Dying, Death, AND Grief IN AN Online Universe
Carla J. Sofka, PhD, MSW is an Associate Professor of Social Work at Siena College in Loudonville, NY. She received her PhD degree in 1992 and her Master's in Social Work in 1987 from Washington University in St. Louis. In addition to teaching practice, research, and introductory courses in the Social Work Program at Siena, she offers an elective entitled “Death: The Final Taboo.” She has also taught online courses (Palliative Care; Popular Culture and Death) for the Thanatology Program at King’s University College at the University of Western Ontario. Her research interests and publications have focused on thanatechnology in death education and grief counseling, “cultural reincarnation,” and museums as healing spaces. Working with her local public library, she and her daughter will be creating a blog for young adult readers and their parents that highlights thanatology issues in young adult literature. She has served as an associate editor for Death Studies since 1994 and served as president of the Association for Death Education and Counseling from 2011 to 2012.

Illene Noppe Cupit, PhD received her PhD in 1979 from the Educational Psychology Department of Temple University. Dr. Cupit came to University of Wisconsin Green Bay in January of 1984, where she currently teaches courses in Dying, Death, and Loss; Infancy & Early Childhood; Gender Development; and Developmental Research Methodology. Her research and publications have focused on college student bereavement, adolescent grief, gender issues in death and dying, and death in child care centers. She is an active member of the Association for Death Education and Counseling, where she was editor of The Forum, its quarterly publication, and is the president-elect for 2012–2013. At her university, she founded the Institute of Dying, Death, and Bereavement. In addition, she founded and directs Camp Lloyd, a week-long summer day camp for grieving children.

Kathleen R. Gilbert, PhD, CFLE, FT is a Professor of Family Studies in the Department of Applied Health Science; Executive Associate Dean in the School of Health, Physical Education and Recreation; and is affiliated faculty in the Workshop in Political Theory and Policy Analysis at Indiana University-Bloomington, where she has been on faculty since 1988. She received her PhD in family studies from Purdue University in 1987. Kathleen has taught a variety of graduate and undergraduate courses on the family and family process, including Grief in a Family Context, an online course offered at the graduate and undergraduate level. She has published and spoken on the topics of loss and bereavement within the family, the use of the Internet as a tool for coping with loss, and online modalities for teaching emotionally charged topics. Among her many publications is the edited volume, The Emotional Nature of Qualitative Research. She was president of the Association for Death Education and Counseling from 2010 to 2011.
Dying, Death, and Grief in an Online Universe

Carla J. Sofka, PhD, MSW
Illene Noppe Cupit, PhD
Kathleen R. Gilbert, PhD, CFLE, FT
Editors
To my husband Mike for his unending support and for sending links to thanatology-related items on Boing Boing; to my daughter Gwyn, who has enriched my life in more ways than I can count (and to both of them who tolerate the “thanatourist” in me on family vacations); and to my online students who have helped me to appreciate the joys and challenges of learning together in cyberspace. —Carla J. Sofka

To my children, Alex and Laura, who hold my hand across the “digital divide” and who have made my life meaningful in a myriad of ways. —Illene Noppe Cupit

To my husband Steve for his encouragement, support, and writing expertise that I drew on throughout the project, and to my colleagues and students with whom I’ve worked in the online universe. —Kathleen R. Gilbert
Contents

Contributors ix
Foreword Kenneth J. Doka, PhD xi
Preface xv
Acknowledgments xvii

PART I: THE COMMUNICATION TECHNOLOGY REVOLUTION AND IMPLICATIONS FOR THANATOLOGY

1. Thanatechnology as a Conduit for Living, Dying, and Grieving in Contemporary Society 3
   Carla J. Sofka, Illene Noppe Cupit, and Kathleen R. Gilbert

2. From Digital Divide to Digital Immortality: Thanatechnology at the Turn of the 21st Century 16
   Kathleen R. Gilbert and Michael Massimi

PART II: BUILDING ONLINE COMMUNITIES OF SUPPORT

3. The Role of Social Networking Sites in Memorialization of College Students 31
   Kimberly Hieftje

4. The Net Generation: The Special Case of Youth 47
   Carla J. Sofka

   Carla J. Sofka

6. Being There: Technology at the End of Life 78
   Jane Moore

7. GriefNet: Creating and Maintaining an Internet Bereavement Community 87
   Cendra Lynn and Antje Rath
8. Attachment at Distance: Grief Therapy in the Virtual World 103
   Robert A. Neimeyer and Gail Noppe-Brandon

9. Bereavement in Online Communities: Sources of and Support for
   Disenfranchised Grief 119
   Lisa D. Hensley

10. Virtual Memorials and Cyber Funerals: Contemporary Expressions of
    Ageless Experiences 135
    Brian de Vries and Susan Moldaw

PART III: SHARING AND GATHERING KNOWLEDGE IN CYBERSPACE

11. Open to Hope: An Online Thanatology Resource Center 151
    Gloria Horsley and Heidi Horsley

12. Death Education 163
    Illene Noppe Cupit, Carla J. Sofka, and Kathleen R. Gilbert

13. Death Education in the Cyberclassroom: Creating a Safe Space for
    Student Learning 183
    Eunice Gorman

14. Research in Thanatechnology 198
    Illene Noppe Cupit

PART IV: THANATECHNOLOGY: RESPONSIBLY LOOKING FORWARD

15. Ethical Considerations When Conducting Grief Counseling
    Online 217
    Louis A. Gamino

16. Dying, Death, and Grief in a Technological World: Implications for
    Now and Speculations About the Future 235
    Illene Noppe Cupit, Carla J. Sofka, and Kathleen R. Gilbert

Appendix A: Informational Support Online: Evaluating Resources 247
   Carla J. Sofka

Appendix B: Resources to Assist With Ethical Issues in Online
   Service Provision 256
   Carla J. Sofka, Joyce Rasdall Dennison, and Louis A. Gamino
Contributors

Gail Noppe-Brandon, LMSW  Find Your Voice, New York, New York

Illene Noppe Cupit, PhD  Professor of Human Development, University of Wisconsin, Green Bay, Wisconsin

Joyce Rasdall Dennison, PhD  Clinical Psychologist, Certified Thanatologist, Pointe Claire, Quebec, Canada

Brian de Vries, PhD  Professor of Gerontology, San Francisco State University, San Francisco, California

Louis A. Gamino, PhD, ABPP, FT  Professor of Psychiatry and Behavioral Science, Texas A&M Health Science Center, College of Medicine, Temple, Texas

Eunice Gorman, RN, BSW, MSW, PhD, RSW  Assistant Professor, Department of Interdisciplinary Programs (Thanatology), King’s University College at the University of Western Ontario, London, Ontario, Canada

Kathleen R. Gilbert, PhD, CFLE, FT  Professor of Family Studies and Executive Associate Dean in the School of Health, Physical Education and Recreation, Indiana University, Bloomington, Indiana

Lisa D. Hensley, PhD  Associate Professor of Psychology, Texas Wesleyan University, Fort Worth, Texas

Kimberly Hieftje, PhD  Associate Research Scientist, Yale University School of Medicine, Milford, Connecticut

Gloria Horsley, MFC, CHS, PhD  President, Open to Hope Foundation, Palo Alto, California

Heidi Horsley, PsyD, MSW  Executive Director, Open to Hope Foundation and Adjunct Professor, Columbia University, New York, New York
Contributors

Cendra Lynn, PhD  Director of GriefNet, Ann Arbor, Michigan

Michael Massimi, MSc, BSc  Department of Computer Science, University of Toronto, Toronto, Ontario, Canada

Susan Moldaw  Gerontology Program, San Francisco State University, San Francisco, California

Jane Moore, EdD, FT  Associate Professor, National College of Education, National Louis University, Des Plaines, Illinois

Robert A. Neimeyer, PhD  Professor of Psychology, University of Memphis, Memphis, Tennessee

Antje Rath, MA, LPC  GriefNet, Moab, Utah

Carla J. Sofka, PhD  Associate Professor of Social Work, Siena College, Loudonville, New York
Foreword

Eons ago, Paleolithic men and women would create, using the best of their limited arts and crude tools, drawings on the walls of caves. These drawings told stories of their deceased relatives and friends—the hunts, their experiences, their lives—lest they be forgotten. Later, the pyramids, the richly adorned tombs, the carefully embalmed mummies, and the hieroglyphics would assure that pharaohs were not forgotten, that their memories live long after they died.

Historically, we have always used our foremost technology in the service of the dead. We have used whatever we had at our disposal to mourn, to support, to share memories, and to tell stories. Carla J. Sofka, Illene Noppe Cupit, and Kathleen R. Gilbert, in this new edited work, *Dying, Death, and Grief in an Online Universe*, reaffirm that principle reminding us that this new digital world offers dramatic technologies and creates considerable opportunities to deal with dying, death, and grief.

I have been deeply involved in one such example. For the past near 20 years, the Hospice Foundation of America (HFA) has sponsored an annual program originally by satellite, now via Internet. The origins of the program began when HFA’s founding president, Jack Gordon, attended a Hospice Conference. Gordon was deeply impressed with the Conference but was disappointed that fewer than 500 participants shared the benefits. He thought that an educational event organized by satellite television could attract 10 times that number. He was mistaken—nearly 100,000 people participated from all over North America and the Caribbean. Since that first conference, the HFA has now expanded its offerings to not only two national conferences but also web-based broadcasts—including an offering on the effects of technology.

Years ago, authors such as John Gunther or Norman Cousins might later share their experience of an illness, their own or another’s, in their writings. Now anyone with access to a computer can share daily blogs on the daily trials and travails experienced. In many ways such as this, the new technology has democratized the process, though the authors are very sensitive to the digital divides that still limit access.

The editors are extraordinarily sensitive to the multiple ways that this new technology has impacted upon the death system or the ways that a society
organizes behavior around dying and death. Chapters in this book consider a range of topics exploring the effects of the technological revolution.

This includes the ways we mourn. Social networking sites have become particularly important opportunities, especially for adolescents and young adults, to acknowledge grief. Blogs may document journeys with grief. Moreover, there are both private individuals and businesses creating web-based memorial sites. In fact, as the chapters here demonstrate, this gives new meaning to the idea of continuing bonds, as individuals even have opportunities to continue a relationship within the virtual world.

Moreover, it adds a new dimension to funeral rituals where video tributes and online guest books are now common. In addition, many families now stream funerals online, allowing a sense of presence to those who cannot be there in person.

It also affects who we mourn. The Internet offers opportunities to create communities in online relationships, chat rooms, social network sites, and even massively multiplayer online role-playing games. Should death or other forms of loss occur, grief would be a natural result. The Internet cuts both ways.

In addition, the new technologies have potentially therapeutic applications. Beyond the therapeutic value of online memorials, there are other sources of grief support. Information—some accurate, some dated—about grief is readily available online. Other chapters explore the proliferation of online support groups and possibilities for grief counseling online.

Although both can have great value especially in areas where access to qualified counselors or support groups is limited, they also illustrate cultural lag. Cultural lag refers to the fact that certain aspects of the culture such as technology can advance faster than the norms and laws that regulate the use of technology. Online counseling offers such examples. As noted in this book, online counseling creates a variety of ethical and legal issues. Can a counselor licensed in one state offer services to a client in another state? Should issues arise that mandate reporting, to which state should the counselor report?

Issues in counseling are bound to become even more complex as generational divides compound the digital revolution. My informed consent statement now includes issues of texting and other forms of multitasking during sessions, as well as my policies that prohibit befriending clients on Facebook. In both grief groups and with individual clients, I have more extended conversations about confidentiality to generations steeped in the openness and transparency of the web.

Interestingly, the term brave new world appears a number of times in the text. The term reminds us that we have entered a new age—there is no going back. Yet, brave new world offers a sense of foreboding of the dystopia Huxley once described.

Dying, Death, and Grief in an Online Universe explores all of these issues and others, such as the implications for death education and research offered by the new technologies. Dying, Death, and Grief in an Online Universe is bound
to be a classic—a fresh look at the ways that technology has already changed the relatively new field of thanatology. And will change it still. The technological revolution is not only irreversible but also fuels itself. The new technology quickens the very pace of change. Each new technological innovation yields others. *Dying, Death, and Grief in an Online Universe* offers an in-depth review that itself will be updated as technology continues to change.

Despite the challenges technology presents to thanatology, we can acknowledge not only its inevitability but also its beauty. Technology now offers opportunities to set up memorials for the person we mourn, free from the constraints of cost, of space, of any rules or regulations. It transcends the limits of space and time. It gives us immediate access. We can visit the site whenever we want or need to, alone or together. We can remember, share, and pass on the stories, even to generations we have not yet met. Although it is a new technology, it fulfills an ancient need.

Kenneth J. Doka, PhD
Professor, The College of New Rochelle
Senior Consultant, The Hospice Foundation of America
The dynamic field of thanatology encompasses rapidly changing societal practices and views about dying, death, and loss that are increasingly influenced by modern communication technology. This book, written primarily for death educators, clinicians, researchers, students of thanatology, and those interested in how technology interacts with thanatology-related issues, will provide cutting-edge information about thanatechnology, defined as communication technology used in the provision of death education, grief counseling, and thanatology research.

In addition to a broad overview of how the communication technology revolution is impacting individuals who are coping with end-of-life issues, death-related and non-death loss, and grief, implications of the “digital divide,” the unequal access to information and communication technologies and one’s capacity to make use of the Internet, will be explored. To assist those interested in the use of thanatechnology as a tool for service provision and death education, the book describes online opportunities for social support (online counseling and informal bereavement support as well as the use of social networking sites to cope with loss) and mechanisms for the memorialization and commemoration of loss (virtual funerals, memorials, and cemeteries). The unique issue of disenfranchised grief experienced by online community members will also be explored. The book highlights the use of blogging as a mechanism for storytelling and the use of Skype as a tool for communication during times of crisis and grief. Strategies for providing death education online are described, including lessons learned while teaching college-based online thanatology courses, as well as the use of Internet radio as a resource for providing education and support to the lay public. To assist anyone considering the use of thanatechnology in grief counseling, death education, or research, additional content addresses ethical issues related to the availability and use of this technology and how technology has shaped and changed the ways in which research in thanatology is being conducted. Implications for future consideration regarding the role of thanatechnology in death education, grief counseling, and research will also be presented. Appendices provide guidance regarding the availability of the following resources online: types of informational support, tools to evaluate the integrity of online resources, and ethical standards to guide the provision of online services.
Creating this resource about thanatechnology has been a labor of love that would not have been possible without the involvement of many talented and dedicated individuals and the investment of time, energy, and resources by those who have supported our work on this book.

Sheri W. Sussman, our Executive Editor from Springer Publishing, championed this book from her initial conversation with Dr. Sofka about the feasibility of a book on this topic to the completion of the project. We thank her for providing steadfast support, guidance, and patience through the process, including the unanticipated challenges that life placed in each of our paths. Thanks to Katie Corasaniti, our associate editor, for helping us to keep track of all the pieces of the puzzle.

It was a joy to work with our contributing authors. These talented death educators, clinicians, and thanatology researchers (many of whom hold more than one of these roles) have shared their gifts as death professionals and authors, contributing their knowledge and wisdom to this book. Special thanks to Pat Enborg, a freelance writer and Montreal journalist, for her contributions to the appendix on ethics resources and to Katie Berthold and Alexandra Melendez for sharing their technological prowess with Dr. Sofka and helping to identify examples of thanatology-related blogs. Gratitude to Dr. Kristin Vespia, Dr. Regan Gurung, and Dr. Melissa Schnurr for their valuable input on thanatechnological issues to Dr. Cupit.

We are each blessed to work for a college or university that has provided support for this project in many ways. Dr. Sofka would like to thank Siena College, Dean Ralph Blasting, and the Committee on Teaching and Faculty Development for support in the form of release time and financial support (a summer stipend and conference travel support). Dr. Cupit would like to thank her colleagues at the University of Wisconsin-Green Bay for fostering a creative and intellectually demanding environment that has enabled her to grow as a scholar. Thanks go out from Dr. Gilbert to Dr. Mohammad Torabi, who was the Chair of her department and, later, Dean of her school, who provided travel support that facilitated her work on this project.
We are also deeply indebted to our students over the years who have accompanied us on our shared journey of learning about thanatechnology and kept us on our computer-mediated toes. Students who have participated in our online courses or have helped us to appreciate the ways that technology can be used effectively in death education have truly been some of our greatest teachers.

And last but certainly not least, thanks to our families for their support and patience throughout this project. Dr. Sofka is grateful to her husband, Mike, for sending links to interesting examples of thanatechnology in cyberspace, and her daughter, Gwyn, for assistance with checking references and proofreading. Dr. Cupit wants to thank her children, Alex and Laura, for putting up with a thanatechnological mom. Dr. Gilbert would like to thank her husband, Steven, for the help he provided in chapter editing so we could come in as close to our page limit as we did!
Part I

The Communication Technology Revolution and Implications for Thanatology
In the mid to late 1990s, thanatologists were observing the technological revolution with mixed emotions. On the positive side, it was exciting that thanatology-oriented information was becoming highly visible in this new frontier called cyberspace. The popularity of the World Wide Web provided us with new hope that dying-, death-, and grief-related topics could become more widely accessible and perhaps much less “taboo.” Because it is always wise to balance optimism with caution, it was equally important for thanatologists to consider the potential challenges and risks that increased exposure to sensitive issues such as suicide and homicide could create. In an attempt to capture the synergy between the topic and the technology that was giving it new exposure, one thanatologist coined the term thanatechnology, defined at that time as “technological mechanisms such as interactive videodiscs and computer programs that are used to access information or aid in learning about thanatology topics” (Sofka, 1997, p. 553). In the past 15 years, technology has changed in ways that once were unimaginable. Therefore, the definition of thanatechnology is being broadened in this book to include all types of communication technology that can be used in the provision of death education, grief counseling, and thanatology research.

Technology has expanded the ways that we as a society think about dying, death, and grief. This chapter will explore how the social construction of these concepts and the way that we interact with those around us are currently changing as computer-mediated communication technology evolves. Brief summaries of the chapters in this book will be presented to preview various ways that thanatechnology is being used by death professionals and laypeople alike.
It is a universal truth that at some point in each person's life, he or she will experience the death of a significant other. Although dealing with illness, death, and grief is common to all individuals, the emotional, cognitive, and physical reactions that accompany these experiences are now known to be affected by individual differences, culture, and historical period, causing each person's experience to be unique.

In many respects, grief reflects a social construction of reality referring to the meanings of death, dying, and grief that evolve from people who share time, place, and culture (Berger & Luckmann, 1966). Although individuals may develop their own unique viewpoint with respect to what death means, sharing that meaning with others helps to validate that perspective and consolidate their concepts about death. For example, in some cultures, the spirit of the deceased continues to be socially active and be a member of the community even after corporeal death (Sweeting & Gillhooly, 1991–1992). Contemporary societies that primarily adhere to a medical model posit that social interaction between the deceased and the living community ends with physical death. However, are these views about death and grief changing as a result of the current technological revolution?

Consider the following examples: In the not too distant past, dying individuals quietly “passed away,” often hidden from view in a hospital bed. It is not uncommon, as illustrated by Sofka in Chapter 5, for terminally ill patients to describe their journey in intimate detail to family and friends—perhaps even millions of “strangers”—on a blog. As described in detail by Moore in Chapter 6, patients can interact with friends and family “in person” with the help of thanatechnology. Does an increased level of communication and “openness” about illness, dying, and death have an impact on the dying person and their dying? Does increased access to information lead to a greater understanding of the disease process? Do we seek different treatment options after we (and friends and family) “surf the net” for hopeful solutions? For the survivors, does it change how they cope with the death?

In the virtual world, if you have an online presence in life, you have the issue of your “digital legacy” to consider as you prepare for your eventual death. Hans-Peter Brondmo, the head of social software and services at Nokia in San Francisco, describes one’s accumulation of websites, blogs, and personal profiles on various social networking sites (SNSs) and other online records of our existence as one’s “digital soul” (Paul-Choudhury, 2011a).

After acknowledging that “We are the first people in history to create vast online records of our lives” (n.p.), Paul-Choudhury (2011a) poses a question worth considering: “How much of it will endure when we are gone?” (n.p.). An individual can preserve the way he or she was prior to illness using images, video, or voiceprint. This can be done with the assistance of a tech-savvy loved one (e.g., see http://kathrynoates.org/, a website created to preserve her memory by her
husband, Sumit Paul-Choudhury) or by purchasing the services of a company such as Deathswitch, Digital Legacy, or Virtual Eternity (see Walker, 2011, for detailed information about these companies).

In the new world of thanatechnology, individuals want their “online soul” preserved to create a “technology heirloom” or even to continue to communicate after death (posthumous messaging via e-mails; see http://www.letterfrombeyond.com/). A new cottage industry has evolved to help with the tasks of digital estate planning (e.g., http://www.digitalestateservices.com/), or you can “do it yourself.” To learn more, consider consulting Your Digital Afterlife by Carroll and Romano (2011), a book that answers the fundamental philosophical (and dare we say thanatechnological) question: “What happens to my digital stuff when I die?” (p. 2). In the contemporary digitized world, getting one’s affairs in order may need to include preparing a “digital will.”

On the other hand, Mayer-Schonberger (as cited in Walker, 2011) encourages us to consider the possibility that “our tools for recording what we see, experience, and think have become so easy to use, inexpensive and effective that it is easier to let information accumulate in our ‘digital external memories’ than it is to bother deleting it. Forgetting has become costly and difficult, while remembering is inexpensive and easy” (n.p.). Perhaps, as Walker (2011) notes, “a great deal of our digital expression is simple communication about the present, intentionally ephemeral” (n.p.). Should we bother to preserve it?

With the rising popularity of SNSs came the challenging problems faced by administrators of these sites when deciding upon a policy to handle the death of a member. Boddy (2004) aptly titled his article “Ghosts in the Machines” and described the reactions of family, friends, and even strangers to one deceased social media user’s continued online presence as ranging from comfort to unease. Depending upon the policies in place on a particular site and the decisions made by family and friends, the digital legacy of an individual could be removed quickly following an individual’s death or may remain indefinitely in cyberspace. Facebook calls this process “memorializing” a deceased user’s site, one which allows only confirmed friends to see the profile or locate it during a search.

In addition to that continuing online presence, thanatechnology makes it possible for your digital presence to be experienced in other places affiliated with dying, death, and grief. The Internet Patrol (2010) describes the “Serenity Panel,” a solar-powered video headstone that allows visitors to the cemetery to celebrate the life of the deceased. Japanese gravestones use two-dimensional bar codes (QR codes), which when scanned by a visitor’s cellphone allows the visitor to view photos, videos, and other information about the deceased (Novak, 2008). Family members are able to view a log of who visits with a special device that keeps a record each time the code is scanned. VirtualEternity.com, a company whose motto is “forever made possible,” helps a customer to convert the personal data that you provide into an avatar. Walker (2011) describes this “intellitar” as the company calls it “sort of like one of those chatbots that some online companies use for automated but more humanish customer service” (Walker, 2011, n.p.). It is designed to give users the gift of immortality.
Dying, Death, and Grief in an Online Universe

With the profiles of the deceased remaining indefinitely on SNSs and sophisticated digital programming that can cause the deceased to once again “come alive at particular places and times through video images or voiceprint,” is thanatechnology creating a type of digital immortality? The impact of these decisions and dilemmas regarding “digital ghosts” (Pescovitz, 2011) remain largely unstudied.

The availability of technology has inspired us to create ways to modulate the pain of loss through the use of computers and handheld devices. Mourning rituals now occur online, including virtual funerals and memorial services (see Chapter 10), Facebook tributes (see Chapter 3), and in online communities of bereavement (see Chapters 4, 5, 7, 10, and 11). Although thanatechnology has clearly changed how, when, and where we grieve, has it changed our grief?

The virtual world has truly opened up new issues and questions for the thanatologist. If the shared meanings of death, dying, and grief are culturally defined, would the globalization of technology ultimately create a uniform sense of the meaning of death and the ensuing grieving process? As de Vries and Moldaw argue (see Chapter 10), the World Wide Web has democratized the grief process, challenging who is entitled to grieve and how they should grieve. New online rituals may evolve within the global community, transcending distance, time, reality, diverse beliefs about death, and traditional expectations for the “proper” way to mourn.

THE DEATH SYSTEM AND THANATECHNOLOGY

One way to understand the above-mentioned issues is by reflecting on how societal structures affect and are affected by death. The social construction of death, dying, and grief is intimately tied to the death system or the “sociophysical network by which we mediate and express our relationship to mortality” (Kastenbaum, 1972, p. 310). Kastenbaum posited that all societies have a death system that organizes how its citizens think, behave, and structure their death experiences. Death systems vary across culture and historical period, but all have common elements (people, places, times, objects, and symbols) and functions (warning and predictions, prevention of death, care for the dying, disposal of the dead, social consolidation, making sense of the death, and socially approved killing; see Figure 1.1 for definition of the elements and functions of the death system).

With the advent of thanatechnology comes new ways of conceptualizing the elements and functions of the death system. Figure 1.2 presents examples of thanatechnology within the framework of the death system. In a nontechnological world, for example, grief was publically expressed within a proximal community. Death frequently came fast, but communications about the death were slow. Perhaps the ringing of a community bell or the beating of a drum signaled the death. For the most part, the mourner had a personal relationship with the deceased or his or her loved ones and may have directly participated in the care of the deceased when he or she was dying. Many traditional societies have specific roles for the mourner in the funeral process (see, for example,
Bliatout’s 1993 description of a Hmong funeral. In addition, the continuing bond with the deceased was based upon a static representation of that person, even if the survivor’s emotions and cognitions regarding the death changed over time.
Figure 1.2  A Thanatechnological Death System*

<table>
<thead>
<tr>
<th>Elements</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>People</td>
<td>People who are memorialized or use technology to express grief and seek social support. Virtual mourners at a virtual funeral in Second Life or in online gaming communities; participants in an online support group. Virtual grief counselor.</td>
</tr>
<tr>
<td>Places</td>
<td>Virtual locations of death, such as online chat rooms; virtual funeral chapel.</td>
</tr>
<tr>
<td>Times</td>
<td>Cyberspace is not time bound—communication is instant and may confers digital immortality. Standardized time across multiple time zones for a virtual ritual (Monday Pet Loss Candle Ceremony); “real time” versus “asynchronous” time for chats and meetings.</td>
</tr>
<tr>
<td>Objects</td>
<td>Technological platforms (websites, blogs). The paraphernalia associated with technology that can be used to communicate and cope with death, such as cell phones, computers, handheld devices. Virtual candles, virtual flowers left at virtual cemetery plots; memorial or tribute websites.</td>
</tr>
<tr>
<td>Symbols</td>
<td>Virtual reality is inherently symbolic as it involves the translation of tangible objects and people into computerized renditions. Emoticons; Txtease / Chatspeak.</td>
</tr>
<tr>
<td>Functions</td>
<td></td>
</tr>
<tr>
<td>Warnings and predictions</td>
<td>Security options on social network sites that memorialize the deceased; text messages and e-mails warning of potential disasters. Death Clock (predicts date/time of death) Informational support (physical indicators of impending death on hospice sites).</td>
</tr>
<tr>
<td>Prevention of death</td>
<td>Suicidal individuals reaching out to friends on Facebook; digital immortality so that in the virtual world one does not die; online medical advice</td>
</tr>
<tr>
<td>Care of the dying</td>
<td>Online support groups for the dying and their caregivers. Webinars for hospice workers; posts on sites such as “The Caring Bridge.”</td>
</tr>
<tr>
<td>Disposal of the dead</td>
<td>Virtual cemeteries; retail websites for funeral goods such as caskets and urns. Internet Memorial Societies.</td>
</tr>
<tr>
<td>Social consolidation</td>
<td>Online communication via SNSs such as Facebook and e-mail; virtual funerals, cyberfunerals—actual funerals broadcast by webcams for survivors who cannot come to the funeral (e.g., military personnel); virtual guest books.</td>
</tr>
<tr>
<td>Making sense of death</td>
<td>Sharing grief through SNSs (e.g., Facebook); finding coherence through Internet support groups; experiencing online therapy sessions through such venues as Skype; thanatologists conducting Internet-based research. Niche blogs or websites that discuss the meaning of life and death, the afterlife, or spirituality and death.</td>
</tr>
<tr>
<td>Socially approved killing</td>
<td>Online games that involve military actions or killing; advocacy sites for the right-to-die, pro-abortion/pro-choice, and the death penalty.</td>
</tr>
</tbody>
</table>

*Note. Elements based on Kastenbaum (1972). Thanatechnological examples generated by the authors.
Chapter 1  Thanatechnology as a Conduit for Living, Dying, and Grieving

(Klass, Silverman, & Nickman, 1996). With the advent of technology, this all has changed. “Waiting time” has become irrelevant because of instant computer-mediated communications. Distance can be erased by using thanatechnology and the World Wide Web. Visitors to online memorials and virtual cemeteries do not necessarily know the deceased or the survivors. They may participate in online discussions or leave flowers at a virtual memorial. Survivors may find such communications comforting and seek refuge in a cloak of anonymity. Those who formerly may not have received social support (e.g., grievers of companion animals) may find support in cyberspace from similarly minded others, who, like themselves, are no longer disenfranchised.

Although a great deal of information in this book supports the potential benefits of thanatechnology, there also may be negative consequences. Although it is important to recognize that people have a choice about what they do and do not read online or to what degree they choose to participate in various online activities, it may not always be possible to predict the outcome of these decisions in advance. Pell (2011) describes a powerful example of the joy and pain that results from the “connected life” (and the unpredictability thereof) found in a bereaved father’s blog:

“Someday I want to be able to sit and look at her pictures, even watch the videos, and remember how great it was when she was here. For now, accidentally seeing a thumbnail image in a directory on my computer or on my phone or on Flickr or on Facebook is enough to spawn an hours-long cycle of anxiety and depression.” (as stated by Daniel Miller, 2010, n.p., capturing his reactions to the links to his deceased daughter via technology).

Unfortunately, the Internet may also attract individuals who seek to inflict psychological harm on others. Two such cases are described in Chapter 4 (the case of Megan Meier, a teenager who committed suicide following incidents of cyberbullying that involved public humiliation) and Chapter 5 (the case of Kaysee, which involves the assumption of a false identity when blogging and the large-scale deception of readers).

In addition, having a virtual presence may complicate the grieving process by rendering the loss as ambiguous. According to Boss (2006), ambiguity occurs when there is no “validation or clarification” (p. 144) to the loss, and the form of ambiguous loss varies dependent upon whether psychological or physical presence is available or absent. In a technological world, might the dead remain both psychologically present and physically (i.e., virtually) present? One possibility arising from such a scenario is that the computer-mediated communications and interactions with a physically deceased but virtually alive loved one may present significant challenges to the formation of a coherent narrative of the loss.

Finally, new rules appear to be evolving that guide how to appropriately and sensitively manage SNSs when someone dies. New culturally appropriate guidelines for proper online behavior when providing social support during times of illness, loss, and grief or when participating in online bereavement rituals are needed. In an article in the Huffington Post describing a soon-to-be published book called the Rules of Netiquette (in press at the time of the writing of this chapter), Spira (2011) provides some examples of the “social media obituary”
that describe the pros and cons of using SNSs to convey information about illness or impending death, to notify others that a death has indeed occurred, or to inform about plans for a funeral or memorial service. One fascinating example described below illustrates how changes in one type of technology, photography, used within the death system at two points in history (19th century as compared with the early 21st century) can be perceived in a totally opposite manner.

In the 1800s, only the wealthy could afford to sit for a session with a photographer. Unlike today when photographs of infants are taken and posted online within hours of birth, it was not common for most families to have portraits of family members, particularly infants and children. The invention of daguerreotypes and carte de visites (types of photographs) made photography more affordable. During times of high infant and child mortality rates, a postmortem photograph taken after the death—may have been the only photograph a family had (Ruby, 1995; Wikipedia, 2011). Some families also had a photograph taken of a deceased adult in a coffin surrounded by memorial bouquets, laid out in his or her parlor (ironically now called the living room). Examples are posted online at Wikipedia (2011) and can easily be found on YouTube by doing a search on memento mori or post mortem photo.

Fast forward to modern times of digital photography, cell phones with cameras, and technology that allow us to post photos within seconds of them being snapped. Because postmortem photographs are not common in the 21st century (except perhaps in the case of stillbirth, Brotman, 2010; Saflund, Sjogren, & Wredling, 2004), Spira (2011) raises this question: “What is appropriate to post at the time of death?” She describes the following:

“When I saw a photo of a newly deceased man on his wife’s Facebook page, I thought it was disgraceful. It wasn’t a photo honoring his memory and life. It was a photograph taken while still in his bed, moments before the ambulance took his body to the mortuary. The visual was not appealing, nor appropriate” (n.p.).

In this case, visitors to a Facebook page are not likely to be expecting (or necessarily desiring) to see a postmortem photograph. Based on the person’s age, life circumstances, and loss history, being exposed to such a photograph without preparation may be traumatic. However, are there circumstances under which a photo like this might be requested? Consider someone who is unable to attend the viewing or funeral and has a coping style that benefits from visual confirmation of a death. A postmortem photograph may be a valuable solution; the question remains whether access to that photo should be provided in a very public space. Becoming “thanatosensitive” in how these technologies are used is crucial (Massimi & Charise, 2009).

This Internet-based etiquette of mourning—mourning netiquette if you will—has the potential to impact the online community across diverse ethnicities/cultures and religions, presenting a more homogenized social construction of death and grief than what we presently see. Depending upon one’s point of view, this can be either a positive or a negative consequence of thanatechnology.

Although the concept of the “death system” as originally described by Kastenbaum (1972) suggests that it is linked to a specific cultural group, a thana-
technological death system, as described in Figure 1.2, may truly be a global one cutting across a number of world views. The meaning making associated with death and grief may take on several new dimensions beyond the traditional individual, family, and cultural/national perspective. In addition to a global perspective, to this we might have to consider a virtual perspective as we modify our social construction of death, dying, and bereavement to encompass another dimension that involves digitized representations and virtual mourning practices that stretch the limits of our imagination.

This book will provide a mere glimpse into the use of thanatechnology by grief counselors, death educators, researchers, and laypeople from a variety of perspectives. Reflective of the field of thanatology, the authors represent a range of disciplinary affiliations: psychology, social work, human development and family relations, nursing, education, and human–computer interaction. Chapters are written in different styles, ranging from the traditional academic style to a more personal or narrative style. To fully understand the implications of thanatechnology, we believe that the issues must be explored through empirical, systematic study using qualitative and quantitative data (Cupit, Chapter 13) and through the “practice wisdom” of those who have been using thanatechnology and observing the impact. Therefore, as described below, research and practice are both represented among the chapters in this book.

SUMMARY OF THE CHAPTERS

Chapter 2 by Kathleen R. Gilbert and Michael Massimi addresses the evolution of the “digital divide” from a division between those who are online and those who are not to several interconnected divides that are associated with the capacity to use technology. Various existing, emergent, and potential future technologies with thanatological applications are discussed. SNSs such as Facebook and MySpace are serving in innovative ways as communities of support. Kimberly Hieftje explores the ways in which SNSs are being used as mechanisms for social support during times of crisis and grief (Chapter 3). Biographic narrative inquiry is used to describe ways in which college students have used SNSs to maintain an ongoing relationship (a continuing bond) with a deceased friend.

A wide range of communication technologies provide opportunities for adolescents and emerging adults to connect in ways that are not possible without the use of this technology. Carla J. Sofka explores the significant benefits and the risks associated with the use of thanatechnology among the net generation (Chapter 4).

Telling one’s story is often considered an integral part of coping with crisis and loss. Following a brief history of blogging, Carla J. Sofka (Chapter 5) describes the purposes that blogs serve for individuals dealing with dying, death, and grief.

Computer-mediated communication technology now provides mechanisms for individuals with life-threatening and terminal illness to communicate “in person” using webcams and Skype. A case study by Jane Moore tells one family’s
story and provides suggestions for incorporating this type of thanatechnology into the services provided by hospice (Chapter 6).

GriefNet.org has served as an Internet community of support for persons dealing with death, grief, and major loss for almost two decades. Cendra Lynn and Antje Raht describe the process of creating and maintaining online support groups for children and adults (Chapter 7). The goals, benefits, and potential drawbacks of these groups are discussed.

Traditional psychotherapeutic sessions involve face-to-contact between a clinician and client. With the advent of online videoconferencing (e.g., Skype) and e-mails, it is now possible to conduct grief therapy online. Robert A. Neimeyer and Gail Noppe-Brandon present a unique account of this “brave new world” as they describe their experiences as therapist (Neimeyer) and client (Noppe-Brandon) who reached across a thousand miles to conduct in-depth grief therapy. This is a personal and professional narrative that highlights the implications of grief therapy in cyberspace (Chapter 8).

As relationships within online communities develop more meaningful roles in the lives of those who participate in them, the potential to experience the loss of these relationships also grows. Following a brief discussion of the relevance of disenfranchised grief in online communities, Lisa D. Hensley presents findings from a survey of individuals who have experienced bereavement in online communities. Suggestions for assisting individuals who are grieving the loss of a relationship from an online community will be provided (Chapter 9).

In the 21st century, one can log on and attend a funeral in cyberspace. Website memorials and virtual cemeteries are some of the ways in which individuals are commemorating the loss of their loved ones. Brian de Vries and Susan Moldaw explore the emerging literature on memorialization on the World Wide Web and the communities that have formed around these memorials. Included is a discussion of the extent to which the funeral industry has used virtual memorialization as well as the consideration of the potential benefits and drawbacks of coping with real-world loss in a virtual environment (Chapter 10).

The availability of the Internet has revolutionized the way that people seek information, and individuals dealing with death, dying, and grief will find a plethora of resources for use in dealing with these life events and challenges. Open to Hope is an online resource center dedicated to helping people find hope again after loss. Gloria and Heidi Horsley describe the Open to Hope Foundation’s use of web-based resources and Internet radio as tools for providing education and support to the lay public (Chapter 11).

Chapters 12 and 13 address how death education may be effectively implemented online. In Chapter 12, Illene Noppe Cupit, Carla J. Sofka, and Kathleen R. Gilbert juxtapose what they have learned about death education with the evolving evidence-based strategies of online instruction. From reading this chapter, death educators considering entering thanatechnological pedagogy can benefit from the experiences of colleagues who have worked hard at best course design for students in cyberspace. One of the central concerns for death educators who teach online is creating a safe environment for students to discuss sensitive
death-related topics. Eunice Gorman (Chapter 13) describes strategies for building community and safety in the online classroom, including course “netiquette,” that is, rules for appropriate behavior in the virtual classroom. Also discussed are ways of building community in the class and facilitating interaction that is appropriately sensitive to the unique mix of students enrolled in each class.

Technology is also being used to conduct thanatology research. Illene Noppe Cupit explores the similarities and differences in conducting thanatological research via computer-mediated communications. To guide researchers in the translation of thanatological research into a technological environment, flowcharts representing decision-making processes for quantitative and qualitative research are presented. Also considered are strategies for collecting online data and aspects of research ethics that are unique to thanatechnological research (Chapter 14).

With new applications of technology come new responsibilities to anticipate and manage any consequences that may arise. The concluding chapters will identify the ethical implications of using communication technologies in the field of thanatology and will summarize the major themes that have emerged out of this examination of thanatechnology.

The provision of grief counseling services online involves a range of ethical issues and challenges. Louis A. Gamino summarizes the types of technology being used to provide Internet counseling, outlines the advantages and disadvantages of online service delivery, and describes the unique ethical challenges inherent in Internet counseling (Chapter 15).

The final chapter (Chapter 16) is intended to summarize and digest what we have learned in this book about our contemporary thanatechnological death system. Upon review of the diverse writings of our contributors, several overarching themes were discerned. We conclude by presenting the implications of thanatechnology for practitioners, researchers, and educators and speculate as to what the future holds for dying, death, and grief in an online universe.

Two appendices have also been included. Appendix A, prepared by Carla J. Sofka, presents a typology of thanatology-related websites. Because of the importance of critically evaluating the reliability and validity of information on these sites, resources to facilitate information literacy and the evaluation of thanatology-related websites are included.

Appendix B, prepared by Carla J. Sofka, Joyce Dennison, and Louis A. Gamino, provides material to support the content on ethical issues in online service provision discussed in Chapter 15. Professional organizations and associations are beginning to develop technology-related guidelines to facilitate ethical practice when providing online services. This appendix provides a summary of the content addressed in these ethical codes, steering a reader to the appropriate resources of six organizations and associations. Tools to evaluate website compliance with ethical guidelines and ethical online practice are included.

In 2006, Time Magazine announced an unusual choice for their “person of the year.” Although encouraging readers to reflect upon the year from an atypical point of view (considering someone other than a famous leader, entertainer, or business mogul), they stated:
... look at 2006 through a different lens and you’ll see another story, one that isn’t about conflict or great men. It’s a story about community and collaboration on a scale never seen before. It’s about the cosmic compendium of knowledge Wikipedia and the million-channel people’s network YouTube and the online metropolis MySpace. It’s about wresting power from the few and helping one another for nothing and how that will not only change the world, but also change the way the world changes (Grossman, 2006, n.p.).

We believe that thanatechnology is changing the way the world deals with dying, death, and grief, creating a thanatechnological death system that is, most likely, evolving as we write (and while you subsequently read) this book. We hope that the information in this book will contribute to the ability of death educators, grief counselors, and thanatology researchers to use the wealth of thanatechnology resources that are available to the fullest potential in an informed, responsible, and ethical manner.

We are excited that you are reading this book because that means that you may already be doing fascinating work with thanatechnology and can also contribute to the knowledge base that is evolving about this subject. We look forward to learning from you and would love to hear your stories and observations about thanatology in an online universe.

REFERENCES


Chapter 1 Thanatechnology as a Conduit for Living, Dying, and Grieving


