

# Courageous Conversations

## *Exploring Matters of Life and Death in Geriatric Rehabilitation*

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Death, dying, loss, and grief are aspects of the human condition, constituting important topics not routinely discussed within personal and professional relationships. This article focuses on the importance of awareness and preparation for these often challenging conversations. In addition, an overview of the knowledge, values, and skills needed to effectively discuss topics of dying, grief, and loss with clients and families is provided. **Key words:** conversation, geriatric rehabilitation professional, thanatology, therapeutic relationship, personal development

This article is a call to develop the courage to dialogue with clients, families, colleagues, and friends about death, grief, and loss. Interestingly, while the label “courage” is typically reserved for heroic public figures who perform magnificent feats in conditions of extreme adversity, the paradox is that any act which challenges societal norms requires this virtue. This is certainly true with the topic of death, as the prevailing cultural bias often denies the wisdom and beauty of aging; including the dying process. This author’s experience suggests that many people often think about death and dying and want to share their thoughts, however they need permission to do so. In the course of our daily interactions, we will often find opportunities to talk about the natural and universal reality of death, dying, loss, and grief. When we provide a safe and nonjudgmental atmosphere for our clients to express themselves openly, we quite often discover how deeply life and death are entwined.

This article is based in theory but the focus of this article will be the practical application of specific communication strategies that will enable health professionals to talk about death and dying in the geriatric rehabilitation setting. This article will begin with a brief review of theory in order to provide a level of evidence-based context. Next, it will be followed by a discussion of the forms of conversations that might emerge in the realm of death, dying, and loss. Finally, practical ideas for generating these conversations will be presented. It is hoped that you will discover that quality conversations are essential to promote an authentic values

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clarification process for our clients regarding the matters of life and death, living and dying.

### THEORETICAL CONTEXT

In 2030, 20% of Americans will be age 65 or above.<sup>1</sup> As geriatric professionals, we encounter loss, grief, dying, and death through the very nature of our clientele. For many persons, dying in America today can be filled with unrelieved physical pain, psychospiritual suffering, loneliness, and loss of dignity.<sup>2</sup> The health care establishment, and even society itself, does not manage the dying experience very positively.<sup>3</sup> In a culture that honors beauty and youth, the fear of dying can be a pervasive feature that renders these topics unspeakable. Discussion of death is still a taboo in our society. As a result, for many people death has been privatized, desacralized, and hidden behind institutional walls.<sup>4</sup>

Life and death issues have recently moved from the private to the public spheres of society to include representations within the courts, media, and the arts. The media’s coverage of current wars and the recent attempts at health care reform have stirred strong emotions. Popular songs, television series, and current books have attempted to bring death and dying issues directly to the consciousness of our society. Nevertheless, many Americans likely share the perception of Woody Allen as reflected in his often used quote, “It’s not that I’m afraid to die, I just don’t want to be there when it happens.”<sup>5</sup>

Given this pervasive avoidance, contemporary society could benefit from a vision of death that is not dissociated from life, but one that embraces the significance and dignity of each individual.<sup>6</sup> In facing their mortality, clients’ values may change that may enhance their life experiences.

Kinnier et al<sup>7(p171)</sup> referred to many authors (eg, Feifel, Frankl, Groff and Grof, Klinger, Lifton, Noble, Tillich, Vandenberg, and Yalom) that describe in the literature of existential psychology “The idea of confrontation with death can serve to shake individuals into reassessing their priorities and may provide them with sagacious insights about life...”. As individuals and as a collective society, our shared cultural perceptions and attitudes toward death, dying, loss, and grief profoundly influence the search for meaning in our lives and living.

Thanatology is the study of death and dying, especially the psychological and societal aspects. Geriatric

rehabilitation professionals can benefit from the development of a personal thanatology, a personal exploration of experiences and attitudes toward death and dying. Consequently, rehab professionals are then prepared to support the efforts of clients and their families as they develop *their* personal thanatologies.

Thanatology is a multidisciplinary field of academic exploration, including the contributions of philosophy, sociology, medicine, nursing, psychology, anthropology, law, education, theology, and spirituality.<sup>8</sup> Within these disciplines, many individual theories have contributed to a greater understanding of the importance of exploring death, dying, grief, and loss. For example, respected thanatologists Charles Corr and Kenneth Doka have described lifespan development and family systems theories as approaches that are useful approaches in the exploration of death and dying. Furthermore, these theorists also noted that the long traditions of philosophical and religious inquiry into the relationship between life and death can also be helpful in facilitating a level of comfort and awareness.<sup>9</sup> Life span development theory, symbolic interactionism theory, empowerment theory with a strengths perspective, and the meaning reconstruction model of grief, all contribute to the theory of this article. Multiperspectives, theories and an interdisciplinary approach are needed to bring deeper understanding to thanatology. It is beyond the scope of this article to delve deep into the theoretical complexity of thanatology.

There are 3 major areas that are important to the preparation of health care professionals when addressing end-of-life issues with their clients: These areas include: (i) interpersonal skills, (ii) ethical and professional principles, and (iii) organizational skills. Thanatologist, Carol Worgin states, "In addition to maintaining an up to date knowledge base, good communication skills are fundamental to the role and responsibility of the professional caregiver. These skills include the ability to use active listening and empathic understanding of an individual's internal and social world." (p. 374)<sup>10</sup>

Geriatric rehabilitation professionals have much to contribute to the field of thanatology. These contributions must start with in a strong sense of individual comfort and acceptance of mortality. An exploration of one's own personal thanatology is thus an imperative aspect of clinical mastery for the skilled geriatric rehabilitation therapist. Professionals working with death and grief must have "an awareness of the influence of culture on their own beliefs, values, and biases as well as maintaining an awareness of cultural beliefs and values in the people to whom they are providing care."<sup>10</sup> The therapist must have a base of knowledge and personal emotional health to be available to listen and dialogue with clients regarding the client's grief, loss, and possible declining health status.

## A PRACTICAL APPROACH TO THE DEVELOPMENT OF A PERSONAL THANATOLOGY

In the course of my clinical practice and teaching, I have designed an approach for developing a personal thanatology. Personal thanatology, is an informal education practice that is summarized in 3 dynamic and circular phases: reflect, share, live. This process consists of (i) reflection and exploration of ones personal experiences, thoughts, memories, beliefs, stories and questions about death and dying; (ii) sharing and retelling these reflections, ideas, and stories with family, friends, and acquaintances; (iii) the development and application of a life philosophy based on a system of personal values and meaning.<sup>11</sup> This author whole-heartedly agrees with thanatologist Robert Kastenbaum who stated that "although the term thanatology is usually defined as the 'study of death', it is perhaps better defined as 'the study of life with death left in'". Reference 12.<sup>12(p77)</sup>

In the following sections, conversations which facilitate the development of a personal thanatology will be described. These include "essential qualities" and "forms of conversations". Both can be used to inform the practice of creating a personal thanatology as well as enhancing and the professional therapist/client relationship.

## COURAGEOUS CONVERSATIONS

Courageous conversations about death, dying, grief, and loss require qualities and attributes that should be kept in mind both personally and professionally. Table 1 reviews the essential qualities of courageous conversations for the geriatric rehabilitation professional.<sup>11</sup>

Every conversation has the potential for fostering new insights about what is important in the individual's definition of quality of life, meaning of life, and, what is essential for them to "die well." Conversations are influenced by the emotion and immediacy of the "who, why, when and where" of the interaction. The individuals and the circumstances of the conversation results in editing and reediting of the words and meanings assigned to the conversation. Ultimately, most conversations can be classified as casual, formal, exploratory or decision based. Each conversation can contribute to the overall understanding of what is important to the provider and the client.

## CONTEXTS OF CONVERSATIONS

Conversations with Self: Conversations begin first from within. Self-reflection on death, dying, grief, and loss is essential for having a healthy personal base from which to support others in your personal and professional life. Each individual has layers of loss. The death of a loved one is an obvious very difficult and often life altering loss. Also difficult are the losses in the course of life such as divorce, job loss, or death of a pet. We need to be aware that the losses

**TABLE 1. Essential Qualities of Courageous Conversations**

Quality	Description
Nonjudgment	Tolerance for the opinions and variety of ideas that will be presented
Compassion	Kindness and sensitivity not only for other's attitudes, but also for ourselves as we explore the complexity of discussing life and death
Honesty	Genuine expression of beliefs: not falling into clichés and societal norms when discussing aging, dying and death
Active listening	Attentive listening for new understandings and deeper meanings that may be expressed
Flexibility	Not being rigid or defensive while dialoguing. Allow the possibility that definitions of words such as health, healing and hope, may change and grow as life evolves
Tolerance for ambiguity and paradox	Sometimes more questions than answers surface during conversations about death. Recognize that life is strong and fragile; simple and complex; joyful and sorrowful
Humor	Laughter is a very useful when talking about the human condition!
Respect	Each individual has the right to his or her own decisions. Be prepared to not state your opinion or agree to disagree respectfully. Never force difficult conversations, respect should always be honored when an individual states they do not want to talk about these topics at the current time.

that our friends and family experience, also affect us personally. Furthermore, reports of loss in the media, as well as and losses within our community and society at large affect our personal layers of loss and grief experiences. A courageous exploration occurs when we face our personal mortality and discover our basic assumptions and beliefs of the very nature of life and death. This process is not necessarily just a philosophical or mental exercise, but can be explored physically, emotionally, and spiritually as well.

**Conversations with Family:** Discussions of death, dying, grief, and loss are difficult for many families regardless of the ease of the relationship. Difficulties may arise for many reasons. Memories and perceptions regarding the same experience may differ between family members. Starting a conversation about death and dying may also appear to be motivated by ulterior motives such as financial concerns. Past experiences that were tragic or which occurred under

extreme conditions may be painful and very emotional to “revisit.” Familial roles regarding influence or control over decision making have their historical impact as well. Conversely, some of the difficulty arises from the anticipation of the loss, literally called “anticipatory grief.” Anticipatory grief arises out of the love shared and pending possibility of what seems to be unbearable sadness.

**Conversations with Friends:** Conversations with friends can be a valuable place to start when discussing death and dying. Friendship often contains an honesty and comfort that allows for the exploration and discovery of many ideas that arise when exploring death. Additionally, there may be an acceptable level of ease that allows for the uncertainty, ambiguity, and questions that surface during the conversations. Friendship often allows for tolerance in exploring what it means to “live well” and ultimately “die well.”

**Conversations with Clients:** The professional, therapist/client relationship has the potential for fostering a rich, deeper understanding of how to best support the client and establish treatment goals. Not only does loss impact the client’s compliance and motivation, but also impacts deeper issues of what brings the client meaning and value in quality of life and living. Geriatric rehabilitation professionals, by preparing personally and professionally for end-of-life conversations, contribute wisdom to the knowledge, values, and skills which are essential for the therapeutic relationship.

**Conversations with Colleagues:** Recognize that peers, colleagues, ancillary staff, and professional contacts all have death and dying issues and layers of loss. Opportunities for compassion and grief support are present daily whether in the break room, parking lot, or at staff meetings.

**Conversations with Acquaintances:** A recent study reported by the New York Times and published in journal of *Psychological Science* suggests that individuals who have deeper “substantive conversations” may be happier in their life overall. This research suggests that since we are “meaning making humans” we strive for connections with one another.<sup>13</sup> As you sit in your favorite coffee shop, stand in the grocery line, or exercise at the gym, take the initiative to talk to strangers and acquaintances about deeper issues than just the weather. Sometimes, interactions with “consequential strangers” generate conversations that have profound affects.<sup>14</sup>

The practical application of all of these types of conversations in both personal and professional life begins in awareness. Actively looking for opportunities and creating environments to foster conversations move the call for courageous conversations from theory to practice.

## PRACTICAL SUGGESTIONS FOR CREATING OPPORTUNITIES FOR COURAGEOUS CONVERSATIONS

A personal, ongoing practice of self-care is essential in maintaining a healthy mind, body, and spirit which better

enables us navigate loss, death, and dying in our personal and professional lives. Courageous conversations within ourselves as well as the deep conversations with others are part of this self-care. This exploration within ourselves has the potential for deep sadness, but this conversation can generate life-enhancing growth as well. If you become deeply disturbed by actively engaging in reflection and/or conversations about death, dying, loss, and grief reach out to health care professionals that specialized in grief counseling.

### **PRACTICAL SUGGESTIONS FOR DEVELOPING A COURAGEOUS CONVERSATION WITH SELF**

*Reflect on the layers of loss in your personal life.* This is an ongoing, dynamic process. Start with a list of losses in your life, not only those through death, but also those losses through life challenges and disappointments. As you gain comfort with this process, consider exploring deeper levels, exploring both the positive and negative impact that resulted from these experiences. This reflection process may result in a new way of viewing the losses of your life. This is a time when a new narrative can be written, not because the story changed, but because you have changed. The very process of reflection is an individualized activity and foundational to clinical mastery. Reflection can be a very deliberate process of attending directly to the question during a walk, a meditation, or journaling session or more of an informal practice of creating the ongoing awareness throughout the day, of the grief and loss affecting your life.

Reflect on personal experiences of death and dying. Think about your “death stories”, such as experiences of being with a dying individual or pet along with your experiences of funerals and memorial services. What beliefs and attitudes are inherited from your parents and family? What beliefs of death and dying have impacted you from the media or our culture at large? What beliefs do you hold about the possibility of an afterlife? What is your understanding and experience of dying, pain management, hospice care? What would be important to you during your dying process?

Read books and articles that are thought provoking and may provide insight into loss, grief, death, and dying. Possible choices include:

- A Year to Live: How to Live This Year as If It Were Your Last by Stephen Levine.
- Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn, MD and Joan Harrold, MD.
- Waking: A Memoir of Trauma and Transcendence by Matthew Sanford
- Understanding Your Grief: Ten Essential Touchstones for Finding Hope and
- Healing Your Heart by Alan D. Wolfelt

- Engaging in personal growth and volunteer opportunities

Active involvement in groups and organizations related to end-of-life care can provide powerful opportunities to expand one’s awareness and comfort with the challenges of the death and dying process. Consider attending education seminars at your community hospice or consider hospice volunteer training if it is of special interest to your personal development. Hospice volunteers can serve in numerous capacities according to their comfort level. Not all of these involve direct contact with dying persons and may include assistance with fundraising, providing office support and participating in community education. In addition to hospice organizations, there are others that welcome the assistance of volunteers. One such example is the “Make a Wish” foundation, the premier wish-granting organization for children with life-limiting conditions. Many churches, synagogues, and other faith-based organizations welcome assistance with programming that explores related topics. Local cancer support groups and wellness communities may also be appropriate avenues for education related to death and dying.

If you are drawn deeper into end-of-life care, seek further higher degrees and certifications in areas such as palliative care and hospice geriatric rehabilitation. The National Hospice and Palliative Care Organization is the national professional organization for persons involved in end-of-life care. Membership is open to all interested health care professionals.

### **PRACTICAL SUGGESTIONS FOR CREATING COURAGEOUS CONVERSATIONS WITH FAMILY**

Remembering the essential qualities of courageous conversations described previously, take the time to ask and actively listen to your family members as they share their experiences, ideas, and beliefs regarding both life and death. These conversations can be further enhanced by starting and ending every conversation with affirmations of love and care. When these dialogues are framed in such a manner, the content of the conversation may not be remembered, but the love and support *will* be.

Examples of helpful questions might include:

- What would you like me to understand about you?
- Are you afraid to die?
- Do you believe death is a door from which to pass through or do you believe that death is a wall, from which there is nothing beyond?
- What is your philosophy of life? What do you value and brings meaning to your life?

Direct questions encourage courageous conversations, however so do everyday occurrences. Discussing movies and books that involve themes of loss, grief, dying, and

death can promote a rich level of dialogue between family members.

### **PRACTICAL SUGGESTIONS FOR CREATING COURAGEOUS CONVERSATIONS WITH FRIENDS**

As stated previously, discussing issues of death and dying with friends may be more comfortable for some individuals. Any of the questions listed previously may be appropriate, in addition to the following:

- Are you comfortable in uncertainty, unknowing and ambiguity?
- A common cliché is “to die for”, what would you really die for?
- What is on your “Bucket List”?
- How do you wish to be remembered?

### **PRACTICAL SUGGESTIONS FOR FOSTERING COURAGEOUS CONVERSATIONS WITH ACQUAINTANCES**

As you meet new people, be aware of opportunities to talk about more substantial topics. Look for opportunities to converse on a deeper level with people that you interact with repeatedly during the course of your natural week’s activities. Natural disasters are a topic that usually connect us and can be openly discussed comfortably. Often, talking about death, dying, and loss motivates people to acknowledge gratitude for life and living. In all relationships, having a personal awareness and sensitivity to loss can help us summon the courage needed to reach out to initiate meaningful conversations with strangers.

### **PRACTICAL SUGGESTIONS FOR BEING PREPARED FOR COURAGEOUS CONVERSATIONS WITH CLIENTS**

The therapeutic relationship with the client is rich with opportunities for courageous conversations. The client medical history often provides important references to the death of key family members. As you conduct your initial examination, be mindful of both verbal and nonverbal references to “loss.” Specifically, what has the client lost in terms of their physical abilities, function, and independence?

When appropriate, clients may begin to share more openly about other personal losses. Examples include loss of income, loss of enjoyment, death of a pet, loss of friendship, loss of routine, or loss of a future “imagined.”

The impact of these can be further discerned through the use of active listening skills which involve asking clarifying questions and reflections of content such as “what I heard you say.”

Although the training of a health professional involves the use of active interventions to support healing, we may often find that our compassionate presence is one

of our most valuable forms of help. Thus, another critical communication skill is the practice of silent, affirming presence when clients appear to be reflective or emotional.

Knowledge of the client’s spiritual belief system can help us provide compassionate care within their system of meaning. However, it is important to avoid assumptions about their attitudes based on their religion, gender, culture, or age. Possible questions might include:

- When do feel most alive?
- What do you think is ultimately most important in life?
- What is your favorite memory?
- Has your definition of hope, health, or healing changed over time?
- How would you describe the spiritual dimension in your life?
- What would you consider your philosophy of life?

Questions such as these may create a strong sense of comfort between the client and therapist. Often after a relationship of trust and caring is established, clients may share conversations with you (a relative stranger) that they have not shared or discussed with family or friends. This is key reason for the development and preparation of your personal comfort and the practice of healthy reflection about personal loss. As physical therapists, a primary psychosocial intervention is one of the nonjudging presence. Should active psychotherapeutic interventions be indicated, we should be prepared to refer clients to health care professionals that specialize in individual grief counseling or grief support groups within their community.

### **PRACTICAL SUGGESTIONS FOR BEING COMFORTABLE WITH COURAGEOUS CONVERSATIONS WITH PEERS**

Most of our interactions with peers occur in the clinical practice setting. When appropriate, an environment that supports open conversations about death, dying, grief, and loss can be fostered within your organization. Along these lines, you may wish to organize or suggest an in-service on a related topic, perhaps including active learning activities such as role-playing or conversational dyads. This author facilitated such a presentation at a recent APTA sponsored event that created enthusiastic feedback.<sup>15</sup>

If your clinical practice setting has a newsletter, this publication can provide another opportunity for opening the conversation with both peers and clientele. Appropriate additions can be made to the clinic library which bring knowledge and insight into grief, loss, death, and dying directly into the work environment. An excellent resource is: *Handbook of Thanatology: The essential body of knowledge for the study of death, dying and bereavement.*<sup>10</sup>

One-to-one conversations can often serve as small acts of kindness in the practice setting. A caring note of support or sympathy card to a co-worker is one such example.

Larger acts of support include offering to substitute for peers who need additional bereavement leave (beyond the customary three to five days) following after the death of a loved one.

Practical suggestions for fostering courageous conversations in your community.

Outreach presentations, workshops, and seminars can be offered to community support groups and institutions such as nursing homes, religious centers, community and service organizations within your community. Writing articles for your local newspaper or magazine can also bring an awareness of the importance of death, dying, grief, and loss issues.

## PRACTICAL SUGGESTIONS FOR FOSTERING COURAGEOUS CONVERSATIONS WITHIN YOUR PROFESSION

The completion of a advanced degree, specialist certification or the acquisition of other credentials in geriatrics, oncology, or end-of-life care can prepare to bring your knowledge values and skills to professional colleagues at a state and national level. Opportunities often exist to present information on death and dying in physical therapy education programs. This author has provided remote video instruction to a third year, DPT class on the importance of personal and professional preparation for end-of-life issues. As part of this instruction, students were encouraged to share their experiences, ideas, thoughts, and questions about death and dying and its impacts on their lives.<sup>16</sup> Researching and writing articles for peer reviewed journals about your experiences in end-of-life care is another valuable approach in the furthering understanding of end-of-life care. Finally, becoming politically involved in your professional organization can help you develop policies and regulations that support patients facing their end-of-life care.

## CONCLUSION

Best-selling author, M. Scott Peck wrote:

“I hope you will abandon the urge to simplify everything, to look for formulas and easy answers, and to begin to think multidimensionally, to glory in the mystery and paradoxes of life, not to be dismayed by the multitude of causes and consequences that are inherent in each experience—to appreciate the fact that life is complex.”<sup>17(p14)</sup>

There are many opportunities for courageous conversations about death and dying, loss and grief within the geriatric rehabilitation profession. Open, nonjudgmental, compassionate conversations will allow for the strength and beauty of the human spirit to shine.<sup>18</sup> Within all of the

complexities of life, the connections and relationships we have with one another reveal the simple truth that we have the potential to dramatically affect the quality of the day and the quality of life for yourself and of each individual we serve.

“To affect the quality of the day, that is the highest of arts.”<sup>19</sup> Henry David Thoreau

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