vowed not to give up. "I never backed down from a fight in my life and I ain't going to start now." Sam, who enjoyed talking about his sexual prowess with his family and anyone

else who would listen, was especially proud that he had shot a man who he found in bed "screwing my first wife". Unlike the rest of the hospice team, I found this family, though a little rough around the edges, to be loving and open.

Mary, who had disclosed that she was OK with dying and was tired a lot of the time now, was concerned about Sam. "Let him go down to the bar and find a new woman. I can't give him what he deserves." Mary and Sam, along with their daughter, spoke with me about other ways for the couple to enjoy themselves sexually. Roz was even willing to take her parents to a sex shop buy toys. We discussed varying sexual positions that might make it easier and less painful for Mary. We also talked about changing the times that Mary and Sam engaged in sexual activity to coincide with the drowsiness caused by the medications that Mary was taking. As Sam also began to accept the changes in Mary's condition, they were able to continue to enjoy the sexual part of their relationship that was so important to them even after almost fifty years of marriage. Roz shared that on the night of their wedding anniversary, after the family had gathered for a party, Mary and Sam retired to their room early to "screw around" while the family (including the older grandchildren) hooted and shouted encouragement from the living room. "We heard the bed squeaking so we new they was goin' at it".

Roz, who was having trouble herself with sexual desire, discussed with me the trouble that she was having accepting her mother's decline. As we processed her emerging feelings, increasing responsibilities as a caregiver and her lack of desire, Roz was able to better understand how her caregiving role and her lack of desire could be related. We discussed making changes in time and location of sexual activity.

Because Roz had associated her home with her mother and her needs, I suggested that she and her husband spend some time at the local motel, enjoy a night at the movies and use fantasy to help build desire. Roz reported that as she began to understand and to accept the changes that her mother had been recently experiencing as being part of a natural process, she had become less fearful, able to relax and better able to enjoy sexual contact with Mark.

As this family was able to freely express themselves regarding sexual needs and concerns, despite the obvious discomfort and open disapproval expressed some members of the hospice staff, the patient, and both the spousal caregiver and adult child caregiver were readily able experience the grief stage of acceptance and sexuality.

Chapter Seventeen

Sexuality and Terminal Illness Survey Methodology

Method

The sexuality and intimacy with terminally ill patients and their caregivers survey was created by the author with the intent of obtaining specific information regarding the attitudes of palliative care practitioners who currently work, or who have previously worked, with terminally ill patients, their families and their caregivers. An anonymous sampling was taken from hospice employees in Central Florida.

Participants

There were twenty three participants, seventeen women and six men; twenty four were Caucasian, two were African American and one was Native American. Ages of participants ranged from eighteen to sixty nine years old. Respondents resided in Central Florida. Participants identified as nurses, social workers, chaplains or other professions. Years of practice of the participants ranged from less than one year to more than twenty years. Education levels of participants ranged from Associate Degree to Ph.D.

Procedure

Approximately one hundred surveys were distributed to hospices in Central Florida. The survey included questions about experience in assisting patients, families and caregivers. Instructions were provided for the unsigned and anonymous surveys to be returned in attached stamped self addressed envelopes. Participants were assured that the surveys would remain anonymous and would not be shared with other members of the

hospice staff. The researcher personally coded the surveys upon completion. Surveys were collated by sex of the participant, religiosity of the participant and profession of the participant and the subsequent quantitative data was analyzed.

Chapter Eighteen

Results of the Demographic Survey

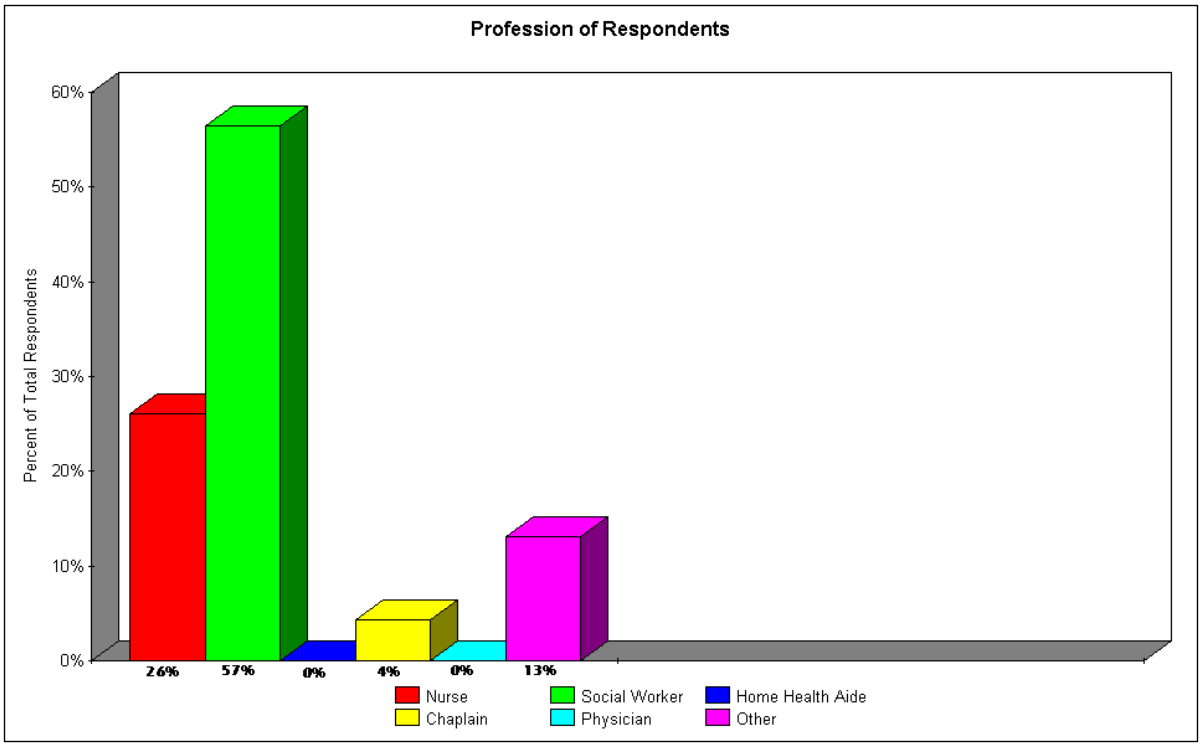

Figure 1

Twenty six percent of the respondents reported their profession as nurse. Fifty seven percent of the respondents reported their profession as social worker. Four percent of the respondents reported their profession as chaplain. None of the respondents reported their profession as physician. None of the respondents reported their position as home health aid. Thirteen percent of the respondents reported their position as other. Respondents described these other categories as social worker/chaplain dual professional and pharmacist/hospice volunteer.

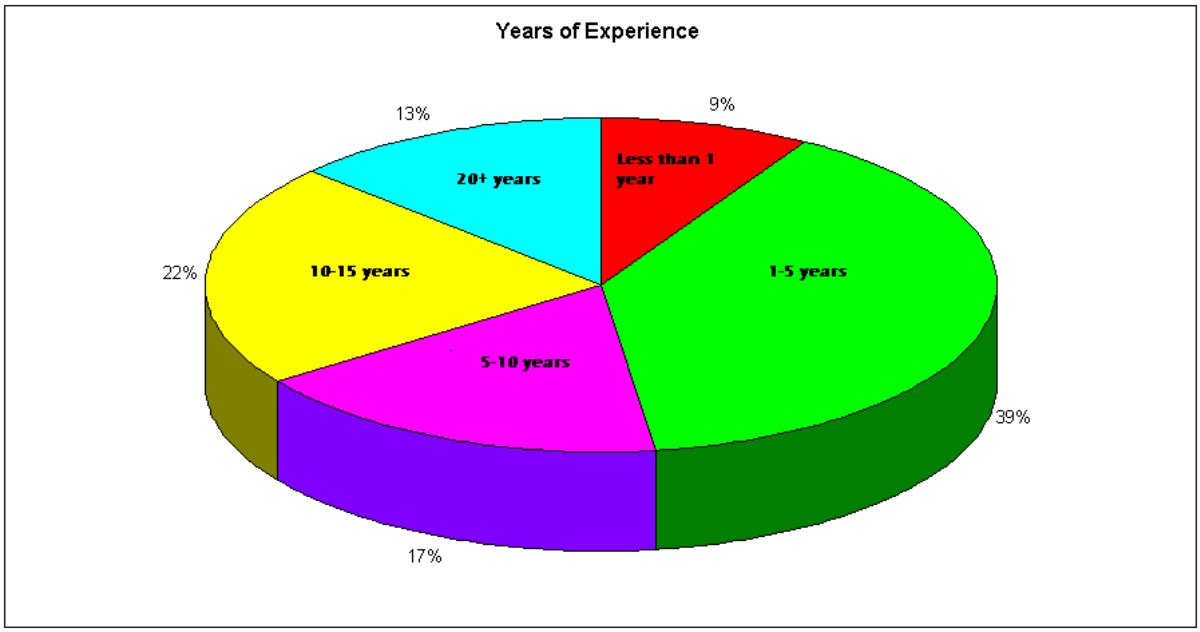

Figure 2

Nine percent of the respondents reported that they have been working with terminally ill patients, families and caregivers for less than one year. Thirty nine percent of the respondents reported that they had been working for one to five years. Seventeen percent of the respondents reported that they had been working for five to ten years. Twenty two percent of the respondents reported that they had been working ten to fifteen years. Thirteen percent of the respondents reported that they had been working with terminally ill patients, families and caregivers for more than twenty years.

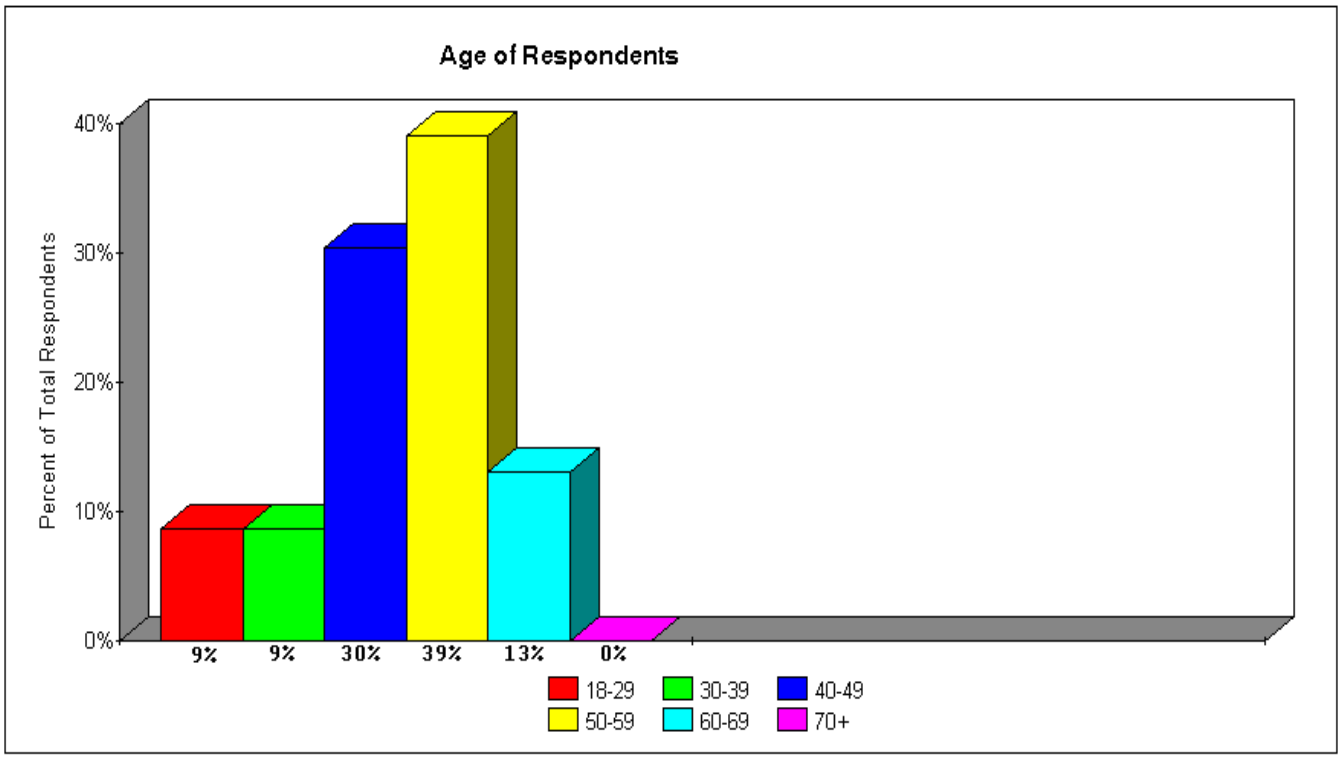

Figure 3

Nine percent of the respondents reported their age as between eighteen and twenty nine. Nine percent of the respondents reported their age as between thirty and thirty nine. Thirty percent of the respondents reported their age as between forty and forty nine. Thirty nine percent of the respondents reported their age as between fifty and fifty nine. Thirteen percent of the respondents reported their age as between sixty and sixty nine. None of the respondents reported their age as seventy or more.

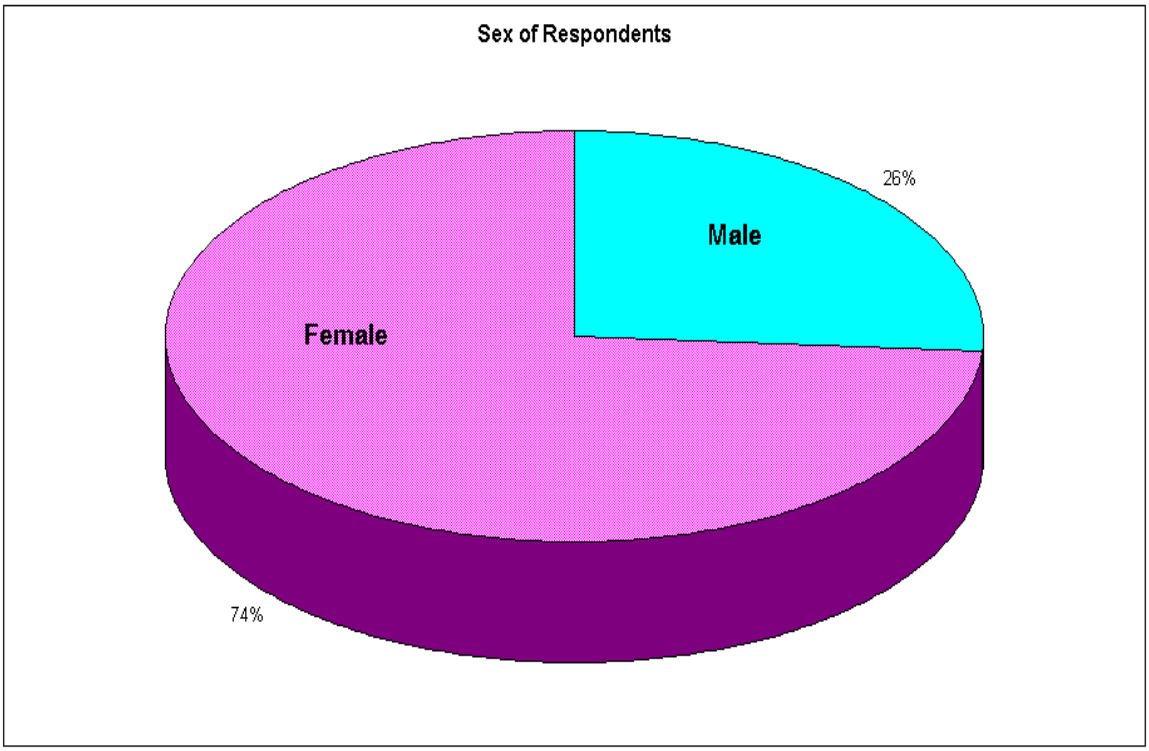

Figure 4

Twenty six percent of the respondents reported their sex as male. Seventy four percent of the respondents reported their sex as female.

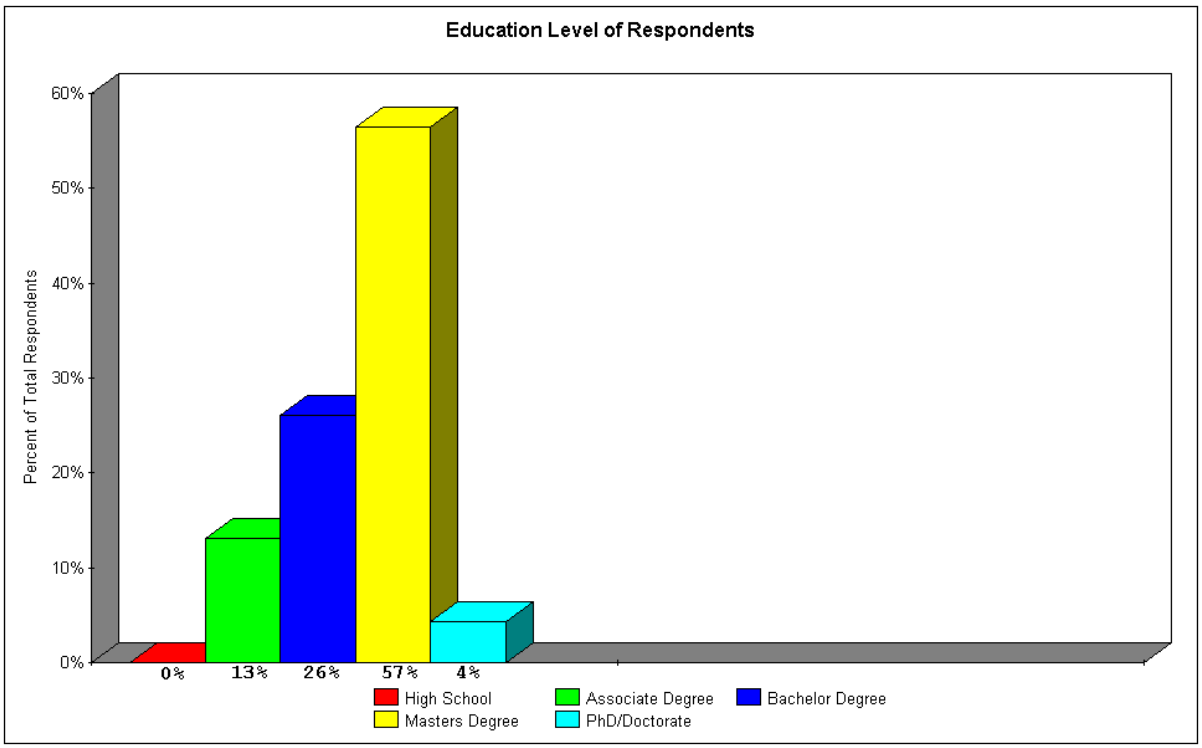

Figure 5

Thirteen percent of respondents reported their highest level of education completed as associate degree. Twenty six percent of respondents reported their highest level of education completed as bachelor degree. Fifty seven percent of respondents reported their highest level of education completed as masters degree. Four percent of respondents reported their highest level of education completed as Ph.D.

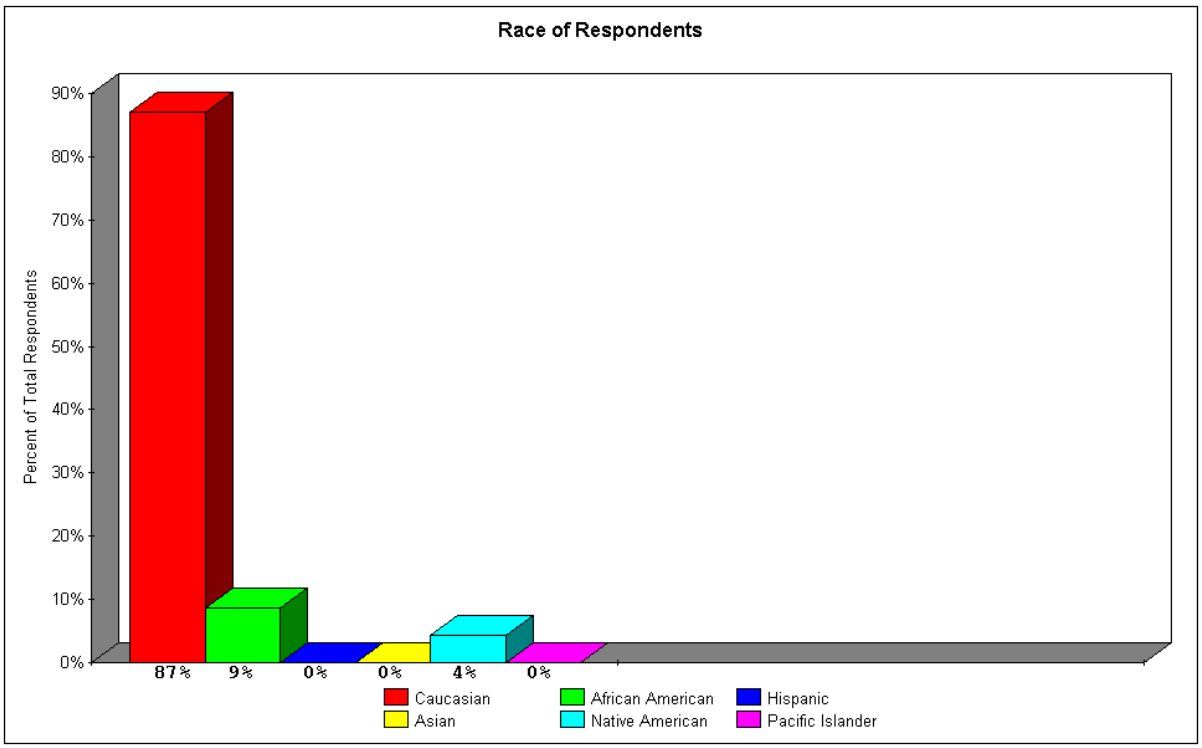

Figure 6

Eighty seven percent of respondents reported their race as Caucasian. Nine percent of respondents reported their race as African American. Four percent of respondents reported their race as Native American.

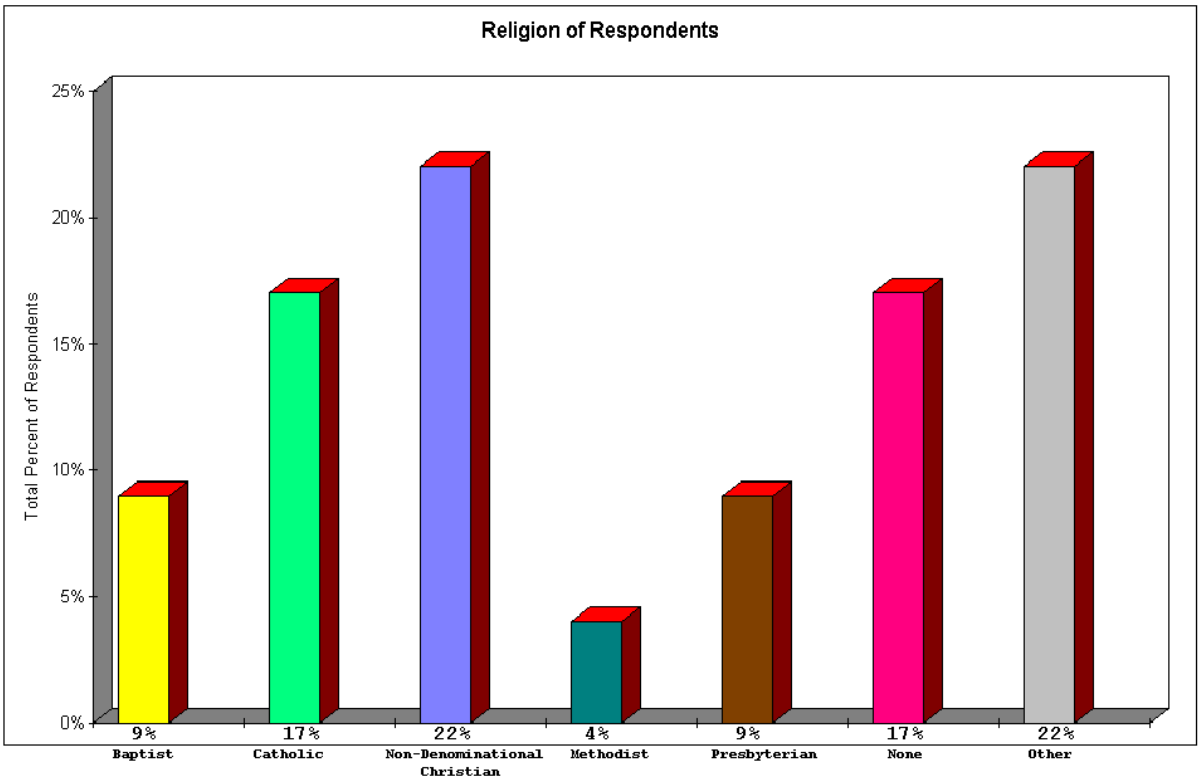

Figure 7

Nine percent of respondents reported their religion as Baptist. Seventeen percent of respondents reported their religion as Catholic. Twenty two percent of respondents reported their religion as Non-Denominational Christian. Four percent of respondents reported their religion as Methodist. Nine percent of respondents reported their religion as Presbyterian. Seventeen percent of respondents reported their religion as none. Twenty two percent of respondents reported their religion as other. Respondents described other religions as Spiritual and Humanist.

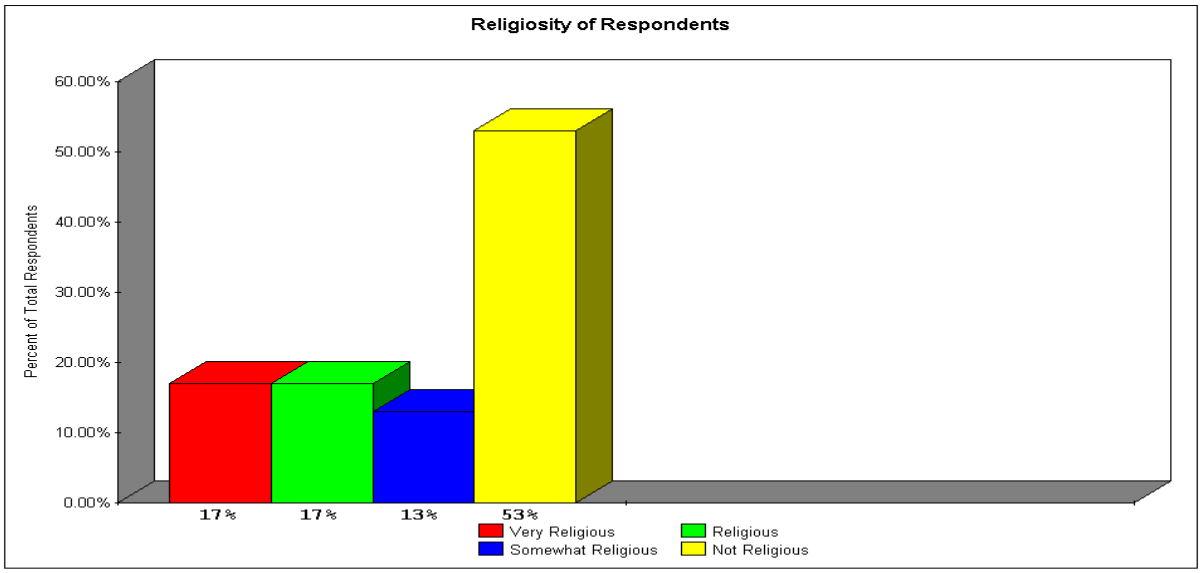

Figure 8

Seventeen percent of respondents reported that they consider themselves very religious. Seventeen percent of respondents reported that they consider themselves religious. Thirteen percent of respondents reported that they consider themselves religious. Fifty three percent of respondents reported that they consider themselves not religious.

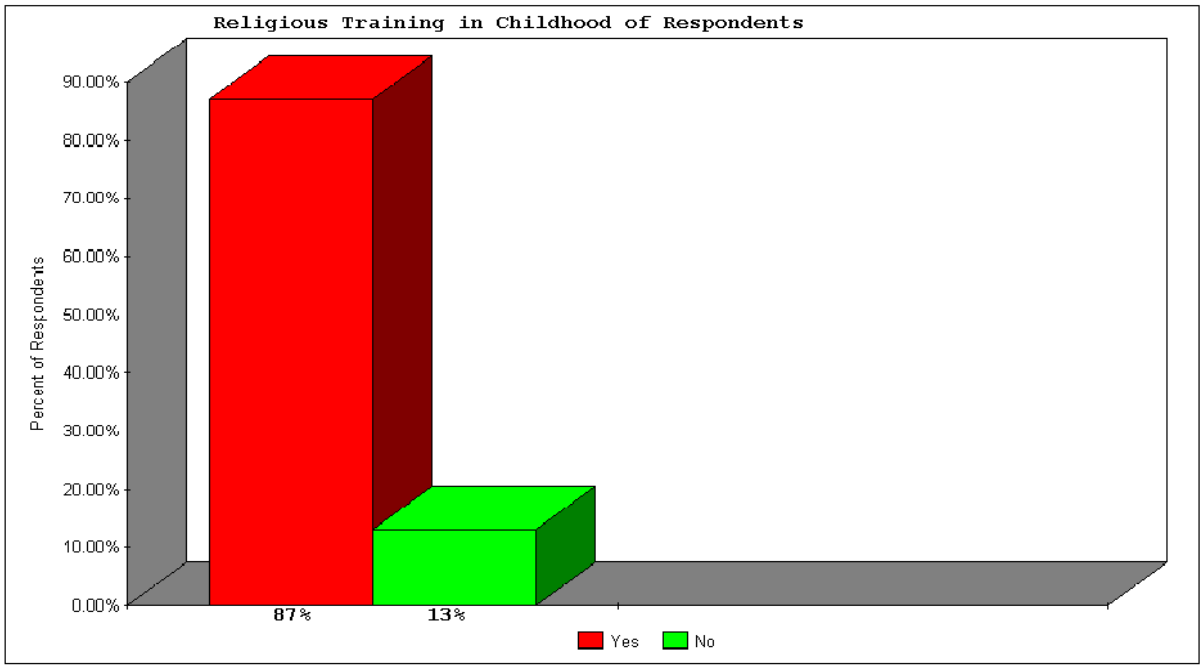

Figure 9

Eighty seven percent of respondents reported that they received religious training as a child. Thirteen percent of respondents reported that they did not receive religious training as a child.

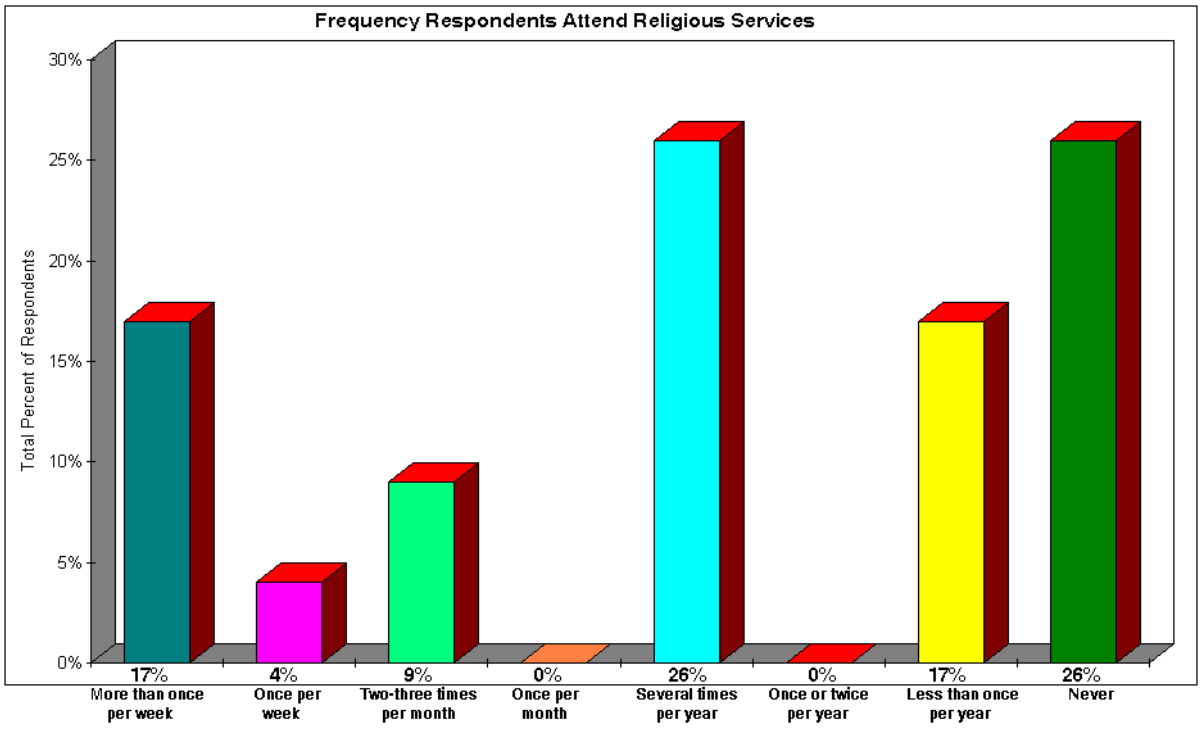

Figure 10

Seventeen percent of respondents reported that they attend religious services more than once per week. Four percent of respondents reported that they attend religious services once per week. Nine percent of respondents reported that they attend religious services two to three times per month. Twenty six percent of respondents reported that they attend religious services several times per year. Seventeen percent of respondents reported that they attend religious services less than once per year. Twenty six percent of respondents reported that they never attend religious services.

Chapter Nineteen

Sexuality Survey Results- Sex of Respondents

1. Do you believe that it is appropriate to discuss sexuality with terminally ill patients?

Male (n=6)

Very appropriate	83.3%
Somewhat appropriate	16.7%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Female (n=17)

Very appropriate	41.2%
Somewhat appropriate	35.3%
Neither appropriate or inappropriate	11.6%
Somewhat inappropriate	5.9%
Very inappropriate	

Researcher's Conclusions

100% of males and 76.5% of females reported that it is appropriate to discuss sexuality with terminally ill patients.

2. Do you feel qualified to discuss sexuality with terminally ill patients?

Male (n=6)

Very qualified	50.0%
Somewhat qualified	50.0%
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	

Female (n=17)

Very qualified	5.9%
Somewhat qualified	41.2%
Neither qualified or unqualified	23.5%
Somewhat unqualified	5.9%
Very Unqualified	23.5%

Researcher's Conclusions

100% of males and 47.1% of females reported being qualified to discuss sexuality with terminally ill patients. 29.4% of females reported being unqualified to discuss sexuality with terminally ill patients.

3. Do you believe that it is appropriate to discuss sexuality with family caregivers of terminally ill patients?

Male (n=6)

Very appropriate	33.3%
Somewhat appropriate	66.7%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Female (n=17)

Very appropriate	5.9%
Somewhat appropriate	52.9%
Neither appropriate or inappropriate	41.2%
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

100% of males reported that it is appropriate to discuss sexuality with the family caregivers of terminally ill patients. 58.8% of females reported that it is appropriate.

4. Do you feel qualified to discuss sexuality with the family caregivers of terminally ill patients?

Male (n=6)

Very qualified	50.0%
Somewhat qualified	50.0%
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	

Female (n=17)

Very qualified	11.8%
Somewhat qualified	29.4%
Neither qualified or unqualified	23.5%
Somewhat unqualified	11.8%
Very Unqualified	23.5%

Researcher's Conclusions

100% of the males reported being qualified to discuss sexuality with the family caregivers of terminally ill patients. 52.9% of the females reported being qualified. 25.3% of the females reported being unqualified.

5. Do you feel sexuality is a concern for terminally ill patients?

Male (n=6)

Some	100%
Most	
All	
None	

Female (n=17)

Some	76.5%
Most	17.6%
All	5.9%
None	

Researcher's Conclusions

100% of males reported that sexuality is a concern for terminally ill patients. 76.5% of females reported that sexuality is a concern for some. 17.6% reported that sexuality is a concern for most and 5.9 % reported that sexuality is a concern for all patients.

6. Do you feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients?

Male (n=6)

Very appropriate	83.3%
Somewhat appropriate	16.7%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Female (n=17)

Very appropriate	35.3%
Somewhat appropriate	41.2%
Neither appropriate or inappropriate	23.5%
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

100% of males and 76.5% of females reported that it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients?

7. Do you feel it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients?

Male (n=6)

Very appropriate	66.7%
Somewhat appropriate	33.3%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Female (n=17)

Very appropriate	5.9%
Somewhat appropriate	47.1%
Neither appropriate or inappropriate	23.5%
Somewhat inappropriate	17.6%
Very inappropriate	5.9%

Researcher's Conclusions

100% of the males and 47.1% of the females reported that it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients. 23.5% of the females reported that it was inappropriate.

8. Do you feel comfortable in discussing sexuality with your terminally ill patients?

Male (n=6)

Very comfortable	66.7%
Somewhat comfortable	16.7%
Neither comfortable or uncomfortable	16.7%
Somewhat uncomfortable	
Very uncomfortable	

Female (n=17)

Very comfortable	23.5%
Somewhat comfortable	35.3%
Neither comfortable or uncomfortable	17.6%
Somewhat uncomfortable	5.9%
Very uncomfortable	17.6%

Researcher's Conclusions

83.4% of males and 58.8% of females reported being comfortable in discussing sexuality with terminally ill patients. 23.5% of females reported being uncomfortable.

9. Do you feel comfortable in discussing sexuality with the family caregivers of terminally ill patients?

Male (n=6)

Very comfortable	66.7%
Somewhat comfortable	16.7%
Neither comfortable or uncomfortable	16.7%
Somewhat uncomfortable	
Uncomfortable	
Very uncomfortable	

Female (n=17)

Very comfortable	17.6%
Somewhat comfortable	35.3%
Neither comfortable or uncomfortable	17.6%
Somewhat uncomfortable	11.8%
Uncomfortable	5.9%
Very uncomfortable	11.8%

Researcher's Conclusions

83.4% of males and 52.9% of females reported being comfortable in discussing sexuality with the family caregivers of terminally ill patients. 29.5% of females reported being uncomfortable.

10. Do you believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Male (n=6)

Some	100%
Most	
All	
None	

Female (n=17)

Some	82.4%
Most	17.6%
All	
None	

Researcher's Conclusions

100% of men and 82.4% of women report that there are some terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. 17.6% of women report that most patients would like to discuss sexuality but are afraid to bring up the subject.

11. Do you believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Male (n=6)

Some	100%
Most	
All	
None	

Female (n=17)

Some	94.1%
Most	5.9%
All	
None	

Researcher's Conclusions

100% of men and 94.1% of women report that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. 5.9% of women report that most would like to discuss sexuality but are afraid to bring up the subject.

12. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

100% of males and 88.2% of females reported that there has not been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 11.8% of females reported that they had changed the subject.

13. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the terminally ill patient?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

100% of males and 94.1% of females reported that they had not changed the subject because they were uncomfortable. 5.9% of females reported changing the subject.

14. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the terminally ill patient?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

100% of the males and 94.1% of the females reported that they did not change the subject. 5.9% of the females reported that they did change the subject.

15. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

100% of the males and 94.1% of the females reported that they did not change the subject. 5.9% of the females reported that they did change the subject.

16. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

83% of the males and 88.2% of the females reported that they did not change the subject. 16.7% of the males and 11.8% of the females reported that they did change the subject.

17. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the caregiver of the terminally ill patient?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

83.3% of the males and 94.1% of the females reported that they did not change the subject. 16.7% of the males and 5.9% of the females reported that they did change the subject.

18. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the caregiver of the terminally ill patient?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

100% of the males and 82.4% of the females reported that they did not change the subject. 17.6% of the females reported that they did change the subject.

19. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

100% of the males and 100% of the females reported that they did not change the subject.

20. Was training in human sexuality part of your formal education or professional training?

Male (n=6)

Yes	83.3%
No	16.7%

Female (n=17)

Yes	52.9%
No	47.1%

Researcher's Conclusions

83.3% of males and 52.9% of females reported that training in human sexuality was part of their formal education or professional training. 16.7% of males and 47.1% of females reported that it was not.

21. Was training in human sexuality part of your agency's orientation process?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

16.7% of males reported that training in human sexuality was part of their agency's orientation process. 83.3% of males and 100% of females reported that it was not.

22. Has a terminally ill patient ever requested your advice regarding sexual desire?

Male (n=6)

Yes	50%
No	50%

Female (n=17)

Yes	35.3%
No	64.7%

Researcher's Conclusions

50.0% of males and 35.3% of females reported that a terminally ill patient had requested advice regarding sexual desire. 50.0% of males and 64.7% of females reported no request.

23. Has a terminally ill patient ever requested your advice regarding sexual arousal?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

66.7% of males and 11.8% of females reported that a terminally ill patient requested advice regarding sexual arousal. 33.3% of males and 88.2% of females reported no request.

24. Has a terminally ill patient ever requested your advice regarding sexual performance?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	41.2%
No	58.8%

Researcher's Conclusions

33.3% of males and 41.2% of females reported that a terminally ill patient requested advice regarding sexual performance. 66.7% of men and 58.8% of women reported no request.

25. Has a terminally ill patient ever requested advice regarding sexual positions?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

16.7% of males and 17.6% of females reported that a terminally ill patient requested advice regarding sexual performance. 83.3% of males and 82.4% of females reported no request.

26. Has a terminally ill patient ever expressed concern regarding unmet sexual needs?

Male (n=6)

Yes	100%
No	

Female (n=17)

Yes	35.3%
No	64.7%

Researcher's Conclusions

100% of males and 35.3% of females reported that a terminally ill patient expressed concern regarding unmet sexual needs. 64.7% of women reported no expression.

27. Has a terminally ill patient ever expressed guilty feelings for having sexual desire?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

50.0% of males and 11.8% of females reported that a patient has expressed guilty feelings. 50.0% of males and 88.2% of females reported no expression.

28. Has a terminally ill patient ever discussed lack of intimacy?

Male (n=6)

Yes	100%
No	

Female (n=17)

Yes	58.8%
No	41.2%

Researcher's Conclusions

100% of males and 58.8% of females reported patients discussing lack of intimacy. 41.2% of females reported no discussion.

29. Please indicate with an X the topics you would be comfortable discussing with a terminally ill patient. (X one box for each).

Male (n=6)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	83.3%		16.7%		
Kissing	83.3%		16.7%		
Sexual touch	66.7%	16.7%	16.7%		
Masturbation	66.7%	16.7%	16.7%		
Oral Sex	50.0%	33.3%	16.7%		
Intercourse	66.7%	16.7%	16.7%		

Female (n=17)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	94.1%				5.9%
Kissing	76.5%	5.9%	11.8%		5.9%
Sexual touch	29.4%	29.4%	23.5%	5.9%	11.8%
Masturbation	17.6%	29.4%	5.9%	29.4%	17.6%
Oral Sex	17.6%	11.8%	17.6%	23.5%	29.4%
Intercourse	23.5%	29.4%	23.5%	11.8%	11.8%

Researcher's Conclusions

83.3% of males and 94.1% of females reported being comfortable with non sexual touch. 5.9% of females reported being uncomfortable. 83.3% of males and 82.4% of females reported being comfortable with kissing. 5.9% of females reported being uncomfortable. 83.4% of males and 58.8% of females reported being comfortable with sexual touch. 17.7% of females reported being uncomfortable. 83.4% of males and 47.0% of females reported being comfortable with masturbation. 47.0% of females reported being uncomfortable. 83.3% of males and 29.4% of females reported being comfortable with oral sex. 52.9% of females reported being uncomfortable. 83.4% of males and 52.9% of females reported being comfortable with intercourse. 23.6% of females reported being uncomfortable.

30. Please indicate with an X your opinions regarding how the following statements apply to terminally ill patients. (X one box for each.)

Male (n=6)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	66.7%	33.3%			
Sexual activity is a duty for partners			33.3%	33.3%	33.3%
Sexual activity is a private matter only to be discussed between partners			33.3%	66.7%	
Interest in sexual activity fades as one grows older	16.7%	33.3%		16.7%	33.3%
Sexual activity is for the young				33.3%	66.7%
Older people are not concerned with sexual activity				16.7%	83.3%

Female (n=17)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	58.8%	41.2%			
Sexual activity is a duty for partners		5.9%	29.4%		64.7%
Sexual activity is a private matter only to be discussed between partners	5.9%	5.9%	29.4%	29.4%	29.4%
Interest in sexual activity fades as one grows older		35.3%	17.6%	23.5%	23.5%
Sexual activity is for the young				5.9%	94.1%
Older people are not concerned with sexual activity				17.6%	82.4%

Researcher's Conclusions

100% of males and 100% of females report that sexual activity is important in assessing quality of life. 66.6% of males and 64.7% of females disagree that sexual activity is a duty for partners. 5.9% of females agree that sexual activity is a duty for partners. 66.7% of males and 58.8% of females disagree that sexual activity is a private matter only to be discussed between partners. 11.8% of females agree that sexual activity is a private matter only to be discussed between partners. 50.0% of males and 35.3% of females agree that interest in sexual activity fades as one grows older. 50.0% of males and 47.0% of females disagree that interest in sexual activity fades as one grows older. 100% of males and females disagree that sexual activity is for the young. 100% of males and females disagree that older people are not concerned with sexual activity.

31. Has a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	23.5%
No	76.5%

Researcher's Conclusions

50.0% of males and 23.5% of females report that a patient has expressed fear of not getting into heaven because of concerns regarding their sexuality. 50.0% of males and 76.5% of females reported no expression.

32. Has a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	23.5%
No	76.5%

Researcher's Conclusions

66.7% of males and 23.5% of females report that a patient has expressed fear of going to hell because of concerns regarding their sexuality. 33.3% of males and 76.5% of females reported no expression.

33. Has a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Male (n=6)

Yes	100%
No	

Female (n=17)

Yes	41.2%
No	58.8%

Researcher's Conclusions

100% of males and 41.2% of females reported patients expressing feelings of guilt due to prior sexual activity. 58.8% of females reported no expression.

34. Has a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

50.0% of males and 17.6% of females reported patients expressing that their terminal illness was a punishment from God due to prior sexual activity. 50.0% of males and 82.4% of females reported no expression.

35. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

66.7% of males and 17.6% of females reported that a patient has expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity. 33.3% of males and 82.4% of females reported no expression.

36. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was medically not possible?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

33.3% of males reported that a patient has expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was not medically possible. 66.7% of males and 100% of females reported no expression.

37. Have you ever initiated a conversation about sexuality with a patient?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	29.4%
No	70.6%

Researcher's Conclusions

66.7% of males and 29.4% of females reported initiating a conversation. 33.3% of males and 70.6% of females reported no initiation.

38. Are you more likely to discuss sexuality with a male terminally ill patient?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

50.0% of males and 11.8% of females reported being more likely to discuss sexuality with a male terminally ill patient. 50.0% of males and 88.2% of females report not being more likely.

39. Are you more likely to discuss sexuality with a male caregiver of a terminally ill patient?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

50.0% of males and 5.9% of females reported being more likely to discuss sexuality with a male caregiver of a terminally ill patient. 50.0% of males and 94.1% of females report not being more likely.

40. Are you more likely to discuss sexuality with a female terminally ill patient?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	64.7%
No	35.3%

Researcher's Conclusions

16.7% of males and 64.7% of females report being more likely to discuss sexuality with a female terminally ill patient. 83.3% of males and 35.3% of females report not being more likely.

41. Are you more likely to discuss sexuality with a female caregiver of a terminally ill patient?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	52.9%
No	47.1%

Researcher's Conclusions

16.7% of males and 52.9% of females report being more likely to discuss sexuality with a female caregiver of a terminally ill patient. 83.3% of males and 47.1% of females report not being more likely.

42. Have you ever initiated a conversation about sexuality with a patient who was under the age of 20?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

16.7% of males and 5.9% of females reported having initiated a conversation about sexuality with a patient who was under the age of 20. 83.3% of males and 94.1% of females reported no initiation.

43. Have you ever initiated a conversation about sexuality with a patient who was between the ages 20 to 40?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=16)

Yes	31.3%
No	68.7%

Researcher's Conclusions

66.7% of males and 31.3% of females reported having initiated a conversation about sexuality with a patient who was between the ages of 20 and 40. 33.3% of males and 68.7% of females reported no initiation.

44. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 40 to 60?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=16)

Yes	31.3%
No	68.7%

Researcher's Conclusions

66.7% of males and 31.3% of females reported having initiated a conversation about sexuality with a patient who was between the ages of 40 to 60. 33.3% of males and 68.7% of females reported no initiation.

45. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 60 to 80?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=16)

Yes	37.0%
No	63.0%

Researcher's Conclusions

66.7% of males and 37.0% of females reported having initiated a conversation about sexuality with a patient who was between the ages of 60 to 80. 33.3% of males and 63.0% of females reported no initiation.

46. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 80 to 100?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=16)

Yes	6.2%
No	93.8%

Researcher's Conclusions

33.3% of males and 6.2% of females reported having initiated a conversation about sexuality with a patient who was between the ages of 80 to 100. 66.7% of males and 93.8% of females reported no initiation.

47. Have you ever initiated a conversation about sexuality with a family caregiver?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	23.5%
No	76.5%

Researcher's Conclusions

50.0% of males and 23.5% of females reported initiating a conversation about sexuality with a family caregiver. 50% of males and 76.5% of females reported no initiation.

48. Have you ever initiated a conversation about sexuality with a family caregiver who was under the age of 20?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

16.7% of males reported initiating a conversation about sexuality with a family caregiver who was under the age of 20. 83.3% of males and 100% of females reported no initiation.

49. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages 20 to 40?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

50.0% of males and 17.6% of females reported initiating a conversation about sexuality with a family caregiver who was between the ages of 20 to 40. 50.0% of males and 82.4% of females reported no initiation.

50. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 40 to 60?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

50.0% of males and 11.8% of females reported initiating a conversation about sexuality with a family caregiver who was between the ages of 40 to 60. 50.0% of males and 88.2% of females reported no initiation.

51. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 60 to 80?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

16.7% of males and 5.9% of females reported initiating a conversation about sexuality with a family caregiver who was between the ages of 60 to 80. 83.3% of males and 94.1% of females reported no initiation.

52. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 80 to 100?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

16.7% of males reported initiating a conversation about sexuality with a family caregiver who was between the ages of 80 to 100. 83.3% of males and 100% of females reported no initiation.

53. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual desire?

Male (n=6)

Yes	83.3%
No	16.7%

Female (n=17)

Yes	29.4%
No	70.6%

Researcher's Conclusions

83.3% of males and 29.4% of females reported a family caregiver of a terminally ill patient has requested advice regarding sexual desire. 16.7% of males and 70.6% of females reported no request.

54. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual arousal?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

66.7% of males reported a family caregiver of a terminally ill patient has requested advice regarding sexual arousal. 33.3% of males and 100% of females reported no request.

55. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual performance?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

50.0% of males and 5.9% of females reported a family caregiver of a terminally ill patient has requested advice regarding sexual performance. 50.0% of males and 94.1% of females reported no request.

56. Has the family caregiver of a terminally ill patient ever requested advice regarding sexual positions?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	5.9%
No	94.1%

Researcher's Conclusions

33.3% of males and 5.9% of females reported a family caregiver of a terminally ill patient has requested advice regarding sexual positions. 66.7% of males and 94.1% of females reported no request.

57. Has the family caregiver of a terminally ill patient ever expressed concern regarding unmet sexual needs?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	23.5%
No	76.5%

Researcher's Conclusions

66.7% of males and 23.5% of females reported a family caregiver of a terminally ill patient has requested advice regarding unmet sexual needs. 33.3% of males and 76.5% of females reported no request.

58. Has the caregiver of a terminally ill patient ever expressed guilty feelings for having sexual desire?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	17.6%
No	82.4%

Researcher's Conclusions

50.0% of the males and 17.6% of the females reported that the caregiver of a terminally ill patient expressed guilty feelings for having sexual desire. 50.0% of the males and 82.4% of the females reported no expression.

59. Has the family caregiver of a terminally ill patient ever discussed lack of intimacy?

Male (n=6)

Yes	100%
No	

Female (n=17)

Yes	35.3%
No	64.7%

Researcher's Conclusions

100% of the males and 35.3% of the females reported that the caregiver of a terminally ill patient discussed lack of intimacy. 64.7% of the females reported no discussion.

60. Please indicate with an X the topics you would be comfortable discussing with the family caregiver of a terminally ill patient. (X one box for each).

Male (n=6)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	66.7%		33.3%		
Kissing	66.7%		33.3%		
Sexual touch	50.0%	16.7%	33.3%		
Masturbation	33.3%	33.3%	33.3%		
Oral sex	33.3%	33.3%	33.3%		
Intercourse	33.3%	33.3%	33.3%		

Female (n=17)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	70.6%	5.9%	11.8%		11.8%
Kissing	70.6%	11.8%	5.9%	5.9%	5.9%
Sexual touch	35.3%	29.4%	11.8%	11.8%	17.6%
Masturbation	17.6%	29.4%	17.6%	17.6%	29.4%
Oral sex	11.8%	5.9%	29.4%	17.6%	35.3%
Intercourse	29.4%	17.6%	17.6%	17.6%	17.6%

Researcher's Conclusions

66.7% of males and 76.5% of females reported being comfortable in discussing non-sexual touch. 11.8% of females reported being uncomfortable discussing non-sexual touch. 66.7% of males and 82.4% of females reported being comfortable in discussing kissing. 11.8% of females reported being uncomfortable in discussing kissing. 66.7% of males and 64.7% of females reported being comfortable in discussing sexual touch. 29.4% of females reported being uncomfortable in discussing sexual touch. 66.7% of males and 47.0% of females reported being comfortable in discussing masturbation. 47.0% of females reported being uncomfortable in discussing masturbation. 66.7% of males and 17.7% of females report being comfortable in discussing oral sex. 52.9 of females reported being uncomfortable in discussing oral sex. 66.7% of males and 47.0% of females reported being comfortable in discussing intercourse. 35.2% of females reported being uncomfortable in discussing intercourse.

61. Please indicate with an X your opinions regarding how the following statements apply to the family caregivers of terminally ill patients. (X one box for each.)

Male (n=6)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	66.7%	16.7%		16.7%	
Sexual activity is a duty for partners			33.3%	33.3%	33.3%
Sexual activity is a private matter only to be discussed between partners			16.7%	83.3%	
Interest in sexual activity fades as one grows older		33.3%		33.3%	33.3%
Sexual activity is for the young				50.0%	50.0%
Older people are not concerned with sexual activity				50.0%	50.0%

Female (n=17)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	47.1%	41.2%	5.9%	5.9%	
Sexual activity is a duty for partners			23.5%	11.8%	64.7%
Sexual activity is a private matter only to be discussed between partners	11.8%	11.8%	11.8%	35.3%	29.4%
Interest in sexual activity fades as one grows older		29.4%	5.9%	35.3%	29.4%
Sexual activity is for the young		5.9%			94.1%
Older people are not concerned with sexual activity			5.9%	5.9%	82.4%

Researcher's Conclusions

83.4% of males and 88.3% of females report that sexual activity is important in assessing quality of life. 16.7% of males and 5.9% of females disagree that sexual activity is important in assessing quality of life. 66.7% of males and 76.5% of females disagree that sexual activity is a duty for partners. 23.6% of females agree that sexual activity is a private matter only to be discussed between partners. 83.3% of males and 64.7% of females disagree that sexual activity is a private matter only to be discussed between partners. 33.3% of males and 29.4% of females agree that interest in sexual activity fades as one grows older. 66.7% of males and 70.6% of females disagree that interest in sexual activity fades as one grows older. 100% of males and 94.1% of females disagree that sexual activity is for the young. 5.9% of females agree that sexual activity is for the young. 100% of males and 88.3% of females disagree that older people are not concerned with sexual activity.

62. Has the family caregiver of a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

33.3% of males reported that the family caregiver of a terminally ill patient expressed fear of not getting into heaven because of concerns regarding their sexuality. 66.7% of males and 100% of females reported no expression.

63. Has the family caregiver of a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

33.3% of males reported that the family caregiver of a terminally ill patient expressed fear of going to hell heaven because of concerns regarding their sexuality. 66.7% of males and 100% of females reported no expression.

64. Has the family caregiver of a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

66.7% of males reported that the family caregiver of a terminally ill patient expressed feelings of guilt due to prior sexual activity. 33.3% of males and 100% of females reported no expression.

65. Has the family caregiver of a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

33.3% of males reported that the family caregiver of a terminally ill patient expressed fear that their illness was a punishment from God due to prior sexual activity. 66.7% of males and 100% of females reported no expression.

66. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity?

Male (n=6)

Yes	66.7%
No	33.3%

Female (n=17)

Yes	11.8%
No	88.2%

Researcher's Conclusions

66.7% of males and 11.8% of females reported that the spousal/partner caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity. 33.3% of males and 88.2% of females reported no expression.

67. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible?

Male (n=6)

Yes	33.3%
No	66.7%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

33.3% of males reported that the spousal/partner caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible. 66.7% of males and 100% of females reported no expression.

68. Has a family caregiver of a terminally ill patient ever expressed a decline in sexual feelings specifically attributed to their role as a caregiver?

Male (n=6)

Yes	100%
No	

Female (n=17)

Yes	47.1%
No	52.9%

Researcher's Conclusions

100% of males and 47.1% of females reported that a family caregiver of a terminally ill patient expressed a decline in sexual feelings specifically attributed to their role as a caregiver. 52.9% of females reported no expression.

69. Have you ever initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver?

Male (n=6)

Yes	50.0%
No	50.0%

Female (n=17)

Yes	25.0%
No	75.0%

Researcher's Conclusions

50.0% of males and 25.0% of females reported initiating a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver. 50.0% of men and 75.0% of women reported no initiation.

70. Do you include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient?

Male (n=6)

Sometimes	66.7%
Most of the time	16.7%
Always	
Never	16.7%

Female (n=17)

Sometimes	23.5%
Most of the time	
Always	
Never	76.5%

Researcher's Conclusions

83.4% of males and 23.5% of females include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient. 16.7% of males and 76.5% of females never include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient.

71. Do you include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of the terminally ill patient?

Male (n=6)

Sometimes	66.7%
Most of the time	16.6%
Always	
Never	16.6%

Female (n=17)

Sometimes	11.8%
Most of the time	
Always	
Never	88.2%

Researcher's Conclusions

83.3% of males and 11.8% of females include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of a terminally ill patient. 16.6% of males and 88.2% of females never include a discussion of sexuality when discussing the dying process/expectations.

72. Do you include a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient?

Male (n=6)

Sometimes	50.0%
Most of the time	16.7%
Always	
Never	33.3%

Female (n=17)

Sometimes	17.6%
Most of the time	
Always	
Never	82.4%

Researcher's Conclusions

66.7% of males and 17.6% of females include a discussion of sexuality when discussing anticipatory grief with the family caregiver of a terminally ill patient. 33.3% of males and 82.4% of females never include a discussion of sexuality when discussing anticipatory grief.

73. Do you assess sexuality/intimacy as part of your initial assessment of the terminally ill patient?

Male (n=6)

Sometimes	33.3%
Most of the time	16.7%
Always	
Never	50.0%

Female (n=17)

Sometimes	35.3%
Most of the time	5.9%
Always	
Never	58.8%

Researcher's Conclusions

50.0% of the males and 41.2% of the females assess sexuality/intimacy as part of the initial assessment of the terminally ill patient. 50.0% of the males and 58.8% of the females do not assess intimacy.

74. Do you assess sexuality/intimacy as part of your regular assessment of the terminally ill patient?

Male (n=6)

Sometimes	50.0%
Most of the time	
Always	16.7%
Never	33.3%

Female (n=17)

Sometimes	29.4%
Most of the time	11.8%
Always	
Never	58.8%

Researcher's Conclusions

50.0% of the males and 41.2% of the females assess sexuality/intimacy as part of the regular assessment of the terminally ill patient. 33.3% of the males and 70.6% of the females do not assess intimacy.

75. Do you have a psychosexual assessment tool to use when working with terminally ill patients?

Male (n=6)

Yes	
No	83.3%
Not applicable	16.7%

Female (n=17)

Yes	11.8%
No	70.6%
Not applicable	17.6%

Researcher's Conclusions

83.3% of males and 70.6% of females do not have a psychosexual assessment tool to use when working with terminally ill patients. 11.8% of females report that they have a psychosexual assessment tool to use when working with terminally ill patients.

76. Would you use a psychosexual assessment tool that was specifically designed for terminally ill patients?

Male (n=6)

Yes	50.0%
No	16.7%
Not applicable	33.3%

Female (n=17)

Yes	70.6%
No	11.8%
Not applicable	17.6%

Researcher's Conclusions

50.0% of males and 70.6% of females would use a psychosexual assessment tool that was specifically designed for terminally ill patients. 16.7% of males and 11.8% of females would not use a psychosexual assessment tool that was specifically designed for terminally ill patients.

77. Have you ever referred a terminally ill patient to a clinical sexologist?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

100% of males and females have never referred a terminally ill patient to a clinical sexologist.

78. Have you ever referred a terminally ill patient to a sex therapist?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

16.7% of males have referred a terminally ill patient to a sex therapist. 83.3% of males and 100% of females have not referred a terminally ill patient to a sex therapist.

79. Have you ever referred the family caregiver of a terminally ill patient to a clinical sexologist?

Male (n=6)

Yes	
No	100%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

100% of males and females have not referred the family caregiver of a terminally ill patient to a clinical sexologist.

80. Have you ever referred the family caregiver of a terminally ill patient to a sex therapist?

Male (n=6)

Yes	16.7%
No	83.3%

Female (n=17)

Yes	
No	100%

Researcher's Conclusions

16.7% of males have referred the family caregiver of a terminally ill patient to a sex therapist. 83.3% of males and 100% of females have not referred the family caregiver of a terminally ill patient to a sex therapist.

81. If you knew of a clinical sexologist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Male (n=6)

Yes	83.3%
No	16.7%

Female (n=17)

Yes	88.2%
No	11.8%

Researcher's Conclusions

83.3% of males and 88.2% of females would refer for services. 16.7% of males and 11.8% of females would not refer for services.

82. If you knew of a sex therapist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Male (n=6)

Yes	83.3%
No	16.7%

Female (n=17)

Yes	94.1%
No	5.9%

Researcher's Conclusions

83.3% of males and 94.1% of females would refer for services. 16.7% of females and 5.9% of males would not refer for services.

83. Do you believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying?

Male (n=6)

Very important	33.3%
Important	33.3%
Somewhat important	16.7%
Somewhat unimportant	16.7%
Unimportant	
Very unimportant	

Female (n=17)

Very important	41.2%
Important	23.5%
Somewhat important	35.3%
Somewhat unimportant	
Unimportant	
Very unimportant	

Researcher's Conclusions

83.3% of males and 100% of females believe that it is important to increase professional knowledge regarding the role of sexuality, death and dying. 16.7% of males believe that it is unimportant.

Chapter Twenty

Sexuality Survey Results - Religiosity

1. Do you believe that it is appropriate to discuss sexuality with terminally ill patients?

Religious (n=11)

Very appropriate	45.5%
Somewhat appropriate	45.5%
Neither appropriate or inappropriate	9.0%
Somewhat inappropriate	
Very inappropriate	

Not Religious (n=12)

Very appropriate	58.3%
Somewhat appropriate	16.7%
Neither appropriate or inappropriate	16.7%
Somewhat inappropriate	8.3%
Very inappropriate	

Researcher's Conclusions

90.1% of religious respondents and 75.0% of not religious respondents report that it is appropriate to discuss sexuality with terminally ill patients. 8.3% of not religious respondents report that it is inappropriate to discuss sexuality with terminally ill patients.

2. Do you feel qualified to discuss sexuality with terminally ill patients?

Religious (n=11)

Very qualified	9.1%
Somewhat qualified	36.4%
Neither qualified or unqualified	27.3%
Somewhat unqualified	
Very Unqualified	27.3%

Not Religious (n=12)

Very qualified	25.0%
Somewhat qualified	41.7%
Neither qualified or unqualified	8.3%
Somewhat unqualified	8.3%
Very Unqualified	8.3%

Researcher's Conclusions

45.5% of religious respondents and 46.7% of not religious respondents report feeling qualified to discuss sexuality with terminally ill patients. 27.3% of religious respondents and 16.6% of not religious respondents report feeling unqualified.

3. Do you believe that it is appropriate to discuss sexuality with family caregivers of terminally ill patients?

Religious (n=11)

Very appropriate	9.1%
Somewhat appropriate	36.4%
Neither appropriate or inappropriate	45.5%
Somewhat inappropriate	9.1%
Very inappropriate	

Not Religious (n=12)

Very appropriate	16.7%
Somewhat appropriate	66.7%
Neither appropriate or inappropriate	16.7%
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

45.5% of religious respondents and 83.4% of not religious respondents report that it is appropriate to discuss sexuality with family caregivers of terminally ill patients. 9.1% of religious respondents report that it is inappropriate.

4. Do you feel qualified to discuss sexuality with the family caregivers of terminally ill patients?

Religious (n=11)

Very qualified	18.2%
Somewhat qualified	27.3%
Neither qualified or unqualified	27.3%
Somewhat unqualified	
Very Unqualified	27.3%

Not Religious (n=12)

Very qualified	25.0%
Somewhat qualified	41.7%
Neither qualified or unqualified	8.3%
Somewhat unqualified	16.7%
Very Unqualified	8.3%

Researcher's Conclusions

45.5% of religious respondents and 46.7% of not religious respondents feel qualified to discuss sexuality with the family caregivers of terminally ill patients. 27.3% of religious respondents and 25.0% of not religious respondents feel unqualified.

5. Do you feel sexuality is a concern for terminally ill patients?

Religious (n=11)

Some	81.8%
Most	18.2%
All	
None	

Not Religious (n=12)

Some	83.3%
Most	8.3%
All	8.3%
None	

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents feel sexuality is a concern for terminally ill patients.

6. Do you feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients?

Religious (n=11)

Very appropriate	27.3%
Somewhat appropriate	36.4%
Neither appropriate or inappropriate	27.3%
Somewhat inappropriate	
Very inappropriate	9.1%

Not Religious (n=12)

Very appropriate	50.0%
Somewhat appropriate	25.0%
Neither appropriate or inappropriate	8.3%
Somewhat inappropriate	8.3%
Very inappropriate	8.3%

Researcher's Conclusions

63.7% of religious respondents and 75.0% of not religious respondents feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients. 9.1% of religious respondents and 16.6% of not religious respondents feel it is inappropriate.

7. Do you feel it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients?

Religious (n=11)

Very appropriate	9.1%
Somewhat appropriate	36.4%
Neither appropriate or inappropriate	36.4%
Somewhat inappropriate	18.2%
Very inappropriate	

Not Religious (n=12)

Very appropriate	25.0%
Somewhat appropriate	50.0%
Neither appropriate or inappropriate	
Somewhat inappropriate	8.3%
Very inappropriate	16.7%

Researcher's Conclusions

45.5% of religious respondents and 75.0% of not religious respondents feel it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients. 18.2% of religious respondents and 25.0% of not religious respondents feel it is inappropriate.

8. Do you feel comfortable in discussing sexuality with your terminally ill patients?

Religious (n=11)

Very comfortable	18.2%
Somewhat comfortable	27.3%
Neither comfortable or uncomfortable	18.2%
Somewhat uncomfortable	9.1%
Very uncomfortable	27.3%

Not Religious (n=12)

Very comfortable	41.7%
Somewhat comfortable	25.0%
Neither comfortable or uncomfortable	8.3%
Somewhat uncomfortable	8.3%
Very uncomfortable	16.7%

Researcher's Conclusions

45.5% of religious respondents and 66.7% of not religious respondents feel comfortable in discussing sexuality with terminally ill patients. 36.4% of religious respondents and 25.0% of not religious respondents feel uncomfortable.

9. Do you feel comfortable in discussing sexuality with the family caregivers of terminally ill patients?

Religious (n=11)

Very comfortable	9.1%
Somewhat comfortable	27.3%
Neither comfortable or uncomfortable	27.3%
Somewhat uncomfortable	9.1%
Uncomfortable	9.1%
Very uncomfortable	18.2%

Not Religious (n=12)

Very comfortable	41.7%
Somewhat comfortable	33.3%
Neither comfortable or uncomfortable	8.3%
Somewhat uncomfortable	8.3%
Uncomfortable	
Very uncomfortable	8.3%

Researcher's Conclusions

36.4% of religious respondents and 75.0% of not religious respondents feel comfortable in discussing sexuality with the family caregivers of terminally ill patients. 27.3% of religious respondents and 16.6% of not religious respondents feel uncomfortable.

10. Do you believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Religious (n=11)

Some	90.9%
Most	9.1%
All	
None	

Not Religious (n=12)

Some	83.3%
Most	16.7%
All	
None	

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject.

11. Do you believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Religious (n=11)

Some	100%
Most	
All	
None	

Not Religious (n=12)

Some	91.7%
Most	8.3%
All	
None	

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject.

12. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

16.7% of not religious respondents reported that there had been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 100% of religious respondents and 83.3% of not religious respondents reported that there had not been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject.

13. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the terminally ill patient?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

8.3% of not religious respondents reported a time when they changed the subject because they were uncomfortable in discussing sexual issues. 100% of religious respondents and 91.7% of not religious respondents reported that there was not a time when they changed the subject.

14. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the terminally ill patient?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

8.3% of not religious respondents reported a time when they changed the subject because they were not sure how to help. 100% of religious respondents and 91.7% of not religious respondents reported that there was not a time when they changed the subject.

15. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

8.3% of not religious respondents reported a time when they changed the subject because they were embarrassed. 100% of religious respondents and 91.7% of not religious respondents reported that there was not a time when they changed the subject.

16. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

25.0% of not religious respondents reported a time when they changed the subject.

100% of religious respondents and 75.0% of not religious respondents reported that there was not a time when they changed the subject.

17. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the caregiver of the terminally ill patient?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

16.7% of not religious respondents reported a time when they changed the subject.

100% of religious respondents and 83.3% of not religious respondents reported that there was not a time when they changed the subject.

18. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the caregiver of the terminally ill patient?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

25.0% of not religious respondents reported a time when they changed the subject.

100% of religious respondents and 75.0% of not religious respondents reported that there was not a time when they changed the subject.

19. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents reported that there was not a time when they changed the subject.

20. Was training in human sexuality part of your formal education or professional training?

Religious (n=11)

Yes	63.6%
No	36.4%

Not Religious (n=12)

Yes	58.3%
No	41.7%

Researcher's Conclusions

63.6% of religious respondents and 58.3% of not religious respondents reported that training in human sexuality was part of their formal education or professional training. 36.4% of religious respondents and 41.7% of not religious respondents reported that training in human sexuality was part of their formal education or professional training.

21. Was training in human sexuality part of your agency's orientation process?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

100% of religious and not religious respondents reported that training in human sexuality was not part of their agency's orientation process.

22. Has a terminally ill patient ever requested your advice regarding sexual desire?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	50.0%
No	50.0%

Researcher's Conclusions

27.3% of religious respondents and 50.0% of not religious respondents reported that a terminally ill patient has requested advice regarding sexual desire. 72.7% of religious respondents and 50.0% of not religious respondents reported that a patient has not ever requested advice.

23. Has a terminally ill patient ever requested your advice regarding sexual arousal?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	33.3%
No	66.7%

Researcher's Conclusions

18.2% of religious respondents and 33.3% of not religious respondents reported that a terminally ill patient has requested advice regarding sexual arousal. 81.8% of religious respondents and 66.7% of not religious respondents reported that a patient has not ever requested advice.

24. Has a terminally ill patient ever requested your advice regarding sexual performance?

Religious (n=11)

Yes	36.4%
No	63.6%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

36.4% of religious respondents and 41.7% of not religious respondents reported that a terminally ill patient has requested advice regarding sexual performance. 63.6% of religious respondents and 58.3% of not religious respondents reported that a patient has not ever requested advice.

25. Has a terminally ill patient ever requested advice regarding sexual positions?

Religious (n=11)

Yes	9.1%
No	81.8%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

9.1% of religious respondents and 25.0% of not religious respondents reported that a terminally ill patient has requested advice regarding sexual positions. 81.8% of religious respondents and 75.0% of not religious respondents reported that a patient has not ever requested advice.

26. Has a terminally ill patient ever expressed concern regarding unmet sexual needs?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	83.3%
No	16.7%

Researcher's Conclusions

27.3% of religious respondents and 83.3% of not religious respondents reported that a terminally ill patient has expressed concern regarding unmet sexual needs. 72.7% of religious respondents and 16.7% of not religious respondents reported that a patient has not ever expressed concern.

27. Has a terminally ill patient ever expressed guilty feelings for having sexual desire?

Religious (n=11)

Yes	9.1%
No	81.8%

Not Religious (n=12)

Yes	50.0%
No	50.0%

Researcher's Conclusions

9.1% of religious respondents and 50.0% of not religious respondents reported that a terminally ill patient has expressed guilty feelings for having sexual desire. 81.8% of religious respondents and 50.0% of not religious respondents reported that a patient has not ever expressed concern.

28. Has a terminally ill patient ever discussed lack of intimacy?

Religious (n=11)

Yes	63.6%
No	36.4%

Not Religious (n=12)

Yes	75.0%
No	25.0%

Researcher's Conclusions

63.6% of religious respondents and 75.0% of not religious respondents reported that a terminally ill patient has discussed lack of intimacy. 36.4% of religious respondents and 25.0% of not religious respondents reported that a patient has not ever discussed lack of intimacy.

29. Please indicate with an X the topics you would be comfortable discussing with a terminally ill patient. (X one box for each).

Religious (n=11)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	81.8%		9.1%		9.1%
Kissing	63.6%	9.1%	18.2%		
Sexual touch	27.3%	27.3%	36.4%		9.1%
Masturbation	18.2%	27.3%	18.2%	27.3%	18.2%
Oral Sex	18.2%	9.1%	27.3%	27.3%	18.2%
Intercourse	18.2%	27.3%	36.4%	18.2%	

Not Religious (n=12)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	100%				
Kissing	100%				
Sexual touch	50.0%	25.0%	8.3%	8.3%	8.3%
Masturbation	41.7%	25.0%		16.7%	16.7%
Oral Sex	33.3%	25.0%	8.3%		33.3%
Intercourse	50.0%	25.0%	8.3%		16.7%

Researcher's Conclusions

81.8% of religious respondents and 100% of not religious respondents report being comfortable discussing non-sexual touch. 9.1% of religious respondents report being uncomfortable with non-sexual touch. 72.7% of religious respondents and 100% of not religious respondents report being comfortable discussing kissing. 54.6% of religious respondents and 75.0% of not religious respondents report being comfortable discussing sexual touch. 9.1% of religious respondents and 16.6% of not religious respondents report being uncomfortable discussing sexual touch. 45.5% of religious respondents and 66.7% of not religious respondents report being comfortable discussing masturbation. 45.5% of religious respondents and 33.4% of not religious respondents report being uncomfortable discussing masturbation. 27.3% of religious respondents and 58.3% of not religious respondents report being comfortable discussing oral sex. 45.5% of religious respondents and 33.3% of not religious respondents report being uncomfortable discussing oral sex. 45.5% of religious respondents and 75.0% of not religious respondents report being comfortable discussing intercourse. 18.2% of religious respondents and 16.7% of not religious respondents report being uncomfortable discussing oral sex.

30. Please indicate with an X your opinions regarding how the following statements apply to terminally ill patients. (X one box for each.)

Religious (n=11)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	63.6%	36.4%			
Sexual activity is a duty for partners		9.1%	27.3%		63.6%
Sexual activity is a private matter only to be discussed between partners		9.1%	45.5%	27.3%	18.2%
Interest in sexual activity fades as one grows older		36.4%	18.2%		9.1%
Sexual activity is for the young				9.1%	90.9%
Older people are not concerned with sexual activity				27.3%	72.7%

Not Religious (n=12)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	58.3%	41.7%			
Sexual activity is a duty for partners			25.0%	25.0%	50.0%
Sexual activity is a private matter only to be discussed between partners	8.3%		16.7%	50.0%	25.0%
Interest in sexual activity fades as one grows older	8.3%	33.3%	8.3%	33.3%	16.7%
Sexual activity is for the young				8.3%	91.7%
Older people are not concerned with sexual activity			8.3%	8.3%	83.3%

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents agree that sexual activity is important in assessing quality of life. 9.1% of religious respondents and none of the not religious respondents agree that sexual activity is a duty for partners. 63.6% of religious respondents and 75.0% of not religious respondents disagree that sexual activity is a duty for partners. 9.1% of religious respondents and 8.3% of not religious respondents agree that sexual activity is a private matter only to be discussed between partners. 45.5% of religious respondents and 75.0% of not religious respondents disagree that sexual activity is a private matter only to be discussed between partners. 36.4% of religious respondents and 41.6% of not religious respondents agree that interest in sexual activity fades as one grows older. 9.1% of religious respondents and 50.0% of not religious respondents disagree that sexual activity fades as one grows older. 100% of religious respondents and 100% of not religious respondents disagree that sexual activity is for the young. 100% of religious respondents and 91.6% of not religious respondents disagree that older people are not concerned with sexual activity.

31. Has a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	33.3%
No	66.7%

Researcher's Conclusions

27.3% of religious respondents and 33.3% of not religious respondents reported that a terminally ill patient had expressed fear of not getting into heaven because of concerns regarding their sexuality. 72.7% of religious respondents and 66.7% of not religious respondents reported no expression.

32. Has a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Religious (n=11)

Yes	36.4%
No	63.6%

Not Religious (n=12)

Yes	33.3%
No	66.7%

Researcher's Conclusions

36.4% of religious respondents and 33.3% of not religious respondents reported that a terminally ill patient had expressed fear of going to hell because of concerns regarding their sexuality. 63.6% of religious respondents and 66.7% of not religious respondents reported no expression.

33. Has a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Religious (n=11)

Yes	63.6%
No	36.4%

Not Religious (n=12)

Yes	45.5%
No	54.5%

Researcher's Conclusions

63.6% of religious respondents and 45.5% of not religious respondents reported that a terminally ill patient had expressed feelings of guilt due to prior sexual activity. 36.4% of religious respondents and 54.5% of not religious respondents reported no expression.

34. Has a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Religious (n=11)

Yes	36.4%
No	63.6%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

36.4% of religious respondents and 16.7% of not religious respondents reported that a terminally ill patient had expressed that their terminal illness was a punishment from God due to prior sexual activity. 63.6% of religious respondents and 83.3% of not religious respondents reported no expression.

35. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

18.2% of religious respondents and 41.7% of not religious respondents reported that a terminally ill patient had expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity. 81.8% of religious respondents and 58.3% of not religious respondents reported no expression.

36. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was medically not possible?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported that a terminally ill patient had expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when not medically possible. 90.9% of religious respondents and 91.7% of not religious respondents reported no expression.

37. Have you ever initiated a conversation about sexuality with a patient?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

27.3% of religious respondents and 41.7% of not religious respondents reported initiating a conversation about sexuality with a patient. 72.7% of religious respondents and 58.3% of not religious respondents reported no initiation.

38. Are you more likely to discuss sexuality with a male terminally ill patient?

Religious (n=11)

Yes 18.2%
No 81.8%

Not Religious (n=12)

Yes 25.0%
No 75.0%

Researcher's Conclusions

18.2% of religious respondents and 25.0% of not religious respondents reported being more likely to discuss sexuality with a male terminally ill patient. 81.8% of religious respondents and 75.0% of not religious respondents reported not being more likely to discuss sexuality with a male terminally ill patient.

39. Are you more likely to discuss sexuality with a male caregiver of a terminally ill patient?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

18.2% of religious respondents and 16.7% of not religious respondents reported being more likely to discuss sexuality with a male caregiver of a terminally ill patient. 81.8% of religious respondents and 83.3% of not religious respondents reported not being more likely to discuss sexuality with a male caregiver of a terminally ill patient.

40. Are you more likely to discuss sexuality with a female terminally ill patient?

Religious (n=11)

Yes	54.5%
No	45.5%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

54.5% of religious respondents and 41.7% of not religious respondents reported being more likely to discuss sexuality with a female terminally ill patient. 45.5% of religious respondents and 58.3% of not religious respondents reported not being more likely to discuss sexuality with a female terminally ill patient.

41. Are you more likely to discuss sexuality with a female caregiver of a terminally ill patient?

Religious (n=11)

Yes	45.5%
No	54.5%

Not Religious (n=12)

Yes	50.0%
No	50.0%

Researcher's Conclusions

45.5% of religious respondents and 50.0% of not religious respondents reported being more likely to discuss sexuality with a female caregiver of a terminally ill patient. 54.5% of religious respondents and 50.0% of not religious respondents reported not being more likely to discuss sexuality with a female caregiver of a terminally ill patient.

42. Have you ever initiated a conversation about sexuality with a patient who was under the age of 20?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

9.1% of religious respondents and 16.7% of not religious respondents reported initiating a conversation about sexuality with a patient. 90.9% of religious respondents and 83.3% of not religious respondents reported no initiation.

43. Have you ever initiated a conversation about sexuality with a patient who was between the ages 20 to 40?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=11)

Yes	54.5%
No	45.5%

Researcher's Conclusions

27.3% of religious respondents and 54.5% of not religious respondents reported initiating a conversation about sexuality with a patient. 72.7% of religious respondents and 45.5% of not religious respondents reported no initiation.

44. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 40 to 60?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=11)

Yes	45.5%
No	54.5%

Researcher's Conclusions

27.3% of religious respondents and 45.5% of not religious respondents reported initiating a conversation about sexuality with a patient. 72.7% of religious respondents and 54.5% of not religious respondents reported no initiation.

45. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 60 to 80?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=11)

Yes	54.5%
No	45.5%

Researcher's Conclusions

27.3% of religious respondents and 54.5% of not religious respondents reported initiating a conversation about sexuality with a patient. 72.7% of religious respondents and 45.5% of not religious respondents reported no initiation.

46. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 80 to 100?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=11)

Yes	18.2%
No	81.8%

Researcher's Conclusions

9.1% of religious respondents and 18.2% of not religious respondents reported initiating a conversation about sexuality with a patient. 90.9% of religious respondents and 81.8% of not religious respondents reported no initiation.

47. Have you ever initiated a conversation about sexuality with a family caregiver?

Religious (n=11)

Yes	36.4%
No	63.6%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

36.4% of religious respondents and 25.0% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 63.6% of religious respondents and 75.0% of not religious respondents reported no initiation.

48. Have you ever initiated a conversation about sexuality with a family caregiver who was under the age of 20?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 90.9% of religious respondents and 91.7% of not religious respondents reported no initiation.

49. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages 20 to 40?

Religious (n=11)

Yes	36.4%
No	63.6%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

36.4% of religious respondents and 8.3% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 63.6% of religious respondents and 91.7% of not religious respondents reported no initiation.

50. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 40 to 60?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

27.3% of religious respondents and 8.3% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 72.7% of religious respondents and 91.7% of not religious respondents reported no initiation.

51. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 60 to 80?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

18.2% of religious respondents and 8.3% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 81.8% of religious respondents and 91.7% of not religious respondents reported no initiation.

52. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 80 to 100?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported initiating a conversation about sexuality with a family caregiver. 90.9% of religious respondents and 91.7% of not religious respondents reported no initiation.

53. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual desire?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	50.0%
No	50.0%

Researcher's Conclusions

27.3% of religious respondents and 50.0% of not religious respondents reported that the family caregiver of a terminally ill patient has requested advice regarding sexual desire. 72.7% of religious respondents and 50.0% of not religious respondents reported no request.

54. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual arousal?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

9.1% of religious respondents and 25.0% of not religious respondents reported that the family caregiver of a terminally ill patient has requested advice regarding sexual arousal.

90.9% of religious respondents and 75.0% of not religious respondents reported no request.

55. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual performance?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

18.2% of religious respondents and 25.0% of not religious respondents reported that the family caregiver of a terminally ill patient has requested advice regarding sexual performance. 81.8% of religious respondents and 75.0% of not religious respondents reported no request.

56. Has the family caregiver of a terminally ill patient ever requested advice regarding sexual positions?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

9.1% of religious respondents and 16.7% of not religious respondents reported that the family caregiver of a terminally ill patient has requested advice regarding sexual positions. 90.9% of religious respondents and 83.3% of not religious respondents reported no request.

57. Has the family caregiver of a terminally ill patient ever expressed concern regarding unmet sexual needs?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

27.3% of religious respondents and 41.7% of not religious respondents reported that the family caregiver of a terminally ill patient has requested advice regarding unmet sexual needs. 72.7% of religious respondents and 58.3% of not religious respondents reported no request.

58. Has the caregiver of a terminally ill patient ever expressed guilty feelings for having sexual desire?

Religious (n=11)

Yes	27.3%
No	72.7%

Not Religious (n=12)

Yes	25.0%
No	75.0%

Researcher's Conclusions

27.3% of religious respondents and 25.0% of not religious respondents reported that the caregiver of a terminally ill patient has expressed guilty feelings for having sexual desire. 72.7% of religious respondents and 75.0% of not religious respondents reported no expression.

59. Has the family caregiver of a terminally ill patient ever discussed lack of intimacy?

Religious (n=11)

Yes	45.5%
No	54.5%

Not Religious (n=12)

Yes	66.7%
No	33.3%

Researcher's Conclusions

45.5% of religious respondents and 66.7% of not religious respondents reported that the family caregiver of a terminally ill patient discussed lack of intimacy. 54.5% of religious respondents and 33.3% of not religious respondents reported no discussion.

60. Please indicate with an X the topics you would be comfortable discussing with the family caregiver of a terminally ill patient. (X one box for each).

Religious (n=11)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	54.5%	9.1%	18.2%		18.2%
Kissing	54.5%	9.1%	18.2%	9.1%	9.1%
Sexual touch	27.3%	27.3%	18.2%	9.1%	18.2%
Masturbation	18.2%	18.2%	18.2%	18.2%	27.3%
Oral sex	18.2%		27.3%	27.3%	27.3%
Intercourse	18.2%	18.2%	27.3%	27.3%	9.1%

Not Religious (n=12)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	83.3%		16.7%		
Kissing	83.3%	8.3%	8.3%		
Sexual touch	50.0%	25.0%	8.3%	8.3%	8.3%
Masturbation	25.0%	41.7%	8.3%	8.3%	16.7%
Oral sex	16.7%	25.0%	25.0%	8.3%	25.0%
Intercourse	50.0%	16.7%	16.7%		16.7%

Researcher's Conclusions

63.6% of religious respondents and 83.3% of not religious respondents report being comfortable with non sexual touch. 18.2% of religious respondents report being uncomfortable with non sexual touch and none of the not religious respondents report being uncomfortable with non sexual touch.. 63.6% of religious respondents and 91.6% of not religious respondents of report being comfortable with kissing. 18.2% of religious respondents report being uncomfortable with kissing. 54.6% of religious respondents and 75.0% of not religious respondents report being comfortable with sexual touch. 27.3% of religious respondents and 16.6% of not religious respondents report being uncomfortable with sexual touch. 36.4% of religious respondents and 66.7% of not religious respondents report being comfortable with masturbation. 45.5% of religious respondents and 25.0% of not religious respondents report being uncomfortable with masturbation. 18.2% of religious respondents and 41.7% of not religious respondents report being comfortable with oral sex. 54.6% of religious respondents and 33.3% of not religious respondents report being uncomfortable with oral sex. 36.4% of religious respondents and 66.7% of not religious respondents report being comfortable with intercourse. 36.4% of religious respondents and 16.7% of not religious respondents report being uncomfortable with intercourse.

61. Please indicate with an X your opinions regarding how the following statements apply to the family caregivers of terminally ill patients. (X one box for each.)

Religious (n=11)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	45.5%	45.5%		9.1%	
Sexual activity is a duty for partners			18.2%	18.2%	63.6%
Sexual activity is a private matter only to be discussed between partners	18.2%	9.1%	18.2%	36.4%	18.2%
Interest in sexual activity fades as one grows older		27.3%	18.2%	18.2%	45.5%
Sexual activity is for the young		9.1%			90.9%
Older people are not concerned with sexual activity			9.1%	9.1%	81.8%

Not Religious (n=12)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	58.3%	25.0%	8.3%	8.3%	
Sexual activity is a duty for partners			33.3%	16.7%	50.0%
Sexual activity is a private matter only to be discussed between partners		8.3%	8.3%	58.3%	25.0%
Interest in sexual activity fades as one grows older		33.3%		50.0%	16.7%
Sexual activity is for the young				25.0%	75.0%
Older people are not concerned with sexual activity				33.3%	66.7%

Researcher's Conclusions

90.0% of religious respondents and 83.3% of not religious respondents agree that sexual activity is important in assessing quality of life. 9.1% of religious respondents and 8.3% of not religious respondents disagree that sexual activity is important in assessing quality of life. 81.8% of religious respondents and 66.7% of not religious respondents disagree that sexual activity is a duty for partners. 27.3% of religious respondents and 8.3% of not religious respondents agree that sexual activity is a private matter only to be discussed between partners. 54.6% of religious respondents and 83.3% of not religious respondents disagree that sexual activity is a private matter only to be discussed between partners. 27.3% of religious respondents and 33.3% of not religious respondents agree that interest in sexual activity fades as one grows older. 63.7% of religious respondents and 66.7% of not religious respondents disagree that sexual activity fades as one grows older. 9.1% of religious respondents agree that sexual activity is for the young. 90.9% of religious respondents and 100% of not religious respondents disagree that sexual activity is for the young. 90.9% of religious respondents and 100% of not religious respondents disagree that older people are not concerned with sexual activity.

62. Has the family caregiver of a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported that the family caregiver of a terminally ill patient expressed fear of not getting into heaven because of concerns regarding their sexuality. 90.9% of religious respondents and 91.7% of not religious respondents reported no expression.

63. Has the family caregiver of a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	9.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 9.3% of not religious respondents reported that the family caregiver of a terminally ill patient expressed fear of going to hell because of concerns regarding their sexuality. 90.9% of religious respondents and 91.7% of not religious respondents reported no expression.

64. Has the family caregiver of a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	16.7%
No	83.3%

Researcher's Conclusions

18.2% of religious respondents and 16.7% of not religious respondents reported that the family caregiver of a terminally ill patient expressed feelings of guilt due to prior sexual activity. 81.8% of religious respondents and 83.3% of not religious respondents reported no expression.

65. Has the family caregiver of a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported that the family caregiver of a terminally ill patient expressed that their terminal illness was a punishment from God due to prior sexual activity. 90.9% of religious respondents and 91.7% of not religious respondents reported no expression.

66. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	33.3%
No	66.7%

Researcher's Conclusions

18.2% of religious respondents and 33.3% of not religious respondents reported that the spousal/partner caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity. 81.8% of religious respondents and 66.7% of not religious respondents reported no expression.

67. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	8.3%
No	91.7%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported that the spousal/partner caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible. 90.9% of religious respondents and 91.7% of not religious respondents reported no expression.

68. Has a family caregiver of a terminally ill patient ever expressed a decline in sexual feelings specifically attributed to their role as a caregiver?

Religious (n=11

Yes	54.5%
No	45.5%

Not Religious (n=12)

Yes	66.7%
No	33.3%

Researcher's Conclusions

54.5% of religious respondents and 66.7% of not religious respondents reported that the family caregiver of a terminally ill patient expressed a decline in sexual feelings specifically attributed to their role as a caregiver. 45.5% of religious respondents and 33.3% of not religious respondents reported no expression.

69. Have you ever initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver?

Religious (n=11)

Yes	18.2%
No	81.8%

Not Religious (n=12)

Yes	41.7%
No	58.3%

Researcher's Conclusions

18.2% of religious respondents and 41.7% of not religious respondents reported initiating a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver. 81.8% of religious respondents and 58.3% of not religious respondents reported no initiation.

70. Do you include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient?

Religious (n=11)

Sometimes	27.3%
Most of the time	9.1%
Always	
Never	63.6%

Not Religious (n=12)

Sometimes	41.7%
Most of the time	
Always	
Never	58.3%

Researcher's Conclusions

36.4% of religious respondents and 41.7% of not religious respondents reported including a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient. 63.6% of religious respondents and 58.3% of not religious respondents reported never including a discussion.

71. Do you include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of the terminally ill patient?

Religious (n=11)

Sometimes	27.3%
Most of the time	9.1%
Always	
Never	63.6%

Not Religious (n=12)

Sometimes	25.0%
Most of the time	
Always	
Never	75.0%

Researcher's Conclusions

36.4% of religious respondents and 25.0% of not religious respondents reported including a discussion of sexuality when discussing the dying process/expectations with the family caregiver of the terminally ill patient. 63.6% of religious respondents and 75.0% of not religious respondents reported never including a discussion.

72. Do you include a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient?

Religious (n=11)

Sometimes	36.4%
Most of the time	
Always	9.1%
Never	54.5%

Not Religious (n=12)

Sometimes	16.7%
Most of the time	
Always	
Never	83.3%

Researcher's Conclusions

45.5% of religious respondents and 16.7% of not religious respondents reported including a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient. 54.5% of religious respondents and 83.3% of not religious respondents reported never including a discussion.

73. Do you assess sexuality/intimacy as part of your initial assessment of the terminally ill patient?

Religious (n=11)

Sometimes	36.4%
Most of the time	
Always	9.1%
Never	54.5%

Not Religious (n=12)

Sometimes	33.3%
Most of the time	8.3%
Always	
Never	58.3%

Researcher's Conclusions

45.5% of religious respondents and 41.6% of not religious respondents reported assessing sexuality/intimacy as part of the initial assessment of the terminally ill patient. 54.5% of religious respondents and 58.3% of not religious respondents reported never assessing sexuality/intimacy as part of the initial assessment of the terminally ill patient.

74. Do you assess sexuality/intimacy as part of your regular assessment of the terminally ill patient?

Religious (n=11)

Sometimes	27.3%
Most of the time	9.1%
Always	9.1%
Never	54.5%

Not Religious (n=12)

Sometimes	41.7%
Most of the time	8.3%
Always	
Never	50.0%

Researcher's Conclusions

45.5% of religious respondents and 41.6% of not religious respondents reported assessing sexuality/intimacy as part of the regular assessment of the terminally ill patient.

54.5% of religious respondents and 58.3% of not religious respondents reported never assessing sexuality/intimacy as part of the regular assessment of the terminally ill patient.

75. Do you have a psychosexual assessment tool to use when working with terminally ill patients?

Religious (n=11)

Yes	9.1%
No	63.6%
Not applicable	27.3%

Not Religious (n=12)

Yes	8.3%
No	83.3%
Not applicable	8.3%

Researcher's Conclusions

9.1% of religious respondents and 8.3% of not religious respondents reported having a psychosexual assessment tool to use when working with terminally ill patients. 63.6% of religious respondents and 83.3% of not religious respondents reported not having a psychosexual assessment tool to use when working with terminally ill patients.

76. Would you use a psychosexual assessment tool that was specifically designed for terminally ill patients?

Religious (n=11)

Yes	63.6%
No	
Not applicable	36.4%

Not Religious (n=12)

Yes	66.7%
No	25.0%
Not applicable	8.3%

Researcher's Conclusions

63.6% of religious respondents and 66.7% of not religious respondents reported they would use a psychosexual assessment tool that was specifically designed for terminally ill patients. 25.0% of not religious respondents reported they would not.

77. Have you ever referred a terminally ill patient to a clinical sexologist?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents reported that they have not referred a terminally ill patient to a clinical sexologist.

78. Have you ever referred a terminally ill patient to a sex therapist?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

9.1% of religious respondents reported they have referred a terminally ill patient to a sex therapist. 90.9% of religious respondents and 100% of not religious respondents reported they have not referred a terminally ill patient to a sex therapist.

79. Have you ever referred the family caregiver of a terminally ill patient to a clinical sexologist?

Religious (n=11)

Yes	
No	100%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

100% of religious respondents and 100% of not religious respondents reported that they have not referred the family caregiver of a terminally ill patient to a clinical sexologist.

80. Have you ever referred the family caregiver of a terminally ill patient to a sex therapist?

Religious (n=11)

Yes	9.1%
No	90.9%

Not Religious (n=12)

Yes	
No	100%

Researcher's Conclusions

9.1% of religious respondents reported they have referred the family caregiver of a terminally ill patient to a sex therapist. 90.9% of religious respondents and 100% of not religious respondents reported they have not.

81. If you knew of a clinical sexologist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Religious (n=11)

Yes	81.2%
No	18.2%

Not Religious (n=12)

Yes	91.7%
No	8.3%

Researcher's Conclusions

81.2% of religious respondents and 91.7% of not religious respondents reported that if they knew of a clinical sexologist in their area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns they would refer for services. 18.2% of religious respondents and 8.3% of not religious respondents reported they would not.

82. If you knew of a sex therapist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Religious (n=11)

Yes	90.9%
No	9.1%

Not Religious (n=12)

Yes	91.7%
No	8.3%

Researcher's Conclusions

90.9% of religious respondents and 91.7% of not religious respondents reported that if they knew of a sex therapist in their area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns they would refer for services. 9.1% of religious respondents and 8.3% of not religious respondents reported they would not.

83. Do you believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying?

Religious (n=11)

Very important	36.4%
Important	27.3%
Somewhat important	36.4%
Somewhat unimportant	
Unimportant	
Very unimportant	

Not Religious (n=12)

Very important	41.7%
Important	25.0%
Somewhat important	16.7%
Somewhat unimportant	16.7%
Unimportant	
Very unimportant	

Researcher's Conclusions

100% of religious respondents and 83.4% of not religious respondents reported belief that it is important to increase professional knowledge regarding the role of sexuality in death and dying. 16.7% of not religious respondents reported belief that it is unimportant.

Chapter Twenty One

Sexuality Survey Results - Profession

1. Do you believe that it is appropriate to discuss sexuality with terminally ill patients?

Nurse (n=6)

Very appropriate	66.7%
Somewhat appropriate	33.3%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Social Worker (n=13)

Very appropriate	53.8%
Somewhat appropriate	15.4%
Neither appropriate or inappropriate	23.1%
Somewhat inappropriate	7.7%
Very inappropriate	

Chaplain (n=1, caution small base)

Very appropriate	100%
Somewhat appropriate	
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Other (n=3, caution small base)

Very appropriate	33.3%
Somewhat appropriate	66.7%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

100% of nurses and 69.2% of social workers reported that it is appropriate to discuss sexuality with terminally ill patients. 7.7% of social workers reported that it is inappropriate to discuss sexuality with terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

2. Do you feel qualified to discuss sexuality with terminally ill patients?

Nurse (n=6)

Very qualified	
Somewhat qualified	50.0%
Neither qualified or unqualified	50.0%
Somewhat unqualified	
Very Unqualified	

Social Worker (n=13)

Very qualified	23.1%
Somewhat qualified	46.1%
Neither qualified or unqualified	7.7%
Somewhat unqualified	7.7%
Very Unqualified	15.4%

Chaplain (n=1, caution small base)

Very qualified	
Somewhat qualified	100%
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	

Other (n=3, caution small base)

Very qualified	33.3%
Somewhat qualified	
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	66.7%

Researcher's Conclusions

50.0% of nurses and 69.2% of social workers reported that they feel qualified to discuss sexuality with terminally ill patients. 23.1% of social workers report being unqualified. No conclusions regarding chaplains and other professions due to small base.

3. Do you believe that it is appropriate to discuss sexuality with family caregivers of terminally ill patients?

Nurse (n=6)

Very appropriate	
Somewhat appropriate	66.7%
Neither appropriate or inappropriate	33.3%
Somewhat inappropriate	
Very inappropriate	

Social Worker (n=13)

Very appropriate	15.4%
Somewhat appropriate	46.1%
Neither appropriate or inappropriate	38.5%
Somewhat inappropriate	
Very inappropriate	

Chaplain (n=1, caution small base)

Very appropriate	
Somewhat appropriate	100%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Other (n=3, caution small base)

Very appropriate	33.3%
Somewhat appropriate	66.7%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

66.7% of nurses and 61.5% of social workers reported that it is appropriate to discuss sexuality with family caregivers of terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

4. Do you feel qualified to discuss sexuality with the family caregivers of terminally ill patients?

Nurse (n=6)

Very qualified	
Somewhat qualified	33.3%
Neither qualified or unqualified	33.3%
Somewhat unqualified	33.3%
Very Unqualified	

Social Worker (n=13)

Very qualified	30.7%
Somewhat qualified	38.5%
Neither qualified or unqualified	15.4%
Somewhat unqualified	
Very Unqualified	15.4%

Chaplain (n=1, caution small base)

Very qualified	
Somewhat qualified	100%
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	

Other (n=3, caution small base)

Very qualified	33.3%
Somewhat qualified	
Neither qualified or unqualified	
Somewhat unqualified	
Very Unqualified	66.7%

Researcher's Conclusions

33.3% of nurses and 69.2% of social workers reported feeling qualified to discuss sexuality with the family caregivers of terminally ill patients. 33.3% of nurses and 15.4% of social workers reported that it is inappropriate to discuss sexuality with terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

5. Do you feel sexuality is a concern for terminally ill patients?

Nurse (n=6)

Some	66.7%
Most	16.7%
All	16.7%
None	

Social Worker (n=13)

Some	92.3%
Most	7.7%
All	
None	

Chaplain (n=1, caution small base)

Some	100%
Most	
All	
None	

Other (n=3, caution small base)

Some	66.7%
Most	33.3%
All	
None	

Researcher's Conclusions

100% of nurses and 100% of social workers reported feeling that sexuality is a concern for terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

6. Do you feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients?

Nurse (n=6)

Very appropriate	50.0%
Somewhat appropriate	50.0%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Social Worker (n=13)

Very appropriate	53.8%
Somewhat appropriate	23.1%
Neither appropriate or inappropriate	23.1%
Somewhat inappropriate	
Very inappropriate	

Chaplain (n=1, caution small base)

Very appropriate	
Somewhat appropriate	100%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Other (n=3, caution small base)

Very appropriate	33.3%
Somewhat appropriate	33.3%
Neither appropriate or inappropriate	33.3%
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

100% of nurses and 76.9% of social workers feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

7. Do you feel it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients?

Nurse (n=6)

Very appropriate	66.6%
Somewhat appropriate	
Neither appropriate or inappropriate	
Somewhat inappropriate	16.7%
Very inappropriate	16.7%

Social Worker (n=13)

Very appropriate	23.1%
Somewhat appropriate	38.5%
Neither appropriate or inappropriate	23.1%
Somewhat inappropriate	15.4%
Very inappropriate	

Chaplain (n=1, caution small base)

Very appropriate	
Somewhat appropriate	100%
Neither appropriate or inappropriate	
Somewhat inappropriate	
Very inappropriate	

Other (n=3, caution small base)

Very appropriate	33.3%
Somewhat appropriate	33.3%
Neither appropriate or inappropriate	33.3%
Somewhat inappropriate	
Very inappropriate	

Researcher's Conclusions

66.6% of nurses and 61.6% of social workers feel it is appropriate to discuss sexuality with adult child caregivers of terminally ill patients. 33.4% of nurses and 15.4% of social workers feel it is inappropriate No conclusions regarding chaplains and other professions due to small base.

8. Do you feel comfortable in discussing sexuality with your terminally ill patients?

Nurse (n=6)

Very comfortable	16.7%
Somewhat comfortable	50.0%
Neither comfortable or uncomfortable	16.7%
Somewhat uncomfortable	
Very uncomfortable	16.7%

Social Worker (n=13)

Very comfortable	46.1%
Somewhat comfortable	30.7%
Neither comfortable or uncomfortable	7.7%
Somewhat uncomfortable	7.7%
Very uncomfortable	15.4%

Chaplain (n=1, caution small base)

Very comfortable	
Somewhat comfortable	
Neither comfortable or uncomfortable	100%
Somewhat uncomfortable	
Very uncomfortable	

Other (n=3, caution small base)

Very comfortable	33.3%
Somewhat comfortable	
Neither comfortable or uncomfortable	33.3%
Somewhat uncomfortable	
Very uncomfortable	33.3%

Researcher's Conclusions

66.7% of nurses and 76.8% of social workers feel comfortable in discussing sexuality with terminally ill patients. 16.7% of nurses and 23.1% of social workers feel uncomfortable in discussing sexuality with terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

9. Do you feel comfortable in discussing sexuality with the family caregivers of terminally ill patients?

Nurse (n=6)

Very comfortable	16.7%
Somewhat comfortable	33.3%
Neither comfortable or uncomfortable	16.7%
Somewhat uncomfortable	33.3%
Uncomfortable	
Very uncomfortable	

Social Worker (n=13)

Very comfortable	38.5%
Somewhat comfortable	38.5%
Neither comfortable or uncomfortable	7.7%
Somewhat uncomfortable	
Uncomfortable	
Very uncomfortable	15.4%

Chaplain (n=1, caution small base)

Very comfortable	
Somewhat comfortable	
Neither comfortable or uncomfortable	100%
Somewhat uncomfortable	
Uncomfortable	
Very uncomfortable	

Other (n=3, caution small base)

Very comfortable	33.3%
Somewhat comfortable	
Neither comfortable or uncomfortable	33.3%
Somewhat uncomfortable	
Uncomfortable	33.3%
Very uncomfortable	

Researcher's Conclusions

50.0% of nurses and 77.0% of social workers feel comfortable in discussing sexuality with the family caregivers of terminally ill patients. 33.3% of nurses and 15.4% of social workers feel uncomfortable. No conclusions regarding chaplains and other professions due to small base.

10. Do you believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Nurse (n=6)

Some	66.7%
Most	33.3%
All	
None	

Social Worker (n=13)

Some	92.3%
Most	7.7%
All	
None	

Chaplain (n=1, caution small base)

Some	100%
Most	
All	
None	

Other (n=3, caution small base)

Some	100%
Most	
All	
None	

Researcher's Conclusions

100% of nurses and 100% of social workers believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. No conclusions regarding chaplains and other professions due to small base.

11. Do you believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

Nurse (n=6)

Some	100%
Most	
All	
None	

Social Worker (n=13)

Some	92.3%
Most	7.7%
All	
None	

Chaplain (n=1, caution small base)

Some	100%
Most	
All	
None	

Other (n=3, caution small base)

Some	100%
Most	
All	
None	

Researcher's Conclusions

100% of nurses and 100% of social workers believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. No conclusions regarding chaplains and other professions due to small base.

12. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

16.7% of nurses and 7.7% of social workers reported a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 83.3% of nurses and 92.3% of social workers did not report a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. No conclusions regarding chaplains and other professions due to small base.

13. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the terminally ill patient?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

7.7% of social workers reported a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 100% of nurses and 92.3% of social workers did not report a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. No conclusions regarding chaplains and other professions due to small base.

14. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the terminally ill patient?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

16.7% of nurses reported a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 83.3% of nurses and 100% of social workers did not report a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. No conclusions regarding chaplains and other professions due to small base.

15. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

7.7% of social workers reported a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. 100% of nurses and 92.3% of social workers did not report a time in which a terminally ill patient broached the topic of sexuality and they changed the subject. No conclusions regarding chaplains and other professions due to small base.

16. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

16.7% of nurses and 15.4% of social workers reported a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject. 83.3% of nurses and 84.6% of social workers did not report a time in which they changed the subject. No conclusions regarding chaplains and other professions due to small base.

17. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the caregiver of the terminally ill patient?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

16.7% of nurses and 7.7% of social workers reported a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject. 83.3% of nurses and 92.3% of social workers did not report a time in which they changed the subject. No conclusions regarding chaplains and other professions due to small base.

18. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the caregiver of the terminally ill patient?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

33.3% of nurses and 7.7% of social workers reported a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject. 66.7% of nurses and 92.3% of social workers did not report a time in which they changed the subject. No conclusions regarding chaplains and other professions due to small base.

19. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

100% of nurses and 100% of social workers did not report a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject. No conclusions regarding chaplains and other professions due to small base.

20. Was training in human sexuality part of your formal education or professional training?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	76.9%
No	23.1%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 76.9% of social workers reported that training in human sexuality was part of their formal education or professional training. 66.7% of nurses and 23.1% of social workers reported that training in human sexuality was not part of their formal education or professional training. No conclusions regarding chaplains and other professions due to small base.

21. Was training in human sexuality part of your agency's orientation process?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

100% of nurses and 100% of social workers reported that training in human sexuality was not part of their agency's orientation process. No conclusions regarding chaplains and other professions due to small base.

22. Has a terminally ill patient ever requested your advice regarding sexual desire?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 38.5% of social workers reported that a terminally ill patient requested advice regarding sexual desire. 50.0% of nurses and 61.5% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

23. Has a terminally ill patient ever requested your advice regarding sexual arousal?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 38.5% of social workers reported that a terminally ill patient requested advice regarding sexual arousal. 50.0% of nurses and 61.5% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

24. Has a terminally ill patient ever requested your advice regarding sexual performance?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 38.5% of social workers reported that a terminally ill patient requested advice regarding sexual performance. 50.0% of nurses and 61.5% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

25. Has a terminally ill patient ever requested advice regarding sexual positions?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 7.7% of social workers reported that a terminally ill patient requested advice regarding sexual positions. 66.7% of nurses and 92.3% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

26. Has a terminally ill patient ever expressed concern regarding unmet sexual needs?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	61.5%
No	38.5%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 61.5% of social workers reported that a terminally ill patient expressed concern regarding unmet sexual needs. 66.7% of nurses and 38.5% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

27. Has a terminally ill patient ever expressed guilty feelings for having sexual desire?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

16.7% of nurses and 23.1% of social workers reported that a terminally ill patient expressed guilty feelings for having sexual desire. 83.3% of nurses and 76.9% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

28. Has a terminally ill patient ever discussed lack of intimacy?

Nurse (n=6)

Yes	83.3%
No	16.7%

Social Worker (n=13)

Yes	69.3%
No	30.7%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

83.3% of nurses and 69.3% of social workers reported that a terminally ill patient discussed lack of intimacy. 16.7% of nurses and 30.7% of social workers reported no discussion. No conclusions regarding chaplains and other professions due to small base.

29. Please indicate with an X the topics you would be comfortable discussing with a terminally ill patient. (X one box for each).

Nurse (n=6)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	100%				
Kissing	100%				
Sexual touch		33.3%	50.0%	16.7%	
Masturbation	16.7%	33.3%	16.7%	16.7%	16.7%
Oral Sex	16.7%	16.7%	16.7%		50.0%
Intercourse	33.3%	50.0%	16.7%		

Social Worker (n=13)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	92.3%				7.7%
Kissing	76.9%		15.4%		7.7%
Sexual touch	46.1%	15.4%	15.4%	7.7%	15.4%
Masturbation	38.5%	23.1%	7.7%	7.7%	23.1%
Oral Sex	30.7%	23.1%	7.7%	15.4%	23.1%
Intercourse	38.5%	23.1%	7.7%	15.4%	15.4%

Chaplain (n=1, caution small base)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch			100%		
Kissing			100%		
Sexual touch			100%		
Masturbation			100%		
Oral Sex			100%		
Intercourse			100%		

Other (n=3, caution small base)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch	100%				
Kissing		66.7%	33.3%		
Sexual touch	33.3%	33.3%	33.3%		
Masturbation	33.3%	33.3%		33.3%	
Oral Sex	33.3%		33.3%	33.3%	
Intercourse	33.3%		66.7%		

Researcher's Conclusions

100% of nurses and 92.3% of social workers report being comfortable with non-sexual touch. 7.7% of social workers report being uncomfortable with non-sexual touch. 100% of nurses and 76.9% of social workers report being comfortable with kissing. 7.7% of social workers report being uncomfortable with kissing. 33.3% of nurses and 61.5% of social workers report being comfortable with sexual touch. 16.7% of nurses and 23.1% of social workers report being uncomfortable with sexual touch. 50.0% of nurses and 61.6% of social workers report being comfortable with masturbation. 33.4% of nurses and 30.8% of social workers report being uncomfortable with masturbation. 33.4% of nurses and 53.8% of social workers report being comfortable with oral sex. 50.0% of nurses and 38.5% of social workers report being uncomfortable with oral sex. 83.3% of nurses and 61.6% of social workers report being comfortable with intercourse. 30.8 % of social workers report being uncomfortable with intercourse. No conclusions regarding chaplains and other professions due to small base.

30. Please indicate with an X your opinions regarding how the following statements apply to terminally ill patients. (X one box for each.)

Nurse (n=6)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	83.3%	16.7%			
Sexual activity is a duty for partners	16.7%				83.3%
Sexual activity is a private matter only to be discussed between partners	16.7%			33.3%	50.0%
Interest in sexual activity fades as one grows older			33.3%	16.7%	50.0%
Sexual activity is for the young					100%
Older people are not concerned with sexual activity					100%

Social Worker (n=13)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life		61.5%	38.5%		
Sexual activity is a duty for partners		7.7%	38.5%	15.4%	38.5%
Sexual activity is a private matter only to be discussed between partners			38.5%	46.1%	15.4%
Interest in sexual activity fades as one grows older	7.7%	53.8%	15.4%	23.1%	
Sexual activity is for the young				15.4%	84.6%
Older people are not concerned with sexual activity			7.7%	23.1%	69.3%

Chaplain (n=1, caution small base)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life		100%			
Sexual activity is a duty for partners			100%		
Sexual activity is a private matter only to be discussed between partners			100%		
Interest in sexual activity fades as one grows older		100%			
Sexual activity is for the young					100%
Older people are not concerned with sexual activity					100%

Other (n=3, caution small base)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	33.3%	66.7%			
Sexual activity is a duty for partners			33.3%		66.7%
Sexual activity is a private matter only to be discussed between partners			33.3%	33.3%	33.3%
Interest in sexual activity fades as one grows older		33.3%		33.3%	33.3%
Sexual activity is for the young					100%
Older people are not concerned with sexual activity					100%

Researcher's Conclusions

100% of nurses and 61.5% of social workers agree that sexual activity is important in assessing quality of life. 16.7% of nurses and 7.7% of social workers agree that sexual activity is a duty for partners. 83.3% of nurses and 53.9% of social workers disagree that sexual activity is a duty for partners. 16.7% of nurses agree that sexual activity is a private matter only to be discussed between partners. 83.3% of nurses and 61.5% of social workers disagree that sexual activity is a private matter only to be discussed between partners. 61.5% of social workers agree that interest in sexual activity fades as one grows older. 66.7% of nurses and 23.1% of social workers disagree that sexual activity fades as one grows older. 100% of nurses and 100% of social workers disagree that sexual activity is for the young. 100% of nurses and 92.4% of social workers disagree that older people are not concerned with sexual activity. No conclusions regarding chaplains and other professions due to small base.

31. Has a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 23.1% of social workers report that a terminally ill patient has expressed fear of not getting into heaven because of concerns regarding their sexuality. 50.0% of nurses and 76.9% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

32. Has a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 23.1% of social workers report that a terminally ill patient has expressed fear of going to hell because of concerns regarding their sexuality. 50.0% of nurses and 76.9% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

33. Has a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	61.5%
No	38.5%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	66.7%
No	33.3%

Researcher's Conclusions

33.3% of nurses and 61.5% of social workers report that a terminally ill patient has expressed feelings of guilt due to prior sexual activity. 66.7% of nurses and 38.5% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

34. Has a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 15.4% of social workers report that a terminally ill patient has expressed that their terminal illness was a punishment from God due to prior sexual activity. 66.7% of nurses and 84.6% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

35. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	30.7%
No	69.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	66.7%
No	33.3%

Researcher's Conclusions

16.7% of nurses and 30.7% of social workers report that a terminally ill patient has expressed that they could pass their terminal illness to their spouse/partner through sexual activity. 83.3% of nurses and 69.3% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

36. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was medically not possible?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers report that a terminally ill patient has expressed that they could pass their terminal illness to their spouse/partner through sexual activity even when not medically possible. 100% of nurses and 92.3% of social workers report no expression. No conclusions regarding chaplains and other professions due to small base.

37. Have you ever initiated a conversation about sexuality with a patient?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 38.5% of social workers reported initiating a conversation about sexuality with a patient. 66.7% of nurses and 61.5% of social workers report no initiation. No conclusions regarding chaplains and other professions due to small base.

38. Are you more likely to discuss sexuality with a male terminally ill patient?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

23.1% of social workers reported being more likely to discuss sexuality with a male terminally ill patient. 100% of nurses and 76.9% of social workers reported not being more likely to discuss. No conclusions regarding chaplains and other professions due to small base.

39. Are you more likely to discuss sexuality with a male caregiver of a terminally ill patient?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

15.4% of social workers reported being more likely to discuss sexuality with a male caregiver of a terminally ill patient. 100% of nurses and 84.6% of social workers reported not being more likely to discuss. No conclusions regarding chaplains and other professions due to small base.

40. Are you more likely to discuss sexuality with a female terminally ill patient?

Nurse (n=6)

Yes	50.0%
No	50.0%

Social Worker (n=13)

Yes	61.5%
No	38.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

50.0% of nurses and 61.5% of social workers reported being more likely to discuss sexuality with a female terminally ill patient. 50.0% of nurses and 38.5% of social workers reported not being more likely to discuss. No conclusions regarding chaplains and other professions due to small base.

41. Are you more likely to discuss sexuality with a female caregiver of a terminally ill patient?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	53.8%
No	46.1%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 53.8% of social workers reported being more likely to discuss sexuality with a female caregiver of a terminally ill patient. 66.7% of nurses and 46.1% of social workers reported not being more likely to discuss. No conclusions regarding chaplains and other professions due to small base.

42. Have you ever initiated a conversation about sexuality with a patient who was under the age of 20?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

16.7% of nurses reported initiating a conversation about sexuality with a patient. 83.3% of nurses and 100% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

43. Have you ever initiated a conversation about sexuality with a patient who was between the ages 20 to 40?

Nurse (n=6)

Yes	40.0%
No	60.0%

Social Worker (n=13)

Yes	46.1%
No	53.8%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

40.0% of nurses and 46.1% of social workers reported initiating a conversation about sexuality with a patient. 60.0% of nurses and 53.8% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

44. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 40 to 60?

Nurse (n=6)

Yes	40.0%
No	60.0%

Social Worker (n=13)

Yes	46.1%
No	53.8%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

40.0% of nurses and 46.1% of social workers reported initiating a conversation about sexuality with a patient. 60.0% of nurses and 53.8% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

45. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 60 to 80?

Nurse (n=6)

Yes	60.0%
No	40.0%

Social Worker (n=13)

Yes	46.1%
No	53.8%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

60.0% of nurses and 46.1% of social workers reported initiating a conversation about sexuality with a patient. 40.0% of nurses and 53.8% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

46. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 80 to 100?

Nurse (n=6)

Yes	20.0%
No	80.0%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

20.0% of nurses and 7.7% of social workers reported initiating a conversation about sexuality with a patient. 80.0% of nurses and 92.3% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

47. Have you ever initiated a conversation about sexuality with a family caregiver?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	46.1%
No	53.8%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

46.1% of social workers reported initiating a conversation about sexuality with a family caregiver. 100% of nurses and 53.8% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

48. Have you ever initiated a conversation about sexuality with a family caregiver who was under the age of 20?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

100% of nurses and 100% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

49. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages 20 to 40?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

38.5% of social workers reported initiating a conversation about sexuality with a family caregiver. 100% of nurses and 61.5% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

50. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 40 to 60?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	30.7%
No	69.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

30.7% of social workers reported initiating a conversation about sexuality with a family caregiver. 100% of nurses and 69.3% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

51. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 60 to 80?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=16)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers reported initiating a conversation about sexuality with a family caregiver. 100% of nurses and 92.3% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

52. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 80 to 100?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

100% of nurses and 100% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

53. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual desire?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	46.1%
No	53.8%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

16.7% of nurses and 46.1% of social workers reported that the family caregiver of a terminally ill patient requested advice regarding sexual desire. 83.3% of nurses and 53.8% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

54. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual arousal?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

23.1% of social workers reported that the family caregiver of a terminally ill patient requested advice regarding sexual arousal. 100% of nurses and 76.9% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

55. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual performance?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

15.4% of social workers reported that the family caregiver of a terminally ill patient requested advice regarding sexual performance. 100% of nurses and 84.6% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

56. Has the family caregiver of a terminally ill patient ever requested advice regarding sexual positions?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

15.4% of social workers reported that the family caregiver of a terminally ill patient requested advice regarding sexual positions. 100% of nurses and 84.6% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

57. Has the family caregiver of a terminally ill patient ever expressed concern regarding unmet sexual needs?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	33.3%
No	66.7%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

16.7% of nurses and 33.3% of social workers reported that the family caregiver of a terminally ill patient requested advice regarding unmet sexual needs. 83.3% of nurses and 66.7% of social workers reported no request. No conclusions regarding chaplains and other professions due to small base.

58. Has the caregiver of a terminally ill patient ever expressed guilty feelings for having sexual desire?

Nurse (n=6)

Yes	16.7%
No	83.3%

Social Worker (n=13)

Yes	23.1%
No	76.9%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

16.7% of nurses and 23.1% of social workers reported that the family caregiver of a terminally ill patient expressed guilty feelings for having sexual desire. 83.3% of nurses and 76.9% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

59. Has the family caregiver of a terminally ill patient ever discussed lack of intimacy?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=13)

Yes	69.3%
No	30.7%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 69.3% of social workers reported that the family caregiver of a terminally ill patient discussed lack of intimacy. 66.7% of nurses and 30.7% of social workers reported no discussion. No conclusions regarding chaplains and other professions due to small base.

60. Please indicate with an X the topics you would be comfortable discussing with the family caregiver of a terminally ill patient. (X one box for each).

Nurse (n=6)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	66.7%	16.7%			16.7%
Kissing	83.3%	16.7%			
Sexual touch	50.0%	33.3%			16.7%
Masturbation	16.7%	33.3%		16.7%	33.3%
Oral sex	16.7%		16.7%	16.7%	50.0%
Intercourse	50.0%	16.7%	16.7%		16.7%

Social Worker (n=13)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	69.3%		23.1%		7.7%
Kissing	69.3%	7.7%	15.4%		7.7%
Sexual touch	38.5%	23.1%	15.4%	7.7%	15.4%
Masturbation	23.1%	30.7%	15.4%	7.7%	23.1%
Oral sex	15.4%	23.1%	23.1%	15.4%	23.1%
Intercourse	30.7%	23.1%	15.4%	15.4%	15.4%

Chaplain (n=1, caution small base)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch			100%		
Kissing			100%		
Sexual touch			100%		
Masturbation			100%		
Oral sex			100%		
Intercourse			100%		

Other (n=3, caution small base)

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch	100%				
Kissing	66.7%	33.3%			
Sexual touch	33.3%	33.3%		33.3%	
Masturbation	33.3%	33.3%		33.3%	
Oral sex	33.3%		33.3%	33.3%	
Intercourse	33.3%		33.3%	33.3%	

Researcher's Conclusions

83.4% of nurses and 69.3% of social workers report being comfortable with non sexual touch. 16.7% of nurses and 7.7% of social workers report being uncomfortable with non sexual touch. 100% of nurses and 77.0% of social workers report being comfortable with kissing. 7.7% of social workers report being uncomfortable with kissing. 83.3% of nurses and 61.6% of social workers report being comfortable with sexual touch. 16.7% of nurses and 23.1% of social workers report being uncomfortable with sexual touch. 50.0% of nurses and 53.8% of social workers report being comfortable with masturbation. 50.0% of nurses and 30.8% of social workers report being uncomfortable with masturbation. 16.7% of nurses and 38.5% of social workers report being comfortable with oral sex. 66.7% of nurses and 38.5% of social workers report being uncomfortable with oral sex. 66.7% of nurses and 53.8% of social workers report being comfortable with intercourse. 16.7% of nurses and 30.8% of social workers report being uncomfortable with intercourse. No conclusions regarding chaplains and other professions due to small base.

61. Please indicate with an X your opinions regarding how the following statements apply to the family caregivers of terminally ill patients. (X one box for each.)

Nurse (n=6)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	66.7%	33.3%			
Sexual activity is a duty for partners			16.7%		83.3%
Sexual activity is a private matter only to be discussed between partners	16.7%	33.3%			50.0%
Interest in sexual activity fades as one grows older			16.7%	16.7%	66.7%
Sexual activity is for the young					100%
Older people are not concerned with sexual activity				16.7%	83.3%

Social Worker (n=13)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	53.8%	23.1%	7.7%	15.4%	
Sexual activity is a duty for partners			30.7%	30.7%	38.5%
Sexual activity is a private matter only to be discussed between partners	7.7%		15.4%	61.5%	15.4%
Interest in sexual activity fades as one grows older		46.1%		46.1%	7.7%
Sexual activity is for the young		7.7%		23.1%	69.3%
Older people are not concerned with sexual activity			7.7%	30.7%	61.5%

Chaplain (n=1, caution small base)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life		100%			
Sexual activity is a duty for partners					100%
Sexual activity is a private matter only to be discussed between partners			100%		
Interest in sexual activity fades as one grows older					100%
Sexual activity is for the young					100%
Older people are not concerned with sexual activity					100%

Other (n=3, caution small base)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life	33.3%	66.7%			
Sexual activity is a duty for partners			33.3%		66.7%
Sexual activity is a private matter only to be discussed between partners			33.3%	33.3%	33.3%
Interest in sexual activity fades as one grows older		33.3%		33.3%	33.3%
Sexual activity is for the young					100%
Older people are not concerned with sexual activity					100%

Researcher's Conclusions

100% of nurses and 76.9% of social workers agree that sexual activity is important in assessing quality of life. 15.4% of social workers disagree that sexual activity is important in assessing quality of life. 83.3% of nurses and 69.2% of social workers disagree that sexual activity is a duty for partners. 50.0% of nurses and 7.7% of social workers agree that sexual activity is a private matter only to be discussed between partners. 50.0% of nurses and 76.9% of social workers disagree that sexual activity is a private matter only to be discussed between partners. 46.1% of social workers agree that interest in sexual activity fades as one grows older. 83.4% of nurses and 53.8% of social workers disagree that sexual activity fades as one grows older. 7.7% of social workers agree that sexual activity is for the young. 100% of nurses and 92.4% of social workers disagree that sexual activity is for the young. 100% of nurses and 92.2% of social workers disagree that older people are not concerned with sexual activity. No conclusions regarding chaplains and other professions due to small base.

62. Has the family caregiver of a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers reported the family caregiver of a terminally ill patient expressed fear of not getting into heaven because of concerns regarding their sexuality. 100% of nurses and 92.3% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

63. Has the family caregiver of a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers reported the family caregiver of a terminally ill patient expressed fear of going to hell because of concerns regarding their sexuality. 100% of nurses and 92.3% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

64. Has the family caregiver of a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	15.4%
No	84.6%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

15.4% of social workers reported the family caregiver of a terminally ill patient expressed feelings of guilt due to prior sexual activity. 100% of nurses and 84.6% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

65. Has the family caregiver of a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers reported the family caregiver of a terminally ill patient expressed that their terminal illness was a punishment from God due to prior sexual activity. 100% of nurses and 92.3% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

66. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	38.5%
No	61.5%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

38.5% of social workers reported the family caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity. 100% of nurses and 61.5% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

67. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	7.7%
No	92.3%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

7.7% of social workers reported the family caregiver of a terminally ill patient expressed fear that they could catch the patient's illness through sexual activity even when medically not possible. 92.3% of nurses and 61.5% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

68. Has a family caregiver of a terminally ill patient ever expressed a decline in sexual feelings specifically attributed to their role as a caregiver?

Nurse (n=6)

Yes	66.7%
No	33.3%

Social Worker (n=13)

Yes	61.5%
No	38.5%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

66.7% of nurses and 61.5% of social workers reported the family caregiver of a terminally ill patient expressed a decline in sexual feelings specifically attributed to their role as a caregiver. 33.3% of nurses and 38.5% of social workers reported no expression. No conclusions regarding chaplains and other professions due to small base.

69. Have you ever initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver?

Nurse (n=6)

Yes	33.3%
No	66.7%

Social Worker (n=12)

Yes	33.3%
No	66.7%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

33.3% of nurses and 33.3% of social workers reported that they have initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver. 66.7% of nurses and 66.7% of social workers reported no initiation. No conclusions regarding chaplains and other professions due to small base.

70. Do you include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient?

Nurse (n=6)

Sometimes	16.7%
Most of the time	
Always	
Never	83.3%

Social Worker (n=13)

Sometimes	46.1%
Most of the time	
Always	
Never	53.8%

Chaplain (n=1, caution small base)

Sometimes	
Most of the time	100%
Always	
Never	

Other (n=3, caution small base)

Sometimes	33.3%
Most of the time	
Always	
Never	66.7%

Researcher's Conclusions

16.7% of nurses and 46.1% of social workers reported that they include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient. 83.3% of nurses and 53.8% of social workers reported never including a discussion of sexuality. No conclusions regarding chaplains and other professions due to small base.

71. Do you include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of the terminally ill patient?

Nurse (n=6)

Sometimes	
Most of the time	
Always	
Never	100%

Social Worker (n=13)

Sometimes	38.5%
Most of the time	
Always	
Never	61.5%

Chaplain (n=1, caution small base)

Sometimes	
Most of the time	100%
Always	
Never	

Other (n=3, caution small base)

Sometimes	33.3%
Most of the time	
Always	
Never	66.7%

Researcher's Conclusions

38.5% of social workers reported that they include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of a terminally ill patient. 100% of nurses and 61.5% of social workers reported never including a discussion of sexuality. No conclusions regarding chaplains and other professions due to small base.

72. Do you include a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient?

Nurse (n=6)

Sometimes	
Most of the time	
Always	
Never	100%

Social Worker (n=13)

Sometimes	38.5%
Most of the time	
Always	
Never	61.5%

Chaplain (n=1, caution small base)

Sometimes	
Most of the time	100%
Always	
Never	

Other (n=3, caution small base)

Sometimes	33.3%
Most of the time	
Always	
Never	66.7%

Researcher's Conclusions

38.5% of social workers reported that they include a discussion of sexuality when discussing anticipatory grief with the family caregiver of a terminally ill patient. 100% of nurses and 61.5% of social workers reported never include a discussion of sexuality. No conclusions regarding chaplains and other professions due to small base.

73. Do you assess sexuality/intimacy as part of your initial assessment of the terminally ill patient?

Nurse (n=6)

Sometimes	50.0%
Most of the time	16.7%
Always	
Never	33.3%

Social Worker (n=13)

Sometimes	38.5%
Most of the time	
Always	
Never	61.5%

Chaplain (n=1, caution small base)

Sometimes	
Most of the time	
Always	
Never	100%

Other (n=3, caution small base)

Sometimes	
Most of the time	
Always	33.3%
Never	66.7%

Researcher's Conclusions

66.7% of nurses and 38.5% of social workers reported that they assess sexuality/ intimacy as part of the initial assessment of the terminally ill patient. 33.3% of nurses and 61.5% of social workers reported that they never assess sexuality. No conclusions regarding chaplains and other professions due to small base.

74. Do you assess sexuality/intimacy as part of your regular assessment of the terminally ill patient?

Nurse (n=6)

Sometimes	50.0%
Most of the time	
Always	
Never	50.0%

Social Worker (n=13)

Sometimes	53.8%
Most of the time	
Always	
Never	46.1%

Chaplain (n=1, caution small base)

Sometimes	
Most of the time	
Always	
Never	100%

Other (n=3, caution small base)

Sometimes	
Most of the time	
Always	33.3%
Never	66.7%

Researcher's Conclusions

50.0% of nurses and 53.8% of social workers reported that they assess sexuality/intimacy as part of the regular assessment of the terminally ill patient. 50.0% of nurses and 46.1% of social workers reported that they never assess sexuality. No conclusions regarding chaplains and other professions due to small base.

75. Do you have a psychosexual assessment tool to use when working with terminally ill patients?

Nurse (n=6)

Yes	
No	83.3%
Not applicable	16.7%

Social Worker (n=13)

Yes	15.4%
No	76.9%
Not applicable	7.7%

Chaplain (n=1, caution small base)

Yes	
No	100%
Not applicable	

Other (n=3, caution small base)

Yes	
No	33.3%
Not applicable	66.7%

Researcher's Conclusions

15.4% of social workers reported that they have a psychosexual assessment tool to use when working with terminally ill patients. 83.3% of nurses and 76.9% of social workers reported that they do not have a psychosexual assessment tool to use when working with terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

76. Would you use a psychosexual assessment tool that was specifically designed for terminally ill patients?

Nurse (n=6)

Yes	66.7%
No	16.7%
Not applicable	16.7%

Social Worker (n=13)

Yes	76.9%
No	15.4%
Not applicable	7.7%

Chaplain (n=1, caution small base)

Yes	
No	
Not applicable	100%

Other (n=3, caution small base)

Yes	33.3%
No	
Not applicable	66.7%

Researcher's Conclusions

66.7% of nurses and 76.9% of social workers reported that they would use a psychosexual assessment tool designed for terminally ill patients. 16.7% of nurses and 15.4% of social workers reported that they would not use a psychosexual assessment tool when working with terminally ill patients. No conclusions regarding chaplains and other professions due to small base.

77. Have you ever referred a terminally ill patient to a clinical sexologist?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

100% of nurses and 100% of social workers reported that they have not referred a terminally ill patient to a clinical sexologist. No conclusions regarding chaplains and other professions due to small base.

78. Have you ever referred a terminally ill patient to a sex therapist?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=16)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

100% of nurses and 100% of social workers reported that they have not referred a terminally ill patient to a sex therapist. No conclusions regarding chaplains and other professions due to small base.

79. Have you ever referred the family caregiver of a terminally ill patient to a clinical sexologist?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	
No	100%

Researcher's Conclusions

100% of nurses and 100% of social workers reported that they have not referred the family caregiver of a terminally ill patient to a clinical sexologist. No conclusions regarding chaplains and other professions due to small base.

80. Have you ever referred the family caregiver of a terminally ill patient to a sex therapist?

Nurse (n=6)

Yes	
No	100%

Social Worker (n=13)

Yes	
No	100%

Chaplain (n=1, caution small base)

Yes	
No	100%

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

100% of nurses and 100% of social workers reported that they have not referred the family caregiver of a terminally ill patient to a sex therapist. No conclusions regarding chaplains and other professions due to small base.

81. If you knew of a clinical sexologist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Nurse (n=6)

Yes	100%
No	

Social Worker (n=13)

Yes	84.6%
No	15.4%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	33.3%
No	66.7%

Researcher's Conclusions

100% of nurses and 84.6% of social workers reported that if they knew of a clinical sexologist in their area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns they would refer for services. 15.4% of social workers reported that they would not refer. No conclusions regarding chaplains and other professions due to small base.

82. If you knew of a sex therapist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Nurse (n=6)

Yes	100%
No	

Social Worker (n=13)

Yes	92.3%
No	7.7%

Chaplain (n=1, caution small base)

Yes	100%
No	

Other (n=3, caution small base)

Yes	66.7%
No	33.3%

Researcher's Conclusions

100% of nurses and 92.3% of social workers reported that if they knew of a sex therapist in their area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns they would refer for services. 7.7% of social workers reported that they would not refer. No conclusions regarding chaplains and other professions due to small base.

83. Do you believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying?

Nurse (n=6)

Very important	50.0%
Important	16.7%
Somewhat important	16.7%
Somewhat unimportant	16.7%
Unimportant	
Very unimportant	

Social Worker (n=13)

Very important	30.7%
Important	38.5%
Somewhat important	30.7%
Somewhat unimportant	
Unimportant	
Very unimportant	

Chaplain (n=1, caution small base)

Very important	
Important	
Somewhat important	100%
Somewhat unimportant	
Unimportant	
Very unimportant	

Other (n=3, caution small base)

Very important	33.3%
Important	33.3%
Somewhat important	33.3%
Somewhat unimportant	
Unimportant	
Very unimportant	

Researcher's Conclusions

88.4% of nurses and 100% of social workers reported that they believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying. 16.7% of nurses reported that they believe it is unimportant. No conclusions regarding chaplains and other professions due to small base.

Chapter Twenty Two

Conclusions

The majority of respondents reported that it is appropriate to discuss sexuality with terminally ill patients. In comparing respondent's answers by sex, religiosity and profession, male respondents (100%) and female respondents (76.5%) reported that is appropriate to discuss sexuality with patients. Religious respondents (90.1%) and not religious respondents (75.0%) reported that it was appropriate. Nurses (100%) and social workers (69.2%) reported that it was appropriate to discuss sexuality with terminally ill patients.

Male respondents (100%) and female respondents (47.1%) reported that they feel qualified to discuss sexuality with terminally ill patients.

Male respondents (100%) and female respondents (58.8%) believe that it is appropriate to discuss sexuality with family caregivers of terminally ill patients. Religious respondents (45.5%) reported that it was appropriate compared to not religious respondents (83.4%).

Male respondents (100%) and female respondents (52.9%) feel qualified to discuss sexuality with the family caregivers of terminally ill patients. Nurses (33.4%) and social workers (69.2%) report feeling qualified to discuss sexuality with caregivers.

The results show that while males feel qualified to discuss sexuality only about half of the females surveyed feel qualified to discuss sexuality. While most respondents feel that it is appropriate to discuss sexuality with terminally ill patients, females, religious

respondents, nurses and social workers all report that it is less appropriate to discuss sexuality with the caregivers of terminally ill patients.

100% of the respondents reported that they feel sexuality is a concern for terminally ill patients.

Most respondents reported that they believe it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients. Females, religious respondents, nurses and social workers all reported that it is less appropriate to discuss sexuality with the adult child caregivers of terminally ill patients.

Male respondents (83.4%) and female respondents (58.8%) feel comfortable in discussing sexuality with terminally ill patients. Religious respondents (45.5%) and not religious respondents (66.7%), nurses (66.7%) and social workers (76.8%) feel comfortable in discussing sexuality with terminally ill patients.

Male respondents (83.4%) and female respondents (22.9%) feel comfortable in discussing sexuality with the family caregivers of terminally ill patients. Religious respondents (36.4%) and not religious respondents (75.0%) report feeling comfortable discussing sexuality with caregivers. Nurses (50.0%) and social workers (77.0%) report feeling comfortable discussing sexuality with caregivers.

The results show that while slightly more than half of the female respondents are comfortable in discussing sexuality with patients, less than one quarter are comfortable in discussing sexuality with caregivers. Religious respondents are less comfortable in discussing sexuality than not religious respondents. By profession, nurses are less comfortable discussing sexuality than social workers.

Male respondents (100%) and female respondents (82.4%) reported that they believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. In examining responses by religion and profession, 100% of both religious and not religious respondents, nurses and social workers reported that they believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject.

Slightly more female respondents (94.1%) reported that they believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. 100% of all other respondents reported that they believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject.

Female respondents (11.8%), not religious respondents (16.7%), nurses (16.7%) and social workers (7.7%) reported that there has been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject.

Female respondents (5.9%), not religious respondents (8.3%) and social workers (7.7%) reported that there has been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject because they were uncomfortable discussing sexual issues with the terminally ill patient.

Female respondents (5.9%), not religious respondents (8.3%) and nurses (16.7%) reported that there has been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject because they were not sure how to help the terminally ill patient.

Female respondents (5.9%), not religious respondents (8.3%) and social workers (7.7%) reported that there has been a time in which a terminally ill patient broached the topic of sexuality and they changed the subject because they were embarrassed by the question.

Male respondents (16.7%), female respondents (11.8%), not religious respondents (25.0%) nurses (16.7%) and social workers (15.4%) reported that there has been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject.

Male respondents (16.7%), female respondents (5.9%), not religious respondents (16.7%), nurses (16.7%) and social workers (7.75%) reported that there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject because they were uncomfortable discussing sexual issues with the caregiver of the terminally ill patient.

Nurses (33.3%), female respondents (17.6%), not religious respondents (25.0%) and social workers (7.7%) reported that there has been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject because they were not sure how to help the caregiver of the terminally ill patient.

No respondents reported that there has been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and they changed the subject because they were embarrassed by the question.

The research shows that more respondents reported changing the subject when a caregiver broached the topic of sexuality as compared to when a terminally ill patient broached the topic of sexuality.

Male respondents (83.3%), female respondents (52.9%), religious respondents (63.6%), not religious respondents (58.3%), nurses (33.3%) and social workers (76.9%) reported that training in human sexuality was part of their formal education or professional training. Only male respondents (16.7%) reported training in human sexuality as part of their agency's orientation process.

Male respondents (50.0%), female respondents (35.3%), religious respondents (27.3%), not religious respondents (50.0%), nurses (50.0%) and social workers (38.5%) reported that a terminally ill patient has requested their advice regarding sexual desire. Male respondents, not religious respondents and nurses received the most requests. Religious respondents received the least requests. Respondents who report as being religious might be less inclined to discuss sexual desire and might provide the patient with verbal and non-verbal cues which would the impede the patient from asking questions.

Male respondents (66.7%), female respondents (11.8%), religious respondents (18.2%), not religious respondents (33.3%), nurses (50.0%) and social workers (38.5%) reported that a terminally ill patient has requested their advice regarding sexual arousal. Male respondents received the most requests. Female respondents received the least requests. We do not know if those patients who were requesting advice were men and, if so, were those men more comfortable in seeking advice from other men.

Male respondents (33.3%), female respondents (41.2%), religious respondents (36.4%), not religious respondents (41.7%), nurses (50.0%) and social workers (38.5%) reported that a terminally ill patient has requested their advice regarding sexual performance. Nurses received the most requests. Male respondents received the least requests. None of the male respondents were nurses.

Male respondents (16.7%), female respondents (17.6%), religious respondents (9.1%), not religious respondents (25.0%), nurses (33.3%) and social workers (61.5%) reported that a terminally ill patient has requested their advice regarding sexual positions. Social workers received the most requests. Religious respondents received the least requests. Social workers received nearly double the request for advice than did nurses. Social workers reported feeling more qualified than nurses to discuss sexuality and this belief might impact their interactions with patients who could perceive social workers as being more amenable to discussion. Again, respondents who report as being religious might be less inclined to discuss sexuality and might provide the patient with verbal and non-verbal cues which would the impede the patient from asking questions.

Male respondents (100%), female respondents (35.3%), religious respondents (27.3%), not religious respondents (83.3%), nurses (33.3%) and social workers (61.5%) reported that a terminally ill patient has requested their advice regarding unmet sexual needs. Male respondents received the most requests. Religious respondents received the least requests. As male respondents (100%) reported that they were qualified to discuss sexuality and (83.4%) reported being comfortable in discussing sexuality with patients it can be concluded that patients are aware of the male respondent's confidence and openness with the topic. Religious respondents (45.5%) report being both qualified and being comfortable in discussing sexuality with terminally ill patients.

Male respondents (50.0%), female respondents (11.8%), religious respondents (9.1%), not religious respondents (50.0%), nurses (16.7%) and social workers (23.1%) reported that a terminally ill patient has expressed guilty feelings for having sexual desire. Male

respondents and not religious respondents reported the most expression. Religious respondents reported the least expression.

Male respondents (100%), female respondents (58.8%), religious respondents (63.6%), not religious respondents (75.0%), nurses (83.3%) and social workers (69.3%) reported that a terminally ill patient has discussed lack of intimacy. Male respondents reported the most discussion. Female respondents reported the least discussion.

The greatest percentage of responses reported in discussion of intimacy. This might reflect both patient's and caregiver's preference for the use of the word intimacy as opposed to the use of the term sexuality. References to this terminology are also reflected in the literature on death and dying.

Male respondents (83.3%), female respondents (94.1%), religious respondents (81.8%), not religious respondents (100%), nurses (100%) and social workers (92.3%) reported being comfortable discussing non-sexual touch with a terminally ill patient.

Male respondents (83.3%), female respondents (82.4%), religious respondents (72.7%), not religious respondents (100%), nurses (100%) and social workers (76.9%) reported being comfortable discussing kissing with a terminally ill patient.

Male respondents (83.4%), female respondents (58.8%), religious respondents (54.6%), not religious respondents (75.0%), nurses (33.3%) and social workers (61.5%) reported being comfortable discussing sexual touch with a terminally ill patient.

Male respondents (83.4%), female respondents (47.0%), religious respondents (45.5%), not religious respondents (66.7%), nurses (50.0%) and social workers (61.5%) reported being comfortable discussing masturbation with a terminally ill patient.

Male respondents (83.3%), female respondents (29.4%), religious respondents (27.3%), not religious respondents (58.3%), nurses (33.4%) and social workers (53.8%) reported being comfortable discussing oral sex with a terminally ill patient.

Male respondents (83.4%), female respondents (52.9%), religious respondents (45.5%), not religious respondents (75.0%), nurses (83.3%) and social workers (61.6%) reported being comfortable discussing intercourse touch with a terminally ill patient.

Not religious respondents and nurses reported being most comfortable discussing non-sexual touch with a terminally ill patient. Religious respondents reported being least comfortable discussing non-sexual touch with a terminally ill patient. Not religious respondents and nurses reported being most comfortable discussing kissing with a terminally ill patient. Religious respondents reported being least comfortable discussing kissing with a terminally ill patient. Male respondents reported being most comfortable discussing sexual touch with a terminally ill patient. Nurses reported being least comfortable discussing sexual touch with a terminally ill patient. Male respondents reported being most comfortable discussing masturbation with a terminally ill patient. Religious respondents reported being least comfortable discussing masturbation with a terminally ill patient. Male respondents reported being most comfortable discussing oral sex with a terminally ill patient. Religious respondents reported being least comfortable discussing oral sex with a terminally ill patient. Male respondents reported being most comfortable discussing intercourse with a terminally ill patient. Religious respondents reported being least comfortable discussing intercourse with a terminally ill patient.

Male respondents (50.0%), female respondents (23.5%), religious respondents (27.3%), not religious respondents (66.7%), nurses (50.0%) and social workers (23.1%) reported that

a terminally ill patient has expressed fear of not getting into heaven because of concerns regarding their sexuality.

Male respondents (66.7%), female respondents (23.5%), religious respondents (36.4%), not religious respondents (33.3%), nurses (50.0%) and social workers (23.1%) reported that a terminally ill patient has expressed fear of going to hell because of concerns regarding their sexuality.

Male respondents (100%), female respondents (41.2%), religious respondents (63.6%), not religious respondents (45.5%), nurses (33.3%) and social workers (61.5%) reported that a terminally ill patient has expressed feelings of guilt due to prior sexual activity.

Male respondents (50.0%), female respondents (17.6%), religious respondents (36.4%), not religious respondents (16.7%), nurses (33.3%) and social workers (15.4%) reported that a terminally ill patient has expressed that their terminal illness was a punishment from God due to prior sexual activity.

Male respondents (66.7%), female respondents (17.6%), religious respondents (18.2%), not religious respondents (41.7%), nurses (16.7%) and social workers (30.7%) reported that a terminally ill patient has expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity.

Male respondents (33.3%), religious respondents (9.1%), not religious respondents (8.3%) and social workers (7.7%) reported that a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was medically not possible.

Male respondents (66.7%), female respondents (29.4%), religious respondents (27.3%), not religious respondents (72.7%), nurses (33.3%) and social workers (38.5%) reported that

they have ever initiated a conversation about sexuality with a patient. Two thirds of male respondents and only a little more than one quarter of female respondents have ever initiated a conversation about sexuality with a patient. Only one third of nurses and a little more than one third of social workers have ever initiated a conversation about sexuality with a terminally ill patient. Males report being approximately two times as likely as females to have initiated a conversation about sexuality with a patient who was between the ages of twenty and eighty. Less than one half of nurses and social workers have initiated a conversation with a patient between the ages of twenty and sixty. Male respondents (33.3%) and female respondents (6.2%) have initiated a conversation with a terminally ill patient between the ages of eighty and one hundred. This is reflective of the societal bias toward the aged and sexuality.

Male respondents (50.0%), female respondents (23.5%), religious respondents (36.4%), not religious respondents (25.0%), and social workers (46.1%) reported that they have ever initiated a conversation about sexuality with a family caregiver. Only one half of the male respondents and less than one quarter of the female respondents reported initiating a conversation. Less than one half of the social workers reported initiating a conversation. There were no nurses in the survey who reported ever initiating a conversation about sexuality with a family caregiver. Males are approximately three times more likely to initiate a conversation with a caregiver between the ages of twenty to sixty than with a caregiver between the ages of sixty to one hundred. Only religious respondents and social workers are more likely to initiate a conversation about sexuality with a caregiver than with a patient.

Male respondents (83.3%), female respondents (29.4%), religious respondents (27.3%), not religious respondents (50.0%), nurses (16.7%) and social workers (46.1%) reported that the caregiver of a terminally ill patient has requested their advice regarding sexual desire. Male respondents received the most requests. Religious respondents received the least requests. Again, respondents who report as being religious might be less inclined to discuss sexual desire and might provide the patient with verbal and non-verbal cues which would the impede the patient from asking questions. Only male respondents reported a greater percentage of caregivers of terminally ill patients than caregivers requesting advice.

Male respondents (66.7%), religious respondents (9.1%), not religious respondents (25.0%) and social workers (23.1%) reported that the caregiver of a terminally ill patient has requested their advice regarding sexual arousal. Male respondents received the most requests. Female respondents and nurses received no requests. We do not know if those patients who were requesting advice were men and, if so, were those men more comfortable in seeking advice from other men. None of the respondents who were nurses were males.

Male respondents (50.0%), female respondents (5.9%), religious respondents (18.2%), not religious respondents (25.0%) and social workers (15.4%) reported that the caregiver of a terminally ill patient has requested their advice regarding sexual performance. Male respondents received the most requests. Nurses received no requests.

Male respondents (33.3%), female respondents (5.9%), religious respondents (9.1%), not religious respondents (16.7%) and social workers (15.4%) reported that the caregiver of a terminally ill patient has requested their advice regarding sexual positions. Male respondents had received the most requests and also received more than double the amount

of requests than did those males whose advice had been requested by patients. Nurses received no requests.

Male respondents (66.7%), female respondents (23.5%), religious respondents (9.1%), not religious respondents (41.7%), nurses (16.7%) and social workers (33.3%) reported that the caregiver of a terminally ill patient has requested their advice regarding unmet sexual needs. Male respondents received the most requests. Religious respondents received the least requests. As male respondents (100%) reported that they were qualified to discuss sexuality and (83.4%) reported being comfortable in discussing sexuality with patients it can be concluded that patients are aware of the male respondent's confidence and openness with the topic. Religious respondents (45.5%) report being both qualified and being comfortable in discussing sexuality with terminally ill patients.

Male respondents (50.0%), female respondents (17.6%), religious respondents (27.3%), not religious respondents (25.0%), nurses (16.7%) and social workers (23.1%) reported that the caregiver of a terminally ill patient has expressed guilty feelings for having sexual desire. Male respondents reported the most expression. Nurses reported the least expression.

Male respondents (100%), female respondents (35.3%), religious respondents (45.5%), not religious respondents (66.7%), nurses (33.3%) and social workers (69.3%) reported that a caregiver of a terminally ill patient has discussed lack of intimacy. Male respondents reported the most discussion. Female respondents reported the least discussion.

Male respondents (66.7%), female respondents (76.5%), religious respondents (63.6%), not religious respondents (83.3%), nurses (83.4%) and social workers (69.3%) reported being comfortable discussing non-sexual touch with the caregiver of a terminally ill patient.

Male respondents (66.7%), female respondents (82.4%), religious respondents (63.6%), not religious respondents (91.6%), nurses (100%) and social workers (77.0%) reported being comfortable discussing kissing with the caregiver of a terminally ill patient.

Male respondents (66.7%), female respondents (64.7%), religious respondents (54.6%), not religious respondents (75.0%), nurses (83.3%) and social workers (61.6%) reported being comfortable discussing sexual touch with the caregiver of a terminally ill patient.

Male respondents (66.7%), female respondents (47.0%), religious respondents (36.4%), not religious respondents (66.7%), nurses (50.0%) and social workers (53.8%) reported being comfortable discussing masturbation with the caregiver of a terminally ill patient.

Male respondents (66.7%), female respondents (17.7%), religious respondents (18.2%), not religious respondents (41.7%), nurses (16.7%) and social workers (38.5%) reported being comfortable discussing oral sex with the caregiver of a terminally ill patient.
Male respondents (66.7%), female respondents (47.0%), religious respondents (36.4%), not religious respondents (66.7%), nurses (66.7%) and social workers (53.8%) reported being comfortable discussing intercourse touch with the caregiver of a terminally ill patient.

Not religious respondents and nurses reported being most comfortable discussing non-sexual touch with the caregiver of a terminally ill patient. Religious respondents reported being least comfortable discussing non-sexual touch with the caregiver of a terminally ill patient. Not religious respondents and nurses reported being most comfortable discussing kissing with the caregiver of a terminally ill patient. Religious respondents reported being least comfortable discussing kissing with the caregiver of a terminally ill patient. Nurses reported being most comfortable discussing sexual touch with the caregiver of a terminally ill patient. Religious respondents reported being least comfortable discussing sexual touch

with the caregiver of a terminally ill patient. Male and not religious respondents reported being most comfortable discussing masturbation with the caregiver of a terminally ill patient. Religious respondents reported being least comfortable discussing masturbation with the caregiver of a terminally ill patient. Male respondents reported being most comfortable discussing oral sex with the caregiver of a terminally ill patient. Nurses reported being least comfortable discussing oral sex with the caregiver of a terminally ill patient. Male, not religious respondents and nurses reported being most comfortable discussing intercourse with the caregiver of a terminally ill patient. Religious respondents reported being least comfortable discussing intercourse with the caregiver of a terminally ill patient.

Male respondents (33.3%), religious respondents (9.1%), not religious respondents (8.3%) and social workers (7.7%) reported that a terminally ill patient has expressed fear of not getting into heaven because of concerns regarding their sexuality. All respondents reported less expression with caregivers than patients.

Male respondents (33.3%), religious respondents (9.1%), not religious respondents (9.3%) and social workers (15.4%) reported that a caregiver of a terminally ill patient has expressed fear of going to hell because of concerns regarding their sexuality. All respondents reported less expression with caregivers than patients.

Male respondents (66.7%), religious respondents (18.2%), not religious respondents (16.7%) and social workers (15.4%) reported that a caregiver of a terminally ill patient has expressed feelings of guilt due to prior sexual activity. All respondents reported the same or less expression with caregivers than patients.

Male respondents (33.3%), religious respondents (9.1%), not religious respondents (8.3%) and social workers (7.7%) reported that a caregiver of a terminally ill patient has expressed that their terminal illness was a punishment from God due to prior sexual activity. All respondents reported less expression with caregivers than patients.

Male respondents (66.7%), female respondents (11.8%), religious respondents (18.2%), not religious respondents (33.3%), and social workers (38.5%) reported that a caregiver of a terminally ill patient has expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity.

Male respondents (33.3%), religious respondents (54.5%), not religious respondents (66.7%), nurses (66.7%) and social workers (61.5%) reported that a caregiver of a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was not medically possible.

Male respondents (100%), female respondents (47.1%), religious respondents (54.5%), not religious respondents (66.7%), nurses (66.7%) and social workers (61.5%) reported that the caregiver of a terminally ill patient has expressed a decline in sexual feelings specifically attributed to their role as a caregiver. One hundred percent of all male respondents and almost fifty percent or more of all other respondents report that a patient has expressed a decline in their sexual feelings related to their role as a caregiver.

Male respondents (50.0%), female respondents (25.0%), religious respondents (18.2%), not religious respondents (41.7%), nurses (33.3%) and social workers (66.7%) reported having initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver. Only social workers reported a greater percentage of initiation of a conversation regarding sexuality and the

caregiving role than patients expressing a decline in their sexual feelings related to their role as a caregiver.

Male respondents (83.4%), female respondents (23.5%), religious respondents (36.4%), not religious respondents (41.7%), nurses (16.7%) and social workers (46.1%) reported that they include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient. Less than twenty percent of the nurses and less than fifty percent of the social workers reported that they discuss sexuality with the patient when they discuss the dying process.

Male respondents (83.3%), female respondents (11.8%), religious respondents (36.4%), not religious respondents (25.0%) and social workers (38.5%) reported that they include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of a terminally ill patient. Only little more than one third of the social workers and none of the nurses reported that they discuss sexuality when discussing the dying process.

Male respondents (66.7%), female respondents (17.6%), religious respondents (45.5%), not religious respondents (16.7%) and social workers (38.5%) reported that they include a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient. Only little more than one third of the social workers and none of the nurses reported that they discuss sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient.

Male respondents (50.0%), female respondents (41.2%), religious respondents (45.5%), not religious respondents (41.6%), nurses (66.7%) and social workers (38.5%) reported that they assess sexuality/intimacy as part of their initial assessment of the terminally ill patient.

Two thirds of nurses and little more than one third of social workers reported that they assess sexuality as part of the initial assessment of the patient. Male respondents (50.0%), female respondents (41.2%), religious respondents (45.5%), not religious respondents (41.6%), nurses (66.7%) and social workers (53.8%) reported that they assess sexuality/intimacy as part of their regular assessment of the terminally ill patient.

Two thirds of nurses and more than one half of social workers reported that they assess sexuality as part of their regular assessment of the patient. Though respondents report regularly assessing sexuality, only little more than one third of the social workers and none of the nurses reported that they discuss sexuality when discussing the dying process. One hundred percent of the respondents reported that they feel sexuality is a concern for terminally ill patients and one hundred percent of the nurses and social workers reported that they believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. Only one third of the nurses and little more than one third of the social workers reported ever initiating a conversation about sexuality with a patient.

None of the nurses and of the social workers relatively few (15.4%) report having a psychosexual assessment tool to use when working with terminally ill patients. Nurses (66.7%) and social workers (76.9%) report that they would, in fact, use a psychosexual assessment tool that was specifically designed for terminally ill patients.

None of the nurses or social workers reported ever referring a terminally ill patient or caregiver of a terminally ill patient to either a clinical sexologist or to a sex therapist. Nurses (100%) and social workers (84.6%) reported that they would refer to a clinical sexologist who specialized in working with terminally ill patients and their caregivers.

Nurses (100%) and social workers (92.3%) reported that they would refer to a sex therapist who specialized in working with terminally ill patients and their caregivers. The slightly higher referrals for sex therapist could be attributed to better name recognition for sex therapy as a discipline.

Male respondents (83.3%), female respondents (94.1%), religious respondents (100%), not religious respondents (83.4%), nurses (88.4%) and social workers (100%) report that they believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying.

Chapter Twenty Three

Limitations of the Study

Limitations of the study included the size and location of the initial study. Due to the nature of the study, the researcher experienced reluctance from several hospice organizations in allowing their employees to participate in the study. As discussion of intimacy, as opposed to discussion of sexuality, is more commonly accepted in the field of loss and grief and death and dying, the researcher purposefully titled the survey sexuality and intimacy with terminally ill patients and their family caregivers. Still, there was significant reluctance from clinical directors in allowing the researcher access to participants. Another limitation is the definition and use of the term sexuality in the survey as the term sexuality can have different meanings for different respondents.

Another limitation was that the study was limited to palliative care practitioners in Central Florida as those participants all served in similar practice settings with limited diversity in staff.

Other limitations included the professions of the respondents who participated in the survey. Most of the survey respondents were either nurses or social workers. The researcher received one response from a chaplain and two respondents were categorized as other professions. Due to the limited number of these respondents, useful data was unable to be analyzed for the study. Also, the researcher did not receive responses from physicians or from the home health aides who spend a significant amount of time serving terminally ill patients and their families.

Chapter Twenty Four

Recommendations

Recommendations include increasing education about the role of sexuality in the dying process with palliative care professionals. Though a majority of nurses and more than one half of social workers reported that they regularly assess sexuality as part of their assessment of the terminally ill patient, just slightly more than one third of the social workers and none of the nurses in the study reported that they include a discussion of sexuality when discussing the dying process. One hundred percent of the respondents reported that they feel sexuality is a concern for terminally ill patients and one hundred percent of the nurses and social workers reported that they believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject. Despite these beliefs, only one third of the nurses and little more than one third of the social workers reported ever initiating a conversation about sexuality with a patient.

As very few respondents reported that training in sexuality was a part of their agency's orientation or training process, opportunities are available for sexologists to provide training and support in this area.

One of the purposes of hospice care is to ameliorate, physical, spiritual and emotional pain experienced by terminally ill patients, their families and their caregivers. The administrators and clinical directors at hospices, and other agencies that provide palliative care services for terminally ill patients, must begin to recognize the benefit of sexological training for their staff members in addressing the emotional, physical and spiritual needs of

terminally ill patients and their caregivers as sexual concerns often cause these patients and caregivers to experience the very physical, spiritual and emotional distress that they are, in fact, trying to reduce.

At a minimum, trainings in sexuality and the dying process can be provided to hospices on a regular basis in the form of in-service trainings or during the orientation process for new hospice employees. Information about sexology, death and dying could also be provided at local and national sexology, hospice, social work and nursing conferences. Education should also be included in curriculum at the university level on courses in gerontology, death and dying and human sexuality.

Training and presentations can also be made at the nursing homes and assisted living facilities where older terminally ill patients often reside. Societal bias toward the aged and sexuality could be seen in the responses of respondents who reported being less likely to initiate conversations about sexuality with older patients and caregivers. The clinical sexologist, most likely, will experience some resistance from administrators in providing trainings in sexuality to either patients or to the staff members who work with the terminally ill.

As a great majority of palliative care practitioners reported that even though they had never referred a terminally ill patient or caregiver to either a sex therapist or to a clinical sexologist, they would be willing to refer patients and caregivers to clinical sexologists and sex therapists if they knew of professionals in their area who specialized in working with terminally ill patients and their caregivers.

There is opportunity for both clinical sexologists and sex therapists to promote their services to palliative care practitioners and to serve this population and its unique needs.

These sexologists could be a valuable resource for those who practice thanatology, the study of death and dying, and help to provide research opportunities as well as clinical services. As thanatology is an interdisciplinary study, much like clinical sexology, and is often practiced by nurses, social workers, psychologists and psychiatrists, thanatological clinical sexology could be promoted as a unique and specialized branch of clinical sexology for the terminally ill in the same way that pediatric clinical sexology examines the unique needs of children.

As there is very little empirical research conducted on death, dying and sexuality, a strong recommendation would be to promote the importance of sexuality in this process. A recommendation would be to recreate this survey on sexuality and intimacy with terminally ill patients and their family caregivers on a larger scale to include seeking participants from across the nation as well as from other disciplines and practice settings.

Appendix A

Composite of Survey

Dear Palliative Care Professional,

I am currently in the Doctoral Program at the American Academy of Clinical Sexologists at Maimonides University where I am completing a Ph.D. in Clinical Sexology. I am conducting a study with individuals who are currently or who have, in the past, worked with terminally ill patients, their families and their caregivers and who are at least eighteen years of age.

As a professional who has experience in working with terminally ill patients, families and caregivers, I am asking you to participate in a study looking at attitudes regarding sexuality and intimacy. The survey includes questions about your experience in assisting patients, families and caregivers as well as information about your educational background, your position, your religion, your length of time working in the field, your age and your gender. This study will take about fifteen minutes to complete.

Your participation in this study is completely voluntary. There are no anticipated risks for participating in this study. In addition, you as a participant are not expected to answer every question and should feel free to answer only the questions that you feel comfortable answering and to discontinue the survey at any time. There is no penalty for refusing to answer any question. Please do not put your name on this survey because it is anonymous.

Any information obtained from this study and in subsequent reports will be discussed only in terms of trends and will not identify any of the respondents. These surveys are anonymous and will not be shared with any other individuals.

As the researcher, I will disseminate the surveys. Please return this unsigned survey in the attached stamped self addressed envelope provided. I will personally code the surveys after they have been submitted. These surveys will not be shared with other staff members of your organization.

There are no personal benefits to the participants; however, I hope that the results of this study will be helpful in the fields of clinical sexology and palliative care. If you have any questions about this study, please feel free to contact Michael Ian Rothenberg, LCSW at 407-823-1089.

Thank you for any information that you can provide. Your input is valuable.

Signed,

Michael Ian Rothenberg, LCSW

Sexuality and Intimacy with Terminally Ill Patients and Their Family Caregivers

Please place an X next to the answer that you believe best answers the questions below.

1. Do you believe that it is appropriate to discuss sexuality with terminally ill patients?

Very appropriate
Somewhat appropriate
Neither appropriate or inappropriate
Somewhat inappropriate
Very inappropriate

2. Do you feel qualified to discuss sexuality with terminally ill patients?

Very qualified
Somewhat qualified
Neither qualified or unqualified
Somewhat unqualified
Very Unqualified

3. Do you believe that it is appropriate to discuss sexuality with family caregivers of terminally ill patients?

Very appropriate
Somewhat appropriate
Neither appropriate or inappropriate
Somewhat inappropriate
Very inappropriate

4. Do you feel qualified to discuss sexuality with the family caregivers of terminally ill patients?

Very qualified
Somewhat qualified
Neither qualified or unqualified
Somewhat unqualified
Very Unqualified

5. Do you feel sexuality is a concern for terminally ill patients?

Some
Most
All
None

6. Do you feel it is appropriate to discuss sexuality with spousal/partner caregivers of terminally ill patients?

   Very appropriate
   Somewhat appropriate
   Neither appropriate or inappropriate
   Somewhat inappropriate
   Very inappropriate

7. Do you feel it is appropriate to discuss sexuality with the adult child caregivers of terminally ill patients?

   Very appropriate
   Somewhat appropriate
   Neither appropriate or inappropriate
   Somewhat inappropriate
   Very inappropriate

8. Do you feel comfortable in discussing sexuality with your terminally ill patients?

   Very comfortable
   Somewhat comfortable
   Neither comfortable or uncomfortable
   Somewhat uncomfortable
   Very uncomfortable

9. Do you feel comfortable in discussing sexuality with the family caregivers of terminally ill patients?

   Very comfortable
   Somewhat comfortable
   Neither comfortable or uncomfortable
   Somewhat uncomfortable
   Uncomfortable
   Very uncomfortable

10. Do you believe that there are terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

    Some
    Most
    All
    None

11. Do you believe that there are family caregivers of terminally ill patients who would like to discuss sexuality but are afraid to bring up the subject?

    Some
    Most
    All
    None

12. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject?

    Yes
    No

13. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the terminally ill patient?

    Yes
    No

14. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the terminally ill patient?

    Yes
    No

15. Has there been a time in which a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

    Yes
    No

16. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject?

    Yes
    No

17. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were uncomfortable discussing sexual issues with the caregiver of the terminally ill patient?

Yes
No

18. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were not sure how to help the caregiver of the terminally ill patient?

Yes
No

19. Has there been a time in which a family caregiver of a terminally ill patient broached the topic of sexuality and you changed the subject because you were embarrassed by the question?

Yes
No

20. Was training in human sexuality part of your formal education or professional training?

Yes
No

21. Was training in human sexuality part of your agency's orientation process?

Yes
No

22. Has a terminally ill patient ever requested your advice regarding sexual desire?

Yes
No

23. Has a terminally ill patient ever requested your advice regarding sexual arousal?

Yes
No

24. Has a terminally ill patient ever requested your advice regarding sexual performance?

Yes
No

25. Has a terminally ill patient ever requested advice regarding sexual positions?

Yes
No

26. Has a terminally ill patient ever expressed concern regarding unmet sexual needs?

Yes
No

27. Has a terminally ill patient ever expressed guilty feelings for having sexual desire?

Yes
No

28. Has a terminally ill patient ever discussed lack of intimacy?

Yes
No

29. Please indicate with an X the topics you would be comfortable discussing with a terminally ill patient. (X one box for each).

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non-sexual touch					
Kissing					
Sexual touch					
Masturbation					
Oral Sex					
Intercourse					

30. Please indicate with an X your opinions regarding how the following statements apply to terminally ill patients. (X one box for each.)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life					
Sexual activity is a duty for partners					
Sexual activity is a private matter only to be discussed between partners					
Interest in sexual activity fades as one grows older					
Sexual activity is for the young					
Older people are not concerned with sexual activity					

31. Has a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

Yes
No

32. Has a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

Yes
No

33. Has a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

Yes
No

34. Has a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

Yes
No

35. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity?

Yes
No

36. Has a terminally ill patient ever expressed fear that they could pass their terminal illness to their spouse/partner through sexual activity even when it was medically not possible?

Yes
No

37. Have you ever initiated a conversation about sexuality with a patient?

Yes
No

38. Are you more likely to discuss sexuality with a male terminally ill patient?

Yes
No

39. Are you more likely to discuss sexuality with a male caregiver of a terminally ill patient?

Yes
No

40. Are you more likely to discuss sexuality with a female terminally ill patient?

    Yes
    No

41. Are you more likely to discuss sexuality with a female caregiver of a terminally ill patient?

    Yes
    No

42. Have you ever initiated a conversation about sexuality with a patient who was under the age of 20?

    Yes
    No

43. Have you ever initiated a conversation about sexuality with a patient who was between the ages 20 to 40?

    Yes
    No

44. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 40 to 60?

    Yes
    No

45. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 60 to 80?

    Yes
    No

46. Have you ever initiated a conversation about sexuality with a patient who was between the ages of 80 to 100?

    Yes
    No

47. Have you ever initiated a conversation about sexuality with a family caregiver?

    Yes
    No

48. Have you ever initiated a conversation about sexuality with a family caregiver who was under the age of 20?

    Yes
    No

49. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages 20 to 40?

    Yes
    No

50. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 40 to 60?

    Yes
    No

51. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 60 to 80?

    Yes
    No

52. Have you ever initiated a conversation about sexuality with a family caregiver who was between the ages of 80 to 100?

    Yes
    No

53. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual desire?

    Yes
    No

54. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual arousal?

    Yes
    No

55. Has the family caregiver of a terminally ill patient ever requested your advice regarding sexual performance?

Yes
No

56. Has the family caregiver of a terminally ill patient ever requested advice regarding sexual positions?

Yes
No

57. Has the family caregiver of a terminally ill patient ever expressed concern regarding unmet sexual needs?

Yes
No

58. Has the caregiver of a terminally ill patient ever expressed guilty feelings for having sexual desire?

Yes
No

59. Has the family caregiver of a terminally ill patient ever discussed lack of intimacy?

Yes
No

60. Please indicate with an X the topics you would be comfortable discussing with the family caregiver of a terminally ill patient. (X one box for each).

	VERY COMFORTABLE	SOMEWHAT COMFORTABLE	NEITHER COMFORTABLE OR UNCOMFORTABLE	SOMEWHAT UNCOMFORTABLE	VERY UNCOMFORTABLE
Non sexual touch					
Kissing					
Sexual touch					
Masturbation					
Oral sex					
Intercourse					

61. Please indicate with an X your opinions regarding how the following statements apply to the family caregivers of terminally ill patients. (X one box for each.)

	STRONGLY AGREE	SOMEWHAT AGREE	NEITHER AGREE OR DISAGREE	SOMEWHAT DISAGREE	STRONGLY DISAGREE
Sexual activity is important in assessing quality of life					
Sexual activity is a duty for partners					
Sexual activity is a private matter only to be discussed between partners					
Interest in sexual activity fades as one grows older					
Sexual activity is for the young					
Older people are not concerned with sexual activity					

62. Has the family caregiver of a terminally ill patient ever expressed fear of not getting into heaven because of concerns regarding their sexuality?

    Yes
    No

63. Has the family caregiver of a terminally ill patient ever expressed fear of going to hell because of concerns regarding their sexuality?

    Yes
    No

64. Has the family caregiver of a terminally ill patient ever expressed feelings of guilt due to prior sexual activity?

    Yes
    No

65. Has the family caregiver of a terminally ill patient ever expressed that their terminal illness was a punishment from God due to prior sexual activity?

    Yes
    No

66. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity?

    Yes
    No

67. Has the spousal/partner caregiver of a terminally ill patient ever expressed fear that they could catch the patient's illness through sexual activity even when it was medically not possible?

    Yes
    No

68. Has a family caregiver of a terminally ill patient ever expressed a decline in sexual feelings specifically attributed to their role as a caregiver?

    Yes
    No

69. Have you ever initiated a conversation with a family caregiver regarding the possibility of a decline in sexual feelings specifically attributed to their role as a caregiver?

    Yes
    No

70. Do you include a discussion of sexuality when discussing the dying process/expectations with a terminally ill patient?

    Sometimes
    Most of the time
    Always
    Never

71. Do you include a discussion of sexuality when discussing the dying process/expectations with the family caregiver of the terminally ill patient?

    Sometimes
    Most of the time
    Always
    Never

72. Do you include a discussion of sexuality when discussing anticipatory grief with the family caregiver of the terminally ill patient?

    Sometimes
    Most of the time
    Always
    Never

73. Do you assess sexuality/intimacy as part of your initial assessment of the terminally ill patient?

    Sometimes
    Most of the time
    Always
    Never

74. Do you assess sexuality/intimacy as part of your regular assessment of the terminally ill patient?

    Sometimes
    Most of the time
    Always
    Never

75. Do you have a psychosexual assessment tool to use when working with terminally ill patients?

Yes
No
Not applicable

76. Would you use a psychosexual assessment tool that was specifically designed for terminally ill patients?

Yes
No
Not applicable

77. Have you ever referred a terminally ill patient to a clinical sexologist?

Yes
No

78. Have you ever referred a terminally ill patient to a sex therapist?

Yes
No

79. Have you ever referred the family caregiver of a terminally ill patient to a clinical sexologist?

Yes
No

80. Have you ever referred the family caregiver of a terminally ill patient to a sex therapist?

Yes
No

81. If you knew of a clinical sexologist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Yes
No

82. If you knew of a sex therapist in your area specializing in working with terminally ill patients and their family caregivers re: their sexual needs/concerns would you refer for services?

Yes
No

83. Do you believe that it is important to increase professional knowledge regarding the role of sexuality in death and dying?

Very important
Important
Somewhat important
Somewhat unimportant
Unimportant
Very unimportant

84. Are you a:

Nurse?
□ Social Worker?
□ Home health aide?
□ Chaplain?
□ Physician?
□ Other?_____

85. How long have you worked with terminally ill patients, families and caregivers?

□ Less than 1 year
□ 1-5 years
□ 5-10 years
□ 10-15 years
□ 20+ years

86. Your age:

□ 18-29
□ 30-39
□ 40-49
□ 50-59
□ 60-69
□ 70+

87. Your sex:

- □ Male
- □ Female

88. Your highest level of education completed:

- □ High school
- □ Associate degree
- □ Bachelor degree
- □ Masters Degree
- □ PhD/Doctorate

89. Your race:

- □ Caucasian
- □ African American
- □ Hispanic
- □ Asian
- □ Native American
- □ Pacific Islander
- □ Other_____

90. What is your religion?

- □ Baptist
- □ Non- Denominational Christian
- Catholic
- □ Methodist
- □ Presbyterian
- □ Lutheran
- □ Jewish
- □ Mormon
- □ Hindu
- □ Orthodox Christian
- □ Muslim
- □ Buddhist
- □ None
- □ Atheist
- □ Other_____

91. Do you consider yourself religious?

- □ Very religious
- □ Religious
- □ Somewhat religious
- □ Not religious

92. Did you have religious training as a child?

- □ Yes
- □ No

93. How often do you attend a religious service?

- □ More than once per week
- □ Once per week
- □ Almost once per week
- □ Two-three times per month
- □ Once per month
- □ Several times per year
- □ Once or twice per year
- □ Less than once per year
- □ Never

Please return completed surveys ASAP in the stamped self addressed envelope provided.
Thank you.

Appendix B

Demographic Results- Sex

84. Are you a:

Male (n=6)

Nurse?	
□ Social Worker?	66.7%
□ Home health aide?	
□ Chaplain?	16.7%
□ Physician?	
□Other?	16.7% (Social Worker/Chaplain dual practitioner)

Female (n=17)

Nurse?	35.3%
□ Social Worker?	52.9%
□ Home health aide?	
□ Chaplain?	
□ Physician?	
□ Other?	11.8% (Pharmacist/Hospice Volunteer)

Researcher's Conclusions

35.3% of females were nurses. 66.7% of males and 52.9% of females were social workers. 16.7% of the males were chaplains. 16.7% of males and 11.8% of females were categorized as other professions.

85. How long have you worked with terminally ill patients, families and caregivers?

Male (n=6)

□ Less than 1 year	
□ 1-5 years	66.7%
□ 5-10 years	16.7%
□ 10-15 years	16.7%
□ 20+ years	

Female (n=17)

□ Less than 1 year	11.8%
□ 1-5 years	29.4%
□ 5-10 years	17.6%
□ 10-15 years	23.5%
□ 20+ years	17.6%

Researcher's Conclusions

11.8% of females have worked with terminally ill patients, families and caregivers for less than one year. 66.7% of males and 29.4% of females have worked 1-5 years. 16.7% of males and 17.6% of females have worked 1-10 years. 16.7% of males 23.5% of females have worked 10-15 years. 17.6% of females have worked 20 or more years.

86. Your age:

Male (n=6)

□ 18-29	16.6%
□ 30-39	16.6%
□ 40-49	16.6%
□ 50-59	33.3%
□ 60-69	16.6%
□ 70+	

Female (n=17)

□ 18-29	5.9%
□ 30-39	5.9%
□ 40-49	29.4%
□ 50-59	41.2%
□ 60-69	11.8%
□ 70+	

Researcher's Conclusions

16.6% of males and 5.9% of females were between 18-29 years old. 16.6% of males and 5.9% of females were between 30-39 years old. 16.6% of males and 29.4% of females were between 40-49 years old. 33.3% of males 41.2% of females were between 50-59 years old. 16.6% of males and 11.8% of females were between 60-69 years old.

87. Your sex:

Male (n=6)

□ Male	100%
□ Female	

Female (n=17)

□ Male	
□ Female	100%

Researcher's Conclusions

100% of males and females reported.

88. Your highest level of education completed:

Male (n=6)

□ High School	
□ Associate Degree	
□ Bachelor Degree	
□ Masters Degree	83.3%
□ PhD/Doctorate	16.7%

Female (n=17)

□ High School	
□ Associate Degree	17.6%
□ Bachelor Degree	35.3%
□ Masters Degree	47.1%
□ PhD/Doctorate	

Researcher's Conclusions

17.6% of females have an Associate Degree. 35.3% of females have a Bachelor Degree.

83.3% of males 47.1% of females have a Masters Degree. 16.7% of males have a Ph.D.

89. Your race:

Male (n=6)

□ Caucasian	83.3%
□ African American	
□ Hispanic	
□ Asian	
□ Native American	16.7%
□ Pacific Islander	
□ Other	

Female (n=17)

□ Caucasian	88.2%
□ African American	11.8%
□ Hispanic	
□ Asian	
□ Native American	
□ Pacific Islander	
□ Other	

Researcher's Conclusions

83.3% of males and 88.2% of females are Caucasian. 11.8% of females are African American.

16.7% of males are Native American.

90. What is your religion?

Male (n=6)

□ Baptist	
□ Non- Denominational Christian	50.0%
Catholic	
□ Methodist	
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	
□ Atheist	
□ Other	50.0% (Humanist)

Female (n=17)

□ Baptist	11.8%
□ Non- Denominational Christian	11.8%
Catholic	23.5%
□ Methodist	5.9%
□ Presbyterian	11.8%
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	23.5%
□ Atheist	
□ Other	11.8% (Spiritual)

Researcher's Conclusions

11.8% of females were Baptist. 50.0% of males and 11.8% of females were Non-Denominational Christian. 23.5% of females were Catholic. 5.9% of females were Methodist. 11.8% of females were Presbyterian. 23.5% of females reported no religion. 50.0% of males and 11.8% of females reported religions categorized as other.

91. Do you consider yourself religious?

Male (n=6)

□ Very Religious	16.7%
□ Religious	16.7%
□ Somewhat Religious	
□ Not Religious	66.7%

Female (n=17)

□ Very Religious	17.6%
□ Religious	17.6%
□ Somewhat Religious	17.6%
□ Not Religious	47.1%

Researcher's Conclusions

33.4% of males and 52.8% of females report being religious. 66.7% of males and 47.1% of females report being not religious.

92. Did you have religious training as a child?

Male (n=6)

□ Yes	100%
□ No	

Female (n=17)

□ Yes	82.4%
□ No	17.6%

Researcher's Conclusions

100% of males 82.4% of females report having religious training as a child. 17.6% of females report having no religious training as a child.

93. How often do you attend a religious service?

Male (n=6)

□ More than once per week	50.0%
□ Once per week	
□ Almost once per week	
□ Two-three times per month	
□ Once per month	
□ Several times per year	
□ Once or twice per year	
□ Less than once per year	16.7%
□ Never	33.3%

Female (n=17)

□ More than once per week	5.9%
□ Once per week	5.9%
□ Almost once per week	
□ Two-three times per month	11.8%
□ Once per month	
□ Several times per year	35.3%
□ Once or twice per year	
□ Less than once per year	11.8%
□ Never	29.4%

Researcher's Conclusions

66.7% of males 70.7% of females report attending religious services. 33.3% of males and 29.4% of females report never attending religious services.

Appendix C

Demographic Results- Religiosity

84. Are you a:

Religious (n=11)

Nurse?	27.3%
Social Worker?	36.4%
Home health aide?	
Chaplain?	9.1%
Physician?	
Other?	27.3%

Not Religious (n=12)

Nurse?	25.0%
Social Worker?	75.0%
Home health aide?	
Chaplain?	
Physician?	
Other?	

Researcher's Conclusions

27.3% of religious respondents were nurses. 36.4% of religious respondents and 75.0% of not religious respondents were social workers. 9.1% of religious respondents were chaplains. 27.3% of religious respondents were reported to be other professions.

85. How long have you worked with terminally ill patients, families and caregivers?

Religious (n=11)

□ Less than 1 year	
□ 1-5 years	36.4%
□ 5-10 years	18.2%
□ 10-15 years	18.2%
□ 20+ years	27.3%

Not Religious (n=12)

□ Less than 1 year	16.7%
□ 1-5 years	41.7%
□ 5-10 years	16.7%
□ 10-15 years	25.0%
□ 20+ years	

Researcher's Conclusions

16.7% of the not religious respondents reported less than 1 year. 36.4 % of the religious respondents and 41.7% of the not religious respondents reported 1-5 years. 18.2% of the religious respondents and 16.7% of the not religious respondents reported 5-10 years. 18.2% of the religious respondents and 25.0% of the not religious respondents reported 10-15 years. 27.3 % of the religious respondents reported 20 years or more.

86. Your age:

Religious (n=11)

□ 18-29	
□ 30-39	9.1%
□ 40-49	36.4%
□ 50-59	36.4%
□ 60-69	18.2%
□ 70+	

Not Religious (n=12)

□ 18-29	16.7%
□ 30-39	8.3%
□ 40-49	25.0%
□ 50-59	41.7%
□ 60-69	8.3%
□ 70+	

Researcher's Conclusions

16.7 % of the not religious respondents reported ages 18-29. 9.1% of the religious respondents and 8.3% of the not religious respondents reported ages 30-39. 36.4% of the religious respondents and 25.0% of the not religious respondents reported ages 40-49. 36.4% of the religious respondents and 41.7% of the not religious respondents reported ages 50-59. 18.2% of the religious respondents and 8.3% of the not religious respondents reported ages 60-69.

87. Your sex:

Religious (n=11)

□ Male	18.2%
□ Female	81.8%

Not Religious (n=12)

□ Male	33.3%
□ Female	66.7%

Researcher's Conclusions

18.2 % of the religious respondents and 33.3% of the not religious respondents reported their sex as male. 81.8% of the religious respondents and 66.7% of the not religious respondents reported their sex as female.

88. Your highest level of education completed:

Religious (n=11)

□ High school	
□ Associate degree	18.2%
□ Bachelor degree	27.3%
□ Masters Degree	45.5%
□ PhD/Doctorate	9.1%

Not Religious (n=12)

□ High school	
□ Associate degree	8.3%
□ Bachelor degree	25.0%
□ Masters Degree	66.7%
□ PhD/Doctorate	

Researcher's Conclusions

18.2 % of the religious respondents and 8.3% of the not religious respondents reported associate degree. 27.3% of the religious respondents and 25.0% of the not religious respondents reported bachelor degree. 45.5% of the religious respondents and 66.7% of the not religious respondents reported masters degree.9.1% of the religious respondents reported Ph.D.

89. Your race:

Religious (n=11)

□ Caucasian	100%
□ African American	
□ Hispanic	
□ Asian	
□ Native American	
□ Pacific Islander	
□ Other	

Not Religious (n=12)

□ Caucasian	75.0%
□ African American	16.7%
□ Hispanic	
□ Asian	
□ Native American	8.3%
□ Pacific Islander	
□ Other	

Researcher's Conclusions

100% of the religious respondents and 75.0% of the not religious respondents reported Caucasian. 16.7% of the not religious respondents reported African American. 8.3 % of the not religious respondents reported Native American.

90. What is your religion?

Religious (n=11)

□ Baptist	9.1%
□ Non- Denominational Christian	18.2%
Catholic	45.5%
□ Methodist	18.2%
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	
□ Atheist	
□ Other	9.1%

Not Religious (n=12)

□ Baptist	8.3%
□ Non- Denominational Christian	16.7%
Catholic	8.3%
□ Methodist	
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	33.3%
□ Atheist	
□ Other	33.3% (Humanist, Spiritual)

Researcher's Conclusions

9.1% of the religious respondents and 8.3% of the not religious respondents reported Baptist. 18.2% of the religious respondents and 16.7% of the not religious respondents reported Non-Denominational Christian. 45.5% of the religious respondents and 8.3% of the not religious respondents reported Catholic. 18.2 % of the religious respondents reported Methodist. 33.3% of the religious respondents reported None. 9.1% of the religious respondents and 33.3% of the not religious respondents reported religion as other.

91. Do you consider yourself religious?

Religious (n=11)

□ Very religious	36.4%
□ Religious	36.4%
□ Somewhat religious	27.3%
□ Not religious	

Not Religious (n=12)

□ Very religious	
□ Religious	
□ Somewhat religious	
□ Not religious	100%

Researcher's Conclusions

36.4% of the religious respondents reported being very religious 36.4% of the religious respondents reported being religious and 27.3% of the religious respondents reported being somewhat religious.

92. Did you have religious training as a child?

Religious (n=11)

□ Yes	100%
□ No	

Not Religious (n=12)

□ Yes	75.0%
□ No	25.0%

Researcher's Conclusions

100% of the religious respondents and 75.0% of the not religious respondents reported having religious training as a child. 25.0% of the not religious respondents reported no training.

93. How often do you attend a religious service?

Religious (n=11)

□ More than once per week	27.3%
□ Once per week	9.1%
□ Almost once per week	
□ Two-three times per month	18.2%
□ Once per month	
□ Several times per year	27.3%
□ Once or twice per year	
□ Less than once per year	18.2%
□ Never	

Not Religious (n=12)

□ More than once per week	8.3%
□ Once per week	
□ Almost once per week	
□ Two-three times per month	
□ Once per month	
□ Several times per year	25.0%

 Once or twice per year
 Less than once per year 16.7%
 Never 50.0%

Researcher's Conclusions

100% of the religious respondents and 50.0% of the not religious respondents reported attending religious services. 50.0% of the not religious respondents reported never attending religious services.

Appendix D

Demographic Results-Profession

84. Are you a:

Nurse (n=6)

Nurse?	100%
□ Social Worker?	
□ Home health aide?	
□ Chaplain?	
□ Physician?	
□ Other?	

Social Worker (n=13)

Nurse?	
□ Social Worker?	100%
□ Home health aide?	
□ Chaplain?	
□ Physician?	
□ Other?	

Chaplain (n=1, caution small base)

Nurse?	
□ Social Worker?	
□ Home health aide?	
□ Chaplain?	100%
□ Physician?	
□ Other?	

Other (n=3, caution small base)

Nurse?	
□ Social Worker?	
□ Home health aide?	
□ Chaplain?	
□ Physician?	
□ Other?	100%

Researcher's Conclusions

100% of nurses and 100% of social workers reported their professions.

85. How long have you worked with terminally ill patients, families and caregivers?

Nurse (n=6)

□ Less than 1 year	
□ 1-5 years	
□ 5-10 years	16.7%
□ 10-15 years	50.0%
□ 20+ years	33.3%

Social Worker (n=13)

□ Less than 1 year	15.4%
□ 1-5 years	61.5%
□ 5-10 years	7.7%
□ 10-15 years	7.7%
□ 20+ years	7.7%

Chaplain (n=1, caution small base)

□ Less than 1 year	
□ 1-5 years	100%
□ 5-10 years	
□ 10-15 years	
□ 20+ years	

Other (n=3, caution small base)

□ Less than 1 year	
□ 1-5 years	
□ 5-10 years	
□ 10-15 years	66.7%
□ 20+ years	33.3%

Researcher's Conclusions

15.4% of social workers reported less than 1 year. 61.5% of social workers reported 1-5 years. 16.7% of nurses and 7.7% of social workers reported 5-10 years. 50.0% of nurses and 7.7% of social workers reported 10-15 years. 33.3% of nurses and 7.7% of social workers reported 20 or more years. No conclusions regarding chaplains and other professions due to small base.

86. Your age:

Nurse (n=6)

□ 18-29	
□ 30-39	
□ 40-49	66.7%
□ 50-59	33.3%
□ 60-69	
□ 70+	

Social Worker (n=13)

□ 18-29	15.4%
□ 30-39	15.4%
□ 40-49	15.4%
□ 50-59	53.8%
□ 60-69	
□ 70+	

Chaplain (n=1, caution small base)

□ 18-29	
□ 30-39	
□ 40-49	
□ 50-59	
□ 60-69	100%
□ 70+	

Other (n=3, caution small base)

□ 18-29	
□ 30-39	33.3%
□ 40-49	33.3%
□ 50-59	33.3%
□ 60-69	
□ 70+	

Researcher's Conclusions

15.4% of social workers reported 18-29 years. 15.4% of social workers reported 30-39 years. 66.7% of nurses and 15.4% of social workers reported 40-49 years. 33.3% of nurses and 53.8 of social workers reported 50-59 years. No conclusions regarding chaplains and other professions due to small base.

87. Your sex:

Nurse (n=6)

□ Male	
□ Female	100%

Social Worker (n=13)

□ Male	30.7%
□ Female	69.3%

Chaplain (n=1, caution small base)

□ Male	100%
□ Female	

Other (n=3, caution small base)

□ Male	33.3%
□ Female	66.7%

Researcher's Conclusions

100% of nurses reported as female. 30.7% of the social workers reported as male and 69.3% of the social workers reported as female.

88. Your highest level of education completed:

Nurse (n=6)

□ High school	
□ Associate degree	50.0%
□ Bachelor degree	50.0%
□ Masters Degree	
□ PhD/Doctorate	

Social Worker (n=13)

□ High school	
□ Associate degree	
□ Bachelor degree	7.7%
□ Masters Degree	92.3%
□ PhD/Doctorate	

Chaplain (n=1, caution small base)

□ High school	
□ Associate degree	
□ Bachelor degree	
□ Masters Degree	
□ PhD/Doctorate	100%

Other (n=3, caution small base)

□ High school	
□ Associate degree	
□ Bachelor degree	66.7%
□ Masters Degree	33.3%
□ PhD/Doctorate	

Researcher's Conclusions

50.0% of the nurses reported having an associate degree. 50.0% of the nurses and 7.7% of the social workers reported having a bachelor degree. 92.3% of the social workers reported having a masters degree.

89. Your race:

Nurse (n=6)

- □ Caucasian 100%
- □ African American
- □ Hispanic
- □ Asian
- □ Native American
- □ Pacific Islander
- □ Other

Social Worker (n=13)

- □ Caucasian 76.9%
- □ African American 15.4%
- □ Hispanic
- □ Asian
- □ Native American 7.7%
- □ Pacific Islander
- □ Other

Chaplain (n=1, caution small base)

- □ Caucasian 100%
- □ African American
- □ Hispanic
- □ Asian
- □ Native American
- □ Pacific Islander
- □ Other

Other (n=3, caution small base)

- □ Caucasian 100%
- □ African American
- □ Hispanic
- □ Asian
- □ Native American
- □ Pacific Islander
- □ Other

Researcher's Conclusions

100% of the nurses and 76.9 % of the social workers reported their race as Caucasian. 15.4% of the social workers reported their race as African American and 7.7% reported their race as Native American.

90. What is your religion?

Nurse (n=6)

- □ Baptist
- □ Non- Denominational Christian 16.7%
- Catholic 33.3%
- □ Methodist 16.7%
- □ Presbyterian
- □ Lutheran
- □ Jewish
- □ Mormon
- □ Hindu
- □ Orthodox Christian
- □ Muslim
- □ Buddhist
- □ None 16.7%
- □ Atheist
- □ Other

Social Worker (n=13)

□ Baptist	15.4%
□ Non- Denominational Christian	23.1%
Catholic	7.7%
□ Methodist	7.7%
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	23.1%
□ Atheist	
□ Other	23.1% (Humanist, Spiritual)

Chaplain (n=1, caution small base)

□ Baptist	
□ Non- Denominational Christian	100%
Catholic	
□ Methodist	
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	
□ Atheist	
□ Other	

Other (n=3, caution small base)

□ Baptist	
□ Non- Denominational Christian	33.3%
Catholic	33.3%
□ Methodist	
□ Presbyterian	
□ Lutheran	
□ Jewish	
□ Mormon	
□ Hindu	
□ Orthodox Christian	
□ Muslim	
□ Buddhist	
□ None	
□ Atheist	
□ Other	33.3%

Researcher's Conclusions

15.4% of nurses report their religion as Baptist. 16.7% of the nurses and 23.1% of the social workers report their religion as Non-Denominational Christian. 33.3% of nurses and 7.7% of social workers report as Catholic. 16.7% of nurses and 7.7% of social workers report as Methodist. 16.7% of nurses and 23.1% of social workers report their religion as none. 23.1% of social workers report their religion as other.

91. Do you consider yourself religious?

Nurse (n=6)

□ Very religious	33.3%
□ Religious	16.7%
□ Somewhat religious	
□ Not religious	50.0%

Social Worker (n=13)

□ Very religious	7.7%
□ Religious	7.7%
□ Somewhat religious	15.4%
□ Not religious	69.3%

Chaplain (n=1, caution small base)

□ Very religious	100%
□ Religious	
□ Somewhat religious	
□ Not religious	

Other (n=3, caution small base)

□ Very religious	
□ Religious	66.7%
□ Somewhat religious	33.3%
□ Not religious	

Researcher's Conclusions

50.0% of nurses and 30.8% of social workers report as being religious. 50.0% of nurses and 69.3% of social workers report as being not religious.

92. Did you have religious training as a child?

Nurse (n=6)

□ Yes	100%
□ No	

Social Worker (n=13)

□ Yes	84.6%
□ No	15.4%

Chaplain (n=1, caution small base)

□ Yes	100%
□ No	

Other (n=3, caution small base)

- □ Yes 100%
- □ No

Researcher's Conclusions

100% of the nurses and 84.6% of the social workers report as having had religious training as a child. 15.4% of the social workers did not report having religious training as a child.

93. How often do you attend a religious service?

Nurse (n=6)

- □ More than once per week 16.7%
- □ Once per week 16.7%
- □ Almost once per week
- □ Two-three times per month
- □ Once per month
- □ Several times per year 33.3%
- □ Once or twice per year
- □ Less than once per year 33.3%
- □ Never

Social Worker (n=13)

- □ More than once per week 7.7%
- □ Once per week
- □ Almost once per week
- □ Two-three times per month 7.7%
- □ Once per month
- □ Several times per year 30.7%
- □ Once or twice per year
- □ Less than once per year 23.1%
- □ Never 30.7%

Chaplain (n=1, caution small base)

□ More than once per week	100%
□ Once per week	
□ Almost once per week	
□ Two-three times per month	
□ Once per month	
□ Several times per year	
□ Once or twice per year	
□ Less than once per year	
□ Never	

Other (n=3, caution small base)

□ More than once per week	33.3%
□ Once per week	
□ Almost once per week	
□ Two-three times per month	33.3%
□ Once per month	
□ Several times per year	
□ Once or twice per year	
□ Less than once per year	33.3%
□ Never	

Researcher's Conclusions

100% of the nurses and 69.2% of the social workers report attending religious services.

30.7% of the social workers report never attending religious services.

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