

# Report on Bereavement and Grief Research

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# Acknowledgments

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# Foreword

In 2000, the Project on Death in America of the Open Society Institute of the Soros Foundation awarded a grant to the Center for the Advancement of Health to further the development of the field of grief. This grant led to the creation of the Grief Research: Gaps, Needs and Actions Project. The focus of the project was on strengthening research on grief and bereavement with the ultimate goal of improving the care that grieving people receive. The project's mandate was to observe the field of grief research as a whole and develop strategies and recommendations to improve and support research. Goals of the project also included building connections among people working in the field and facilitating the use of research to guide the provision of the best possible care. To guide the work of the project, a scientific advisory committee (SAC) was formed, composed of senior researchers and practitioners with high credibility, broad expertise and vision. SAC members were invited to participate in round table discussions in the summer of 2001. A report of these discussions was one of the products of this project and served as a good foundation for the remaining work of the project (the report is available at [www.cfah.org](http://www.cfah.org)). The work of the project was broken into five work groups: monograph, research agenda, research funding, communication and bridging. Each group was tasked with a specific goal and objectives and SAC members elected to join a work group of their interest.

The following publication would not have been possible without the contributions and significant guidance from members of the scientific advisory committee, most particularly the monograph work group of the SAC. However, the full committee was not asked to endorse the conclusions or recommendations for research included in the report, which they saw in draft form prior to final revisions before its release. Responsibility for the release version of the report rests with the Center for the Advancement of Health.

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# Introduction

Bereavement – the loss of a loved one through death – is a universal human experience. Researchers are engaged in a process of asking and investigating central questions about the nature and experience of bereavement and grief. These include: What are the best ways to study and understand bereavement and grief? What is normal grief? How do our relationships affect the experience of grief? How do people respond to and cope with grief? What are the health effects of grief? For whom is intervention indicated? What types of interventions are most effective in helping people deal with grief?

Grief has been characterized as the quintessential mind-body problem. In investigating the ways in which the experiences of the death of a loved one affect us, the study of grief serves as an example of multidisciplinary work. As such, it is characterized by divergent philosophies of science, different theoretical concerns and approaches and different methodologies, but perhaps the common desire to define and give form to grief in the service of reducing pain and suffering.

## *Purpose and scope*

In 2000, the Project on Death in America commissioned the Center for the Advancement of Health to assess the state of research on grief. The purpose was to provide a base from which to make recommendations to strengthen grief research and to facilitate the use of evidence to guide the provision of high quality, appropriate bereavement- and grief-related care. As part of this effort, a scientific advisory committee was formed. Members of the scientific advisory committee were brought to the Center for the Advancement of Health (CFAH) in three groups for roundtable meetings in the summer of 2001 to begin the process of assessing the state of the field. Information generated from these meetings is summarized in Report on Phase I of the Grief Research: Gaps, Needs & Actions Project (Center for the Advancement of Health, 2001). The project is referred to as Grief Research.

One key strategy we have used in assessing the state of grief science is to update the 1984 Institute of Medicine report, Bereavement: Reactions, Consequences, and Care (Osterweis, Solomon & Green, 1984). This report was commissioned by the Office of Prevention of the National Institute of Mental Health of the National Institutes of Health and provided a comprehensive assessment of extant research on issues related to grief and health.

Updating this report is important now for many reasons:

- Most deaths in the United States occur in health care settings – about 60 percent are estimated to occur in hospitals or medical centers, and an additional 16 percent occur in other health care institutions, such as nursing homes or hospices (APA Online, 2003).
- Research on grief and its effects, and on the care provided to bereaved individuals and families, has increased greatly in both frequency and scope over the past 20 years.
- Advances in biomedical research in the past 20 years have the potential to substantially improve our understanding of how the experience of grief may translate into biological changes that then translate into poor health.
- Demographic trends, including the aging of the large “baby boom” generation, are likely to place greater service and economic demands on the health care system, including increasing needs for care related to end-of-life issues.

Good science is the gold standard in health care. To provide care for grieving individuals that is appropriate and of consistently high quality, it is important to act from a solid base of evidence. Specific issues in the alignment of bereavement and grief research and practice are addressed in Chapter 3.

Research on bereavement and grief has burgeoned in the past 20 years, with the publication of scores of research reports, reviews and compendia. This report therefore serves as a road map to information identified in that time period as critical to understanding advances in research on bereavement and grief, with a focus on grief and health. It is intended to provide researchers, practitioners, decision makers and funders with a broad overview of where the field is in the process of identifying a core body of knowledge and to guide readers to sources of more detailed information on core topics. The report identifies central current themes and theoretical approaches to the study of grief in general as well as major unresolved questions and disagreements in the field. It also is intended to provide readers with distilled and focused summaries of research on specific topics in research on bereavement and grief, focusing on the application of this research to health and the health care system. This report is descriptive, however, and is not intended to serve as a foundation for the development of clinical practice guidelines or prematurely force consensus or agreement on issues that merit further investigation.

## *Overview and organization*

The report is divided into three major sections. The first section sets the stage for an update and synthesis of the grief research literature. One of the ways in which bereavement-related research has advanced subsequent to the publication of *Bereavement: Reactions, Consequences, and Care* by the Institute of Medicine in 1984 is simply in the number of comprehensive reviews and considerations of grief research that have been published. In this section, influential major works in the field are identified and core themes in the study of bereavement and grief are highlighted. In addition, this section includes an examination of issues related to using research evidence and knowledge to improve care. A central concern of the Grief Research project was how evidence is most effectively

used to improve care, with a particular focus on health care settings. Issues in generating knowledge and applying it to clinical care, some general in nature and some specific to grief research and care, are identified and discussed. Resources for more in-depth consideration of these issues are highlighted.

In the second section, specific developments in the bereavement and grief literature are reviewed. This section begins with an overview of the processes used to identify research literature for review in this report and the criteria utilized in assessing the quality of the research reviewed. A description of the waves of literature identification conducted, the inclusion and exclusion criteria, and the process undertaken to review the literature and create evidence tables is included in Chapter 4. Evidence summaries generated from the literature are included in Appendices A and B.

Selected empirical literature is then reviewed, synthesized and critically summarized, beginning with research on physical and mental health outcomes hypothesized to be associated with bereavement and grief, with an emphasis on advances in investigation of the biological processes through which the experience of grief may result in illness or compromised health.

Research on bereavement and grief within the context of the health care system conducted from 1985 to the present is reviewed to fully capture the extant empirical literature relevant to the goals and focus of the project. Specific areas of research that are addressed include the education and training of health care professionals in the provision of care related to grief; health care practice; recognizing when additional or specialized care is needed in response to grief; the effects of loss and grief on health care providers; and practice and policy issues, including who should provide care for grieving individuals and families under what circumstances, and who should pay for such care; and the economic costs of grief-related health effects.

Research on the efficacy and effectiveness of grief interventions is addressed next. This section utilizes reviews of the intervention literature to summarize and assess findings regarding the effectiveness and efficacy of interventions with bereaved persons. To the extent possible, interventions are organized by age group of the recipients of the interventions (i.e., children, adolescents, adults and the elderly) and whether the intervention is targeted to individuals or families.

The third section includes a brief summary and conclusions and suggestions for health-related research on grief and bereavement.

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APA Online: End-of-Life Care Issues: Historical Changes Affecting End-of-Life Care; <http://www.apa.org/pi/eol/historical.html>; accessed 5.4.03.

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# Themes in Research on Bereavement and Grief

This chapter lays the groundwork for an examination of advances in the understanding of bereavement and grief that have resulted from recent empirical research on these phenomena. To establish a common starting point for consideration of these advances, bereavement and grief are defined and core themes and trends in recent research are highlighted.

## *Defining bereavement and grief*

In their simplest definitions bereavement refers to the loss of a loved one by death and grief refers to the distress resulting from bereavement. Although definitions of these phenomena remain the subject of debate, bereavement has been defined further by some theorists and researchers as a “. . . broad term that encompasses the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one” (Christ, Bonanno, Malkinson & Rubin, 2003, p. 554). Bereavement as understood from this perspective includes the internal psychological processes and adaptation of family members and expressions and experiences of grief. It also encompasses changes in external circumstances such as alterations in relationships and living arrangements (Christ et al., 2003).

Grief is seen as a more specific phenomenon and has been defined by some researchers as referring to a “. . . complex set of cognitive, emotional and social difficulties that follow the death of a loved one. Individuals vary enormously in the type of grief they experience, its intensity, its duration, and their way of expressing it” (Christ et al., 2003, p. 555).

Distinctions between bereavement and grief have been inconsistently maintained in research. Therefore, both terms will be used in referring to research in this field in general.

## *Themes and trends in current research on bereavement and grief*

In the years subsequent to the publication of *Bereavement: Reactions, Consequences, and Care* by the Institute of Medicine in 1984, scientific interest in bereavement has led to an explosive increase in bereavement-related research and its publication in peer-reviewed scientific journals. In the years subsequent to the publication of *Bereavement: Reactions, Consequences, and Care* by the Institute of Medicine in 1984, scientific interest in bereavement has led to an explosive increase in bereavement-related research and its publication in peer-reviewed scientific journals." Scientific

interest in bereavement and grief has also led to the publication of numerous comprehensive reviews, books and other materials. Examples of these research-oriented publications include two editions of the Handbook of Bereavement (Stroebe, Stroebe, & Hansson, 1993; Stroebe, Hansson, Stroebe, & Schut, 2001), which taken together provide a comprehensive examination of theory, research, interventions and outcomes in bereavement and grief. Also in 2001, a special issue of the American Behavioral Scientist was devoted to research on bereavement and grief (2001, vol. 44, no. 5). In recent years, the Institute of Medicine of the National Academy Science has published three reports on end-of-life care relevant to research on bereavement and grief, Approaching Death: Improving Care at the End of Life (IOM, 1997), Improving Palliative Care for Cancer (IOM, 2001), and When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families (IOM, 2003).

The themes and trends in bereavement and grief research identified here have been culled from a variety of sources, drawing heavily on input from the Scientific Advisory Committee (SAC) of the Grief Research Project (CFAH, 2001), on multiple reviews and major publications including Bonanno (2001a), IOM (2003), Parkes (2001), Stroebe (2001), Stroebe, Hansson, Stroebe, & Schut (2001), Wortman & Silver (2001), and a reading of the recent bereavement and grief research literature (see Chapters 5, 6 & 7 of this report). Some of these themes and trends are more discernible and have been more completely fleshed out than others. It is important to note also that there is tremendous variability in perspectives among researchers in bereavement and grief and it is highly likely that core themes and issues would be characterized differently by others; these are not consensus definitions.

## Themes and trends<sup>1</sup>

- Theoretical diversification - No one disciplinary or theoretical paradigm is currently dominant in bereavement and grief research. The past 20 years have seen the application and development of multiple theories and perspectives by researchers from a variety of disciplinary backgrounds. There has been increasing interest on the part of behavioral and social scientists in bereavement and grief and their consequences and a waning of the influence of psychiatric and clinical perspectives on this research. The ‘grief work’ perspective, based in Freudian psychoanalytic theory and the seminal research of Lindemann on survivors of the Coconut Grove nightclub fire in Boston (see Parkes, 2001; Stroebe, 2001), dominated thinking about bereavement and grief at the time of the publication of the IOM report in 1984. From the perspective of the grief work hypothesis, “... it is necessary to bring the reality of the loss into awareness to avoid complications in the course of grief” (Stroebe, 2001). Some theorists and researchers (e.g., Bonanno, 2001a) suggest that the absence of empirical evidence in support of the grief work

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<sup>1</sup> The references cited below are typically review articles or review chapters to which the reader is directed as sources of more in-depth information regarding the specific issues presented here.

The authors thank Roxane Silver, Martica Hall, Holly Prigerson, Paul Rosenblatt, and Robert Weiss for their contributions to this chapter.

perspective has led to its demise. Others maintain that although “. . . there simply has been very little empirical evidence that working through grief is a more effective process of coming to terms with loss than not working through it” (Stroebe, 2001, p. 855), it may be premature to conclude that the grief work hypothesis is dead. These researchers suggest that more precise specification of the nature of “grief work” and additional research into specific elements of the processes involved are needed before the hypothesis can be completely disregarded (e.g., Stroebe, 2001). Theories that continue to be influential in the study of bereavement and grief include attachment theory (e.g., Weiss, 2001; Shaver & Tancredy, 2001), which provides a framework for understanding the effects of bereavement in terms of the disruption of “affectional bonds” and in terms of individual differences in response to loss. Examples of theoretical perspectives that are emerging as important wellsprings of research include “meaning-making” or meaning reconstruction (e.g., Neimeyer, 2001; Neimeyer, Prigerson & Davies, 2001), which emphasizes responses to bereavement from the perspective of the human striving to make sense of troubling events and which is often expressed in the organization of experiences into narrative form. Cognitive stress theory (e.g., Folkman, 2001) has also been influential in recent research on bereavement and grief, especially in terms of recognition of the role played by positive emotions in adaptive response to bereavement. The dual process model of coping (e.g., Stroebe & Schut, 2001) posits that bereaved individuals oscillate between two types of coping – loss-oriented coping and restoration-oriented coping – in adapting to the death of a loved one. Loss-oriented coping refers to efforts to resolve the loss experience itself; restoration-oriented coping refers to efforts to master or adapt to challenges associated with the changes in life circumstances resulting from bereavement. The social-functional perspective on grief and emotion has shifted attention away from an emphasis on the expression of negative emotions and hypothesizes that recovery following the loss of a loved one is made more likely when grief-related distress is minimized and positive emotion is activated or facilitated (Bonanno, 2001b, p. 493).

- The experience of loss may be universal, but responses to loss are widely variable and there is no one clearly defined course or process of bereavement or grieving. Responses to bereavement may be influenced by characteristics such as age and stage of development, gender, history of loss and/or trauma, history of major depressive disorder, the nature and quality of the relationship with the deceased, type of loss (e.g., anticipated, violent or traumatic), and many other factors. Recent research also reflects a heightened awareness that the experience and expression of grief are influenced by factors such as familial relationships and expectations, social networks, religion and culture. The majority of the population appears to cope effectively with bereavement-related distress, and most people do not experience problematic grief or adverse bereavement-related health effects. However, the characteristics and course of normal responses to bereavement have not been fully identified, making it more difficult to define problematic responses (CFAH, 2001).
- Progress is being made in distinguishing complicated grief from normal grief and in identifying the risks that it poses. Researchers have hypothesized that a small, though significant, percentage of the population experiences complicated (also known as traumatic or pathological) grief and that these individuals are at greatest risk for adverse health effects (e.g., Prigerson & Jacobs,

2001). The nature of complicated grief and its relationship to other syndromes and conditions, and how it should be defined, assessed and classified are, however, the subjects of significant and persistent debate in the field (e.g., Stroebe et al., 2000). Recent empirical research on complicated grief is reviewed in more detail in Chapter 5.

- Maintaining continuing psychological and emotional bonds with the deceased is not necessarily an indication of problematic grieving. The “breaking of bonds” with a deceased loved one has been characterized in the past as a critical component of working through grief (e.g., Stroebe, 2001). Research with bereaved parents and others (see, for example, Klass & Walter, 2001; Stroebe, 2001; Wortman & Silver, 2001) indicates that maintaining psychological and emotional ties to the deceased through a variety of mechanisms is not unusual and can be associated with positive adaptation to bereavement.
- Positive emotions are possible following loss (e.g., Bonnano, 2001a). The loss of a loved one may change a person – possibly in positive ways – for his or her lifetime; investigators have found that some individuals report experiencing positive transformations as the result of struggling with their losses (e.g., Calhoun & Tedeschi, 2001).
- Some individuals do not experience distress or grief (as commonly understood) following bereavement. A sizeable minority of people do not experience (or do not report experiencing) distress following loss (e.g., Bonanno, 2001b; Wortman & Silver, 2001). Some researchers speculate that this need not indicate “absent grief” or delayed grief reaction (e.g., Bonanno, 2001b), both of which have been considered problematic from the “grief work” perspective. It has been suggested that bereavement in some circumstances may represent the end of a difficult situation (e.g., a stressful caregiving situation or painful terminal illness, or even the end of an abuse relationship; Wortman & Silver, 2001), leading to a lessening of distress rather than an increase in negative emotions. Also, as indicated above, struggling with the experience of loss may lead to personal growth even in the absence of negative circumstances preceding the bereavement (e.g., Calhoun & Tedeschi, 2001).
- Reviews of studies of bereavement interventions indicate that grief counseling may not be helpful for many people experiencing normal grief and may even have negative effects (e.g., Jordan & Neimeyer, 2003; Schut, Stroebe, van den Bout, & Terheggen, 2001). Reviews indicate that interventions may be more helpful for individuals experiencing complicated grief. Recent research on bereavement interventions is reviewed in Chapter 7.
- Advances have been made in identifying, measuring and understanding the biological effects of bereavement, especially in terms of neuroendocrine, immunologic and sleep responses in grieving individuals (e.g., Goodkin et al., 2001; Hall & Irwin, 2001). Advances in identifying and measuring the biological effects of bereavement may pave the way for clearer understanding of the pathways through which problematic grieving may lead to negative health outcomes. Physiological outcomes associated with bereavement and grief is discussed in more detail in Chapter 5.

- Grief is best defined not as an exclusively medical problem, but it is an individual and societal event with potential medical implications. Death most frequently occurs in health care settings, which means that health care providers may be the point of contact for post-loss care and services for bereaved individuals and families. Although most bereaved individuals do not experience long-term negative physical or mental health effects, recent research indicates that complicated grief can have a negative impact on health and well being. The issue of whether complicated grief should be categorized as a medical problem is a complicated one (e.g., IOM, 2003). Categorizing grief as a medical problem could lead to greater availability of interventions for individuals and families who need such services. Concerns also exist; however, that categorizing grief as a medical problem could also have negative consequences, such as treating people who do not need treatment, or causing harm through the provision of ineffective or poorly conceptualized treatment (CFAH, 2001). These issues are explored in greater detail in Chapters 5 and 6 of this report.
- Bereavement and grief researchers and practitioners are becoming increasingly aware of the need to better align research and practice, which would result in improved research practice as well as improved care for the bereaved. Critical issues in linking bereavement research and practice are addressed in Chapter 3.

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# Using Research on Bereavement on Grief to Improve Care

A specific goal of the Grief Research project was to lay the groundwork for improved bereavement care within the health care system through an examination of the current state of health-related research on bereavement and grief, and a consideration of the ways in which bereavement research and practice might better inform each other.

The general question of how to better align health care practice and the evidence generated by formal empirical research has become the focus of increasingly intense scrutiny and activity. For example, the National Committee for Quality Assurance (NCQA), an independent, nonprofit organization that monitors quality in the healthcare industry, recently released a report on health care quality (NCQA, 2003) highlighting the disparity between evidence and medical practice in the provision of care for a number of diseases and conditions. The NCQA report documents the costs in lives, health status, and health care expenditures resulting from the failure to consistently provide care that has been found to be effective in the treatment and management of a variety of conditions. Other organizations and agencies, including the private, non-profit Center for the Advancement of Health, and the federal Agency for Healthcare Research and Quality (<http://www.ahrq.gov>) and the National Institute of Mental Health of the National Institutes of Health (e.g., Bridging Science and Service; <http://www.nimh.nih.gov/publist/994353.htm>) have made closing the gap between science and practice a top priority.

Improving care through the alignment of research and practice is an issue of critical concern in relation to bereavement care. Recent reviews of grief counseling interventions, for example, indicate that the efficacy of such care may be low and that some bereaved individuals may have done better had they not received the intervention (e.g., Jordan & Neimeyer, 2003). In addition, although thinking about bereavement and grief has evolved in many ways since the first empirical studies of bereaved individuals were conducted in the mid-20<sup>th</sup> century (e.g., Balk, in press; Parkes, 2001), material in current publications specifically targeted to practitioners often reflects older understandings of bereavement and grief that have been supplanted or modified by advances in research (Wortman & Silver, 2001).

Concerns about improving the quality of care are a critical motivating factor behind efforts to bridge the gap between research and practice. This gap has often been characterized in terms of problems such as the poor dissemination of research results to practitioners, difficulties in communication between researchers and providers, and the apparent failure of practitioners to apply available

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research findings. It is beyond the scope of this document to examine in detail the multiple complex issues comprising the general issue of bridging the gap between research and practice.

This chapter is intended to serve, however, as a brief introduction to key concepts in current thinking about improving the connections between research and practice, and to set the stage for subsequent chapters that review the recent empirical literature addressing selected topics in bereavement and grief.

A starting point in considering how bereavement research and practice might be better aligned is to acknowledge that the goals, interests, and professional cultures of researchers and practitioners may differ significantly. The most significant overlap between the concerns of researchers and practitioners is likely to be in a joint commitment to the use of the best available information to guide the provision of the best possible care.

This leads to the consideration of two issues that are critical to the successful alignment of research and practice. The first issue pertains to the quality of the empirically-generated evidence that is intended to guide practice, and how to ensure that it is valid, reliable, timely and relevant to the demands of practice. The second issue is the identification of the factors that influence behavior change in practitioners, because practitioner behavior is the final common pathway through which all attempts to improve clinical care must pass.

### *The best possible information to guide practice*

Two endeavors have typically been identified as essential elements of the translation of research into practice, knowledge production and knowledge utilization. Knowledge production has been seen primarily as the province of researchers and knowledge utilization (or the failure to utilize empirically-generated knowledge) as the domain of practitioners. In reality, it is likely that these processes are more complex and interwoven, and that knowledge production and utilization would be seen more beneficially as the shared provinces of researchers and practitioners (and perhaps consumers of care as well).

What factors contribute to the production of knowledge about bereavement and grief that is of high quality and is likely to be used by practitioners? What factors currently characterize the study of bereavement and grief and influence the quality of the evidence that is available to practitioners?

### Research quality

The study of grief and bereavement is fundamentally multidisciplinary in nature (Parkes, 2001). The three disciplines that currently produce the most research on bereavement and grief are psychology, medicine and nursing (Neimeyer & Hogan, 2001), but disciplines such as social work, sociology, anthropology, and the biological sciences, among others, also play very active roles. Disciplines differ

in the research questions and hypotheses they generate, and in the methods they use to gather and analyze information. They may also differ in philosophies of knowing,<sup>3</sup> in the types of evidence that are considered useful, and in thresholds of certainty – in their assertions of how much of what types of evidence are needed to draw definitive conclusions. Disciplinary differences play a role in debates in bereavement research and practice regarding the nature and quality of research evidence.

As defined here, the quality of the information generated by research includes elements such as research design and methods, measures, and ethical considerations (see also Stroebe, 2003, for a discussion of these issues). Issues of the appropriateness and applicability of research approaches, methodologies and analytic strategies to different goals are also elements that contribute to the final quality of the information produced.

## Research design and methods

Empirical research methods used in the study of bereavement and grief fall into two major categories – quantitative methods and qualitative methods. Quantitative research generally involves the collection of objective data that can be quantified (counted) and analyzed to produce information based on the aggregation of data across many subjects. The goals of quantitative research include the identification of causal factors, prediction, and producing findings that can be generalized beyond the specific samples of subjects studied. Qualitative research also is characterized by the systematic and rigorous collection of data, but the data collected are typically in narrative form rather than numeric form. Qualitative research has been characterized as oriented to discovery and the generation of hypotheses, rather than to the testing of hypotheses. A goal of qualitative research is to understand a phenomenon from the perspective of individuals experiencing it, to understand the lived experience of participants (Moss, personal communication, 2003; Neimeyer, personal communication, 2003; Rosenblatt, personal communication, 2003).

Fairly standard criteria exist for evaluating the quality of empirical, quantitative research. These basic considerations include:

- the psychometric properties (reliability and validity) of the measures used
- the types of data gathered – did the study rely only on self-reports from subjects or were other types of data, such as interview data or behavioral observations, included?
- the representativeness of the sample of subjects studied, which affects the extent to which the findings of the study can be generalized
- the design of the study in terms of time course – was the research designed to follow subjects over a period of time rather than gather data at only one time (or to ask them to recollect experiences and feelings from the past)?

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<sup>3</sup> The authors acknowledge that there are different theories of what constitutes knowledge and how to evaluate its truth value, a point that was explored in some detail in meetings of the Scientific Advisory Committee of the Grief Research project. An examination of different epistemologies is beyond the scope of this report, however.

- controlling for potentially confounding factors – factors that systematically bias the findings, but that were not included or measured as part of the research design (Bonanno, 2003).

In addition, empirically generated evidence has frequently been ranked in terms of quality; evidence from meta-analyses of multiple, controlled well-designed experimental studies is considered strongest, followed by well-designed quasi-experimental studies and well-designed non-experimental studies. Case reports and clinical examples have generally been considered of extremely limited evidentiary value from this perspective (Connor, 2003).

The development of quality criteria and evidentiary standards for qualitative research has been the subject of extensive debate, with various standards emphasized at different times by different researchers. These have included “literary and scientific criteria, methodological rigor and conformity, [and] the real world significance of the questions asked” among others. Consensus has not been achieved regarding these standards, however, and new approaches to the assessment of quality in qualitative research are being developed (Sandelowski & Barroso, 2002, p. 2).

Greater attention to research design and methods, particularly to the careful development and testing of measures and to the assurance of their validity and reliability, is needed to improve the quality of research on bereavement and grief. Neimeyer and Hogan (2001) and Stroebe (2003) also recommend that researchers consider using both quantitative and qualitative methods as a way of improving bereavement research and the information it generates. They “advocate a stance of methodological pluralism, respecting both numbers and narratives and the distinctive forms of understanding that each can promote” (Neimeyer and Hogan, 2001, p. 113).

## Ethical issues

Although traditional assessments of research quality may not typically include the extent to which researchers understand and comply with ethical principles, these principles play an essential role in the design of research, the methods used, and the ways in which research is carried out, thereby affecting quality from a practical perspective as well as an ethical one.

Core ethical issues in bereavement research have been identified by Cook (2001) and Rosenstein (2003), to which the reader is referred for detailed and thoughtful considerations of these issues.

Several of the ethical concerns and responsibilities identified are particularly relevant to the question of how best to link research and practice. Intervention studies can be particularly ethically problematic because of the tension that exists between the need to generate data to inform clinical practice and the potential harm to the bereaved that may result through their participation in research. As an example of this, Cook (2001, pp. 129-130) discusses the ethical questions raised for one investigator who used a traditional control group design to study the effectiveness of a social support intervention for bereaved college students. Bereaved students in the control group (who received no alternative treatment or placebo) were far more likely to drop out of the study after their

completion of the first assessment of depression, stress and coping than were bereaved students in the intervention group. This raised concerns for the investigator that completing the instruments had intensified distress for students in both the control and intervention groups. Students in the intervention group had an opportunity to discuss this intensification of distress in the support group, but bereaved students in the control group did not. This left the investigator with questions about the ethical obligations of researchers to research participants who may become distressed, and the ethical consequences of using a research design that was scientifically most appropriate (and therefore ethically indicated), but that may have resulted in “less persuasive outcome data as a result of the high drop-out rate among the bereaved controls” (Cook, p. 130). Which ethical principle takes precedence? How can researcher best protect participants protected from the possibility of research-induced distress while also generating data that can be used to provide high quality and appropriate care in the future?

Little is known about how the application of ethical principles in bereavement research affects participants, either for good or for ill. In addition, little is known about the ways in which compliance with appropriate ethical safeguards may affect the gathering of data and the applicability of research to clinical situations. This suggests that bereavement researchers and practitioners have a responsibility to work together to identify issues to be investigated to reduce ethical dilemmas in conducting and applying such research (Cook, 2001; Rosenstein, 2003).

## Assessment of current research quality

In their review and critique of methods and measures used in research on bereavement and grief, Neimeyer & Hogan (2001) assess the general quality of the research. Their assessment indicates that thoughtful discretion in the application of research findings is warranted at present, observing that “[a]lthough the human experience of bereavement has often been studied, it has not often been studied well” (p. 111). They further observe that the tremendous growth in the volume of research that has been conducted on bereavement and grief might lead one to “assume that a great deal is now known about the human encounter with loss, providing a secure grounding for both grief theory and therapy. Unfortunately, however, this is not the case ...” (Neimeyer & Hogan, 2001, p. 89).

## *What factors influence behavior change in providers?*

In clinical settings, actual changes in practice are enacted at the level of the individual practitioner. Planned change, however, is typically considered the responsibility of the organization, institution or government, with emphasis on the accumulation of new formal knowledge that will replace the (presumably faulty) knowledge of practitioners (Stake, 1986, p. 91). This is consistent with information-based theories of learning, in which the acquisition of knowledge is seen as a dispassionate process: The availability of information is seen not only as necessary but sufficient to trigger action or behavioral change. However, as is indicated by continuing gaps between research

and practice (e.g., NCQA, 2003), “formal knowledge is not necessarily a stepping stone to improved practice” (Stake, 1986, pp. 93-94).

If formal knowledge (the evidence generated by research) does not in itself lead to changes in practice, what other factors might be operating? Stake (1986), writing about practice in education, proposed a model of the determinants of action that includes not only formal knowledge, but also knowledge derived from experience.<sup>4</sup> In this model, formal theory and codified data (typically produced from quantitative research) contribute to the development of formalistic generalizations about specific phenomena. Experience contributes to the development of naturalistic generalizations about the same phenomena. Formalistic generalizations and naturalistic generalizations in combination lead to personal understanding on the part of the practitioner. Personal understanding leads to internal conviction. Internal conviction, in combination with external demand (e.g., organizational policies and procedures, practice guidelines), leads to action (Stake, 1986, p. 96).

Naturalistic generalizations develop when new experiences are added to old, causing the re-examination of problems. This leads to changes in understanding, which in turn leads to changes in practice (Stake, 1986, p. 90). Both direct and vicarious experience can contribute to the experientially-derived knowledge that guides practice and to changes in practice.

According to Stake, research can play a critical role in the development of naturalistic generalizations (and in changing provider behavior) by evoking vicarious experience:

Formal research reports may contain the detailed description necessary to generate vicarious experience for readers, thereby modifying the reader’s ever-developing naturalistic generalizations. But the author of the formal research report seldom assumes a commitment to facilitate the vicarious experience” (Stake, 1986, p. 94, emphasis in the original).

Failure to recognize the role of experience as well as the role of formally derived knowledge in guiding practice may therefore make it much more difficult for researchers and practitioners to connect and for research evidence to be used to improve care.

One reason that a great deal of quantitative research – even of a very informative kind – often doesn’t go anywhere is because it subordinates the consumers of the research (clinicians/practitioners) to the role of receiving information from researchers, implying that they can only receive knowledge from an external authority and that the knowledge itself originates outside the experience of the clinician. The obligations of the clinician are to interpret, incorporate and act on knowledge – we are active agents in the construction and use of knowledge (Neimeyer, personal communication, 2003).

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<sup>4</sup> The argument here is not that experientially-derived knowledge (or clinical judgment) is superior to formally-derived knowledge or quantitatively-based knowledge. The work of Meehl (1996) and others (e.g., Hamilton, 2001; Dawes, unpublished) have clearly described the value of statistically-based prediction rules in a wide variety of clinical settings in which predictions and diagnoses must be made. A full discussion of the merits of statistical and clinical decision-making is beyond the scope of this report. The points being made here, however, are that practice *is* guided by experiential knowledge (and in the absence of good quality formal knowledge, it must be), and that to change practice, the experiential knowledge of the practitioner must be acknowledged and brought into the process.

Vicarious experience, according to Stake, is elicited by information that is presented in context, in a more-or-less natural state – “time-bound, place-bound, personality-bound” – and is “the most coherent and immediately relevant” to practitioners (1986, p. 95). Information that is presented in this way can be characterized as being high in “experiential proximity” – it is recognizable by the practitioner in terms of his or her everyday experience.

Many examples exist of research information presented in this way. This approach, as it applies to bereavement research and care, is illustrated by two recent publications of different types. Prigerson & Jacobs (2001) use a case example to illustrate and recommend approaches that could be used by physicians in interactions with bereaved patients. Verbatim material from interviews with a patient and her physician, and recommended strategies for caring for and communicating with bereaved patients, are set in the context of information derived from research on the symptoms and outcomes of uncomplicated and complicated bereavement. The recent report by the Institute of Medicine on end-of-life and palliative care for children and families (IOM, 2003) also weaves comments from parents, children and providers together with research-derived knowledge and experience-based judgments to make a compelling case for improvements in care and how they can be achieved.

### *Strategies to better align bereavement and grief research and practice*

The appropriate application of research to the improvement of practice rests on the availability of high quality evidence relevant to practice needs. Improving research quality is a critical element of any strategy to better align research and care. In terms of bereavement and grief research, assessments of general quality suggest that research could be improved by:

- investing resources and time in the development of measures specific to the study of bereavement and grief and to ensuring their validity and reliability;
- using multiple methods of research that are well-matched to the goals of the research and the questions being asked. Conscious engagement in the methodological pluralism recommended by Neimeyer & Hogan (2001) is one strategy that could be used to maximize both the quality of the information generated through different methodologies and applicability to practice;
- engaging researchers and practitioners in consideration of the ethical challenges involved in producing and using research on grief and bereavement.

Assuming the availability of applicable high-quality research, the next important challenge in improving the alignment of research and practice may be to report research in ways that maximize its “experiential proximity” to providers. The suggestion here is that the ways in which research is reported affect the likelihood that it will lead to desired changes in provider behavior and ultimately to improved care. Formally derived information that is too distant from the experience of the practitioner is unlikely to evoke vicarious experience and therefore may be unlikely to result in changes in practice behavior. The hypothesis remains to be tested that changes in research reporting – changes designed to maximize experiential proximity and trigger the development of naturalistic generalizations – will lead to changes in provider behavior.

Finally, it is important to note two related factors. The first is that formal, empirically generated evidence may also not be sufficient to change the “practice” of research. Concepts that have been characterized by some investigators as “myths” (Wortman & Silver, 2001) because they have not been supported by empirical evidence continue to guide the work of researchers as well as practitioners. The process of changing assumptions that guide research also appears to be evolutionary and gradual. It is critical that researchers have the opportunity to expand their experience-based knowledge as well.

This is related to the second proposition – that the successful alignment of bereavement and grief research and practice cannot occur without continuing dialogue among researchers and practitioners (and also potentially with bereaved persons). The need to examine the derivation and nature of the theories and the concepts that undergird research and practice becomes a commitment as well as an expectation that research will examine assumptions driving theories that inform researchers and practitioners and a pledge that researchers and practitioners will collaborate in these very examinations. Researchers need the front-line experience with bereaved persons that practitioners give them, even if for researchers these experiences may be vicarious (Balk, personal communication, 2003).

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## Summary of the Literature Selection Criteria and Identification Process and Results

As described in Chapter 1, the chapters in this section are based on empirical evidence as related to grief and health outcomes (Chapter 5), grief and health care professionals and the health care system (Chapter 6) and interventions (Chapter 7). This chapter provides an outline of the inclusion criteria that each study had to meet to be considered, and a summary of the process used to select and identify relevant literature. It ends with a summary of the literature that was eventually considered in these chapters.

### *Literature selection criteria*

As previously stated, the goal of this report is to update the field of grief research as it relates to health, using the Institute of Medicine's report in 1984 and the Handbook of Bereavement (Stroebe, Hansson, Stroebe, & Schut, 2001) as starting points. In general, all evidence published in peer-reviewed journals on topics relevant to grief and health since the year 2000 was considered. However, evidence for the health systems chapter (Chapter 6) considered all publications subsequent to 1985, as the Handbook of Bereavement (Stroebe et al., 2001) did not directly report on this area of research. In addition, evidence recommended by the SAC members as significant or relevant to the topic areas that was published prior to the year 2000 but that was not cited in the Handbook of Bereavement was considered for inclusion in the report.

In addition to consideration of the year of publication, five criteria were used to select literature for inclusion. The study had to:

- 1) be published in English
- 2) focus on mourning loss from the death of a person (this could be either individual or community loss);
- 3) have some association with grief and health and the health care system;
- 4) study biological/physiological effects on bereaved persons before and after a death; or
- 5) study physical and mental health outcomes in bereaved persons before and after a death.

When reviewing the selected literature for chapters 5 and 6, a second screening process was used. In order to be cited in these chapters, an article had to contain results from original quantitative or qualitative research. Although review articles and practice guidelines were instrumental in helping to frame and inform these chapters, they have not been included as cited articles.

## *Literature identification*

Four strategies were used to identify relevant literature:

- A literature search was conducted through the American Psychological Association under the direction of Dr. Robert Neimeyer, Professor, University of Memphis, to identify all end-of-life (EOL) or grief-related articles published between 1985 and 1999. This search yielded approximately 4,000 citations. Of the 4,000 citations, 1,000-1,500 were flagged as potentially grief- and health-related and were sent to CFAH for further review. About 400 abstracts were found to be grief-related; full copies of these articles were obtained and considered for inclusion.
- A Medline search was conducted by CFAH staff to identify any grief- and health-related articles published from 2000 to 2003. For literature that dealt specifically with grief and health care/health professionals, the Medline search was extended back to 1985. This search yielded approximately 80 citations.
- A survey was conducted to obtain all publications by SAC members relevant to grief and health. From the list of 290 SAC publications submitted to CFAH staff, about 45 were identified as related to grief and health.
- Several articles were identified through a tree search of publications. As CFAH staff reviewed articles, any potentially relevant citations were flagged and considered for inclusion. Special attention was paid to articles that dealt with the health care system. Approximately 15 articles were identified through this strategy.

## *Literature review and selection results*

All articles that met the first phase of the literature identification process as described above were entered into a reference manager. More than 550 citations were entered. Although all of these references were reviewed for the drafting of this report, not all of them are referenced because they did not meet the inclusion criteria.

More than 100 articles met inclusion criteria and were considered for citation in chapters 5 and 6. Evidence summaries for each of these articles are located in Appendix A and B respectively. During the literature review process for chapter 7, several recently published excellent and robust reviews of the intervention literature were identified. Although more than 80 intervention studies were found, Chapter 7 relies primarily on these reviews. References for each chapter are listed at the end of every chapter.

It should be noted that while reviewing each study, an informal quality rating (using the following selection criteria: response rate, use of standardized measurements and analytic techniques) was conducted to provide insight as to strength of the body of evidence for these chapters.

## References

Stroebe M, Hansson R, Stroebe W & Schut H. (eds.) (2001). Handbook of bereavement research: consequences, coping and care. Washington, DC: American Psychological Association.

## Outcomes of Bereavement

This chapter reviews selected evidence regarding the relationship between bereavement and physical and mental health. The number and variety of outcomes that have been studied in relation to bereavement, as well as the number and variety of factors that are hypothesized to affect outcomes, lead to many challenges in the organization and interpretation of the literature.

As has been mentioned in previous chapters, the period subsequent to the publication of the Institute of Medicine report on bereavement in 1984 has been characterized by the publication of many noteworthy and comprehensive reviews of research on bereavement and grief and its effects. The strategy we have used for this chapter is to identify and refer the reader to pertinent reviews and to more closely examine recent empirical evidence (published in or subsequent to the year 2000) related to bereavement and grief outcomes.

The literature review processes used to identify the research reviewed here is described in Chapter 4 of this report. Thirty-two studies were deemed to be of sufficient quality and pertinence to the topics addressed here to merit the development of evidence summaries. These evidence summaries can be found in Appendix A. Information drawn from a subset of these studies (and several excellent reviews) is presented in this chapter. The research described here represents the studies of highest quality available from the pool of identified literature.

Based on the multiple perspectives from which research on bereavement-related outcomes have been studied, there are many ways in which this chapter could have been organized – by outcomes studied; by type of death (e.g., anticipated, unanticipated, violent); by the relationship of bereaved individuals to the deceased; or by age or stage of life course of bereaved individuals. These potential organizing characteristics are often mixed within studies (i.e., types of relationship to the deceased and types of death may be mixed in a sample in which researchers are interested in multiple outcomes).

The vast majority of empirical studies we identified to be considered for review were studies of adults. Many studies include adults from a broad range of ages (e.g., from early 20s to mid-50s, or from younger than 40 to older than 70). Rather than separate the studies in which the samples are restricted to elderly persons, we have chosen to review them together with research on adult participants of a broad age range.<sup>5</sup> Within this broad category, we have organized studies by topics including, physiological processes; pre-loss experiences; a general category of post-loss adjustment, which is further subdivided; and complicated grief. Reviews of research on children and adolescents are then briefly summarized.

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<sup>5</sup> See Moss, Moss, & Hansson (2001) for a comprehensive review and analysis of bereavement in elderly persons.

## *Research on adults*

### Physiological processes, physical health and mortality

At the time of the publication of the IOM report on bereavement in 1984, the existing evidence suggested that bereavement was related to decrements in physical and mental health in adults. Findings from many studies indicate that mortality risk is increased following the death of a spouse, an effect that some research suggests is stronger for men (Christakis & Iwashyna, 2003). Other studies have shown increases in mortality for both men and women (see Goodkin et al., 2001 for a brief review).

Duberstein (2000), in his review of the evidence regarding the association between bereavement and mortality, cautions, however, that numerous methodological issues confound the interpretation of published findings regarding this relationship and that the conclusion that bereavement is associated with increased mortality should be considered tentative (p. 281). He argues that prospective data on grief, depression, immune function and neuroendocrine function are needed before it will be possible for researchers to substantiate claims of causal relationships between bereavement and mortality, or between bereavement and a general weakening of the ability to respond to or cope with disease (Duberstein, 2000, p. 285).

Hall & Irwin (2001), in their review of research on physiological functioning in bereavement, suggest that results from cross-sectional and longitudinal studies indicate that changes in multiple physiological systems (including the immune and neuroendocrine systems, and in sleep) take place during bereavement. However, limitations in study design and methodology have made it impossible, to date, to determine whether bereavement-related changes in physiology are mechanisms for functioning or are non-causally related to functioning in some way. Echoing Duberstein (2000), they suggest “that much additional work is needed to determine whether the imbalance in these various behavioral and physiological systems leads to an increased morbidity and mortality” and call for “the evaluation of changes in disease-specific biological mechanisms underlying the association between bereavement, depression and physical illness” (Hall & Irwin, 2001, p. 487).

Goodkin et al. (2001) observe that “[h]ealth status is one step removed from immune function, which is itself one step removed from the multiple psychosocial changes occurring with bereavement” (p. 682).

They propose a “stressor-support-coping” predictive model for the physiological effects of bereavement (Goodkin et al., 2001, pp. 682-683), in which stressors are associated with psychological distress, which can be modified by social support and coping. The stressor, support and coping variables of the model have been found to be predictive of a number of different types of outcomes, including psychological distress, immunological measures and physical health outcome measures (Goodkin et al., 2001). Goodkin and colleagues have tested this model in bereavement support groups.

Recent empirical work in this area includes a study by Christakis & Iwashyna (2003), who used hospitalization records from the Centers for Medicare & Medicaid Services and mortality statistics to examine the effects of hospice use on mortality in a matched cohort study of 195,553 elderly spouses of patients who died between 1993 and the end of 1997. The mean age of participants at the time of bereavement was slightly less than 75 years; participants were primarily women (80 per cent) and white (94 per cent). Analyses controlling for confounding factors indicated that mortality at 18 months following bereavement was significantly lower for wives of men who used hospice care than for their matched controls. Bereaved widows of hospice users also were more likely to survive than widows of non-hospice users over the entire 1000-day follow-up period of the study. The same pattern existed for bereaved husbands of hospice users, but was not statistically significant. The results suggest that the use of hospice care may affect not only the well-being of patients but the health of their spouses, have a beneficial impact on mortality rates following bereavement.

### Pre-loss experiences and health and adjustment following bereavement

Schulz et al. (2001) studied the effects of pre-bereavement caregiving on post-bereavement health in a longitudinal matched case-control study of elderly persons. Participants in this study were 129 individuals aged 66 to 96 years (74 per cent women, 90 per cent white) who divided into three groups: caregivers with strain, caregivers with no strain and non-caregivers. Results indicate that the strained caregiver group reported higher levels of symptoms of depression and worse health practices (e.g., forgetting to take medication, not having enough time to exercise, not being able to slow down and get enough rest when sick, not having enough time to go to the physician) during the pre-bereavement (caregiving) period than caregivers with no strain or non-caregivers. Following the death of their spouse, strained caregivers reported improved health practices and no increases in symptoms of depression. Antidepressant use did not change, and no significant increases in weight loss were observed. In contrast, post-loss non-caregivers reported increasing levels of symptoms of depression and increases in antidepressant use and weight loss were observed. No changes in self-reported health risk behaviors were observed. Caregivers with no strain represented a middle ground between strained caregivers and non-caregivers, reporting small but significant increases in symptoms of depression. No changes were reported or observed in health risk behaviors, antidepressant use or weight. These findings suggest that for elderly women, responses to the death of a spouse may vary by caregiving status. For strained caregivers, the death of a spouse may represent a significant reduction in burden, and the death itself does not increase levels of distress.

These findings are echoed by those of Chentsova-Dutton et al. (2002), who examined depression and grief reactions in a longitudinal study of 48 adult children and spousal caregivers of hospice patients and 36 controls. Participants were studied prior to the death and at three points in the year following the death. There were no significant differences between adult child-caregivers and spouse-caregivers in reports of grief, depression or other symptoms of distress. Symptoms of grief decreased over time in general, but some symptoms remained fairly intense at the last assessment 13 months following the death. Caregivers reported significantly higher levels of depression at the assessments prior to death and two months following the death, but by seven months following the death these

levels had subsided and there were no differences between caregivers and controls. The authors suggest that depression is “at least as likely to emerge in the context of caregiving as it is in the post bereavement period” (Chentsova-Dutton et al., 2002, p.53), and that death of a family member under these circumstances does not further increase caregivers’ distress.

Carr et al. (2000) examined the effects of marital quality (assessed prior to loss) on post-bereavement adjustment in a longitudinal matched case-control study (the Changing Lives of Older Couples study). The combined samples for the study included 406 bereaved spouses and 87 controls with a mean age of approximately 74 years. About three-quarters were female and about 85 per cent white. Results of the study indicate that widowhood was associated with poorer psychological well-being at six months post-loss after adjusting for demographic and contextual factors. The effect of widowhood on depression was not altered by consideration of marital quality variables. Levels of yearning for the lost spouse were highest for those widows who had experienced the highest levels of emotional warmth and dependence on their spouse for tasks such as home repair and financial management; widows who suffered conflicted marriages reported lower levels of yearning. The authors suggest that experiences of depression, anxiety and yearning following the loss of a spouse may be quite dissimilar and that “psychological adjustment to widowhood varies considerably on the basis of the nature of one’s marriage” (Carr et al., 2000, p. S205).

The effects of perceptions of the circumstances surrounding the death and preparedness for death on post-loss health and functioning were studied by Barry, Kasl & Prigerson (2002) in a sample of 112 bereaved individuals (mean age of slightly less than 64 years, 71 per cent women, 91 per cent white). Perceptions of the circumstances surrounding the death, the bereaved person’s perception of being prepared for the death, and measures of physical health and psychological well-being were obtained in a baseline interview conducted four months post-loss. Physical and psychological health measures were obtained a second time approximately nine months post-loss. The authors found that rates of complicated grief, major depressive disorder and post-traumatic stress disorder decreased over time. However, perceptions of a lack of preparedness for the death were associated with complicated grief at baseline and at the follow-up interview and with a diagnosis of major depressive disorder at follow-up. Perceptions of the death as more violent (than peaceful) were associated with major depressive disorder at baseline but not at follow-up. The authors suggest that the perception of being unprepared for the death may be indicative of possible difficulties in acknowledging and accepting the impending loss, and may also be an indicator of potential complications of bereavement.

## Post-loss adjustment

Overviews of the role of coping in adjustment to bereavement have been published by Nolen-Hoeksema (2001) in terms of the negative consequences of ruminative coping and Folkman (2001) in terms of the application of stress and coping theory to the understanding of bereavement. Folkman suggests that although “[t]he widespread conviction that coping can make a difference in loss-related adjustment is reflected in the burgeoning popular literature [and] . . . the rich literature

for counselors and clinicians on therapeutic approaches for bereaved individuals” research is lacking on how people cope with loss and what the effects of these coping efforts are (2001, pp. 563-564).

Bonanno and colleagues (Bauer & Bonanno, 2001; Bonanno & Field, 2001; Field & Bonanno, 2001; Safer, Bonanno, & Field, 2001; Field, Gal-Oz, & Bonanno, 2003) have conducted a program of research investigating post-bereavement functioning and adaptation in a sample of 69 widowed persons (67 per cent female, 80 per cent white) between the ages of 21 and 55 (mean age slightly more than 47 years) who had suffered the death of a spouse/partner. The research has utilized a variety of measures, including self-reported and interview-rated grief, symptoms of depression, self-reported somatic complaints, self-rated emotion, observer-rated emotion, autonomic reactivity, participants’ descriptions of their relationship with their spouse, measures of marital quality, continuing attachment, self-blame and blame of the deceased in their investigations. The findings from this program of research are complex and varied and include indications that:

- participants who adjusted well to spousal bereavement appeared to depict their lives as mostly good with a limited number of setbacks and tended to focus on “what they did” rather than on broader qualities of “who they were” when observing the important or valued aspects of their lives.
- facial expressions of negative emotion six months post-loss were associated with a higher level of somatic complaints at five years post-loss. The dissociation of negative emotion (high autonomic arousal rates with low expressed emotion) was associated with reduced depression at five years post-loss.
- higher levels of emotional processing at six months tended to be related to higher-than-expected levels of grief symptoms at five years.
- self-blame and blame of the deceased play roles in post-loss adjustment. Self-blame was significantly associated with symptoms of grief and with a maladaptive form of continuing attachment. Blame of the deceased person was inversely associated with measures of marital adjustment. The results suggest that self-blame may be a form of avoidant coping with that may adversely affect long-term adjustment.
- greater satisfaction with the past relationship with the deceased spouse was associated with higher scores on a measure of continuing bonds with the deceased person. High scores on this scale were associated with higher levels of grief-specific symptoms over a five year period. The extent to which the bereaved person uses continuing bonds rather than the type of expression involved may be more important in relation to bereavement-related adjustment.
- participants who overestimated past levels of grief-related ideation were less likely to show objective improvement over time, and those who underestimated their initial grief symptoms and ideation improved relatively more over time.

The authors suggest that evidence from this body of work calls into question the “grief work” and “delayed grief” hypotheses and challenges the assumptions that the expression of distress is a critical aspect of adjustment following bereavement.

## *Risk and protective factors*

Three types of factors have been identified as being potentially affecting risk for poor outcomes of bereavement (see, e.g., Stroebe & Schut, 2001). These are:

- situational factors related to the death, such as whether the death was sudden or anticipated
- person factors such as gender and characteristics prior to the death such as emotional stability, religious beliefs and practices and self-esteem
- interpersonal factors such as the availability of social and emotional support from family and friends.

These factors may act to increase risk (e.g., sudden death, or lack of social and emotional support) or may play a protective role (e.g., availability and use of social and emotional support from family, friends and community) (Hansson & Stroebe, 2003).

## Meaning-making and post-loss adjustment

Davis & Nolen-Hoeksema (2001) studied the ways in which the bereaved person make meaning of the loss of a loved one in a longitudinal study of 205 adults (74 per cent women, 81 per cent white, mean age slightly over 51 years) who were followed for 18 months after the death. Forty-four per cent of participants had lost a parent, 35 per cent their spouse/partner, 9 per cent a child, and the remaining 12 per cent a sibling, other relative or close friend. Interviews of participants included questions about whether they had been able to make sense of the death and if they had found anything positive in their experience. The researchers found that participants seem to make sense of their loss by seeking to understand the event in terms of their existing worldviews. If the event is comprehensible in terms of existing worldviews, then making sense of the loss does not appear to be a significant challenge. If the event is perceived to be at odds with existing worldviews, the bereaved individual is faced with the task of revisiting either their interpretations of the loss or their worldviews. Differences in the ability to make sense of the loss were related to having religious or spiritual beliefs (as reported in a pre-loss interview), with those who reported such beliefs more likely to make sense of the loss. Making sense of the loss in the first six months following the death was related to lessening of emotional distress; making sense for the first time at later interviews was not related to changes in levels of distress. Participants who were unable to make sense of the loss within the first six months after the death were also likely to be unable to make sense of it later. A majority of respondents (70 per cent to 80 per cent) at each interview reported that they had perceived benefits in the loss experience. These individuals also showed improvements in emotional adjustment with time. The most commonly reported benefits were that the experience led to growth in character, the strengthening of relationships and changes in perspective. Making sense of the loss and finding benefit in it were not related, indicating that these are two distinct processes.

Gamino and colleagues (Gamino, Sewell & Easterling, 2000; Gamino, Hogan & Sewell, 2002) also examined survivors' efforts to make meaning of a loss, distress and personal growth in qualitative

and quantitative analyses of data from 85 respondents (75 per cent women, average age of almost 51 years, 89 per cent white) who lost spouses (42 per cent), parents (37 per cent), children (12 per cent) and others (e.g., siblings, grandparents, friends, 9 per cent). Bereavement had occurred for 88 per cent of respondents within the 3 years immediately prior to the study. Qualitative analyses indicated that people use multiple forms of meaning in seeking to come to terms with the reality of a loved one's death. Categories of meaning that emerged from participants' responses appeared to refer primarily to the pain and suffering associated with bereavement (e.g., feeling the absence, disbelieving the death) or to more positive and hopeful dimensions of loss (e.g., experiencing relief, continuing the connection). Quantitative analyses indicated that personal growth following bereavement is associated with factors such as having an opportunity to say goodbye to the loved one, seeing some good resulting from the death, a measure of intrinsic spirituality and spontaneous positive memories of the deceased. Factors associated with higher levels of negative grief affect were: younger age of the decedent, traumatic death and a perception that the death was in some way preventable.

The relationship between spiritual beliefs and bereavement outcome was studied by Walsh and colleagues (Walsh et al., 2002) in a sample of relatives and friends of dying patients recruited from a palliative care center in London. Participants were primarily women (67 per cent), white (86 per cent), spouses/partners of the dying patient (40 percent), adult children (40 percent) and other relatives or friends (20 percent). Relatives and friends of the 129 patients who died during the course of the study composed the sample. The nature and strength of participants' spiritual beliefs and practice were assessed by interview and participants were divided into three groups – those with no spiritual beliefs, low strength of belief and high strength of belief. After controlling for confounding variables, strength of spiritual belief predicted intensity of grief over a period of 14 months post-bereavement: Participants with high strength of belief had a linear pattern of recovery over the 14 month period. Participants with low strength of belief showed little change by nine months post-bereavement but recovered quickly thereafter. The symptoms of grief of participants with no spiritual belief showed a temporary decline at nine months but intensified at 14 months post-bereavement. The authors suggest that strength of spiritual beliefs may play a role in the timing and quality of the resolution of grief following the death of a loved one.

## Complicated or traumatic grief

Prigerson & Jacobs (2001) review recent research on symptoms of complicated (also known as traumatic) grief and evaluate the strength of evidence supporting the establishment of complicated grief as a “distinct clinical entity” (p. 613). Prigerson and Jacobs suggest that symptoms can be conceptualized as falling into the two categories – symptoms of separation distress and symptoms of traumatic distress. The evidence also supports the designation of complicated/traumatic grief as a diagnostic entity distinct from normal grief, bereavement-related depression and anxiety and post-traumatic stress disorder. Studies also suggest that bereaved individuals with high scores on measures of complicated/traumatic grief have poorer mental and physical health than those with low scores on such measures (Prigerson et al., 1997). Consensus criteria for traumatic grief as a distinct

disorder have been developed and subjected to preliminary empirical tests (e.g., Prigerson et al., 1999).

Stroebe et al. (2000) also evaluate available evidence and suggest that further research is needed, both on “pathological” grief (as they term it) as a potentially distinct clinical entity and on the possible ramifications of the incorporation of pathological grief into formal systems of diagnosis and classification.

Recent empirical research on traumatic/complicated grief by Prigerson and colleagues (Prigerson et al., 2001) explores the relationship between traumatic grief, disability and the underutilization of health services in a sample of widowed persons. Twelve per cent of the sample (110 participants, 91 of whom completed all measures) received a diagnosis of traumatic grief. Characteristics that distinguished participants who met criteria for traumatic grief from those who did not were the presence of a major depressive episode and high blood pressure. Those who met criteria for traumatic grief had adjusted mean functional disability scores five times the adjusted mean for those without traumatic grief. After controlling for age, sex, high blood pressure, major depressive episode and functional disability, participants who met traumatic grief criteria were significantly less likely to access any form of health care (inpatient, outpatient, mental or physical).

Ott (2003) also investigated the relationship between complicated grief and mental and physical health in a sample of individuals who had lost a spouse between three months and 18 months prior to entering the study. The sample included 94 widows and 24 widowers (mean age of slightly less than 61 years, 97 per cent white) who remained in the study at the six-month assessment. Of these participants, 26 per cent met criteria for complicated grief at all three time points (entry into study, three-month assessment, six-month assessment). They did not differ from the group that did not meet criteria for complicated grief on sociodemographic measures or participation in professional counseling or grief support groups but identified significantly more life stressors and less perceived social support. The results indicated that those in the complicated grief group experienced a significant decrease in mental health, a decreased sense of well-being, decreased functioning in life roles and an increase in problematic symptoms compared to the group that did not meet criteria for complicated grief.

## Bereaved parents

The death of a child may lead to more intense grief than the loss of a spouse or parent (e.g., Christ, Bonanno, Malkinson, & Rubin, 2003). Recent comprehensive reviews of research on parental response to the loss of a child indicate that bereaved parents may be at risk of developing complicated grief (Christ et al., 2003). Increases in anxiety and other types of distress are common in bereaved parents who lose children at any point in the life cycle, with the effects of loss moderated by time since the loss and by gender of the parent (Rubin & Malkinson, 2001). Other problems that have been described as occurring between parents after the death of a child include conflict and anger, breakdown in communication, differences in grief intensity and expression

between women and men and low levels of intimacy (Christ et al., 2003). The maintenance of some type of continuing connection or bond with the child is common (Rubin & Malkinson, 2001).

Rubin & Malkinson (2001) observe that

Ultimately, there are no significant deaths that are not in and of themselves notable risk factors because of their ability to derail a life trajectory and to distort adequate functioning. Yet among bereaved individuals are many who find within themselves and their surroundings the requisite support and resources to reorganize their lives following the death of their loved child (pp. 232-233).

This observation is echoed by the findings of Murphy et al. (1999)<sup>6</sup> who studied the health, health behaviors and health care utilization of parents in 204 families following the death of a child by accident, homicide or suicide (see also the section on Loss through violent means below). Longitudinal data were provided by 155 parents (106 mothers and 49 fathers) who ranged in age from 32 to 61 years (mean 45 years); 86 per cent were white. At one year post-loss, 81 per cent of mothers and 85 per cent of fathers rated their health as good-to-excellent, and 20 per cent of the parents reported being in poor health, compared with 16 per cent of adults of comparable age in a national sample. Mothers who rated their health as poor were 11 times more likely to report mental distress than mothers who reported their health as good-to-excellent. Fathers in poor physical health were 15 times more likely to experience other negative outcomes, including mental distress and symptoms of trauma. Mothers reported making more physician visits and higher use of medication than fathers, but the rates of both for mothers decreased over time while rates for fathers remained constant. More than half of the mothers (60 per cent) and 36 per cent of fathers sought some form of counseling. Mothers' reports of engaging in health-protective behaviors were significantly associated with fewer-stress related illnesses, days absent from work and non-productivity at work.

A study of mental health outcomes in the same sample (Murphy et al., 2003) indicated that parents felt it took three or four years for them to put their child's death into perspective (the cause of death did not influence this). Parents of children who died by suicide were more likely to accept the death than parents of children who died by homicide or accident; parents of children who died by homicide had significantly higher levels of symptoms of post-traumatic stress disorder. Marital satisfaction decreased over time for parents regardless of the cause of the child's death and reached its lowest levels five years following the death.

The conclusions that can be drawn from these studies are limited by the lack of a comparison group (the sample was recruited for participation in an intervention) and collection of data from before bereavement. However, the results suggest that further investigation of the factors associated with poor parental health following the violent death of a child is warranted to tease apart the relationships between poor health and significantly elevated risks of mental distress and poor

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<sup>6</sup> Although it was reported prior to 2000, this study is included here because of its specific focus on physical health outcomes.

adjustment in both mothers and fathers. Further study of differences in the reactions of fathers and mothers, and in responses to different types of deaths, also seems warranted.

## Pregnancy loss and perinatal loss

Van & Meleis (2002) examined coping with grief after involuntary pregnancy loss in a sample of 74 African-American women (average age of slightly less than 32 years, 60 per cent married or living with a partner). Respondents reported that they perceived their involuntary pregnancy loss (IPL) as the loss of their baby rather than the loss of their pregnancy and that they coped with their loss by using self-help strategies such as deliberately connecting with others and relying on their religious and spiritual beliefs and practices. Responses also indicated that memories of the baby helped participants deal with their grief.

Meaning-making and attachment in perinatal bereavement were examined by Uren & Wastell (2002) in a cross-sectional study of 109 Australian women who experienced the loss of a child either through stillbirth or neonatal death. At the time of assessment, the length of time since the loss ranged from two months to 207 months; the loss for 33 per cent of participants had occurred within the past 12 months. Psychological distress, symptoms of perinatal grief, spiritual orientation, responses to trauma and attachment-related aspects of phenomenological experience were among the factors assessed. Most of the participants (77 per cent) reported that the death of their baby led to a marked decline in their ability to function, and 91 per cent saw the death as the worst thing that had ever happened to them; however 68 per cent also reported that they were able to attribute something positive to the experience. There was considerable variation in reports of searching for meaning in the loss, and attempts to make meaning of the loss diminished over time. Many of the participants felt that their social environment did not provide them with permission to grieve.

Rich (2000) studied the impact of post-pregnancy loss services on grief outcomes in perinatal bereavement in cross-sectional survey study of 249 women and 114 men (partners). Slightly more than half (54 per cent) of participants were recruited from perinatal bereavement support groups. Participants had experienced from one to 14 pregnancies resulting in one to 12 losses. Length of pregnancy ranged from 30 to 42 weeks. Almost all of the participants (95 per cent) were white; mean age was slightly more than 32 years. Symptoms of perinatal grief, use of post-loss services and actual and preferred timing of service use were assessed. Social support services were received by most participants, but there were gender differences in the receipt of services such as talking with a doctor to review the reasons for the loss of the pregnancy and receiving counseling, with more women than men receiving these services. Mothers' perinatal grief scores were higher than fathers, and were predicted by different factors, suggesting that there is important gender differences in response to perinatal loss that should not be ignored.

## HIV/AIDS, coping and post-bereavement adjustment

Folkman and colleagues (see e.g., Folkman, 2001) have carried out a program of research investigating coping and loss in a sample of gay and bisexual men in the San Francisco Bay area. In a recent study (Moskowitz, Folkman & Acree, 2003), the role of positive psychological states in recovery from bereavement was examined in a sample of 86 men who had at least three years of post-bereavement follow-up in the study. The average age of participants was 39; 29 per cent were HIV+ at entry into the study (none seroconverted over the course of the study). Measures used in the study were: depressive mood, positive state of mind, positive and negative life events, resources (including education, income, social support, optimism, religiosity and positive aspects of caregiving), physical health, loss and coping. Outcomes were defined as the time it took for individuals to return to a normative level of symptoms of depression and normative levels on the scale assessing positive states of mind. High levels of optimism and positive states of mind and low levels of the use of the coping strategy of cognitive escape and avoidance at one month post-bereavement were associated with more rapid declines to normative levels of symptoms of depression. High levels of positive states of mind and the use of the coping strategy of distancing at one month post-bereavement were associated with a more rapid increase in levels of positive states of mind to normative levels. The authors suggest that the ability of bereaved individuals to achieve positive psychological states shortly after bereavement may have a greater effect on recovery than does depressive mood experienced at the same time and that positive states of mind may offer some protection against the elevation of depressive mood over long periods.

AIDS-related grief and coping with loss were studied by Sikkema and colleagues (Sikkema et al., 2003) in a cross-sectional study of 268 participants (65 per cent men; 54 per cent African-American, 27 per cent white, 13 per cent Latino; 46 per cent diagnosed with AIDS). Participants reported knowing, on average, 30 loved ones and friends who had died from AIDS; 41 per cent identified their spouse or partner as their primary loss, which had occurred (on average) about 40 months prior to the study. Grief symptoms, symptoms of depression, stress associated with traumatic experiences, mood, health status, substance use, social support and coping were assessed. Non-whites reported significantly higher grief reactions than whites. They were also more likely to use avoidance coping in response to the loss of a loved one. In general, the use of escape-avoidance and self-controlling coping strategies were associated with higher levels of grief symptoms after adjusting for background and psychosocial characteristics, as were loss of a spouse, loss of a close family member, history of injection drug use and depressive symptoms. The authors suggest that the findings support the development of interventions for coping with AIDS-related bereavement in people living with HIV that focus on the reduced use of avoidant coping strategies.

## Loss through violent means

The loss of loved ones through violent means (e.g., suicide or homicide) has been hypothesized to be potentially more traumatic than bereavement through other causes of death.

Harwood and colleagues (Harwood, Hawton, Hope & Jacoby, 2002) investigated in a longitudinal case-control study the grief experiences and problems with legal procedures experienced post-bereavement by relatives and friends bereaved through the suicide of an older person (aged 60 or older). Participants were primarily middle-aged women (60 per cent, mean age slightly less than 55 years); 45 per cent of participants were children of the deceased, 20 per cent were friends, 19 per cent were spouses, 11 per cent were siblings and 6 per cent had other relationships with the deceased; controls were age- and sex-matched with cases and had been bereaved by the death of a person 60 years or older through natural causes. Levels of depressive symptoms were similar in the suicide-bereaved group and those bereaved by natural causes. However, problems with the coroner's office and with media coverage of the inquest resulting in distress were reported by 42 per cent and 39 per cent of the sample, respectively.

Cerel, Fristad, Weller & Weller (2000) studied parental and family functioning in 15 families bereaved by suicide of one parent. These families were compared to families in which a parent died by reasons other than suicide or homicide. Assessments of symptoms of psychopathology in surviving parents indicated that suicidally bereaved parents did not differ from non-suicidally-bereaved parents in reports of psychopathology; surviving parents in both groups experienced mild depression at one month post-loss and reported declining symptoms of depression over time. Suicidally bereaved families were found to be more impaired than non-suicidally-bereaved families on four indices of family stability, including marital status and previous mental health interventions for any family member.<sup>7</sup>

Meaning-making by individuals who had lost a loved one by homicide was investigated in a qualitative study by Armour (2003). Thirty-eight participants from 14 families were interviewed 18 months to 23 years after the homicide of their family member (mean of 7.5 years). Armour found that a central theme of meaning following loss by homicide was "the intense pursuit of what matters" (2003, p. 519). Meaning was created for the bereaved by declaring truth, fighting for what is right, and living in ways that "benefit others or give significance to the survivor's life" (2003, p. 534).

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<sup>7</sup>Readers are also referred to a summary of recent workshop sponsored by the Office of Rare Diseases, NIH, the National Institute of Mental Health and the American Foundation for Suicide Prevention that provides an overview of research on the suicidally-bereaved. The summary can be accessed at [www.afsp.org](http://www.afsp.org).

## Loss through terrorism

Silver and colleagues (Silver, Holman, McIntosh, Poulin & Gil-Rivas, 2002) examined psychological responses in response to the terrorist attacks of September 11, 2001 in a Web-based survey. Data were gathered within the first month of the attack and at two months and six months following the attack; full longitudinal data were available from 787 adults living outside of New York City. Mental and physical health history, the occurrence of stressful events prior to September 11, global distress, the use of coping strategies and other data were gathered. Very few of the participants (4 per cent) experienced direct loss as the result of the attacks and only 2 per cent reported direct firsthand exposure; 38 per cent reported no direct firsthand exposure and 60 per cent reported watching the attacks occur live on television. After adjusting for pre-September 11 mental and physical health, the odds of experiencing high levels of symptoms of post-traumatic stress were associated with gender and the use of specific coping strategies. Women and persons who used strategies such as denial or disengagement from coping were more likely to experience high levels of symptoms. The use of specific coping strategies was also associated with the odds of experiencing global distress after adjusting for pre-September 11 mental and physical health and other factors. Individuals who reported using active coping were more likely to report lower levels of distress during the six months following the attacks. The results indicate that the potential psychological effects of a major national trauma are not limited to individuals who directly experience the event or experience loss from the event. The use of specific coping strategies is associated with reports of symptoms over time following the event.

## *Research on children and adolescents*

Recent reviews of theory and research regarding bereavement in children (Oltjenbruns, 2001) and adolescents (Balk & Corr, 2001; Christ, Siegel & Christ, 2002) highlight the critical importance of taking a developmental perspective in investigating and understanding the effects of bereavement and grief. It is also important to consider the relationship of the child to the deceased – children can be bereaved by the loss of parents, siblings, grandparents and other relatives, peers or friends.

Oltjenbruns has observed that the research on outcomes related to children's bereavement is inconclusive and often contradictory, in part due to serious methodological shortcomings (2001). She cites the Harvard Childhood Bereavement Study (e.g., Silverman & Worden, 1992) of children following the loss of a parent as stronger methodologically than many others in the field. Results from this program of research indicate that the child's gender and age at bereavement, in combination with factors such as the gender of the parent who died and the suddenness of the death, affected outcomes such as children's emotional experiences, their efforts to maintain a connection to the deceased parent, their involvement in social networks and changes in family routines. Differences between bereaved children and non-bereaved controls in outcomes such as anxiety, social problems, social withdrawal and lower self-esteem tended not to appear until two years post-loss (Oltjenbruns, 2001, p. 185).

Some studies of sibling loss suggest that bereaved children may experience feelings of isolation and feeling different from peers, and that they are at greater risk for externalizing and internalizing problems in the two years following the death. Parent reports also indicate that siblings may have problems with sleeping, nightmares, anxiety and symptoms of post-traumatic stress (Christ et al., 2003, pp. 563-564). Oltjenbruns also observes, however that “[d]ifficult and challenging as the grief experience is, most children seem to have the capacity to deal effectively with loss” (2001, p. 180).

Balk & Corr (2001) observe that research on bereavement in adolescents has had a short history and there is little empirical literature available regarding the effects of loss, especially with regard to the loss of friends and peers and that existing research is limited by reliance on cross-sectional designs gathering retrospective data. The available research indicates, however, that adolescents who have lost parents or siblings report experiencing psychological distress and problems in peer relationships. One difficult issue for bereaved adolescents appears to be that few of their friends and peers are willing to talk about bereavement and loss, raising questions for the person bereaved about how to respond when their grief is ignored (Balk & Corr, 2001).

No empirical studies focusing exclusively on bereavement and grief in children or adolescents were identified for inclusion in this review.

### *Summary and conclusions*

The number and variety of outcomes investigated (and diversity in the research designs and measures used) in research on the possible physical and mental health outcomes associated with bereavement make it difficult to draw definitive conclusions regarding potential associations between uncomplicated bereavement and negative outcomes. As observed by Lindstrom (2002):

The field of bereavement research is ... complicated by the fact that the losses are varied: spouse/parent/child/relative/friend; sudden/expected; accident/natural/inflicted/self inflicted; and that cultural norms and religious/philosophical convictions also are parts of the intricate field of bereavement. Any investigation would have to take these factors into consideration (p. 19).

Taking all of these factors into consideration when conducting research represents a huge challenge both in intellectual terms and in terms of the resources required, and the benefits in knowledge that would derive from meeting these challenges remain an ideal yet to be realized.

However, existing research suggests that uncomplicated (“normal”) bereavement is not associated with enduring negative consequences for most people (see also Chapter 2).

Symptoms of traumatic distress have been identified as a principal element of complicated (or traumatic grief), indicating that poor psychological outcomes are part of complicated grief by definition. A growing body of work on complicated grief indicates that individuals experiencing

complicated grief also may be at increased risk for poor physical health outcomes. Additional research is needed, however, to clarify the nature of these associations and to identify the specific psychological and biological pathways through which complicated grief is expressed in poor physical health outcomes.

Although the quality of research on bereavement and health and physical outcomes has improved since the publication of the IOM report in 1984, serious methodological problems continue to characterize much of the research in this area.

Among the most serious of the problems that limit the generalizability of the findings of research on bereavement and physical and mental health outcomes is the nature of the samples studied: Most studies of bereavement and grief outcomes (still) have been primarily of middle-aged or elderly white women. There have been very few studies of people of color or people from diverse cultural backgrounds, or representative of other types of diversity (e.g., socioeconomic status, sexual orientation).

Additional methodological problems that continue to plague research on bereavement outcomes includes high attrition; demographic differences between cases and controls; differences in length of time since loss; recruitment techniques that lead to biases in sample characteristics; and a variety of other problems that have been characterized elsewhere.

Priority areas for continued research and theoretical clarification that were identified by members of the Scientific Advisory Committee of the Grief Research Project (CFAH, 2001) include<sup>8</sup>:

- The relationships and interactions between physiological, behavioral and support mechanisms in shaping bereavement experience, and in placing some bereaved persons at greater risk.
- The relevance of pre-loss experience, caregiving, marital quality, family conflict and other related factors to bereavement reactions and experiences.
- The ways in which circumstances of the death may shape bereavement experiences.
- The nature and structure of effective coping in adaptation and recovery (sorting out such components as meaning-making, appraisal mechanisms, and loss- vs. restoration-focused coping).
- Theoretical formulations of traumatic grief, complicated grief, stigmatized grief, and the implications of each for assessment, prevention and treatment.
- The need for more nuanced understanding of the implications of who it was that died (e.g., parent, child, spouse, sibling, partner, caregiver, friend) for bereavement.
- The need for further purposeful specification of developmental influences on the nature and implications of bereavement across the lifespan, isolating and relating critical developmental variables, processes and patterns.

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<sup>8</sup> The authors thank Robert Hansson for his contributions to this section.

- The need for more purposeful identification and consideration of potential resilience and protective factors.
- The need for a more structured understanding and empirical verification of the efficacy of prevention and intervention strategies.

Other specific research recommendations that may contribute to advances in knowledge regarding physical and mental health outcomes associated with bereavement are outlined in Chapter 9.

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# Health Care Professionals and Health Systems Issues

Most deaths in the United States occur in health care facilities, primarily hospitals, nursing homes and hospice facilities. This means that providers in the health care system are likely to be the point of first contact for bereaved individuals and families who may need care.

The 1984 Institute of Medicine report included a chapter on the Roles of Health Professionals and Institutions in caring for the bereaved. The chapter did not review the empirical evidence related to this topic – there was none available at the time. However, the Committee did identify factors that limited the attention paid to bereaved persons by health care professionals, offered practical guidance and made recommendations for future research.

It is encouraging that we have found quantitative and qualitative empirical research to review that pertains to the education and training of health care professionals; their reactions to bereavement, the stresses associated with providing care to dying persons and bereaved persons; and the provision of services to bereaved persons in health care settings. However, very little research has been conducted in these areas, both in absolute terms and relative to the amount of research that has been conducted on other aspects of bereavement subsequent to the publication of the IOM report on bereavement in 1984. In addition, research on bereavement and health professionals and institutions has lagged behind the field of bereavement research in general in terms of quality and methodological rigor.

The literature review processes used to identify the research reviewed here are described in Chapter 4 of this report. Thirty-six studies were deemed to be of sufficient quality and pertinence to the topics addressed here to merit the development of evidence summaries. These evidence summaries can be found in Appendix B. Information drawn from a subset of these studies is presented in this chapter; the research described here represents the studies of highest quality available from the pool of identified literature.

## *Education and training of health care professionals*

### Education and training regarding end-of-life issues

The education of health care professionals regarding bereavement care is often wrapped into education regarding end-of-life issues in general. Studies in which bereavement education is the primary focus of investigation are rare. Two descriptive studies of the education and training of physicians in issues related to end-of-life care indicate that although medical schools and

practitioners themselves consider these topics worthy of study, there are significant gaps in education and training.

Dickinson & Field (2002) surveyed 112 academic deans at medical schools in the United States and 23 preclinical deans or directors of medical education in medical schools in the United Kingdom on teaching about end-of-life issues. More than 70 per cent of schools in both countries reported that they covered end-of-life topics including: attitudes toward dying and death; communication with dying patients and their families; grief and bereavement; psychological aspects of dying; analgesics for chronic pain; and advance directives. However, only 18 per cent of medical schools in the United States and 13 per cent of schools in the United Kingdom offered a separate course on death and dying. In 13 per cent of schools in both countries, issues related to the end of life were covered in just one or two lectures.

Barclay, Wyatt, Shore, Finlay, Grande, & Todd (2003) studied general practitioners in Wales to ascertain how well prepared they are to care for the dying. They asked respondents to indicate the training they had received during four career stages (clinical medical student, junior hospital doctor, general practitioner trainee and general practitioner principal). The sample for the study comprised 590 general practitioners randomly selected from the lists of the Health Authorities covering Wales; overall response rate for the study was 68 per cent. The investigators found that training in bereavement care and communication was more common in later years of practice than in medical school or during the junior hospital doctor stage of training. Fewer than half of respondents received training in bereavement care (43 per cent) or communication (47 per cent) as medical students, and only 23 per cent reported receiving training in bereavement care or communication during the junior hospital doctor years. However, 70 per cent reported that as general practitioner trainees they received training in bereavement. General practitioner principals are responsible for their own training. Two thirds of GP principals reported that in their self-selected training they covered all five aspects of palliative care included in the survey (pain control, control of other symptoms, use of syringe driver, communication skills and bereavement care).

## Education and training of health care professionals regarding recognizing and acting on the signs and symptoms of bereavement-related problems

Substantial work has been conducted in the development of diagnostic criteria and diagnostic instruments to be used in the identification of complicated grief and in distinguishing complicated grief from bereavement-related depression and anxiety. However, to date there is no published empirical research on the use of screening tools (for use, for example, in primary care settings) to help identify individuals experiencing or at risk of bereavement-related problems. There is also no published empirical research on the education and training of health care professionals in the area of the identification of individuals at risk for experiencing complications of bereavement.

## *Summary*

There is a recognized need for special education and training for health professionals in caring for bereaved persons (see, e.g., Wright, Johns & Joseph, 2003). However, studies of good quality that specifically address the availability of such education and training are very rare and most have focused on physicians. The available studies indicate that many health professionals have received no training in this area. Of those who did receive training, many felt that it was inadequate. The United Kingdom may be somewhat more advanced in the provision of such training to physicians at specific stages of their careers. Results from the small number of studies conducted indicate that health care providers would like to have more training regarding bereavement and the care of bereaved persons.

### *Health care providers attitudes and emotional reactions*

#### Loss and grief experienced by health care professionals

The effects of working with dying patients and caring for bereaved persons have been investigated in both quantitative and qualitative studies of varying quality. In many cases, the effects of loss and grief have been investigated as part of more general studies of stress or “burnout” experienced by providers caring for dying persons.

In one study specifically addressing grief in health care providers, Redinbaugh and colleagues (Redinbaugh et al., 2003) investigated physicians’ emotional reactions to the death of a patient in a cross-sectional survey using a semi-structured interview and self-administered questionnaire. The original sample for the study comprised 246 physicians at two academic teaching hospitals; 188 physicians (76 per cent) completed an interview. It is important to keep in mind that by far the majority of physicians participating (82 per cent) had not given care to the patient who died prior to hospital admission. Seventy-four per cent of physicians reported that taking care of the patient had been a very satisfying or satisfying experience. Longer care was associated with more satisfying experiences and greater feelings of closeness to the patient.

On average, physicians reported experiencing two out of the 14 grief symptoms about which they were asked. The most commonly reported symptoms were feeling upset when thinking about the patient (reported by 47 per cent) and feeling “numb” (reported by 24 per cent). More than half of the physicians (55 per cent) said the patient’s death disturbed them very little, while about one quarter (23 per cent) said that it was very disturbing. There were no differences in emotional reactions by level of training. Female physicians, however, reported more symptoms of grief than did males. Duration of care was positively associated with the number of grief symptoms reported and with finding the death more disturbing and emotionally powerful.

Most of the physicians (83 per cent) reported that they needed little emotional support from colleagues to cope with the death. However, there were significant differences by level of training –

interns reported needing more support than did attending physicians. In addition, female physicians reported needing more emotional support than did males. About one-third (35 per cent) of physicians reported that their needs for support had gone unmet.

The responses of nursing home staff to residents' deaths have been explored in depth by Moss & Moss (2002). This work suggests that health care providers may experience "disenfranchised grief" (e.g., Doka, 2002) when they feel that their loss is not considered legitimate (by the families of the patients with whom they work, by their institutions or others), and when they feel their relationship with the person who died doesn't give them the right to feel or express grief (Moss & Moss, 2002). Qualitative explorations of the nursing home environment indicate that "[s]taff members carefully monitor their own feelings and expressions in their attempt to reach an appropriate balance between feelings of loss and the expectations of the world of work" and to abide by social and cultural norms in the nursing home environment (Moss & Moss, 2002, p. 206). The authors also suggest that disenfranchised grief has costs, directly for staff members and indirectly for others, such as other staff members and surviving residents in the nursing home. Disenfranchised grief also may have benefits, however, for example in the emotional distance it provides for staff members, enabling them to perform their jobs. Consideration of the nature and effects of disenfranchised grief in health care workers raises questions about the conditions under which grief should be expressed and shared with other staff members, and the ways in which bereaved caregivers can be supported by administrative and managerial staff, among others (Moss & Moss, 2002, pp. 212-213).

Moss and colleagues (Moss, Moss, Rubinstein, & Black, 2003) studied bereavement reactions in nursing home staff through a qualitative examination of their social construction of the meaning of their relationships with dying and deceased residents in two religiously-affiliated, non-profit nursing homes. Interviews were conducted with 26 floor staff (certified nursing assistants, licensed practical nurses and registered nurses). Twenty-four of the participants were female, 20 were African American and 6 were European American, and 18 had worked in their respective facility for 5 years or more. Analyses of the interviews indicated that staff members spontaneously spoke of having "family-like thoughts, feelings, and behaviors toward long-term residents," recounted stories of deaths in their own families and "described how the meanings of resident deaths and family deaths were interrelated" (Moss et al., 2003, p. S290). The authors suggest that the family metaphor provides a means (through a cultural script) for staff members to express their grief. The metaphor of family provides a structure through which staff can understand death and bereavement in the context of the nursing home and helps them connect their personal and work experiences.

Vachon (1987) studied sources of stress in 581 palliative care and hospice workers in Canada, the United States, Europe and Australia. The sample included physicians (38 per cent), nurses (42 per cent), social workers (13 per cent), volunteers (3 per cent), physiotherapists (3 per cent), clergy (2 per cent) and others (9 per cent). Results from this qualitative study indicated that the work environment and occupational role of respondents are major sources of stress. The average number of stressors reported by palliative care staff members was 8.78; this was fewer than the average number of stressors reported by caregivers working in emergency rooms, obstetrics, intensive care units and chronic care, but greater than the average number reported by staff working in oncology units,

pediatric chronic care and pediatric intensive care. Communication problems with others in the system, with team members, with administration, and with patients and their families comprised 4 of the 10 most frequently cited specific stressors. Other commonly stressors included role ambiguity and role conflict. One finding specifically related to caregivers' own feelings of loss or grief was that the length of time clients were in the program appeared to affect the degree of stress experienced by staff when the patient died.

Other qualitative studies of nurses' experiences in caring for dying individuals, and their responses to this work, also do not focus specifically on the bereavement and grief experienced by nurses but consider this as part of an array of emotional responses. One study of 23 nurses working in a medical center specializing in cancer care found that the nurses appear to be driven by a deep concern for patients and families that creates a great deal of stress when poor staffing, excessive use of registry nurses and other circumstances make it more difficult to provide the highest-quality nursing care (Cohen & Sarter, 1992). Similarly, nurses caring for terminally ill patients in a nursing home had high expectations of the type of care they should provide and identified both positive and negative effects of caring for a dying resident (Irvin, 2000). Forming a meaningful relationship with the patient was important, and nurses reported that their personal and past experiences of the death of a family member often affected their relationship with the resident and positively affected the resident's care. Stressful aspects of such work included organizational constraints such as lack of time and frustration with the attitudes of physicians. Nurses in this study also expressed a need for support as a means of coping with the stresses involved in caring for dying patients (Irvin, 2000).

### Health care professionals' death concerns and anxiety

Carr & Merriman (1996) compared the death attitudes of a convenience sample of 106 hospice workers and 76 hospital personnel, who completed the Death Attitude Index and the Templar Death Anxiety Scale. They found that hospice workers reported more comfort with death than did hospital workers. However, death attitudes and anxiety also varied by discipline and education: nurses' aides in both settings had the highest levels of anxiety and were the least comfortable with death. Nurses in the hospital setting were not as comfortable in dealing with dying patients as hospice nurses. The investigators also found an effect of training on death attitudes: Personnel who had participated in a seminar or had received training on death and dying reported being more comfortable with death compared to those who had not received training.

Kirchberg, Neimeyer & James (1998) studied the death concerns and empathic responses of beginning counselors to client situations involving death and grief. Fifty-eight masters-level counseling students completed scales including the Multidimensional Fear of Death Scale and the Carkhuff Rating Scale for empathic understanding; participants also viewed and responded (written responses) to eight videotaped enactments of client situations in which the presenting problem was either death-related or non-death-related.

Participants in the study reported significantly greater discomfort in responding to situations involving death and dying than to the situations that were also serious but not relevant to death. Participants with higher levels of personal fear of death were also more likely to be uncomfortable with situations involving death and dying. Respondents were found to be significantly (but only slightly) more empathic in responding to the death-relevant client situations, but the levels of empathy exhibited were low overall. Investigators also found that beginning counselors with a higher sense of fatalism, a subfactor suggesting despair in the face of death, were likely to score lower in terms of empathy.

## Interventions with health care professionals to lessen their bereavement-related distress

Very few studies have been conducted of services provided to health care professionals to help them deal with distress they may experience related to bereavement. The studies that have specifically examined the effects of interventions on health care professionals' distress (as distinct from studies simply describing what types of services are available) are of limited quality, primarily because of problems with research design (e.g., no control or comparison groups) and sample bias. Results of these studies (see Appendix B) indicate that providers are generally satisfied with the support group interventions in which they participate, but that participation does not affect "burnout" or reported levels of stress. More rigorous research is needed, however, before conclusions can be drawn about the effects – positive or negative – of interventions with health care professionals to reduce their bereavement-related distress.

## Models of health professionals' grieving process

Information gathered using qualitative methods has been used by investigators to construct models of the grieving process in health care professionals who experience multiple, repeated losses. In separate studies, Papadatou (2000) and Kaplan (2000) interviewed nurses who work with dying children and proposed models of grieving that highlight both the experience of intense feelings of grief by health care professionals and their use of strategies to balance, repress or avoid those feelings to continue to function professionally. Papadatou (2000) proposes a model of grieving that is individual and social-interactive and that involves a process of "fluctuation" between focusing on the experience of loss and moving away from the grief reactions associated with the loss. Fluctuation makes it possible for providers to ascribe meaning to the deaths of individual patients and to recommit themselves to life and their work; the lack of fluctuation may contribute to difficulties such as feeling overwhelmed. Kaplan's (2000) model highlights the "emotional tension" providers experience as they struggle to balance intense feelings after patients' deaths with their desire and need to provide competent care to other patients and families. This balance is central to the ability of providers to continue working in their profession. Health care providers also experience a lack of support – either through the lack of formal support systems in the workplace (Kaplan, 2000) or

from colleagues (Papadatou, 2000) in dealing with their emotional reactions to the deaths of patients and with the emotional intensity of their work.

## *Summary*

Many health care providers experience grief – sometimes profound grief – when a patient dies. Duration of care for a patient is associated with the closeness health care professionals feel toward the patient and tends to increase their feelings of grief. Convergent evidence from several different studies indicates that female health care professionals report more symptoms of grief than male health care professionals. Bereaved health professionals may alternately focus on and avoid feelings of grief as they seek to balance these often intense feelings with their desire to provide good care to other patients. Some studies have found that health care providers who receive education and training regarding death and dying are more comfortable with death. Bereaved health care providers frequently report that they lack emotional support in the workplace.

## *Health care systems issues*

Systems-level issues include the extent to which bereavement-related services are being provided by health care institutions and organizations, the types of services being provided and whether these services are appropriate and sufficient to meet the needs of those being served, including staff. Few studies have focused specifically on bereavement services; most of the research that exists has been conducted on bereavement care provided by hospices.

## Provision of bereavement-related services to individuals and families

Hospices. Data gathered by the National Hospice and Palliative Care Organization (NHPCO, formerly the National Hospice Organization) indicate that, on average, the families of hospice patients receive 3.4 bereavement contacts (home visit, appointment or telephone contacts) from hospice providers (NHPCO, [http://www.nhpc.org/files/public/Facts\\_Figures\\_Jan\\_03.pdf](http://www.nhpc.org/files/public/Facts_Figures_Jan_03.pdf); accessed August 17, 2003).

Lattanzi-Licht (1989) surveyed provider members of the National Hospice Organization to determine the type and scope of the bereavement services offered. Of the provider members responding (268 of 439 surveyed), 89 per cent reported that bereaved family members received personal contacts, which consisted of phone calls by bereavement staff, phone calls by nurses providing care prior to the death, or visits to bereaved persons by bereavement personnel. Group meetings were also provided by about one-quarter of responding programs; this was the type of service that many providers indicated they would increase if resources were available. Most of the hospices (77 per cent) indicated that they used some type of bereavement assessment process to identify individuals who might be at high risk for bereavement-related problems. However, programs indicated that they were

not inclined to provide bereavement services only to individuals identified as being at high risk (NHPCO standards require hospice to follow up with all families for at least 12 months based on need). In addition, hospices reported making relatively very few referrals to outside counseling (on average, about 7 per cent of clients were referred or sought outside counseling). Providers of bereavement services included social workers (36 per cent) and nurses (25 per cent). Survey responses indicated that four times as many volunteers as staff were involved in the provision of bereavement care. Virtually all hospices (93 per cent) reported offering initial general training for all caregivers.

In a statewide survey of California hospices, Foliart, Clausen & Siljstrom (2001) found that all of the hospices responding (131 of 160) indicate that they offer telephone support, scheduled mailings, grief brochures and pastoral care as part of their bereavement services, and most (89 per cent) provide bereavement services at no charge. No clear relationship was found between the size of the hospice and the bereavement services offered.

Primary care settings. Payne and colleagues (Payne, Jarrett, Wiles & Field, 2002) conducted a qualitative study of counseling strategies for bereaved persons in primary care settings in the United Kingdom. The 29 counselors participating in the study estimated that their involvement in bereavement care ranged from 3 per cent to 50 per cent of their case load (mean 13 per cent). Almost all of the counselors (90 per cent) indicated that bereavement-related counseling made up 20 per cent or less of their case load. Counselors were asked about the models of bereavement they used, the styles of counseling used, communication within the primary care health team about bereaved patients and referrals. Responses from counselors indicated that they often drew on concepts of stages, phases and/or tasks of bereavement but they recognized that grieving was an individual process and they did not necessarily use stage models in working with clients. Slightly more than a quarter of respondents (28 per cent) indicated that they believe it is useful to identify normal stages for clients. Few counselors made reference to theoretical sources or “name” authors. They reported drawing on a variety of broad conceptual approaches to counseling bereaved persons, including person-centered, psychodynamic and non-directive counseling. Counselors reported that referrals of bereaved individuals by general practitioners to professional counselors are relatively rare.

Main (2000) studied recently bereaved patients’ perceptions of and satisfaction with the care they and their deceased loved received from a single general practice in the United Kingdom. Respondents were 23 patients (all over age 60, 74 per cent women) who had been bereaved at least six months and did not have health problems associated with their bereavement. Most respondents felt that communication with the general practitioner and hospital had been adequate and reported that the manner of the health service staff had been comforting and supportive. For respondents whose bereavement was acknowledged by their general practitioner, most reported appreciating it and felt it was proper that the practitioner had brought it up. Respondents who reported that there had been problems in communication were able to recall exact remarks and remained upset about them. The majority of those participating felt communication and contact from the general practice office with people who had been recently bereaved was important and should happen. Some respondents reported that they were upset when their bereavement was not mentioned by their

general practitioner because they felt unable to bring it up unless the physician mentioned it, and this precluded them from asking questions.

Nursing homes. Moss and colleagues (Moss, Braunschweig, & Rubinstein, 2002) surveyed 400 nursing homes regarding the terminal care provided to residents with dementia and care provided to families during the end-of-life period and following the death. In extensive qualitative interviews with a subset of 50 of the facilities, they found that 11 had held funerals on site in the past year, but that administrators in general preferred that funerals be held off site. Holding memorial services on site was more positively regarded by respondents, however fewer than half of the sites participating in the qualitative interview reported that they had held any memorial services in their facility in the past year. Best practices in terminal care of residents with dementia reported by the facilities included “staff treats resident like family” (reported by 48 per cent of facilities) and providing “emotional support for the family” (reported by 30 per cent of facilities). Least good practices reported included the “training of staff specifically around care of dying residents with dementia,” which was cited by 63 per cent of facilities as an area that was least well handled, and “training the staff around issues of death and dying” (35 per cent). Murphy, Hanrahan & Luchins (1997) surveyed 111 nursing homes in the lower peninsula of Michigan to determine the type of grief and bereavement care being offered. They found that the services being offered were extremely limited. Although more than half (55 per cent) of the homes sent sympathy cards to family members after a death, and 44 per cent went to the funeral home or funeral of a patient who died in the facility, almost none (1 per cent) of the facilities visited, made phone calls or provided materials on bereavement or the grieving process to the primary caregiver or family. The facilities (99 per cent) also did not provide information about bereavement support group meetings available on site or in the community.

Sidell et al., (1998) reported that very few residential and nursing homes for older persons in the UK used the services of bereavement counselors, and we know of no systematic study of use (*vis a vis* availability) of bereavement counselors in US nursing homes.

## Systems-level needs assessments

Llamas and colleagues (Llamas, Llamas, Pickhaver & Miller, 2001) investigated staff perceptions of the palliative care needs of cancer patients and their own needs for education and training (including training regarding bereavement care). The extent to which those needs were being met by existing services was also assessed. The study was conducted with a convenience sample of all clinical oncology staff in a large Australian hospital, with responses from 83 per cent of staff (221 nurses, physicians, radiation therapists and other allied health professionals). The results indicate a desire on the part of staff to provide comprehensive care, but also gaps in terms of the training and support they receive to make that care possible. Most respondents (91 per cent) believed that palliative care should be a fundamental part of the care of cancer patients, but only 24 per cent had received any formal palliative care education. Two-thirds of respondents (66 per cent) characterized inadequate palliative care education as a critical problem and 93 per cent said they would like additional education in this area. Almost half (45 per cent) said that they had needed emotional

and/or spiritual support at least once in the past six months because of issues arising from the care of terminally ill patients. A majority of the staff was either unaware of available formal support services, such as a staff counselor, or did not perceive such services as sources of support, and 79 per cent indicated that there was a need for improved formal mechanisms of staff support.

## Interventions to change management and/or organizational practices related to staff functioning and distress

No peer-reviewed empirical studies were found in this area.

### *Summary*

The available evidence suggests that hospices provide bereavement care on a regular basis that incorporates a variety of elements, including pastoral care, written information and contacts by telephone or in person. Research on services by other types of facilities, however, is limited and no conclusions can be drawn about the nature or adequacy of the care provided to bereaved individuals and families because so little information is available.

Interventions to change management and organizational practices related to staff functioning and distress either are not being undertaken or are not being formally evaluated. Interventions to address health care providers' responses to loss and bereavement are also relatively rare. In terms of the needs of staff for support and other types of services, the little information available suggests that few services are available or utilized, and that communication between systems of care and staff regarding available services needs improvement.

### *Policy issues*

Who should provide care for bereaved persons?

There is a substantial literature presenting non-empirically derived or evaluated practice guidelines that suggest that many different people can and should care for bereaved persons. This literature is not reviewed here. The empirical literature reviewed for other sections of this report indicates that many types of professionals, including physicians, nurses, clergy, social workers, and hospice volunteers, can and do provide bereavement care. However, no peer reviewed empirical comparisons of the effectiveness or cost-efficiency of different types of providers, or combinations of providers (e.g., the use of care teams) were found specifically pertaining to the provision of bereavement care.

## What are the economic costs of grief?

Prigerson and her colleagues (Prigerson, Maciejewski & Rosenheck, 2000) examined the relationships among widowhood, marital harmony, health service use and health care costs in respondents drawn from a larger, nationally representative sample of adults participating in the Americans' Changing Lives study. Sixty-one of the 755 respondents studied were widowed; this group was significantly older, more likely to be female, of lower SES at baseline and less likely to have health insurance coverage at follow-up than the respondents who were still married during the study period. The widowed group (who had been widowed at some point in the prior three years) had higher mean levels of depressive symptoms, number of chronic conditions and functional disability at follow up after adjusting for baseline characteristics. The widowed group also averaged higher numbers of physician visits and days spent in a nursing home, and averaged higher estimated health care costs in 1989. Marital harmony moderates the relationship between widowhood and health care costs in this sample, however: Estimates of adjusted total health care costs and adjusted outpatient costs were significantly higher for widows who reported having harmonious marriages than for widows who reported that their marriages were discordant.

We were unable to find any peer-reviewed publications estimating the economic impact of grief on the economy in general. One estimate of the economic impact of grief on American business has been published by The Grief Recovery Institute Educational Foundation, a non-profit organization that creates and establishes programs for individuals and organizations to promote recovery from losses of all types. (The Grief Recovery Institute Educational Foundation, 2003). The cost factors used in calculating the "Grief Index" developed by the Grief Recovery Institute Educational Foundation include population statistics (births, deaths, divorces); estimates of lost effective work time; estimates of lost productivity; estimates of lost sales; estimates of accidents and illnesses affecting work time; estimates of business losses as the result of poor decision-making; employee wage and benefit statistics; and costs of training, retraining and replacing personnel. The estimate derived for the "hidden annual cost of grief in America's workplace" related to the death of a loved one is \$37.5 billion, based on an assumption of one primary workplace griever for each death. The estimated annual hidden cost of grief related to the death of extended family members, colleagues and friends is \$7 billion. These estimates must be considered preliminary and interpreted and used with caution pending replication and further research.<sup>9</sup>

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<sup>9</sup> Readers interested in economic policy-related issues such as employers' bereavement-related leave policies and payment for bereavement care are directed to Dr. Stephen Connor, Director of Research at the National Hospice and Palliative Care Organization, [www.nhpc.org](http://www.nhpc.org) for additional information.

## *Summary and conclusions*

Improving care for bereaved individuals and families requires deeper knowledge and understanding of the role of health care professionals and institutions in providing such care. A small body of research on bereavement and health care providers, and more broadly, on bereavement in the health care system, has been conducted subsequent to the publication of the IOM report in 1984. This research represents a step forward in knowledge about bereavement and the health care system. However, very few studies have been carried out in this area in comparison to the amount of research that has been conducted since 1984 in other areas.

Although the quality of research on bereavement, health care providers and health care systems has improved, basic issues in research design and methodology remain a concern. Limitations include sampling issues, including the almost exclusive use of samples of convenience. In addition, studies of health care professionals have included primarily samples of white providers. Research on samples that are representative of the racial and ethnic diversity in the population of health care professionals (and how this may differ by discipline) is needed, as is research on the possible effects of differences in ‘grief perspectives’ when providers and bereaved persons are from different cultural, racial or ethnic backgrounds.

Anecdotal accounts indicate that most bereaved individuals and families seek support outside the health care system (e.g., from family members, friends and religious/faith communities). Given these patterns, opinions vary regarding the role that health care providers should play in assisting bereaved persons. At a minimum, however, physicians and other health care providers should be capable of responding compassionately to bereaved persons, talking with them and recognizing when some individuals experience complicated grief. They also should be able to assess the likelihood that patients are at risk for or are experiencing problematic grief reactions. Questions that remain open include:

- how do administrators of health organizations and institutions (e.g., hospitals, nursing homes) express and implement attitudes, policies and practices toward bereaved residents, staff and families?
- who should provide what type of more intensive interventions within health care settings?
- what types of education and training are needed to prepare and support health care providers in caring for bereaved persons?
- how should bereavement care provided within the health care system (including the mental health system) be linked to non-medical resources, such as peer support groups and other community resources?

Recommendations for research on these and other health-related issues are presented in Chapter 9 of this report.

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# Interventions

A review of the best evidence available at the time of the publication of the IOM report *Bereavement: Reactions, Consequences, and Care in 1984* led to the conclusion that

. . . very little is known about the ability of any intervention to reduce the pain and stress of bereavement, to shorten the normal process, or to mitigate its long-term negative consequences. While the few controlled studies that have been conducted report contradictory findings, subjective reports attesting to the helpfulness of interventions abound (IOM, 1984, p. 274).

The years subsequent to the publication of the IOM report on bereavement in 1984 have witnessed the development and implementation of a large number of intervention programs for bereaved persons. These interventions vary in terms of strategies used (e.g., group interventions or interventions with individuals) and in terms of the populations targeted (e.g., anyone who has experienced the death of a loved one, those at risk of bereavement complications, those experiencing complicated grief). However, “[t]he basic idea behind offering help is to benefit the bereaved individual, to help him or her to deal with the emotional and practical problems following the loss of a loved one” (Schut, Stroebe MS, van den Bout, & Terheggen, 2001, p. 705), regardless of the type of intervention offered.

Several qualitative and quantitative reviews<sup>10</sup> of research on bereavement interventions have been published recently or are in press (e.g., Ayers & Sandler, 2003; Ayers, Kennedy, Sandler, & Stokes, 2003; Hansson & Stroebe, 2003; Jacobs & Prigerson, 2000; Jordan & Neimeyer, 2003; Neimeyer, 2000; Schut et al., 2001). These reviews comprehensively and exhaustively examine the available empirical literature evaluating the efficacy of interventions for bereaved persons, critiquing the research on theoretical and methodological grounds and examining the strength of the evidence that interventions help bereaved individuals. The primary strategy we have used in this chapter is to “review the reviews” – to summarize information and conclusions drawn from recent published reviews of empirical research evaluating bereavement interventions (see Schut et al., 2001, for a detailed examination of the methodological characteristics and intervention strategies used in this research).

Research on the efficacy of bereavement interventions has been categorized by some reviewers (Schut et al., 2001) using a prevention framework. Interventions are characterized in terms of the population targeted: Primary preventive interventions are open to all bereaved people, to anyone

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<sup>10</sup> Qualitative reviews involve “a scholarly analysis of the existing literature, from which the reviewer draws reasoned conclusions about the state of knowledge in a given area of inquiry. . . [A] quantitative review (or meta-analysis) is a statistical technique (or group of techniques) that allows objective data from many different studies to be combined to produce a numerical answer to the question [of how effective a particular treatment is]” (Jordan & Neimeyer, 2003)

who has experienced a loss through death. For research purposes, primary preventive interventions in some studies have been targeted to specific groups, such as widows. The focus in primary preventive interventions is on those experiencing uncomplicated (normal) bereavement. Secondary preventive interventions are designed to serve people who are at risk for complications of bereavement, for example to people who experience a loss through the suicide or homicide of a loved one. Tertiary preventive interventions are targeted to people who are experiencing bereavement-related problems (e.g., complicated or traumatic grief), and typically consist of psychotherapeutic treatments (Schut et al., 2001).

Findings from reviews of bereavement intervention research are considered first in terms of research on adults and then research on children and adolescents (which may include interventions with their parents as well).

### *Interventions with adults*

#### Interventions with adults experiencing uncomplicated bereavement

A growing body of evidence indicates that interventions with adults who are not experiencing complicated grief “cannot be regarded as beneficial in terms of diminishing grief-related symptoms” (Schut et al., 2001, p. 731; see also Hansson & Stroebe, 2003; Jordan & Neimeyer, 2003; Neimeyer, 2000). Qualitative and quantitative reviews alike have reached the conclusion that there is very little evidence supporting the efficacy of primary preventive interventions such as “crisis teams visiting family members within hours of the loss, self-help groups with the goal of fostering friendship, programs to educate bereaved persons about the tasks of working through one’s grief, cognitive-restructuring and behavioral-skills programs, treatments involving the sharing of information, emotions, and support, and brief group psychotherapy” with adults who are experiencing uncomplicated bereavement (Hansson & Stroebe, 2003, p. 519).

Neimeyer (2000) conducted a meta-analysis of 23 scientifically adequate outcome studies of grief therapy published between 1975 and 1998. To be included in the meta-analysis, studies had to offer a psychosocial intervention (psychotherapy, counseling or facilitated group support) and randomly assign participants (who had to have experienced the death of a loved one) to control and intervention groups (Neimeyer, 2000, p. 543). Two measures were used to characterize the effectiveness of the studies. The first was provided an estimate of the degree of benefit associated with participation in the intervention. The second was an estimate of “treatment-induced deterioration, which represents the proportion of participants who are worse off after treatment than they would have been if they had been assigned to the control group” (p. 544). For participants experiencing uncomplicated bereavement, there was “essentially no measurable positive effect on any [outcome] variable” and “nearly one in two clients suffered as a result of treatment” (Neimeyer, 2000, p. 546). These findings differ from findings for individuals experiencing complicated or traumatic bereavement (see below).

## Interventions for populations at risk: Secondary preventive interventions

The available evidence suggests that interventions for individuals at risk for complications of bereavement may result in some benefit, at least in the short term. Findings are inconsistent, however, and vary based on factors such as the gender of the participants and whether participants were screened for risk before participating in the studies, which appears to increase the likelihood that the interventions would be successful (e.g., Schut et al., 2001).<sup>11</sup>

## Interventions for individuals experiencing complicated (traumatic) grief or depressions of bereavement

Because the concept of traumatic (complicated) grief has emerged in the bereavement research literature fairly recently, no controlled studies exist that pertain directly to the treatment of traumatic grief (Jacobs & Prigerson, 2000, p. 479).

In a meta-analysis of bereavement interventions (Neimeyer, 2000) separately examined studies in which treatment was offered for individuals who were traumatically bereaved (as distinct from studies of interventions focusing on uncomplicated bereavement reactions). These analyses indicated that the studies focusing on interventions for traumatic bereavement “showed a reliable positive effect” and that treatment-induced deterioration was substantially lower than it was found to be in studies of interventions with individuals experiencing uncomplicated bereavement (p. 546).

Jacobs and Prigerson (2000) reviewed evidence from controlled clinical trials of psychotherapeutic treatments conceptually relevant to the treatment of traumatic grief. They suggest that studies of psychodynamically-oriented treatments and behavioral/cognitive treatments indicate “some proven effectiveness and hold promise for Traumatic Grief” (Jacobs & Prigerson, 2000, p. 488).

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<sup>11</sup> *Additional sources of information on the status of research on interventions with bereaved individuals at specific risk for complications of bereavement*

*HIV/AIDS* – Goodkin et al. (2001) describe findings from a study of a randomized-controlled trial of a bereavement support group intervention with HIV-1 seropositive and seronegative bereaved men, indicating that the intervention had significant beneficial effects on psychological, neuroendocrine, neurological, immunological and virological status that may also have translated into clinical health benefits (p. 692).

*Loss through violent means* – Hatton (2003) examined the value of bereavement interventions for survivors of homicide from the perspective of providers of homicide bereavement counseling. Results indicate that caregivers’ attitudes toward theory-based or clinical interventions are generally consistent with results of outcome studies with trauma survivors. The effectiveness of interventions with suicide survivors was examined as part of a recent workshop on research on suicide survivors (NIMH/NIH & American Foundation for Suicide Prevention, 2003); a preliminary summary report from the conference is available at <http://www.afsp.org/index-1.htm>

*Perinatal loss* – The Cochrane Review found that no randomized trials exist evaluating any type of general support or specialized psychological support or counseling for women and families experiencing perinatal bereavement. Therefore no evidence is available to indicate whether or not providing these types of services after perinatal loss is beneficial (Chambers & Chan, 2003).

Zisook and Schuchter (2001) propose a model for the treatment of the depressions of bereavement that is based on a review of interventions for bereavement-related depressions and relevant treatment studies. They found that there have been no studies of preventive interventions investigating the group that may be at highest risk for post bereavement depression, which comprises individuals who have experienced major depression in the past (p. 789). They also found that very little data have been published on controlled trials of the treatment of bereavement-related depression, whether these are psychotherapy/support treatments or pharmacotherapy. They “strongly advocate that all persons with a recurrent mood disorder facing the imminent or recent death of a loved one be considered for prophylactic treatment. Whether the treatment is antidepressant medication, psychotherapy or both should be individualized for each person” (p. 789) and that “[m]ajor depressions should be actively treated whenever they occur” (p. 790). They suggest that the treatment of choice (psychotherapy, pharmacotherapy or some combination of both) depends on patient characteristics and history because there is no evidence to indicate that there is a single best form of psychotherapy or a single best antidepressant medication (Zisook & Schuchter, 2001, p. 791).

### *Interventions with children and adolescents*

Reviews by Ayers and colleagues (Ayers & Sandler, 2003; Ayers, Kennedy, Sandler & Stokes, 2003, p. 224) indicate that controlled trials of prevention programs for bereaved children and adolescents have been carried out. They reviewed the available evidence from the few studies or programs of research that utilized control groups in their evaluations of the success of bereavement intervention programs with children and adolescents (not all studies used random assignment), which have been oriented primarily toward children who are bereaved as the result of the loss of a parent.

The “interventions offered to bereaved children and their families have typically provided information and education on grief and provided opportunities for expressing and understanding feelings, remembering and/or commemorating the death, and developing family communication” (Ayers & Sandler, 2003, p. 218). Fewer studies have incorporated strategies to improve parenting skills; recent evidence indicates that such strategies can be effective in promoting positive parenting and in promoting better coping and other positive outcomes in female children (e.g., Sandler et al., in press).

Ayers and colleagues (Ayers & Sandler, 2003; Ayers et al., 2003) conclude that the evidence from the very few controlled evaluations of preventive interventions for bereaved children (and adolescents) must be considered equivocal. They call for intervention studies that focus on mediating factors such as age, gender and level of individual and family resources, factors that have been demonstrated to relate to healthy outcomes in bereaved children (Ayers & Sandler, 2003; Ayers et al., 2003)

## *Summary and conclusions*

Reviews and meta-analyses of evidence available from well-designed and conducted empirical studies of the efficacy and effectiveness of bereavement interventions indicate that:

- For adults experiencing normal (uncomplicated) grief, interventions
  - “are likely to be unnecessary and largely unproductive” Jordan & Neimeyer, (2003)
  - may be harmful for significant percentage of people e.g., Neimeyer, (2000).
- For adults at risk of developing complicated grief, interventions may provide some benefit, at least in the short term (e.g., Schut et al., 2001).
- For adults experiencing complicated grief, the available evidence indicates that psychotherapeutic interventions are likely to provide some benefit (e.g., Jacobs & Prigerson, 2000; Jordan & Neimeyer, 2003). Treatment guidelines for the depressions of bereavement have been suggested based on existing evidence (Zisook & Schuchter, 2001).

Investigators have suggested that several factors may explain general findings that bereavement interventions appear to be of low efficacy. Jordan & Neimeyer (2003) suggest that “grief counseling may not be needed by most mourners; grief counseling may not work in the form that it is typically delivered in research studies; and the positive effects of grief counseling may be masked by methodological issues in the design and implementation of the studies.” The need for improved research design and methods in intervention studies and more explicit connections between theory and intervention are echoed by other reviewers (e.g., Ayers & Sandler, 2003; Schut et al., 2001). It has also been suggested that it would be most productive for intervention researchers to concentrate their efforts on studying interventions targeted to persons at risk of experiencing complicated grief Jordan & Neimeyer, (2003).

In light of evidence that formal intervention is generally not helpful or justified for older individuals who are experiencing uncomplicated bereavement, Hansson and Stroebe (2003) suggest that “helping professionals are likely to be most effective by providing support to natural helpers,” who include family, neighbors, friends and “members of familiar religious, social, or business groups” (pp. 519-520).

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## Summary and Conclusions

To be able to think in terms of past, present, and future, to love and to grieve, is part of the human existential plight and dignity. Grief may add meaning and perspective to one's life just as shadows give depth to a landscape. (Lindstrom, 2002, p.20).

We return here to the observation with which we started – bereavement is a universal human experience. It is an experience that has been studied with increasing frequency and sophistication from multiple different perspectives in the years subsequent to the publication of the 1984 IOM report on bereavement (Osterweis, Solomon & Green, 1984).

The research that has been conducted on bereavement and grief (and complications thereof) has led to changes in the way these experiences are understood as both psychological and biological phenomena. As indicated in the preceding chapters, theories that have formed the foundation for both popular and professional understandings of grief and its resolution have been challenged on the basis of findings from empirical studies of bereavement and grief. This research indicates that there is tremendous variability in “normal” responses to bereavement, including findings that some bereaved people may not experience distress, and positive emotions and experiences are possible (and potentially common) following loss. Productive steps have been taken in the identification of factors that may increase the risk of complicated or problematic grief reactions or provide some protection from complications. Advances have been made in critical areas such as the investigation of the biological effects of bereavement and grief and of the roles played by different styles of coping in response to bereavement. Advances also have been made in thinking about complicated (or traumatic) grief and its relation to other conditions and outcomes.

Recent work in bereavement and grief, as indicated in reviews and commentaries on the field, suggests that there are significant disconnects between the information generated by researchers and the information that is being used to guide the provision of services to the bereaved. One compelling and serious indication of this is the evidence from well-conducted studies of interventions that challenges the efficacy and effectiveness of grief interventions for those experiencing uncomplicated bereavement. This evidence also indicates that concerns are warranted about the potential of interventions to cause harm to some individuals. Another indicator is the relative paucity of research on bereavement and grief within the health care system: Gaps in knowledge exists both in terms of the nature and effects of the services health care professionals provide to bereaved individuals and families and in terms of the effects of loss on the health care providers themselves.

As Lindstrom (2002) has observed, the slowness with which change occurs in theories and systems of thought (in “paradigms”) is not unique to the field of bereavement and grief. But it does appear that the field is at a critical juncture in terms of actively working to align research and practice – to

explicitly make provisions for practice and research to influence each other – as the bereavement and grief research enterprise matures and moves forward (see also Chapter 3).

Recommendations for research that may help move the field in productive directions, with a special focus on health-related research, are outlined in the next chapter.

A few other points warrant mention here. Aligning bereavement and grief research and services will require changes on the part of researchers and practitioners, but it is also likely to require much deeper consideration of how grief is understood within the context of specific social and cultural environments. This includes the scientific environment and culture, the practice environment and culture, and the general culture.

For example, the ways in which research results are interpreted and used must be more clearly understood and guided. It is difficult to organize, make sense of and apply research findings that cannot be situated within a larger framework of some kind, whether that framework is specifically a formal theory of bereavement and its consequences or a more general lay understanding of loss as an element of human existence. The harm that can result from the desire to make use of information absent a clear understanding of where information fits in a bigger scheme of things is exemplified in the problems that have arisen from the confusion of description with prescription in the field of bereavement and grief. Studies that describe the reactions of bereaved individuals (in samples that may be biased and unrepresentative for a host of reasons) should not be used to prescribe the ways in which “normal” individuals will respond to bereavement. Descriptions of responses should also not be used as the unexamined or untested basis for interventions with bereaved individuals. It is extremely unlikely that researchers intend that research findings be used inappropriately, or that the consumers of research intend to use those findings inappropriately. This suggests that researchers, practitioners and other consumers of research must be involved collectively in the development of frameworks to guide research and to interpret and use research findings.

It also seems that the time may be ripe for efforts to marry the information being derived from empirical research with the information about bereavement and grief that is available simply because it is a universal experience of potentially great power and import. Experiences of grief have given life to music, art and literature of tremendous emotional intensity and beauty. The nature and meaning of death are issues of central import in most (if not all) religions. Mourning rituals and practices – public expressions of grief – are influenced by multiple cultural, social and familial factors. Weaving these understandings of grief and bereavement together with the understanding that can be derived from the scientific study of grief may be an important aspect of more effectively situating bereavement and grief research within a coherent conceptual framework.

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# Health-focused Research Agenda

The following priority recommendations for health-related research on bereavement and grief are drawn from the evidence reviewed and summarized in this report pertaining to bereavement-related health outcomes, the role of health care providers and health care systems in providing care for bereaved persons, and the efficacy and effectiveness of bereavement and grief interventions.

## *General issues*

- Research and conceptual work are needed to develop clearer frameworks for understanding the diversity and complexity of grief and bereavement research, both within a larger cultural context and with awareness that normal grief may take many forms.

## *Health outcomes*

- Additional research is needed to determine whether the risks of morbidity and mortality are increased for bereaved individuals, and if so, the conditions under which such deleterious effects are likely to occur.
- Methodologically rigorous studies are needed to:
  - Determine whether there are unique direct effects of bereavement on physical health outcomes (including specific diseases and conditions, and/or overall health status);
  - Clarify the roles played by factors such as:
    - sociodemographic characteristics (e.g., gender, age or stage of life development, race/ethnicity, and socioeconomic factors such as income, education);
    - relationships and roles (for example, the effects of grief on parents' capacities to care for their children after the death of a spouse); and
    - resilience and protective factors (e.g., coping styles, the quantity and quality of supportive social relationships, philosophical or religious orientations, and the environmental context).
  - Differentiate the potential direct effects of bereavement on physical health outcomes from the potential indirect effects of bereavement. Some pathways of effect may be physiological (e.g., compromised immune function) while others may be social (e.g., diminished capacity to function socially, which discourages would-be helpers). Further discrimination of potential direct and indirect effects may be accomplished by research addressing questions such as:
    - Are possible adverse effects of bereavement on health mediated or moderated by psychological and/or physical distress; the use of deleterious coping strategies (e.g., drug or alcohol abuse, ruminative coping); or adverse health behaviors (e.g., poor self-care, smoking, overeating)?
- Additional research also is needed to:
  - Resolve debates within the field regarding the identification of complicated grief and whether it comprises a distinct diagnostic entity;

- Guide the further development of valid and reliable tools or processes (with reasonable predictive validity) for use in the identification of those who may be at risk for problematic bereavement;
- Further understand relationships between differential patterns of grief response and negative physical and mental health outcomes, and the physiological pathways involved;
- Ascertain when and whether grief interventions are warranted for whom and under what conditions, and if necessary, to develop and evaluate interventions to prevent and treat grief complications.
- The recommended research will require improvements in and standardization of measures, methods and models to assess normal and pre-bereavement baseline levels of multiple factors accurately, with the aim of understanding how grief diverges from baseline functioning and what would constitute “recovery”. These are particularly difficult problems because baseline functioning differs from person to person, and because “recovery” may mean something different than return to baseline levels. Factors for which improved measures are needed include:
  - psychological status (e.g., vulnerability to depression);
  - physical health status;
  - health behaviors;
  - immune (e.g., susceptibility to respiratory illnesses), neuroendocrine and sleep functioning (e.g., sleeplessness and the sleep-wake cycle); and
  - factors such as accident proneness and vulnerability to accident.

### *Health care providers and health care systems*

#### Effects on health care providers

- Additional research is needed to understand the effects of caring for bereaved persons and experiencing repeated losses/bereavement on the physical and psychological well-being of health care providers (e.g., examining the effects of grief overload and caregiver burnout).
- Research is also needed to understand the ways in which personal bereavement may hinder and/or help the work of health care providers.
- If health care providers are at increased risk for physical and psychological sequelae, research should be conducted to determine what types of interventions at the individual or organization levels might be beneficial in preventing, or mitigating, the deleterious effects of repeated exposure to loss and bereavement.

#### Best practice in bereavement care

- Additional research is needed to determine what constitutes “best practice” for health care providers and institutions in providing care to individuals and families in the period immediately preceding as well as immediately following a death.
  - Research on best practice should include the investigation of issues such as health care organizations’ responses to deaths that occur within the system, in which conflicts of interest may arise between the provision of supportive bereavement care and policies oriented toward the protection of institutions from legal action or complaints.

- Research should address the means by which health care providers and institutions can continue to provide care and services, if needed or requested, beyond the immediate aftermath of a death.
  - Questions to be investigated could include:
    - Does best practice depend on the setting, the circumstances surrounding the death, the age of the deceased, the cultural or racial/ethnic background of bereaved persons, the institutional support for palliative care and/or bereavement services, and involvement of mental health professionals such as social workers?
    - What types of preparation for the death (e.g., in terms of communications such as clinicians conveying realistic life expectancy estimates, when possible) enhance the likelihood of uncomplicated grief in the deceased patient's survivors?
    - What can be learned about the appropriate timing and modality of interventions from studies of treatment following traumatic experiences?
- Research is needed to determine:
  - Whether health care providers in different practice settings currently identify individuals and families who may be at risk for problematic bereavement outcomes; and if so,
  - What types of care (none, referral, on-site provision of services) are provided in cases in which indicators of increased risk (or evidence of problematic grief responses) exist;
  - What models of linkages or connections between health care providers/institutions and community services have been most effective in ensuring that bereaved persons receive appropriate care?

## Health care utilization and costs

- Research is needed to determine:
  - Whether increased health care utilization and increased health care costs are associated with bereavement per se or with complicated or problematic grief; and
  - Whether these associations differ in specific populations (e.g., cohort effects, ethnic and cultural differences, religious differences); and
  - Whether various health insurance options (e.g., private payer insurance, Medicare, systems of managed care, no or inadequate health insurance) are associated with differential health care utilization and health care costs in persons experiencing bereavement.

## Education and training of health care providers

- Research is needed to:
  - Assess health care providers' perceptions of bereavement and its potential mental and physical health consequences. For example, what do health care providers perceive as normal bereavement, or as complicated or problematic bereavement?
  - Identify the roles health care providers see for themselves in caring for the bereaved;
  - Identify the perceptions of health care organizations and systems regarding their responsibilities for the provision of care, roles of providers and reimbursement for care;

- Identify best practices in the education and training of health care providers – ascertain the types of education and training (in both content and method) that would be most useful to health care professionals in:
  - improving care of bereaved persons, and
  - helping providers deal with the challenges of providing bereavement care and their own reactions to bereavement;
- Ascertain specialized needs for education and training among different types of health care providers and among providers in different settings; determine what types of continuing education and/or ongoing supports are needed to optimize the application of education and training to improved care.

### *Bereavement interventions*

- Additional research is needed to:
  - Determine whether (and under what conditions or circumstances) bereavement interventions are indicated – or not indicated – for individuals and families experiencing uncomplicated grief;
  - Determine the content and processes of interventions (including peer and community support groups) that are likely to be most effective in preventing health problems and promoting well-being in individuals at risk of poor health outcomes.

**APPENDIX A**

**EVIDENCE SUMMARIES FOR CHAPTER 5  
OUTCOMES OF BEREAVEMENT**

## **SELECTED EVIDENCE**

### **Health Outcomes**

Qualitative

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### **Principal Investigator(s)**

Armour M. (2003). Meaning making in the aftermath of homicide

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### **Study Design**

Open-ended interview with each family

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### **Sample Description**

- ◆ 14 families who had experienced the homicide of a family member were recruited from 3 sites. The total number of participants was 38, of whom 92% were white, 5% were African-American and 3% were Korean-American. Mean length of time since the homicide was 7.5 years (range 18 months to 23 years).
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### **Selected Measures**

- ◆ Meaning making was depicted by the following essential theme: “the intense pursuit of what matters is the meaning in my life.” 48% of respondents indicated that this theme completely represented their experience and 35% felt it substantially represented their experience
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### **Selected Outcomes**

- ◆ “The intense pursuit of what matters” is a form of coping composed of intentional acts that have symbolic meaning. Its implied purpose is to restore or find meaning in a changed life through problem solving or striving to attain visionary goals. Although acts are geared toward desirable results, meaningfulness related to the post-homicide experience rests primarily on the process of the pursuit rather than the specific outcome. Over time, engagement in numerous meaning-making ventures reconstructs a self-identity as homicide survivors both “relearn the self” and “relearn the world”
  - ◆ For homicide survivors, meaning-making grounded in action has attributes that are shaped by the trauma. Meaning making is both interpersonally and intrapersonally interactional
  - ◆ Manifestations of the theme, “the intense pursuit of what matters is the meaning in my life” included: 1) declarations of truth, consists of pronouncements that define territories of insincerity and personal autonomy; 2) fighting for what’s right, is composed of acts that respond to specific injuries; and, 3) living in ways that give purpose to the loved one’s death, encompasses acts that transcend the murder in a life-affirming way. Each is conveyed in two ways. Declarations of truth include declarations that expose hypocrisy and declarations of self determination. Fighting for what’s right includes fighting for what’s mine and fighting to correct what’s wrong. Living in ways that give purpose to the loved one’s death is conveyed by using experience to benefit others and living life deliberately in an effort to give positive value to the homicide
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## **SELECTED EVIDENCE**

### **Health Outcomes**

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Quantitative  
Cross section

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### **Principal Investigator(s)**

Baldewicz T, Goodkin K, Blaney N, Chor-Posner G, Kumar M, Wilkie F, Baum M and Eisdorfer C. (2000). Cobalamin level is related to self-reported and clinically rated mood and to syndromal depression in bereaved HIV-1+ and HIV-1- homosexual men

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### **Study Design**

Questionnaires, structured clinical interview for psychopathology, a medical history and physical examination and phlebotomy

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### **Sample Description**

- ◆ 159 bereaved homosexual men (90 HIV-1+ and 69 HIV-1-) who were evaluated at the baseline of a randomized clinical trial of a bereavement support group intervention. 6 months prior to enrollment, each participant had experienced the loss of a close friend or intimate partner to AIDS and report a negative impact of this loss
  - ◆ Men were excluded from this study if they 1) had a CD4 cell count < 50; 2) had an HIV-1 related opportunistic infection or tumor requiring treatment at enrollment; 3) were dependent on alcohol or other psychoactive substances within the past 6 months; 4) had used intravenous substances within the past 2 years; 5) had a history of or current major psychiatric disorder; 6) used prescribed immunostimulants
  - ◆ 65% of the sample was white, 23% Latino, 9% African-American with a mean age of 38.34 years and on average 14.72 years of education. The HIV-1+ subjects were predominately early symptomatic (n=68), with fewer asymptomatic (n=17) and late symptomatic (n=5)
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### **Selected Measures**

- ◆ Plasma cobalamin level was determined by a radioisotope dilution assay and was used as a continuous measure. In this study, the normal range was defined as 240 to 1000 pg/ml, marginal deficiency as 200 to 240 and overt deficiency as < 200 pg/ml
- ◆ Self-reported mood state was measured by the Profile of Mood States (POMS), a 65-item questionnaire used to assess overall psychological distress with subscales for depression-dejection, tension-anxiety, anger-hostility, vigor-activity, fatigue-inertia and confusion-bewilderment. Overall distress was measured as the total mood disturbance score (TMD) which is a composite of the sum of five subscales, all but vigor-activity
- ◆ The Structured Interview Guide for the Hamilton Anxiety and Depression Rating Scales (SIGH-AD) is an examiner-administered clinical mood rating scale containing the 17-item Hamilton Rating Scale for Depression and the 14-item Hamilton Anxiety Rating Scale, modified for patients with HIV-1 infection
- ◆ The Structured Clinical Interview for DSM-III-R Axis I disorders (non-patient version) modified for the HIV-1 infected was used to assess current depression and anxiety disorders
- ◆ Major life events occurring over the prior 6 months were measured as the number of negatively rated events using a modified version of the Life Experiences Survey
- ◆ Perceived available social support was measured with the 6-item short form of the Social Support Questionnaire which assesses the total number of potentially available supportive persons

- ◆ Coping style was assessed using the 52-item dispositional COPE. 4 coping variables represented by 2 composite scores, active coping and disengagement/denial and 2 subscales, focus on and venting of emotion and turning to religion
  - ◆ Serum albumin level was measured by standard rate nephelometry. Normal values were 3.5 to 5.5 g/dll
  - ◆ Plasma pyridoxine status was determined by a bioassay of erythrocyte transaminase activity and was used as a continuous variable. Results were reported as an activity coefficient (AC) with higher values of the activity coefficient indicating lower levels of pyridoxine activity
  - ◆ Clinical staging determined by a medical history and physical examination was used to characterize HIV-1 disease progression
  - ◆ Antiretroviral medication and multivitamin use were recorded as separate categorical variables (yes/no)
  - ◆ Constitutional symptoms (fever, diarrhea, fatigue, night sweats and weight loss of > 10% of body weight) were noted as being present or absent
  - ◆ Self-report of alcohol and other psycho-active substance use was recorded by class of substance and frequency of use
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### **Selected Outcomes**

- ◆ Of this sample, 23.7% were marginally (8.2%) or overtly (15.7%) cobalamin (vitamin B12) deficient. There were no significant differences in mean cobalamin level between the HIV-1+ and HIV-1- groups
- ◆ Cobalamin level was inversely related to overall distress level and accounted for 4% of the variance in TMD
- ◆ Cobalamin level was significantly inversely associated with the depression-dejection, tension-anxiety and confusion-bewilderment scores after controlling for HIV-1 serostatus and psychosocial variables
- ◆ Cobalamin level was inversely related to depressed mood and accounted for 4% of the variance in HRSD. Cobalamin level was inversely related and accounted for 6% of the variance in HARS
- ◆ 16% of the sample met the DSM-III-R criteria for a current major depressive disorder (MDD) or had bereavement-related depressive symptoms consistent with the diagnosis of MDD. Of this subsample, a significantly higher proportion had cobalamin levels that were in the overtly or marginally deficient ranges (42%) compared with only 20% of subjects not meeting MDD criteria
- ◆ Cobalamin level was a significant predictor of MDD after controlling for HIV-1 serostatus and psychosocial variables
- ◆ Evidence supports relationship of cobalamin and depression: cobalamin level was associated with 3 measures of depression—self-reported depressed mood, clinically rated depressed mood and diagnosis of major depressive disorder

There was a significantly higher mean frequency of alcohol use in subjects with marginal or deficient levels of cobalamin compared to those with normal levels

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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Survey  
Longitudinal

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### **Principal Investigator(s)**

Barry L, Kasl S and Prigerson H. (2002). Psychiatric disorders among bereaved person: The role of perceived circumstances of death and preparedness for death

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### **Study Design**

Face-to-face interviews conducted by Masters degree-level, trained interviewers approximately 4 and 9 months after the death

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### **Sample Description**

- ◆ Approximately 70% of the sample was recruited through the Bridgeport/Fairfield division of the AARP Widowed Persons Service (WPS), a community-based outreach program that serves as an information clearinghouse. Additional participants were recruited through the Chaplain's Office of the Hospital of St. Raphael in New Haven (26%) and personal referral (3%)
  - ◆ 265 bereaved persons enrolled; 145 person completed follow-up assessments; 122 included in this study
  - ◆ 71% of respondents were women with an average age of 63.7 years and on average 14 years of education. 91% were white. 88% had suffered the loss of a spouse, 3% loss of a child, 8% a parent and 2% a sibling
- 

### **Selected Measures**

- ◆ Complicated grief was measured with the 32-item Inventory of Complicated Grief Revised (ICG-R)
  - ◆ Major depressive disorder (MDD) and post-traumatic stress disorder (PTSD) diagnoses were assessed with the MDD and PTSD modules of the Structured Clinical Interview for the DSM-IV (SCID) Axis I modules. The DSM-IV (SCID) was also used to assess previous history of MDD, PTSD, generalized anxiety disorder (GAD) and panic disorder
  - ◆ Perception of circumstances surrounding the death was measured with 3 questions regarding the perception of the peaceful or violent nature of the death, the suffering and the duration of the death experience
  - ◆ Perception of readiness for the death was assessed by asking, "How prepared did you feel for the death?"
  - ◆ Physical health was assessed by 2 self-report measures: functional disability and chronic conditions
    - A 12-item subscale of the Established Populations for Epidemiological Studies of the Elderly questionnaire that asks about the ability to perform everyday tasks such as walking across a room, bathing, dressing, using the toilet and getting from bed to a chair was used to assess functional disability
    - Participants were asked whether they had ever been told by a doctor that they any of the following chronic conditions: heart attack, cancer, diabetes, high blood pressure, broken hip, other broken bones or cirrhosis
- 

### **Selected Outcomes**

- ◆ 53% had no impairment in physical functioning; 59% had no more than one medical condition and approximately 14% reported having at least one previous psychiatric diagnosis
- ◆ Rates of psychiatric illness decreased over time: at baseline 11% had CG, 9% MDD, 6% PTSD and follow-up 8% CG, 6% MDD and 3% PTSD

- ◆ Perception of feeling unprepared for the death was significantly associated with CG and MDD. The perception of the death as violent was associated with presence of MDD. Age and education were the only demographic characteristics that were associated with the presence of any psychiatric illness, with younger age associated with MDD and fewer years of formal schooling associated with MDD and PTSD
  - ◆ The likelihood of a CG diagnosis at baseline increased by 2.55 per each 1-unit increase in feelings of lack of preparedness for the death, after controlling for potential confounders such as the number of months since the loss and previous history of psychiatric disorders. The result held at follow-up, approximately 9 months after the death
  - ◆ Perceptions of suffering and the duration of the death experience were not significantly associated with CG at enrollment or follow-up
  - ◆ Likelihood of MDD at follow-up increased 1.93 times for each 1-unit increase in feelings of lack of preparedness. Perceptions of the death as violent were significantly associated with MDD at enrollment. The odds of a SCID diagnosis of MDD at baseline increased by 1.50 for each 1-unit increase in feelings of how violent the death was, after adjustment. This perception did not predict MDD at follow-up
  - ◆ Results suggest that feelings of one's own lack of preparedness may reflect difficulty acknowledging and accepting an impending and permanent separation from a loved one and, for this reason, may be related to complications in post-loss separation from this person
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## SELECTED EVIDENCE

### Health Outcomes

Quantitative  
Longitudinal

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### Principal Investigator(s)

Bonanno G and Field N. (2001). Examining the delayed grief hypothesis across 5 years of bereavement

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### Study Design

Self report symptom questionnaires via mail between 3 and 5 months post death; a structured grief symptom interview and open-ended narrative interview at 6 months post death was conducted by trained interviewers. The structured grief symptom interview and self report symptom questionnaires were repeated at 14, 25 and 60 months post death. This study uses data from the 6 month interview and 60 month questionnaire

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### Sample Description

- ◆ Participants recruited by newspaper advertisements, posted notices and referrals from a variety of institutions within the San Francisco Bay area
  - ◆ Participants had to be between the ages of 21 and 55, have been married or living with their deceased partner for at least 3 years and sustained the death of a spouse/partner between 3 and 6 months earlier
  - ◆ 56 bereaved participants from the original study were considered for the 5 year follow-up. 39 (70%) completed it
  - ◆ Sample was 70% female with an average age of 49.19 years; 87% were white; 46% were employed full-time. Respondents had been married to the deceased an average of 18.2 years.
  - ◆ There were no significant differences between the 5-year sample and the original sample
- 

### Selected Measures

- ◆ Interviewer-rated grief was assessed using a 28-item, structured clinical interview that included items for intrusive experiences, behaviors that minimize the finality of the loss and difficulties adapting to the loss.
- ◆ Self reported grief was assessed by the 13-item Texas Revised Inventory of Grief (TRIG)
- ◆ Self reported depression was measured using the 21-item Beck Depression Inventory (BDI)
- ◆ The interviewer-rated grief, TRIG and BDI were combined into a weighted composite score
- ◆ Self reported somatic complaints were assessed using an 18-item checklist used in the Whitehall II Study
- ◆ Self-rated emotion, participants were asked to rate how often during the narrative interview they had experienced each of 3 positive emotions (interest, surprise, enjoyment) and 4 negative ones (fear, guilt, anger, distress)
- ◆ Heart rate change was measured using EKG from a wrist and forearm sensor. Heart rate change was computed by subtracting each participant's average baseline heart rate from his/her average heart rate during each interview topic
- ◆ Affective-autonomic response dissociation score was based on the self-rated negative emotion and heart rate change. Positive scores indicated that a participant had reported less negative emotion and had relatively higher heart rate responsivity while talking about the lost relationship. Data were available for 28 (72%) of participants
- ◆ Facial expressions of negative emotions were coded from the first 5 minutes of the narrative interview in which participants spoke about their loss using the emotion-relevant version of the Facial Action Coding System. A

composite score, indicating the total negative emotion shown in the face was used in this study. Data were available for 24 (62%) of participants

- ◆ Negative verbal content was coded from transcripts of the narrative interviews. Each interview was segmented into content units based on the intuitive understanding of the natural boundaries of a complete thought or idea. Each content unit was analyzed for descriptions of thoughts and emotions defined as subjective, evaluative information associated with accounts of personal opinions, beliefs, attitudes or feelings. Only content units with negative valence were considered in this study. Data were available for 30 (77%) of participants

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### **Selected Outcomes**

- ◆ At 5 years post death, 9% (n=3) of the sample had elevated scores (defined as scores above the 6-month median for a given measure) on the interviewer-rated grief score; 5% (n=2) on the TRIG; 13% (n=5) on the BDI; 6% (n=2) on the weighted composite grief-depression score; and 15% (n=6) had elevated scores on the somatic complaints
  - ◆ 2 participants showed delayed elevations (i.e. participant scored below the median at 6 months but scored above the median at 5 years) on the interviewer-rated grief score and 1 participant showed a delayed elevation in self-reported depression on the BDI. Measurement error may explain these results as chance variations could account for all 3 of the delayed elevations and each of the 3 participants showing a delayed elevation did so on only 1 measure and had low levels of symptoms on the other 3 measures
  - ◆ Not a single case of delayed symptom elevations was observed on the weighted grief-depression composite score, a measure used to maximize the probability of capturing the true (latent) grief variable
  - ◆ Facial expressions of negative emotion at 6 months post death were associated with greater somatic complaints at the 5 years post death and the dissociation of negative emotion at 6 months was associated with reduced depression at 5 years. These correlations remained significant even when controlling for baseline levels of somatic complaints and depression
  - ◆ Traditional conceptions of delayed grief include the assumption that grief-related emotion was avoided at early points in the bereavement. Only 1 of the 7 possible associations between delayed increases and symptoms and 6-month levels of emotion was there any indication of emotional avoidance. The one measure that showed this relationship, affective-autonomic dissociation, was also evidenced at 6 months by 13 participants, none of whom showed delayed increases in symptoms
  - ◆ Greater emotional processing at 6 months tended to be associated with higher than expected 5-year symptom scores. Talking about negative content at 6 months correlated with a significantly slower reduction in 5-year levels of interviewer-rated grief and a marginally slower reduction in 5-year BDI scores. Showing facial expressions of negative emotion at 6 months correlated with significantly slower reduction in 5-year levels of interviewer-rated grief; the weighted grief-depression composite score and a marginally slower reduction in 5-year TRIG scores. Finally affective-autonomic dissociation at 6 months correlated with significantly quicker reduction in 5-year levels of interviewer-rated grief
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal  
Matched Case Control

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### **Principal Investigator(s)**

Carr D, House J, Kessler R, Nesse R, Sonnega J and Wortman C. (2000). Marital quality and psychological adjustment to widowhood among older adults: a longitudinal analysis

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### **Study Design**

Face-to-face interviews conducted at baseline (6/87-4/88) and 6, 18 and 48 months post death

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### **Sample Description**

- ◆ 1532 married individuals living in the Detroit SMSA participating in the Changing Lives of Older Couples. Respondents had to be English-speaking members of a married couple in which the husband was aged 65 or older. All sample members were not institutionalized and were capable of participating in a 2-hour interview. 65% participated.
  - ◆ Of the 319 respondents who lost a spouse during the study, 86% (n=276) participated in at least 1 follow-up
  - ◆ Controls were selected from the original 1,545 were selected to match the widowed persons on age, race and sex
  - ◆ Two samples were used in this study:
    - 290 persons (203 widowed persons and 87 controls) who were interviewed at the 6-month follow-up. 74% were women
    - 203 bereaved persons (64% of participants who lost a spouse). 74% were women
- 

### **Selected Measures**

- ◆ Depression was measured by the 9 negative items from the 20-item CES-D
  - ◆ Anxiety was assessed with 10 items from the Symptom Checklist 90 Revised
  - ◆ Yearning was assessed with 4 questions: in the last month have you a) found yourself longing to have your spouse with you; b) had painful waves of missing your spouse; c) experienced feelings of intense pain or grief over the loss of your spouse; d) experienced feelings of grief, loneliness or missing your spouse.
  - ◆ Three dimensions of marital relationship: warmth-closeness, instrumental dependence (both male- and female-typed tasks) and conflict. Questions were drawn from a modified version of the Dyadic Adjustment Scale (DAS).
  - ◆ Spousal and personal health was assessed at baseline by two questions: "Has your spouse had a serious illness, injury, surgery or accident in the past months?" and "How satisfied are you with your health?"
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### **Selected Outcomes**

- ◆ Widowed persons had significantly higher depression levels at the 6-month follow-up than controls. They did not differ significantly from controls in terms of anxiety
- ◆ Widowed persons reported significantly lower levels of dependence on their spouses for male- and female-typed instrumental tasks at baseline. Widowed persons and controls did not differ significantly in terms of marital

warmth or conflict at baseline. The spouses of widowed persons were significantly more likely to have had a serious illness at baseline compared to the spouses of controls

- ◆ Widowhood was associated with poorer psychological well being, after adjusting for demographic and contextual factors. The effect of widowhood on depression did not change appreciably after marital quality variables were added to the model as moderators.
  - ◆ The effect of widowhood on anxiety was no longer significant when instrumental dependence was incorporated into the analysis. Compared with the married controls, widowed persons who reported high levels of dependence on their spouse for male-typed tasks such as home repair and financial management had significantly higher levels of anxiety at follow-up
  - ◆ Adjustment to widowhood was most difficult for those who experienced the highest levels of emotional warmth and instrumental dependence in their marriages. Those who suffered conflicted marriages evidenced lower levels of yearning. Results from 3 follow-ups suggest that those in conflicted marriages did not experience delayed yearning; rather, they experienced better adjustment in both the long and the short term following widowhood
  - ◆ Dependence on one's spouse for performing male-typed tasks increased yearning significantly, yet reliance on one's spouse for performing female-typed tasks was not significantly linked to yearning
  - ◆ Dependence on one's spouse for performing male-typed tasks influenced yearning differently for men and women. An increase in instrumental dependence for male-typed tasks was associated with a decrease in yearning for men and an increase in yearning for women.
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Charlton R, Sheahan K, Smith G and Campbell I. (2001). Spousal bereavement—implications for health

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### **Study Design**

Medical record abstraction from 1 year prior to 1 year after the death of a spouse

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### **Sample Description**

- ◆ 122 bereaved spouses who were patients of a semi-rural commuter village general practice in the West Midlands, UK. 5% of practice population (2300). 22 spouses were excluded due to missing bereavement date or incomplete medical records
  - ◆ Of 100 bereaved spouses, 78% were female with a mean age of 65.9 years. The year of bereavement ranged from 1940 to 1999
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### **Selected Measures**

- ◆ Consultations for physical and psychological illness including location of consultation, telephone advice, surgery or home visit
  - ◆ Physical ailments were divided into minor, major, acute, chronic, screening and organized review
  - ◆ Prescriptions for physical and psychological illness
  - ◆ Only total consultations and prescriptions used in analyses
- 

### **Selected Outcomes**

- ◆ Mean consultation rate per person increased 2-fold from 1980 to 1999
  - ◆ Mean increase in consultations for physical illness from 4.35 per person per year before the bereavement to 4.99 per person per year after bereavement and for psychological illness from 0.21 to 0.45
  - ◆ There was an increase in the total number of prescriptions per person per year in the year after bereavement in comparison with the year before bereavement, particularly for psychological illness from 0.76 to 1.34
  - ◆ Only the mean increase in total consultations was statistically significant (5.99 to 7.60). There were no significant differences by age or sex
  - ◆ Findings might lend some support that bereavement has little or no effect on health
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Case/Control  
Longitudinal

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### **Principal Investigator(s)**

Chentsova-Dutton Y, Shucter S, Hutchin S, Strause L, Burns K, Dunn L, Miller M and Zisook S. (2002).  
Depression and grief reactions in hospice caregivers: from pre-death to 1 year afterwards

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### **Study Design**

Structured interview and self-administered questionnaires completed at home two weeks prior to patient's death (T1), again at 2 months (T2), 7 months (T3) and 13 months (T4) after the death

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### **Sample Description**

- ◆ Caregivers (Cases): 112 adult children and spousal caregivers of hospice patients in San Diego, CA enrolled in the study. 63 (56%) dropped out before Time 4. 48 completed T2, T3 and T4
    - 18 (38%) of longitudinal sample were adult child caregivers; 30 (62%) were spouse caregivers
    - There were no significant differences between cases who completed all interviews and those who did not
  - ◆ Controls: volunteers from the community who were over 18 years old, had not experienced the death of a first-degree relative or a friend within the past 2 years and spoke English. 47 (67%) dropped out before T4. 36 completed T2, T3 and T4
    - 11 (31%) of longitudinal sample of controls were adult child caregivers; 25 (69%) were spouses
  - ◆ Caregivers tended to be older and less well educated than controls
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### **Selected Measures**

- ◆ Demographical bereavement questionnaire
  - ◆ Hamilton Depression Rating Scale (HDRS) administered by trained research assistant
  - ◆ Self-Rated Brief Symptom Inventory (BSI), yields two global indices: Positive Symptom Distress Index (PSDI) and the General Severity Index (GSI) and the subscales: anxiety, hostility, depression, somatization, interpersonal sensitivity, phobic anxiety, obsessive-compulsive symptoms and paranoid ideation
  - ◆ Texas Revised Inventory of Grief (TRIG)
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### **Selected Outcomes**

- ◆ 23% of caregivers had HRSD scores  $\geq 12$  (mild depression) compared to no controls. Caregivers reported significantly higher levels of depression than controls at T1 and T2 but not at T3 and T4. By 7 months after the death, levels of caregivers' depression subsided to equal those of population controls. Only 2% of caregivers continued reporting mild symptoms of depression at 13 months after the death. Comparison of prebereavement and T2 depression levels suggested that the death of a family member was not associated with a further increase in depressive symptomatology
- ◆ Caregivers' mean scores were significantly higher than controls on the PSDI and the GSI. Caregivers' mean scores were significantly higher than controls over time for anxiety, hostility and depression. They did not differ significantly from controls on somatization, interpersonal sensitivity, phobic anxiety and paranoid

ideation. Caregivers' anxiety and hostility levels diminished over time, whereas controls' levels of anxiety remained relatively stable and low. None of the subscales showed an increase after the death

- ◆ Adult child and spouse caregivers did not differ over time on the overall levels of psychopathology
  - ◆ There was no main effect of family role or gender on grief. Present feelings, *still cry when thinking of the person, get upset when thinking of the person, preoccupied with thoughts about the person*, decreased from T2 to T4. Intensity of grief feelings was highest at 2 months and lowest at 1 year after the death
  - ◆ Results do not support hypothesis that the death of a family member further increases caregivers' distress. Caring for and losing a parent appears to be every bit as debilitating as the trauma experienced by bereaved spouse caregivers
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cohort study (matched)  
Longitudinal

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### **Principal Investigator(s)**

Christakis N and Iwashyna T. (2003). The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses

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### **Study Design**

Data were collected from hospitalization records from the Health Care Financing Administration, mortality statistics from the Vital Status file collected 18 months after the last day of follow-up for health care use and the census

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### **Sample Description**

- ◆ Participants drawn from the Care after the Onset of Serious Illness (COSI) study, a population-based cohort of 1,241,935 elderly patients initially diagnosed in 1993 with one of 13 leading causes of death
  - ◆ Participants included 195,553 spouses of patients who died at some point during the period between their diagnosis in 1993 and the end of 1997
  - ◆ Sample is 80% women. 15.8% (30,916) used hospice care. The median time before the decedent's death that s/he spent in hospice care was 22 days. During the follow-up period (from 1993 to the middle of 1999), 30,081 (19.3%) of the bereaved wives died and 16,488 (41.3%) of the bereaved husbands died
  - ◆ Cases were matched to controls based on sex and a propensity score that determined the probability of using hospice care, based on variables known or suspected to affect the decision to use hospice care. 24,721 of the women whose husbands used hospice care were successfully matched to a control (99.92%) and 6117 of the male cases were successfully matched to a control (99.04%)
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### **Selected Measures**

- ◆ Use and timing of hospice care
  - ◆ Mortality of both patients and spouses
  - ◆ Economic status as measured by the median income of the census tract in which the patient lived and whether or not participants received Medicaid
- 

### **Selected Outcomes**

- ◆ Bereaved wives of husbands who used hospice care showed statistically significantly lower mortality than matched wives whose deceased husband did not use hospice care. 5.4% of bereaved wives died by 18 months after the death of their husband when their deceased husband did not use hospice care, compared to 4.9% when their deceased husband used hospice care (adjusted odds ratio equal to 0.92). The same pattern existed for bereaved husbands but was not statistically significant.
  - ◆ Findings suggest a possible beneficial impact of hospice, as a particularly supportive type of end-of-life care, on the spouses of patients who died. Hospice care might attenuate the ordinarily increased mortality associated with becoming widowed
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Davis C and Nolen-Hoeksema S. (2001). Loss and meaning

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### **Study Design**

Structured interviews conducted in-person by trained clinical psychology graduated students 3 months before the death and 1, 6, 13 and 18 months after the death

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### **Sample Description**

- ◆ Participants, all of whom at the time of initial contact were losing a loved one to a terminal illness, were recruited through a number of hospices in the San Francisco Bay area
  - ◆ Of the 455 people who agreed to participate, 328 completed a pre-loss interview on average 3 months before their family member's death; 362 participated in an interview 1 month post death; 360 6 months post death; 313 13 months post death and 280 18 months post death. This study reports on data from 205 family members who participated in the pre-loss interview as well as the 6- and 13-month post-loss interviews
  - ◆ There were no significant differences between family members who were included in the study and those who were excluded on any of the variables of interest except distress. Those who were included were less distressed at pre-loss and marginally less distress at 6 months.
  - ◆ 74% of the sample was women with a mean age of 51.2 years. Median level of education was "some college" and median annual income was in the range of \$30,000 to \$35,000. 81% were white, 6% were Mexican-American, 5% were African-American. Slightly more than half of the respondents were the primary caregivers for the ill loved one. 72% of respondents lost a loved one to cancer, 14% to AIDS. 44% of respondents lost their parent; 35% their spouse/partner; 9% a child; 7% a sibling; 5% another relative or close friend. The mean age of the deceased at the time of his/her death was 63.7 years
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### **Selected Measures**

- ◆ Depressive symptoms were measured with the self-report Inventory to Diagnose Depression (IDD)
  - ◆ Positive affect was measured with positively valenced items from the state version of the State-Trait Anxiety Inventory
  - ◆ The measure of post-traumatic stress symptoms was designed for this study and contained items reflecting feelings of numbness and preoccupation with thought.
  - ◆ A composite measure of distress was created by summing the standardized scores of depressive symptoms, positive affect (reversed) and post-traumatic stress symptoms
  - ◆ Making sense of loss was assessed at each interview by asking participants whether they felt that they were able to make sense of the death. Responses were coded in two ways: whether the family member reported being able to make sense of the loss and how what they said gave them meaning
  - ◆ Benefit-finding notion of meaning was assessed by asking family members if they had found anything positive in their experience. Responses were coded first in terms of whether family members reported finding anything positive and then in terms of what it was about the experience that they found to be positive
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## **Selected Outcomes**

- ◆ The three most common meaning explanations reported were that the death was predictable in some way; it was consistent with the family member's perspective on life; or religious or spiritual beliefs provided meaning
  - ◆ People appear to make sense of their loss by considering the event in terms of existing worldviews. If the loss is consistent with these worldviews then making sense does not appear to represent a significant coping issue. However, when the event is perceived to be inconsistent with these worldviews, people are faced with the difficult task of either revising their interpretation of the loss or revising their worldviews to accommodate the loss
  - ◆ The older the deceased was at the time of death, the easier it was for family members to make sense of the loss. 87% of those losing a loved one in the oldest age category (older than 72.15 years of age at death) were able to make sense of the loss, compared to 60% of those losing a loved one in the youngest group (younger than 57.25 years of age)
  - ◆ Those who reported in the pre-loss interview that they had religious or spiritual beliefs were 2.65 times more likely to make sense of the loss than those who reported they did not
  - ◆ People unable to make sense of their loss within the first 6 months were generally unable to make sense of it later. Of the 39 family members who were unable to make sense of the loss at 6 months post death, only 8 reported making sense at a later interview
  - ◆ Making sense of loss in the first 6 months post death was significantly associated with decrements in emotional distress, making sense for the first time at later interviews was not significantly associated with changes in emotional distress
  - ◆ 70-80% of family members at each interview reported perceiving benefits to their experience. The most common benefits were that the experience with the event led to a growth in character, a gain in perspective and a strengthening of relationships. Participants who reported that they had accrued some benefit from the loss showed significant improvements in emotional adjustment with time
  - ◆ Whether the bereaved family member was able to find benefit in the loss was not significantly associated with his/her ability to make sense of it. These data support the argument that sense making and benefit finding represent two distinct processes in the meaning-making process and suggest that they represent two distinguishable psychological issues for the bereaved
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Engler A and Lasker J. (2000). Predictors of maternal grief in the year after a newborn death

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### **Study Design**

Questionnaire via mail

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### **Sample Description**

- ◆ Participants were recruited from 5 large medical centers and 1 state health department in the mid-Atlantic region of the US via word of mouth and postings on internet newsgroups.
  - ◆ To be eligible, participants had to be at least 18 years old, have experienced a newborn death within the previous year and be able to read and write English
  - ◆ Of the 374 women eligible to participate, 75 (20%) completed a questionnaire. 77% of the mothers were white; 64% were Christian; 72% had had no previous pregnancy losses; 76% had experienced problems with this pregnancy; 52% had other living children; 65% had had no other losses in the year since the newborn death
  - ◆ 59% of the newborns were male. Mean gestational age was 31.5 weeks. Mean birth weight was 1644 grams. Mean interval since the death was 183 days
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### **Selected Measures**

- ◆ Perinatal Grief Scale, Short Version (PGS), a 33-item scale measured total grief after pregnancy loss
  - ◆ Personal Resources Questionnaire, 85, Part II (PRQ), the 25-item PRQ measured perceived social support
  - ◆ Relationship Satisfaction Questionnaire (RSQ) included 10 items and measured satisfaction with the participant's primary intimate relationship
  - ◆ Ways of Coping Scale, Revised (WOC), a 63-item scale divided into 3 subscales: emotion-focused coping (32 items), problem-focused coping (12 items) and mixed coping (6 items). Two items, "I was inspired to do something creative about the problem" and "I came out of the experience better than when I went in" had item-to-total correlations of <20 so they were removed from analysis
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### **Selected Outcomes**

- ◆ Regression analysis revealed that social support (PRQ) and emotional-focused coping explained 43% of the variance in total scores on the PGS. As perceived support decreased and the use of emotional-focused coping strategies, strategies based on denying the reality of the loss, increased, grief increased
  - ◆ There were significant correlations between grief and emotional-focused coping (positive), perceived support (negative) and relationship satisfaction (negative)
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Field N and Bonanno G. (2001). The role of blame in adaptation in the first 5 years following the death of a spouse

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### **Study Design**

Self report symptom questionnaires via mail between 3 and 5 months post death; a structured grief symptom interview and open-ended narrative interview at 6 months post death was conducted by trained interviewers. The structured grief symptom interview and self report symptom questionnaires were repeated at 14, 25 and 60 months post death.

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### **Sample Description**

- ◆ Participants recruited by newspaper advertisements, posted notices and referrals from a variety of institutions within the San Francisco Bay area
  - ◆ Participants had to be between the ages of 21 and 55, have been married or living with their deceased partner for at least 3 years and sustained the death of a spouse/partner between 3 and 6 months earlier
  - ◆ 56 bereaved participants from the original study were considered for the 5 year follow-up. 39 (70%) completed it. Monologue blame measures were not available for 2 subjects. For this study, sample consists of 37
  - ◆ Sample was 68% female with an average age of 48.5 years; 92% were white; 54% were employed full-time. Respondents had been married to the deceased an average of 18.2 years.
  - ◆ There were no significant differences between the 5-year sample and the original sample
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### **Selected Measures**

- ◆ Judges rated the extent of blame toward the deceased and self-blame expressed in the verbal content of participants' speech. Deceased-blame reflected the extent to which the bereaved held the deceased accountable for the negative consequences of the loss. Self-blame reflected bereaved participants' perceived failure to live up to their own or the deceased's expectations as to how they should have behaved prior to or following the death
- ◆ Continuing attachment variables were part of a structured grief interview conducted 6 months post death. Aspects of continuing attachment were operationalized using items addressing sense of the deceased's presence; maintaining the deceased's possessions; seeking comfort through contact with belongings; gaining comfort through memories. Participants were asked to indicate to what extent each of these types of continuing attachment was true for them during the previous months. Judges rated each of the continuing attachment items from videotapes of the interview
- ◆ Post-loss emotions measure assessed commonly experience emotions in bereavement that included guilt, anger at deceased, loving, distress, hopelessness, regret, nostalgia and gratitude. It was administered at 60 months post death. Only the two blame-related items were used in this study
- ◆ Perceived social support was measured by 3-item subscales assessing perceived support from friends and relatives in terms of willingness to listen, attempt to understand and provide assistance
- ◆ Symptom Checklist (SCL-90-R) is a measure of psychological distress. It consists of 9 subscales and a Global Severity Index (GSI). Only the GSI was used in this study

- ◆ Texas Revised Inventory of Grief (TRIG) is a measure of grief-specific symptomatology that contains a retrospective component consisting of 8 items inquiring about bereaved individuals' experience at the time of the death and a "present feelings" component consisting of 13 items. Only the present feelings component was used in this study
  - ◆ Expectancy of the death was assessed by the length of forewarning defined as the interval between receiving the first news of the spouse's terminal illness and the spouse's death
  - ◆ Dyadic Adjustment Scale (DAS) is a measure of perceived relationship satisfaction. The total DAS score was used in this study
  - ◆ NEO Five-Factor Inventory (NEO-FFI) consists of 60 items measuring the five broad dimensions of personality (neuroticism, extraversion, agreeableness, conscientiousness and openness). This study focused on neuroticism
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### **Selected Outcomes**

- ◆ There were no significant correlations between self-blame and expectancy, dyadic adjustment and neuroticism. Deceased-blame was significantly inversely correlated with dyadic adjustment. This indicates a tendency to blame the deceased is at least partly an expression of the perceived quality of the prior relationship
  - ◆ Self-blame at 6-months post death was significantly related to the 5-year measure of guilt but not to anger toward the deceased. In contrast, deceased-blame was marginally significantly related to anger toward the deceased but not guilt
  - ◆ Self-blame was significantly positively correlated with grief-specific symptoms (TRIG) at 14, 25 and 60 months post death. It was marginally significantly related to general symptoms at 60 months
  - ◆ Deceased-blame had a negative impact on general symptoms (SCL-GSI) at 14 months post death but not at 25 or 60 months post death. Deceased-blame continued to be significantly correlated with general symptoms at 14 months after adjusting for dyadic adjustment.
  - ◆ Self-blame had a significant, positive association with maintaining the deceased's possessions and recurrent sense of deceased's presence. Self-blame was associated with a maladaptive form of continuing attachment indicative of failure to accept the reality of the loss.
  - ◆ Deceased-blame had a significant, negative association with comfort through memories and a marginal, negative association with recurrent sense of deceased's presence, indicating this form of blame motivates an emotional distancing from the attachment
  - ◆ Maintaining the deceased's possessions at least partially mediated the relationship between self-blame and grief-specific symptoms
  - ◆ Social support was not significantly correlated with 14-month general symptoms; therefore, it did not mediate the relationship between deceased-blame and general symptoms. These findings suggest that the mechanism through which deceased-blame affects 14-month symptoms is more likely to be intrapersonal rather than interpersonal
  - ◆ Study findings for self-blame suggest that it may serve as a form of avoidant coping with detrimental implications for long-term adjustment to bereavement. These results for self-blame are in keeping with the clinical bereavement literature on maladaptive variants of guilt in maintaining a sense of control over the death and as an attempt to undo the loss
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Field N, Gal-Oz E and Bonanno G. (2003). Continuing bonds and adjustment at 5 years after the death of a spouse

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### **Study Design**

Self report symptom questionnaires via mail between 3 and 5 months post death; a structured grief symptom interview and open-ended narrative interview at 6 months post death was conducted by trained interviewers. The structured grief symptom interview and self report symptom questionnaires were repeated at 14, 25 and 60 months post death

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### **Sample Description**

- ◆ Participants recruited by newspaper advertisements, posted notices and referrals from a variety of institutions within the San Francisco Bay area
  - ◆ Participants had to be between the ages of 21 and 55, have been married or living with their deceased partner for at least 3 years and sustained the death of a spouse/partner between 3 and 6 months earlier
  - ◆ Of the 89 participants who originally entered the study, 56 bereaved participants were considered for the 5 year follow-up. 39 (70%) completed it
  - ◆ Sample was 67% women with an average age of 48.7 years; 92% were white; 51% were employed full-time. Respondents had been married to the deceased an average of 17.9 years
  - ◆ There were no significant differences between the 5-year sample and the original sample
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### **Selected Measures**

- ◆ The CBS, developed for this study as a measure of continuing bonds expression, consisted of 11 items covering a range of ways of maintaining a tie with the deceased including memories, maintenance of possessions, identification with deceased, legacy of deceased, deceased as a standard and reminiscence. It was measured at 60 months
- ◆ Empty-chair monologue task was administered at 6 months post death. Trained judges rated each the extent of helplessness, self-blame and blame toward the deceased in the verbal content of the participant's speech. A higher score indicated greater helplessness.
- ◆ Reciprocal Attachment Questionnaire (RAQ) was designed to assess patterns of adult attachment. 43 items composed of four 7-item insecure attachment patterns (compulsive care-seeking, angry withdrawal, compulsive care-giving, compulsive self-reliance) and five 3-item attachment criteria scales (secure base, separation protest, proximity-seeking, use of the attachment figure, availability). This study used the compulsive care-seeking subscale
- ◆ Symptom Checklist (SCL-90-R) is a measure of psychological distress. It consists of 9 subscales and a Global Severity Index (GSI). Only the GSI was used in this study
- ◆ Beck Depression Inventory (BDI) is a 21-item scale that assessed the presence and severity of various affective, cognitive, motivational, vegetative and psychomotor symptoms of depression
- ◆ Texas Revised Inventory of Grief (TRIG) is a measure of grief-specific symptomatology that contains a retrospective component consisting of 8 items inquiring about bereaved individuals' experience at the time of the death and a "present feelings" component consisting of 13 items. Only the present feelings component was used in this study

- ◆ Positive States of Mind (PSM) is a brief measure of current capacity to experience positive mental states including focused attention, productivity, responsible care-taking, restful repose, sharing sensuous nonsexual pleasure and sensuous sexual pleasure
  - ◆ Expectancy of the death was assessed by the length of forewarning defined as the interval between receiving the first news of the spouse's terminal illness and the spouse's death
  - ◆ Dyadic Adjustment Scale (DAS) is a measure of perceived relationship satisfaction. The total DAS score was used in this study
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### **Selected Outcomes**

- ◆ Continuing bonds were associated with greater grief severity at 5 years post death. The relationship between the CBS and measures of adjustment was largely restricted to grief-specific symptoms
  - ◆ Regression analysis revealed that blaming the deceased and helplessness were both significantly associated with the CBS. Blaming the deceased was predictive of less use of continuing bonds, while helplessness was associated with more use of continuing bonds.
  - ◆ Regression analysis indicated that dyadic adjustment was significantly positively associated with the CBS. Compulsive Care-seeking was not significantly related to the CBS
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Qualitative

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### **Principal Investigator(s)**

Gamino L, Hogan N and Sewell K. (2002). Feeling the absence: a content analysis from the Scott and White Grief Study

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### **Study Design**

Written narrative

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### **Sample Description**

- ◆ 85 respondents recruited from non-psychiatric and psychiatric sources; larger group (n=45) consisted of individuals connected to a major medical-surgical teaching hospital in central Texas who had recently experienced the loss of a loved one. The second group (n=40) included outpatients from the medical school's psychiatry clinic who had been referred to the study
  - ◆ 78% were women with an average of 50.9 years and an average of 15.1 years of education; 89% were white, 5% Latino, 2% African-American; 44% were married, 39% widowed, 11% separated/divorced and 7% were never married
  - ◆ Causes of death included illness (75%), accidents (14%), suicides (9%) and homicides (1%)
  - ◆ Decedent types included spouses (42%), parents (37%), children (12%) and others (9%) such as siblings, grandparents or friends. 88% of the respondents had lost their loved one within 3 years of the study
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### **Selected Measures**

- ◆ How do the bereft [bereaved?] come to explain the deaths of their loved ones?
  - ◆ What meaning(s) do survivors assign to their bereavement experiences?
  - ◆ How do the bereaved understand the impact on their lives of their loved ones' deaths?
  - ◆ Product (what accrued meaning, if any, participants might have found in their loved one's death) rather than the process (how participants came to find meaning) that was the focus of the study
- 

### **Selected Outcomes**

- ◆ 9 major meaning constructs that emerged from the content analysis were named: Feeling the Absence; Experiencing Relief; Disbelieving the Death; Changing Relationships; Focusing on Negativity; Experiencing Meaninglessness; Continuing the Connection; Invoking an Afterlife; Going on with Life
- ◆ Majority of participants (76%) endorsed more than one of these 9 major meaning constructs in their essays—they had multiple ways of knowing and understanding what the loved one's death meant to them
- ◆ 81% of participants described feeling the absence which included 6 distinct facets or subcategories: yearning; companionship; lost dreams; void; depersonalization; finality
- ◆ 26% of respondents focused on being grateful that their loved one's suffering was over
- ◆ 11% of respondents had not yet assimilated fully the death of the loved one; disbelieving the death meant suspending full acknowledgement of the death by finding it hard to believe that the death had occurred and that it was a permanent loss

- ◆ 16% of respondents reported changes in their interpersonal relationships, either realizing greater love and support from family and friends or finding increased distance in personal relationships. Changing Relationship meant altering one's social position with the salient persons in one's life given the departure of the decedent; movement could be to cohere more closely or to disengage from others
  - ◆ 31% of respondents voiced prominent negative emotions regarding the death circumstances, the decedent and/or themselves. Focusing on negativity means feeling sentiments of anger and blame (at the situation or the decedent) or guilt regarding one's omissions or commissions toward the decedent
  - ◆ 7% of respondents referred to having no sense of purpose in life and believing that there is little meaning in life without the loved one
  - ◆ 16% of respondents voiced sentiments that showed evidence of an abiding attachment to their deceased loved ones that found its expression in non-physical ways of remaining connected
  - ◆ Invoking an Afterlife relied on deeper levels of religious and/or cosmic frameworks to form a meaning matrix for understanding the death of the loved one. 21% included Judeo-Christian notions of God, heaven and an afterlife
  - ◆ 29% of respondents described a process from which meaning was extracted painfully and gradually. Going on with Life meant determining to go on with one's life without the decedent, recreating oneself with a new sense of autonomy and developing a new awareness of life's preciousness
  - ◆ People use multiple forms of meaning to grasp the reality and significance of a loved one's death. Human experience of bereavement is a complex process with a host of different dimensions that cannot be reduced easily to a single outcome or unitary concept
  - ◆ The meaning categories seemed referent either to the pain and suffering of bereavement (e.g. Feeling the Absence, Disbelieving the Death, Focusing on Negativity and Experiencing Meaninglessness) or to more positive, hopeful dimensions of bereavement (e.g. Experiencing Relief; Continuing the Connection; Invoking the Afterlife; Going on with Life). Final 3 categories seemed to connote involvement in "recovery" processes of bereavement
  - ◆ The majority of responses to the question, What does the death of your loved one mean to you?, consisted of literal answers that were concrete, pragmatic, and spoke to the consequences of being bereft. Participants in the sample seemed to associate meaning mostly with these tangible, instrumental outcomes of bereavement, whether social, emotional or circumstantial
  - ◆ The minority of respondents addressed meaning at a more philosophical or existential level
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Matched Case-Control  
Longitudinal

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### **Principal Investigator(s)**

Harwood D, Hawton K, Hope T and Jacoby R. (2002). The grief experiences and needs of bereaved relatives and friends of older people dying through suicide: a descriptive and case-control study

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### **Study Design**

Semi-structured interviews conducted 6 and 12 months after death, usually in participant's home.

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### **Sample Description**

- ◆ Cases: 85 (44% response) relatives or close friends of people aged 60 years or older who died by suicide in 6 cities in England between January 1995 and May 1998
    - Characteristics of suicide victims: 68% male; mean age was 72 years; 80% white and British born; 35% were married; 49% were living alone
    - Characteristics of participants bereaved through suicide: 60% female; mean age 54.8 years; 45% were children of the deceased; 20% friends; 19% spouses, 11% siblings, 6% other. 60% were married; 56% employed full-time
  - ◆ Controls: 46 people who had been bereaved by the death of a person 60 years old or over through natural causes in hospital. Age- and sex-matched with the cases
  - ◆ There were no significant differences with regard to age, sex, marital status, ethnic origin or time between bereavement and interview. Control subjects were more likely to be spouses. Participants in the suicide group were more likely to have been in contact less than weekly with the deceased
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### **Selected Measures**

- ◆ Questions/problems encountered with the police, hospital, coroner's office or media reporters
  - ◆ Aspects of bereavement including changes in physical health, tobacco and alcohol consumption
  - ◆ Help received from professionals or voluntary agencies
  - ◆ Recommendations for improving the care of the bereaved
  - ◆ Grief symptomatology as measured by Grief Experience Questionnaire (GEQ), consisting of 11 subscales including: somatic reactions, general grief reactions, search for explanation, loss of social support, stigmatization, guilt, responsibility, shame, rejection, self-destructive behavior, unique reactions (a miscellaneous group of experiences hypothesized to be specific to bereavement through suicide such as feeling that the deceased was getting even with the informant by dying, etc.)
  - ◆ Mood assessment by the Montgomery and Asberg Depression Rating Scale (MADRS)
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### **Selected Outcomes**

- ◆ 15% of the sample reported problems with the police. 42% reported problems in their dealings with the coroner's office. 20% mentioned the delay between death and inquest. Of the 48 participants who read a newspaper report of the inquest, 27 (56%) described distress caused by the report
- ◆ 49% of the sample had MADRS scores in the depressed range ( $\geq 7$ )

- ◆ Alcohol intake increased since the bereavement in 14% of the sample
  - ◆ 13% of the sample had received specific bereavement counseling (7 from CRUSE and 4 from other counseling agencies). 20% had received specific support or counseling from their clergy. 4 people had had new contact with a community psychiatric nurse and 5 with a psychiatrist. 4 people had continued contact with a member of a psychiatric team who had been involved in the care of their deceased relative since before the bereavement
  - ◆ Scores on the GEQ subscales, unique reactions, stigmatization, shame and rejection, were significantly higher in the group bereaved through suicide than the control. Levels of depressive symptomatology (MADRS) were similar in the two groups (48% in the suicide group, 39% in the control)
  - ◆ Comparison of children of the deceased indicated that scores on rejection and unique reactions were higher in the suicide group than the control. Stigma and shame scores did not differ significantly
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Kamm S and Vandenberg B. (2003). Grief communication, grief reactions and marital satisfaction in bereaved parents

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### **Study Design**

Questionnaire via mail

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### **Sample Description**

- ◆ Participants were recruited from recipients of the Bereaved Parents of the USA, the Compassionate Friends newsletters and through announcements placed on an internet website dedicated to bereavement
  - ◆ To qualify, parents had to have experienced the death of a child (between the ages of 2 and 18) and to be married to the deceased child's other parent
  - ◆ Questionnaires were mailed to 68 pairs of parents, 36 couples (53%) participated. 93% were white with an average age of 47 years. The time since their child's death averaged 4 years 10 months. 89% of parents reported that they had little (less than a week) or no time to prepare for the death of their child
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### **Selected Measures**

- ◆ Attitudes towards Emotional Expression Scale was used to assess attitudes about grief communication. Participants were instructed to respond to 20 items reflecting their beliefs about expressing their grief-related emotions with their partner. Higher scores indicate more negative attitudes
  - ◆ Revised Grief Experience Inventory (RGEI) a 22-item measure was derived from the larger 135-item Grief Experience Inventory. Higher scores reflect less severe grief reactions. Only the total score used
  - ◆ Index of Marital Satisfaction (IMS), a 25-item scale, measures the severity of problems and the degree of positive feelings in the marital relationship. Higher scores indicate a greater severity of relationship difficulties
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### **Selected Outcomes**

- ◆ Longer time since death was associated with less severe grief reactions. Attitudes about communication and grief also changed over time
- ◆ Couples with more positive attitudes toward grief communication, i.e. valued open communication, and shorter time since the death of their child had the most severe grief reactions. Over a longer time, these couples had the least severe grief reaction
- ◆ Findings suggest couples with more positive attitudes about grief communication demonstrated greater marital satisfaction
- ◆ Husbands' and wives' attitudes toward grief communication scores were significantly correlated
- ◆ Husbands and wives demonstrated significant differences in their attitudes toward grief communication; women had more positive attitudes about grief communication than men
- ◆ For MEN, attitudes about grief communication are related to their grief. Men with more positive attitudes toward grief communication and shorter time since the death of their child had the most severe grief reactions.

Over a longer time, these men had the least severe grief reactions. Attitudes about grief communication were not related to their marital satisfaction

- ◆ For WOMEN, attitudes about grief communication were related to marital satisfaction but not grief. Women who were the least positive about grief communication demonstrated marital distress during the first five years post-death. In contrast, women with moderately and highly positive attitudes about grief communication demonstrated good marital satisfaction during this period
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Marwit S and Meuser T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease

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### **Study Design**

Self-administered questionnaire via mail

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### **Sample Description**

- ◆ 205 caregivers of persons with progressive dementia recruited through the Memory and Aging Project at Washington University. 166 (81%) completed questionnaire
  - ◆ 83 adult child caregivers; 86% female with mean age of 51.81 years; 94% were white
  - ◆ 83 spouse caregivers; 66% female with mean age of 71.47 years; 91% were white
- 

### **Selected Measures**

- ◆ Clinical Dementia Rating (CDR): was administered as a measure of care recipient impairment
  - ◆ Beck Depression Inventory (BDI): measure key symptoms and attitudes associated with clinical depression
  - ◆ Geriatric Depression Scale (GDS): is a 30-item yes/no scale designed to measure symptoms of clinical depression as typically manifested by older adults
  - ◆ Anticipatory Grief Scale (AGS): designed specifically for dementia caregivers and is composed of 27 grief related items rated on a 5 point scale
  - ◆ Caregiver Well-being Scale—Basic Needs Subscale: asked caregivers to rate the degree to which 22 strengths-based needs are met in their current life situation
  - ◆ Caregiver Strain Index (CSI): 13-item yes/no scale related to the potential difficulties of caregiving
  - ◆ Perceived Social Support Questionnaire Family subscale: 20-item scale designed to measure the extent to which an individual perceives that his/her needs for support, information and feedback are fulfilled by family
  - ◆ Caregiver Grief Items: 184 grief-related items generated from statements made by 45 adult child and 42 spouse caregivers during 16 focus groups. 40% of items were direct or modified quotations. 60% were paraphrased quotations or manufactured items. All scored on 5-point scale
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### **Selected Outcomes**

- ◆ Final 50-item Marwit-Meuser Caregiver Grief Inventory (MM-CGI) yielded 3 factors:
  - Personal Sacrifice Burden, individual losses in the caregiver's present life related to the caregiver role itself such as personal freedom. This factor was highly correlated with CSI
  - Heartfelt Sadness and Longing, intrapersonal emotional reactions that accompany caregiving. This factor had lowest correlation with BDI
  - Worry and Felt Isolation, feeling of losing connections with and support from others. This factor was negatively correlated with Perceived Social Support Questionnaire

- ◆ All 3 factors appear to be grief-related factors; all share some variability with depression, strain, and perceived family support; each retained certain unique grief-specific components
  - ◆ For adult child caregivers, personal sacrifice burden increases from “very mild” to “moderate” dementia and then decrease at “severe” dementia, the stage being most closely related to nursing home placement. In contrast, for spousal caregivers, personal sacrifice burden increased at from “moderate” to “severe” dementia
  - ◆ Heartfelt Sadness and Longing increased with severity of dementia (e.g. highest for severe dementia) for both adult child caregivers and spousal caregivers
  - ◆ Worry and Felt Isolation increased at from “mild” to “moderate” dementia for adult child caregivers but from “moderate” to “severe” dementia for spousal caregivers
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Moskowitz J, Folkman S and Acree M. (2003). Do positive psychological states shed light on recovery from bereavement? Findings from a 3-year longitudinal study

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### **Study Design**

Face-to-face interviews every 2 months for 2 years, then every 6 months for an additional 3 years. Physical exams were conducted every 6 months throughout the study. Participants whose partners died were interviewed approximately 2 weeks and 4 weeks after the death.

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### **Sample Description**

- ◆ Gay or bisexual men from the San Francisco Bay area were recruited through advertisements in the gay press, public service announcements, referrals from clinics and gay organizations and annual mailings to selected zip codes.
  - ◆ To be eligible as a caregiver, participant had to identify as gay/bisexual, be in a committed relationship, share living quarters with a partner with an AIDS diagnosis. Caregivers could not have more than 2 symptoms of HIV disease, a diagnosis of AIDS or use IV drugs
  - ◆ Care recipient had to need help with at least two activities of daily living
  - ◆ 86 men who met above criteria became bereaved over the course of the study and had at least 3 years of post-bereavement follow-up
  - ◆ Participants had been in a committed relationship with a partner on average 7 years at entry into the study. Their mean age was 39. 57% had a college degree. 29% were HIV+ at entry; none seroconverted over the caregiving period
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### **Selected Measures**

- ◆ Depressive mood measured by the CES-D
- ◆ Positive States of Mind (PSOM) was used to capture the ability to achieve 6 positive psychological states over the previous week: focused attention, productivity, responsible caretaking, restful repose, sharing and sensuous nonsexual pleasure
- ◆ Positive and negative life events were measured every 6 months with the Life Experiences Survey modified for use with gay men
- ◆ Resources:
  - highest level of education
  - income
  - optimism measured by Life Orientation Test
  - social support measured with the Social Support Questionnaire, yields 3 subscales perceived emotional support, material support, social integration
  - Religiosity was assessed with a 10-item measure of religious/spiritual beliefs and activities
  - Positive aspects of caregiving, a 6-item scale developed for this study
- ◆ Physical health included 3 variables: HIV serostatus, antiviral use and self-report of 20 symptoms, CD4 cell count

- ◆ Loss assessed by a count of the number of close friends, former lovers or family members who had died from AIDS in the 12 months prior to entry into the study
  - ◆ Daily hassles were measured using a modified version of the Hassles Scale
  - ◆ Coping was assessed using a 74-item, modified version of the Ways of Coping. Factor analysis revealed 8 factors: accepting responsibility, behavioral escape/avoidance, cognitive escape/avoidance, distancing, confrontive coping, seeking social support, positive reappraisal and planful problem solving
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### **Selected Outcomes**

- ◆ At a group level, depressive mood remained elevated and positive states of mind remained lower than in a comparison group of HIV+ non-bereaved gay men over the course of the study
  - ◆ On an individual level, patterns of post-bereavement CES-D and PSOM were quite diverse and erratic; chose to examine dependent variables as the length of time it took individuals to return to a normative level on the CES-D ( $< 16$ ) and the PSOM ( $> 14$ )
  - ◆ 7% (n=6) of respondents had CES-D that never went above 16; 38% (33) scores never went below 16. The mean number of months until CES-D went below 16 for those whose scores went below 16 over the course of the study (n=53, 47%), was 20.6 months (SD=10.6)
  - ◆ 2% (n=2) of respondents had PSOM that never went below 14; 53% (46) scores never went above 14. The mean number of months until PSOM went above 14 for those whose scores went above 14 over the course of the study (n=40), was 21.1 months (SD=9.2)
  - ◆ High levels of optimism and positive states of mind and low levels of cognitive escape/avoidance at 1 month post-bereavement were associated with a more rapid decline of the CES-D below 16
  - ◆ High levels of positive states of mind and use of distancing at 1 month post-bereavement predicted a more rapid increase of the PSOM above 14
  - ◆ Results suggest that the processes that produce positive psychological states are not the same as those that produce negative states
  - ◆ The ability to attain positive psychological states, such as productivity and focused attention shortly after bereavement has a greater impact on recovery from bereavement than does concurrent depressive mood, suggesting positive states of mind may protect against prolonged elevation in depressive mood
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## **SELECTED EVIDENCE**

### **Health Care Professional**

Quantitative  
Longitudinal

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#### **Principal Investigator(s)**

Murphy S, Johnson L, Wu L, Fan J and Lohan J. (2003). Bereaved parents' outcomes 4 to 60 months after their children's deaths by accident, suicide, or homicide: a comparative study demonstrating differences

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#### **Study Design**

Paper and pencil questionnaires administered in small groups at 4, 7 and 12 months post death and by mail at 24 and 60 months post death. (Data from the 7-month questionnaire was not used in this study.)

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#### **Sample Description**

- ◆ Parents were recruited from 6 most populous counties in two Pacific Northwest states from official death records
  - ◆ Criteria for inclusion were the deceased child had to have died, unmarried, between the ages of 12 and 28 by accident, homicide or suicide within 72 hours of the initial traumatic and 2 to 7 months preceding entrance into the study. The parent (biological, step or adoptive) had to agree to be randomized to treatment or control group and had to reside within a 3-county area in order to attend weekly intervention sessions and/or provide data
  - ◆ 571 death records met the study criteria over a period of 3 years. 329 (58%) families were contacted, 204 families (261 individuals) agreed to participate (62% response rate).
  - ◆ 261 (171 mothers and 90 fathers) provided baseline data. 173 parents (115 mothers and 58 fathers) remained in the study 5 years later (67%)
  - ◆ Parents' ages ranged from 32 to 61 with a mean of 45 years. 86% were white. 65% were employed. Mean years of schooling was 13.8. 75% of the parents professed a religious affiliation. 63% of the mothers were married or partnered. 85% of fathers were living with a spouse or partner. 90% were biological parents, 5% were adoptive and 5% were stepparents
  - ◆ The average age of the deceased child was 20.7 years; 65% were male. The most common cause of death was accidents (57%), suicide (25%). Time since the deaths of their children ranged from 6 weeks to 7 months, with a mean of 130 days
  - ◆ Parents who remained in the study were 2.5 years older at baseline than those who dropped out, were slightly better educated and the deceased child was 12 months older
  - ◆ Of the 173, 105 (61%) of the parents were randomly assigned to the intervention group, a bereavement group, and 68 (39%) were assigned to the control group. Data have been pooled for this study as there were no statistically significant differences for any of the four outcomes
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#### **Selected Measures**

- ◆ Mental distress was measured by the 53-item Brief Symptom Inventory (BSI). The BSI yields an overall measure of distress, the Global Severity Index (GSI) and 9 subscales
- ◆ The incidence of PTSD was measured by the Traumatic Experience Scale (TES). The TES is an 18-item measured based on DSM-III R PTSD criteria and yields a total score and 3 subscale scores (reexperiencing, avoidance and hyperarousal)
- ◆ Marital satisfaction was measured by the 10-item Marital Satisfaction subscale of the Dyadic Adjustment Scale (DAS). Higher scores signify greater marital satisfaction

- ◆ Parents' ratings of acceptance of their children's death was assessed using a single yes/no item, *I will never accept it/I have definitely accepted it*
  - ◆ One open-ended question asked parents' perceptions of the amount of time needed to accommodate the death of their child, *At what year during your bereavement do you feel you were able to put your child's death into perspective and get on with your own life?* The options for response were the first, second, third or fourth year after the death of support items were included in this study
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### **Selected Outcomes**

- ◆ Parents whose children died by suicide had the highest acceptance scores at all time points compared with the other two groups
  - ◆ Parents whose children died by homicide had significantly higher TES scores than parents in the other two groups
  - ◆ Marital satisfaction decreased significantly over time and reached its lowest levels 5 years post death, although the child's cause of death did not significantly influence this outcome
  - ◆ Parents' perceptions of their accommodation of their child's death showed no significant differences among the three groups
  - ◆ Change over time in all 4 outcomes was highly significant, on average parents improved over time
  - ◆ Although 70% of respondents indicated that it took 3 or 4 years to put their child's death into perspective and get on with their lives, 5 years after the deaths, parents' reports of mental distress and trauma were still 2 to 3 times higher than scores obtained from normative samples of adults in the same age range
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Ott C and Lueger R. (2002). Patterns of change in mental health status during the first two years of spousal bereavement

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### **Study Design**

Cohort sequential design. As participants volunteered for the study, they were assigned into the time frame closest to the death—3, 6, 9, 12, 15 and 18 months. Data were collected 3 times, each approximately 3 months apart. A fourth retrospective data point, representing the time during the first 3 months of bereavement, was collected for each participant. First data collection was conducted in home and consisted of an interview and questionnaire. Two subsequent questionnaires sent via mail

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### **Sample Description**

- ◆ Participants were recruited through 4 hospice programs, 9 churches, 4 support groups and a mortician in a major Midwestern metropolitan area
  - ◆ The first 120 healthy spouses who agreed to participate in the study represented 29% of total participants (n=421) identified by the agencies. 118 (98%) completed the study
  - ◆ 78% were women, with a mean age of 60.65 years. 97% were white. The group was well-educated, with a mean of 14.17 years of education and was from a relatively high socioeconomic status. All participants had experienced the death of a spouse between 3 and 18 months prior to the study. 59% expected the death of their spouse. 53% participated in a grief support group
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### **Selected Measures**

- ◆ Integra Outpatient Tracking Assessment (IOTA) was used to assess overall mental health status. 68-items yield 3 subscales: subjective well-being, current symptoms and current life functioning
    - Subjective Well-being Scale (SWB) of the IOTA includes 4 questions related to distress, energy and health, emotional and psychological adjustment and life satisfaction
    - Current Symptoms Scale (CS), consists of 40 items representing 7 diagnostic categories of the DSM III-R. These diagnoses include: adjustment disorder, anxiety, depression, bipolar disorder, obsessive-compulsive disorder, phobia and substance abuse
    - Current Life Functioning Scale (CLF) contains 24 items that assess the extent to which emotional and psychological problems interfere with the ability to function in major areas of life: family, intimacy, social, health, work and self-management
  - ◆ Mental Health Index (MHI), is a combined scale of the SWB, CS and CLF
  - ◆ Abbreviated Mental Health Inventory (RMHI) was used to assess the participants' overall mental health status within the first 3 months of bereavement
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### **Selected Outcomes**

- ◆ There were no significant differences between cohort groups, therefore MHI scores at each time were determined by merging scores for all cohorts

- ◆ During the first 3 months of bereavement, overall mental health status is comparable to that of individuals seeking outpatient mental health treatment.
  - ◆ Consistent improvement in overall MHI that is most rapid in the first 3 months, peaks at 15 months and remains fairly stable over the next 9 months. By the 9-month of bereavement, the MHI cutoff marking the boundary between a clinical and a non-clinical population was reached.
  - ◆ By 12 months post death, participants had achieved the non-clinical cutoff on the SWB scale
  - ◆ Participants did not reach a non-clinical cutoff on the CS over the 24 months of bereavement
  - ◆ Functioning scores (CLF) increased from 58.08 at 3 months to 63.03 at 15 months and then dropped below the non-clinical level (T score=60) during the next 9 months
  - ◆ A T score of 70, which is the mean of the general population, was not achieved on any of the 3 subscales over the 24 months of bereavement, indicating some level of difficulty continued
  - ◆ Overall pattern of change in bereavement identified in this study reflects the psychotherapy dosage model with a steep rate of initial change during the first 6 to 9 months of bereavement followed by a more gradual rate of improvement later in the process
  - ◆ That well-being changed more than symptoms which in turn changed more than functioning is typical of the type of change described by the psychotherapy phase model
  - ◆ Patterns of change for individuals vary, making it important to consider clinical and demographic characteristics that influence the patterns of recovery
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Pearce M, Chen J, Silverman G, Kasl S, Rosenheck R and Prigerson H. (2002). Religious coping, health and health service use among bereaved adults

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### **Study Design**

Face-to-face interviews conducted within the first 6 months of bereavement and again 4 months later

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### **Sample Description**

- ◆ Respondents were recruited monthly from lists of the AARP Widowed Persons Service, Bridgeport/Fairfield division. WPS is a community-based outreach program that serves as an information clearinghouse. 62% of participants contacted agreed to participate (182/294).
  - ◆ There were no significant differences in age, sex or race between participants and those who refused. Participants were significantly better educated.
  - ◆ 89 participants were recruited from other sources (29 through the Chaplain's Office of the Hospital of St. Raphael in New Haven, 6 through personal referrals and 54 through other means). This non-WPS sample had a significantly greater number of psychiatric outpatient visits in the prior 60 days than the WPS sample
  - ◆ 6 participants had missing baseline data so the final study sample included 265 bereaved individuals. 74% of the sample was female with a mean age of 62 years. 90% of participants had recently lost a spouse, 8% had lost a parent, 1% parent had lost a child and 1% had lost a sibling. The mean time from loss was 6.27 months
  - ◆ 4-month follow-up interviews had been conducted with 62% of the sample (164/265). Of those approached for the 4-month follow-up interview, 98% were re-interviewed
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### **Selected Measures**

- ◆ Physical health was assessed by 2 self-report measures: functional disability and chronic conditions
  - A 12-item subscale of the Established Populations for Epidemiological Studies of the Elderly questionnaire that asks about the ability to perform everyday tasks such as walking across a room, bathing, dressing, using the toilet and getting from bed to a chair was used to assess functional disability
  - Participants were asked whether they had ever been told by a doctor that they any of the following chronic conditions: heart attack, cancer, diabetes, high blood pressure, broken hip, other broken bones or cirrhosis
- ◆ Health promoting behaviors were assessed by 15 items that asked participants about their engagement in a variety of health behaviors, such as exercise, sleep, concern about nutrition and annual physical check-ups. Participants were also asked if they currently smoked cigarettes or drank alcohol
- ◆ Current mental health status was measured by the Structured Clinical Interview for the DSM-IV (SCID) Axis I modules
- ◆ Social support was assessed using a shortened version of the Interpersonal Support Evaluation List (ISEL) consisting of 16 statements about the perceived availability of potential social resources in 4 areas: material aid (tangible); someone to talk to about one's problems (appraisal); comparisons of self with others (self-esteem); and people with whom to share activities (belonging)
- ◆ Health service use over the past 2 months was measured by a self-reported assessment of inpatient physical and mental health service use and outpatient physical and mental health use. No participants report inpatient mental health service use so it was not included in the analyses

- ◆ Health costs were estimated by multiplying the number of annual units of each service used by the estimated unit costs for each type of service
  - ◆ Religious coping was measured by two religious coping questions from the Religious Coping Index (RCI). The first question, “What helps you cope with the loss?” If a religious response was given, a score of 10 was assigned; if a non-religious response was given, a score of 0 was assigned. The second question asked “To what extent do your religious beliefs or activities help you cope with or handle the loss?” The 5-level response was scaled 0 “Not at all” to 10 “It was the most important thing that keeps me going”. The 2 items were summed to give a religious coping score that ranged from 0 to 20
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### **Selected Outcomes**

- ◆ Two religious coping categories were created: low religious coping was defined as a score  $\leq 7.5$ ; high religious coping was defined as a score  $> 7.5$ . 33% of the sample was categorized as high religious coping
  - ◆ Participants who had high religious coping were significantly older, more concerned about nutrition, drank less alcohol and had more functional disabilities at baseline than did those with low religious coping scores. There were no significant associations between degree of religious coping and psychiatric diagnoses or any type of physical or mental health service use
  - ◆ Higher scores on the religious coping measure predicted having a greater number of functional disabilities at baseline. At follow-up, those with higher religious coping scores had no worse health than did those with lower religious coping scores, after controlling for baseline health status
  - ◆ At baseline, those with high religious coping scores had significantly fewer outpatient physician visits within the last 60 days than did those with low scores, after controlling for age, concern about nutrition, and baseline chronic conditions and functional disabilities. This translated into a significant difference in average cost for physician visits: \$74.70 for those with high religious coping compared to \$112.20 for those with low religious coping. This results in a savings of \$225 per year
  - ◆ There were no significant differences in the number of physician visits at follow-up or for the number of medical hospitalizations and mental health service use at baseline or follow-up for those with high versus low religious coping
  - ◆ Despite the expectation that health would decline, bereaved individuals who relied more heavily on religion to cope with their loss did not experience a significant increase in health problems. Instead, they demonstrated a trend toward fewer disabilities at follow-up, controlling for baseline health, health service use and health behaviors. Conversely, bereaved individuals who had lower religious coping scores demonstrated a trend toward more functional disabilities and chronic conditions from baseline to follow-up, suggesting a decline in health over time
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Prigerson H, Cherlin E, Chen J, Kasl S, Hurzeler R and Bradley E. (2003). The stressful caregiving adult reactions to experiences of dying (SCARED) scale. A measure for assessing caregiver exposure to distress in terminal care

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### **Study Design**

Face-to-face interview within 1 week of the hospice inpatient admission

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### **Sample Description**

- ◆ 390 caregivers of terminally ill patients at the largest hospice facility in CT, identified by hospice staff as the patient's next-of-kin were approached to participate. 100 caregivers refused research contact. 205 (61%) participated
  - ◆ There were no significant differences in sex or kinship relationship to the patient between the caregivers who participated and those who refused
  - ◆ The mean number of months of providing care was 21.6. The mean length of stay of patients in hospice before death was 25.9 days. The average caregiver had been caring for the patient for almost 2 years before the hospice admission
  - ◆ 76 caregivers were interviewed before the death of the patient and 129 were interviewed within the month after the death. Only those 76 caregivers interviewed while actually providing care for the hospice patient were included in this study
  - ◆ 71% were female; 76% were age 65 years or older. 71% had received more formal schooling than a high school diploma. 75% were currently married. Only 32% of the caregivers were spouses, 36% were daughters, 13% sons and 20% were another family member or friend
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### **Selected Measures**

- ◆ Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED), assessed the frequency and associated fear and helplessness of particular distressing caregiving experiences including witnessing the patient's severe pain or discomfort; inability to eat or swallow or choking; vomiting; dehydration; sleeplessness; falling, collapsing or passing out; confusion or delirium; or other distressing experiences. Caregivers were also asked if they felt the patient had "had enough" and if they had ever thought "the patient was dead when he/she was not dead." Scale yields a SCARED event frequency score and a SCARED total score
- ◆ Major depressive disorder (MDD) was measured with the Major Depressive Disorder module of the Structured Clinical Interview for the DSM-IV (SCID) Axis I Modules
- ◆ Complicated grief was assessed with the 19-item, pre-loss version of the Inventory of Complicated Grief designed for use among caregivers of terminally ill loved ones
- ◆ Caregiver burden was assessed with a 9-item version of the Zarit Burden Interview. 6 items measured caregiver burden and 3 items measured gratification
- ◆ Caregivers were asked to indicate whether they assisted the patient with each of 12 activities (6 ADL, 6 IADL). Positive responses were added for caregiving ADL and IADL summary scores
- ◆ Quality of life was assessed with the Medical Outcomes Survey (MOS) Short Form-36 (SF-36), a brief measure of subjective health status and functioning. 8 domains were measured including: physical and social

functioning; role limitations due to physical problems and due to emotional problems; mental health; energy; pain; change in health; and general health perception

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### **Selected Outcomes**

- ◆ 64% of respondents assisted with at least one activity of daily living (ADL) such as dressing, eating, ambulating, toileting or hygiene. 82% of the respondents provided IADL such as shopping, housework, accounting, food preparation, transportation assistance. The average number of ADLS and IADLS was 2.2 and 3.2, respectively
  - ◆ 20% of respondents indicated their health had declined from what it was a year earlier. 95% had at least one activity restriction due to impaired health
  - ◆ 30% of respondents met SCID criteria for MDD. 8% met the consensus criteria for CG
  - ◆ The 10 distressing events listed in the SCARED were a fairly common occurrence among the interviewed caregivers. The least frequently reported experience was thinking that the patient died before his/her actual death (30%). The most frequently reported experience was witnessing the patient in severe pain or discomfort (80%). Respondents also endorsed witnessing these distressing experiences quite often. 62% who reported witnessing the patient in severe pain or discomfort did so daily. On a daily basis, 47% reported the patient's sleeplessness, 43% observed the patient unable to eat or swallow/choking, 41% thought the patient had "had enough".
  - ◆ Fear was shown to be less common than helplessness. The least fear-provoking experience was the patient's insomnia; the most fear-provoking included watching the patient collapse and "other". Most of the SCARED events did evoke feelings of helplessness. Insomnia elicited the least degree of helplessness and being unable to swallow/choking, collapsing, delirium, thinking the patient had enough or other distressing events evoked the greatest sense of helplessness
  - ◆ After adjusting for caregiver's age, sex, kinship relation to the deceased, number of chronic conditions and caregiver burden, the odds of MDD increased by 2.09 for each SD increase in the SCARED total score and by 3.08 for each SD increase in the SCARED even frequency score.
  - ◆ After adjusting for caregiver's age, sex, kinship relation to the deceased, number of chronic conditions and caregiver burden, a higher SCARED total score was significantly associated with greater impairment in mental health, social functioning, energy and general health perceptions. A higher SCARED event frequency score was significantly associated with greater impairment in only mental health and role-elimination domains
  - ◆ Results indicate the SCARED shows promise as a screening tool for identifying aspects of caregiving that pose substantial risk for MDD and quality-of-life impairment and exposures that might be targeted by interventions to improve the mental health and functioning of caregivers
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Survey  
Longitudinal

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### **Principal Investigator(s)**

Prigerson H, Maciejewski P and Rosenheck R. (2000). Preliminary explorations of the harmful interactive effects of widowhood and marital harmony on health, health service use, and health care costs

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### **Study Design**

Interviews conducted in home at enrollment (1986) and 3 years later

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### **Sample Description**

- ◆ Respondents participated in Americans Changing Lives (ACL), a longitudinal study of productivity and successful aging in the middle and later years of life.
  - ◆ Nationally representative sample of people over age 25 living in the continental US; blacks and individuals aged 60 or over were sampled at twice the rate
  - ◆ 3617 respondents were interviewed in their house; 2867 (83%) were re-interviewed 3 years later
  - ◆ Study focuses on those who were married and living with their spouse, who had not been widowed previously and who were age 50 years or older at enrollment (n=968). 755 (78%) completed the follow-up.
  - ◆ Respondents who enrolled in the study but did not participate in the follow-up assessment (n=183) were significantly older, less wealthy, more likely to be male, had significantly higher levels of depressive symptoms, worse functional health, more chronic conditions and lower life-satisfaction than those retained in the analyses (n=755)
  - ◆ 61 were widowed. The widowed group was significantly older, more likely to be female, of lower SES at baseline and less likely to have health insurance coverage at follow-up than the respondents who remained married
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### **Selected Measures**

- ◆ Marital harmony, ACL contained a marital satisfaction and harmony index composed of items from scales created by Parks and Weiss and Perlin and Schooler. Index was modified to include baseline assessments of the degree of marital satisfaction, love, and affection; frequency of thoughts of separation/divorce, disagreements, feeling upset by the marriage; extent of agreement with statements that they would “feel lost without...” and “no one could replace” their spouse; frequency with which the spouse pushed, slapped or hit the respondent. A median-split of the baseline score for marital harmony was used to divide respondents into a marital harmony group (n=366) and a marital discord group (n=389)
- ◆ Health services utilization, self-reported assessments of the number of nights spent in a hospital in the past 6 months, the number of days spent in a nursing home over the past 6 months, the number of visits to a medical doctor, and the number of visits to a psychiatrist over the past 3 months (doubled to reflect same time period as hospital visits)
- ◆ Health costs were estimated by multiplying the number of units of each service used by the estimated unit costs for each type of service.
- ◆ SES, the ACL provided a 4-category measure of SES: low, lower-middle, upper-middle, high. SES was dichotomized to reflect whether or not the respondent was of low SES

- ◆ Life satisfaction was assessed using an index comprising 4 items that asked respondents the extent to which they agreed with statements about their happiness, satisfaction and lack of regrets. Higher scores corresponded to lower levels of life satisfaction
  - ◆ Depressive symptoms were measured using an 11-item version of the CES-D
  - ◆ Chronic conditions, self report of 10 chronic conditions experienced in the past year
  - ◆ Functional health status was assessed with an index with 1 indicating confinement to a bed or chair to 4 indicating ability to do heavy housework
  - ◆ Health insurance coverage at assessment (yes/no)
- 

### **Selected Outcomes**

- ◆ Mean level of depressive symptoms, number of chronic conditions, and functional disability at follow-up all reflected greater impairment for the widowed group compared to the married group after adjusting for baseline characteristics
  - ◆ Average number of physician visits and days spent in a nursing home at follow-up were significantly higher for the widowed group compared to the married group
  - ◆ Means for total health care costs in 1989 were significantly higher for respondents who became widowed between the 1986 and 1989 assessments than for those who remained married
  - ◆ Mean total costs were significantly lower for respondents with high marital harmony after adjusting for baseline and follow-up characteristics
  - ◆ While marital harmony appears to be protective of health and to be associated with lower health care costs among married respondents, the reverse appears to be true among widowed respondents
    - Outpatient costs were significantly lower for respondents who scored high on marital harmony than they were for those who scored low. No statistically significant difference in inpatient costs
    - Respondents who became widowed in the context of a harmonious marriage had the highest average total costs in 1989, 32% higher than those for widowed respondents who had discordant marriages.
    - Respondents with harmonious marriages who became widowed had the highest average adjusted outpatient costs in 1989, 42% higher than the outpatient costs among those widowed in the discordant marriages. They were no statistically significant difference in inpatient costs
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Rich D. (2000). The impact of post pregnancy loss services on grief outcome: Integrating research and practice in the design of perinatal bereavement programs

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### **Study Design**

Questionnaire via mail

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### **Sample Description**

- ◆ 54% of participants who returned questionnaires were recruited from internet e-mail to perinatal bereavement support groups
  - ◆ Participants were 18 years old or older, women and their male partners who experienced pregnancy losses between January 1992 and September 1997. 391 of 540 participants (72%) returned a questionnaire. The final sample included 363 participants: 249 women and 114 of their male partners. Participants ranged in age from 18 to 47 (mean 32.3 years). 95% were white.
  - ◆ Participants experienced from 1 to 14 pregnancies (on average 3.09) resulting in 1 to 12 losses (on average 2.12) and had a total of 0 to 10 living children. Length of pregnancy ranged from 30 to 42 weeks gestational age (on average 21.57 weeks), with 39.1% first trimester losses, 26.5% second trimester losses and 34.4% third trimester losses.
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### **Selected Measures**

- ◆ Grief as measured by the Perinatal Grief Scale (PGS) short form, 33 items covering thoughts and feelings of the bereaved parent. Only the total grief score was used in this study
  - ◆ Postloss services (medical, spiritual/religious, emotional support, social support) received
  - ◆ Actual timing of services and preferred timing of services
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### **Selected Outcomes**

- ◆ Social support services were received by most participants. Mothers and fathers reported talking with family (96%). Significantly more mothers than fathers reported talking to friends (97% vs 91%), meeting with a doctor to review the reasons for pregnancy loss (93% vs 83%) or to plan a future pregnancy (86% vs 75%) and receiving counseling (42% vs 25%)
- ◆ Mothers had significantly greater PGS scores than fathers (mean 92.48 vs 73.99)
- ◆ The final regression model for mothers included months since loss (negative), attending individual counseling (positive) and attending support group (positive) and accounted for 17% of the variance in PGS score
- ◆ The final regression model for fathers included length of pregnancy (positive), talking with friends (positive) and timing of talking with friends (positive) and accounted for 16% of the variance in PGS score

- ◆ Once the sample was analyzed separately by sex, demographic variables accounted for significantly less of the variance in grief scores than was previously assumed, suggesting demographic variables alone may be inadequate predictors of grief
  - ◆ Service variables contributed to the prediction of grief scores above and beyond demographic predictors for both mothers and fathers
  - ◆ Findings suggest that there are significant gender differences in response to perinatal loss and with regard to need for service interventions. Couples should be assessed individually for risk of poor grief outcome and for referral to service options. Bereaved fathers should not be neglected
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Safer M, Bonanno G and Field N. (2001). "It was never that bad": biased recall of grief and long-term adjustment to the death of a spouse

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### **Study Design**

Self report symptom questionnaires via mail between 3 and 5 months post death were repeated at 14, 25 and 60 months post death. This study uses data from the 6 month interview and 60 month questionnaire

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### **Sample Description**

- ◆ Participants recruited by newspaper advertisements, posted notices and referrals from a variety of institutions within the San Francisco Bay area
  - ◆ Participants had to be between the ages of 21 and 55, have been married or living with their deceased partner for at least 3 years and sustained the death of a spouse/partner between 3 and 6 months earlier
  - ◆ 56 bereaved participants from the original study were considered for the 5 year follow-up. 39 (70%) completed it. 37 were used for this study
  - ◆ Sample was 70% female with an average age of 48.36 years; 91% were white; 51% were employed full-time. Respondents had been married to the deceased an average of 18.2 years.
  - ◆ There were no significant differences between the 5-year sample and the original sample
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### **Selected Measures**

- ◆ Self reported grief was assessed by the 13-item Texas Revised Inventory of Grief (TRIG)
  - ◆ Grief-related intrusive ideation and avoidant thoughts were measured using the 7-item intrusion and the 8-item avoidance subscales of the Impact of Events Scale (IES)
  - ◆ At the 5-year follow-up, participants completed a recall of symptoms questionnaire using the TRIG and IES with modified instructions to specify that the items should be completed in reference to "when you first entered the study"
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### **Selected Outcomes**

- ◆ Participants reported less grief, less intrusive ideation and fewer avoidant thoughts at 5 years compared to 6 months post death. Compared to their 6-month ratings, 92% reported fewer grief symptoms, 92% less intrusive ideation and 68% fewer avoidant thoughts
- ◆ Current ratings were significantly lower than recalled ratings for grief symptoms, intrusive ideation, avoidant thoughts, indicating that participants were not simply restating their current levels of grief when asked to recall their grief
- ◆ 68% of participants overestimated their initial intrusive ideation; that is, they recalled having more grief-related intrusive ideation than what they had actually reported at 6 months. There was no significant distortion in recalling avoidant thoughts or grief symptoms

- ◆ In regression models, current levels of intrusive ideation, avoidant thoughts and grief symptoms predicted recalled levels even though participants were experiencing much lower levels than either their initial ratings or their recalled ratings. Current levels predicted recalled levels slightly better than initial levels, even though initial levels were much closer to recalled levels
  - ◆ Concept of “retrospective reappraisal” suggests that recalled grief should be positively correlated with current functioning. In this study, there was evidence for retrospective reappraisal, as across different measures, current levels of grief were predicted by recalled levels of grief. For example, recalled intrusive ideation significantly predicted ratings of both current avoidant thoughts and grief symptoms, and recalled grief symptoms significantly predicted current levels of both intrusive ideation and avoidant thoughts
  - ◆ There was an inverse relationship between symptom changes over time and measures of recall distortion. Participants who improved relatively less over time tended to overestimate their initial grief symptoms and thoughts and those who improved relatively more over time tended to underestimate their initial grief symptoms and thoughts
  - ◆ Results call into question the usefulness of focusing on past grief, as is often encouraged in therapy. Participants who overestimated past grief, presumably the more likely candidates for therapy, tended to show the least objective improvement over time. Focusing on past grief may be particularly counterproductive for individuals with relatively low levels of grief-related symptoms and distress, who tended to recall relatively less grief
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Case Control (matched)  
Longitudinal

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### **Principal Investigator(s)**

Schulz R, Beach S, Lind B, Martire L, Zdaniuk B, Hirsch C, Jackson S and Burton L. (2001). Involvement in caregiving and adjustment to death of a spouse. Findings from the Caregiver Health Effects Study

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### **Study Design**

Structured, face-to-face interview. Four waves of data collection: 3 annual interviews with 4<sup>th</sup> conducted 2 years after 3rd

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### **Sample Description**

- ◆ Sample for Caregiver Health Effects Study (CHES) drawn from the Cardiovascular Health Study (CHS), a population-based study of elderly people (5201 men and women 65 years or older randomly selected from HCFA Medicare enrollment lists from 4 US communities)
  - ◆ Total CHES sample 819 people: 392 caregivers, i.e., individuals whose spouse had difficulty with at least 1 activity of daily living (ADL) or instrumental activity of daily living (IADL) and 427 noncaregiver controls matched for age and sex
  - ◆ This study included 129 cases widowed at wave 2, 3 or 4 and their controls, aged 66 to 96 years.
  - ◆ Sample was divided into 3 groups: 1) noncaregiver (n=40); 2) caregiver no strain (n=37) and 3) caregiver with strain (n=52) based on 3 indicators measured at the interview prior to spouse's death: 1) level of spousal disability; 2) extent to which participants helped the spouse with tasks related to the disability; 3) level of strain associated with this helping behavior
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### **Selected Measures**

- ◆ Depressive symptoms as measured by 10-item Center for Epidemiologic Studies-Depression (CES-D). Predeath measure within 1 year of the death for 88%, postdeath for 85%
  - ◆ Antidepressant medication use (yes/no): CHS protocol required that participants bring medications to yearly clinic visit. Predeath within 1 of the death for 91%, postdeath 94%
  - ◆ Health risk behaviors (count of 6 behaviors): based on self report of 6 behaviors including missing at least 1 MD appointment in last 6 months; not having time to go the MD; not having time to exercise; forgetting to take medication; not getting enough rest in general; not being able to slow down and get enough rest when sick. Predeath within 1 year of the death for 67%, postdeath 68%
  - ◆ Weight: as recorded by a laboratory technician using standardized balance-beam scale. Predeath within 1 year of the death for 93%, postdeath 93%
  - ◆ Models adjusted for age at entry to CAHES, race, sex, education, physical health status (count of 6 prevalent CV diseases based on medical records, EKG and MD report) and time to pre and postbereavement
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## **Selected Outcomes**

- ◆ Caregivers who report caregiving strain have higher levels of depression symptoms and have worse health practices prebereavement than noncaregivers or caregivers who report no strain
  - ◆ Following the death of their spouse, strained caregivers had improved health practices and no further increase in depression symptoms, antidepressant use or significant weight loss. The death of a spouse among strained caregivers represents a significant reduction in burden and does not further tax their ability to cope
  - ◆ Strained caregivers who remain in the caregiving role report increasing levels of depression symptoms over time, although they start out at lower levels of depression symptoms reflecting the fact that they are at earlier stages of the caregiving role
  - ◆ In contrast to strained caregivers, noncaregivers after the death of their spouse, had increased depression symptoms and antidepressant use, significant weight loss but no change in health risk behaviors. The negative effects of bereavement for this group may result from the relatively unpredictable nature of their spouse's death
  - ◆ Caregivers who report no strain represent a middle ground between strained caregivers and non-caregivers. After the death of their spouse, they exhibited smaller, though still significant, increases in depression symptoms and no change in antidepressant use, health risk behaviors or weight
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Sikkema K, Kalichman C, Hoffmann R, Koob J, Kelly J and Heckman T. (2000). Coping strategies and emotional well-being among HIV-infected men and women experiencing AIDS-related bereavement

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### **Study Design**

Questionnaires individually administered with a research staff member present

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### **Sample Description**

- ◆ 199 HIV-infected clients of Milwaukee's major AIDS service organizations or outpatient medical clinics. 4,000 AIDS cases and nearly 6,500 HIV infection cases diagnosed in Wisconsin, primarily Milwaukee
  - ◆ On average, participants were 36.7 years old and had completed 12.3 years of education. 167 (84%) were men. 59% were African-American, 32% were white, 4% were Hispanic. 65% described their sexual orientation as gay or bisexual and 35% identified themselves as heterosexual. 37% of participants were HIV-infected but not experiencing any symptoms, 27% had illness symptoms that did not alter their daily routine and 36% had HIV-related illnesses that interfered with daily functioning. The average CD4 cell count among participants was 305
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### **Selected Measures**

- ◆ Loss and bereavement experiences were measured by the number of people with HIV infection or AIDS participants knew, the number of persons they knew who died as a result of AIDS, their relationship to the deceased, the time since their death, whether or not the participant served as a caregiver and whether the participant lived with the deceased
  - ◆ Health status
  - ◆ Grief reaction as measured by the 12-item Grief Reaction Index (GRI). Higher scores indicated greater severity of grief severity
  - ◆ Coping with HIV infection was assessed by a modified, 21-item version of the Ways of Coping Questionnaire. The scale, which describes a range of thoughts and acts that people may use to deal with the internal or external stressors, was administered to assess ways of coping with the loss of a loved one to AIDS among those who had experienced a loss. Factor analysis yielded 5 factors with 2 or more items: planful problem solving; avoiding coping; emotional suppression; seeking social support; minimizing
  - ◆ Perceived social support was measured by the Instrumental Support Evaluation List (ISEL), a 40 item scale. Higher scores indicated greater levels of perceived social support
  - ◆ Depression was measured using the Beck Depression Inventory (BDI)
  - ◆ Global psychiatric distress and specific types of distress symptoms were measured by the SCL-90-R, resulting in a Global Severity Index as well as depression, somatization, anxiety, interpersonal sensitivity, hostility and phobic anxiety subscales
  - ◆ Traumatic stress as measured by the Impact of Events Scale (IES), a 15-item scale that assesses two categories of experience in response to the stressful event, intrusive experiences and avoidance. Higher scores reflect more stressful impact
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## **Selected Outcomes**

- ◆ 80% (160) of participants had experienced loss of a spouse or partner to AIDS. 80% of those participants who described any bereavement experiences reported that they had experienced multiple and repetitive bereavements due to the loss of partners, family members or friends to AIDS. 68% (108) reported experiencing grief reaction symptoms in the past month
  - ◆ Among 108 participants currently experiencing AIDS-related grief symptoms, it had been 10 months since loss or most significant loss; 45% of HIV-infected individuals indicated that they had assisted in caregiving for the person who died of AIDS. More white (67% vs 49%) and more gay/bisexual men (64% vs 39%) were currently experiencing grief symptoms
  - ◆ 108 HIV+, AIDS-bereaved respondents had elevated scores on BDI. Total scores, cognitive/affective and somatic subscale scores all greater than clinical cut-offs for depression. Their scores on the GSI and the SCL-90-R interpersonal sensitivity, hostility and phobic anxiety scales were comparable to normative scores among psychiatric outpatients. Scores on the two IES subscales, intrusive experiences and avoidance, exceeded scores in a normative sample of persons who had lost their parents to death in the past 2 months
  - ◆ Severity of grief was significantly associated with sex (women had higher severity), number of HIV-related illness symptoms in the past year (greater severity related to greater number)
  - ◆ Grief was most closely associated with avoiding coping, emotional suppression and depression
  - ◆ For whites, grief was associated with avoiding coping, emotional suppression and depression. For minorities, grief was associated with avoiding coping
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Sikkema K, Kochman A, DiFranceisco W, Kelly J and Hoffmann R. (2003). AIDS-related grief and coping with loss among HIV-positive men and women

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### **Study Design**

Self-administered questionnaire and a clinician-rated structured interview

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### **Sample Description**

- ◆ Participants were recruited through brochures, posters and personal contacts with AIDS service organizations and HIV care providers in Milwaukee WI and New York NY
  - ◆ Eligible participants were HIV positive (verified by a health provider) and had lost a loved one(s) to AIDS not less than 1 month or more than 2 years at the time of the study
  - ◆ 268 persons participated. 35% were women with a mean age of 40.1 years and a mean educational level of 12.8 years. 54% were African-American, 27% white, 13% Latino. 51% of participants were men who identified themselves as gay or bisexual. 25% of the sample reported a history of IV drug use. 46% of the sample had been diagnosed with AIDS
  - ◆ Participants reported knowing an average of 30 loved ones and friends who had died from AIDS. 41% identified a spouse or partner as their primary loss. On average, a participant's primary loss had occurred 40.4 months prior to the assessment
  - ◆ Men were significantly more likely to have been recruited in Milwaukee, were better educated and had been living with HIV/AIDS for a longer period of time than women. Women were significantly more likely than men to have seen a therapist in the past month for either mental health or substance abuse
  - ◆ White participants were significantly more likely to have been recruited in Milwaukee, had higher levels of education and were more likely to have been prescribed psychotropic drugs in the previous 4 months than non-white participants. A significantly greater percentage of non-white participants reported seeing a therapist in the past month and were more than twice as likely as whites to identify a family member as their primary AIDS-related loss
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### **Selected Measures**

- ◆ History of AIDS-related losses included the number of friends, lovers/spouses, family members, casual sexual partners and acquaintances known to have died of AIDS
- ◆ Health status included the date they learned of their HIV-positive status and whether or not they had been diagnosed with AIDS. Physical symptoms were assessed by self-report using a 20-item scale that included 12 symptoms found in HIV disease and 8 more general symptoms
- ◆ Grief Reaction Index, a 12-item measure of common grief symptoms including numbness, denial and preoccupation with the deceased
- ◆ Beck Depression Inventory (BDI), a 21-item scale used to measure clinical depression. Higher scores indicate greater depression. The cognitive-affective (12-items) and somatic (9-items) subscales were used in this study
- ◆ Impact of Events Scale (IES), measures stress associated with traumatic events. It consists of 2 subscales: one reflecting intrusive stress experiences and the other reflecting avoidance of ideas, feelings and situations associated with a traumatic stressor. Higher scores reflect more stressful impact

- ◆ Instrumental Support Evaluation List (ISEL) measure the respondent's perceived social support resources along 4 dimensions, each assess with 10-item subscales. The subscales reflect tangible, appraisal, self-esteem, and belonging support. Higher scores are indicative of greater perceived support
  - ◆ Ways of Coping Questionnaire is a 66-item inventory that assesses the respondent's style of coping with stressors. Subscales reflect the following coping styles: confrontive, distancing, self-controlling, seeking social support, acceptance of responsibility, escape/avoidance, planful problem solving and positive reappraisal
  - ◆ Mood was evaluated using the SIGH-AD, an interview guide that combines the Hamilton Depress Scale (HAM-D) and the Hamilton Anxiety Scale (HAM-A).
  - ◆ Substance use in the past 30 days
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### **Selected Outcomes**

- ◆ The average Grief Reaction Index score was 19.3, an average level of grief reaction slightly higher than that found in earlier research on AIDS-related bereavement among gay men in NYC. Participants exhibited mild depression (scores >9 on the BDI). The average levels of traumatic stress related to the loss(es) exceeded the levels in a normative sample of adult volunteers who had a recently deceased parent
  - ◆ Women reported significantly higher levels of anxiety (HAM-A) and scored higher on the IES avoidance subscale than men. Men drank alcohol and smoked marijuana more frequently than women.
  - ◆ Non-white participants reported significantly higher grief reactions and were more likely to use avoidance responses to the traumatic experience of a lost loved one than whites. Non-white participants averaged more frequent use of cocaine and were significantly more likely to have injected drugs in the past than white participants
  - ◆ The regression model accounted for more than 50% of the total variance in grief reaction. Background, behavioral, psychosocial predictors explained 36.3% of the variance. Individual coping strategy was a strong predictor of grief reaction and accounted for 14.1% of the variance
  - ◆ Higher levels of grief reactions (GRI) were associated with escape-avoidance and self-controlling coping strategies after adjusting for background, psychosocial characteristics. Other significant predictors of grief reactions included loss of a spouse/partner, loss of a close family member, history of injection drug use and depressive symptoms
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Survey  
Longitudinal

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### **Principal Investigator(s)**

Silver R, Holman E, McIntosh D, Poulin M and Gil-Rivas V. (2002). Nationwide longitudinal study of psychological responses to September 11

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### **Study Design**

Web-based surveys administered 9 to 23 days, 2 and 6 months after the attacks on September 11

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### **Sample Description**

- ◆ Of 3,496 adults in a national probability sample that participated in web-based surveys, 2,729 (78%) completed a survey 9 to 23 days after the attacks on September 11 (Wave 1). 75% completed it within 9 to 14 days after the attacks
  - ◆ Due to budgetary constraints, a random sample of 1069 adults who were  $\geq 18$  years old, lived outside of New York, NY and had completed the Wave 1 survey were contacted to participate in Wave 2. 933 (87%) completed a survey 2 months after the attacks (Wave 2)
  - ◆ Wave 3 was conducted 6 months after the attacks. 787 adults completed the Wave 3 survey, 84% of the Wave 2 sample
  - ◆ A comparison of the weighted demographic breakdown of participants from Waves 1 and 2 and the September 2001 Current Population Survey indicate the sample is representative of the US population
  - ◆ Individuals who completed the Wave 2 survey (n=933) were not significantly different from nonrespondents (n=136) on pre-September 11 physical and mental health history, sex, marital status, race/ethnicity, education or income. Nonrespondents were significantly younger than respondents. The same relationships existed between the individuals who completed Wave 3 and those who did not.
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### **Selected Measures**

- ◆ Mental and physical health history was assessed with a survey completed by 96% of participants between 6/17/00 and 9/4/01. 60% of the sample completed these measures before 12/31/00. Respondents reported whether they had ever had an anxiety disorder or depression and whether they had received such a diagnosis from a physician. Two scores were computed: the number of self-diagnosed and the number of physician-diagnosed mental health disorders
  - ◆ Standard Acute Stress Reaction Questionnaire (SASRQ) was used to assess early acute stress symptoms as well as social and work-related functioning
  - ◆ Impact of Events Scale-Revised assessed post-traumatic stress symptoms at waves 2 and 3. The 22-item measure assessed the extent to which respondents were distressed by September 11. A continuous mean score of all items and an index of high vs low post-traumatic stress symptoms were used in this study
  - ◆ Anxiety about future terrorist attacks was assessed at waves 2 and 3 with 2, modified items from the Vaughan Perceived Risk Scale. Respondents reported how often in the past week they had fears about the possibility of another terrorist attack or whether they worried that an act of terrorism would personally affect them or a family member in the future
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- ◆ Global distress in the prior week was assessed at wave 2 using the Hopkins Symptom Checklist (HSCL) and at wave 3 with the 18-item Brief Symptom Inventory (BSI). Both measures assessed the degree to which respondents were distressed by symptoms of depression, anxiety and somatization
  - ◆ Occurrence of stressful events before September 11 were assessed at wave 2 using a checklist on which participants reported whether they had ever experienced any of 30 negative life events and if so, at what age(s). The number of stressful events during childhood, adulthood and the prior year were calculated
  - ◆ September 11-related experiences including the hours per day they watched TV coverage of the attacks and their degree of exposure to and loss due to the attacks. Severity of exposure was assessed with an item measuring physical proximity to the attacks.
  - ◆ At wave 1, respondents completed the Brief COPE, a measure of 14 different coping strategies used in response to a particular stressor: self distraction, active coping, denial, substance use, emotional support seeking, instrumental support seeking, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame
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### **Selected Outcomes**

- ◆ 38% of the sample reported no direct firsthand exposure to the attacks. 60% reported watching them occur live on TV. 2% reported direct firsthand exposure
  - ◆ 96% did not experience loss in the attacks
  - ◆ 15% watched TV coverage less than 1 hour per day; 43% watched 1-3 hours/day; 26% 4 to 6 hours/day; 16% watched more than 6 hours/day
  - ◆ Two months after the attacks, 65% reported fears of future terrorism at least sometimes; 60% reported fear of harm to family as a result of terrorism. 6 months after the attacks, fears of future terrorism were still present at least sometimes for 38% and fear of harm to family was reported by 41%
  - ◆ After adjusting for pre-September 11 mental and physical health and time of survey, the odds of experiencing high levels of post-traumatic stress symptoms were significantly higher for women and for individuals who used denial, self-distraction or self-blame, sought social support or disengaged from coping efforts. The odds of post-traumatic stress symptoms were reduced by the use of acceptance. Direct vs no direct exposure and watching the attacks on TV were not significant predictors of post-traumatic stress symptoms after controlling for demographic characteristics and coping strategies
  - ◆ After adjusting for pre-September 11 mental health status, demographics, and time the severity of loss experienced in the attacks and several coping behaviors, denial, self-distraction or self-blame, sought social support or disengaged from coping, significantly predicted higher levels of global distress. Individuals who reported active coping had significantly lower levels of distress during the 6 months following the attacks
  - ◆ Data show that 6 months after the events on September 11, the effects continued among individuals who were, for the most part, not directly affected by the attacks. Post-traumatic stress symptoms while declining over the 6 months, were still elevated. Individuals continued to have substantial anxiety about future terrorist attacks
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross section

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### **Principal Investigator(s)**

Uren T and Wastell C. (2002). Attachment and meaning-making in perinatal bereavement

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### **Study Design**

Questionnaire via mail

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### **Sample Description**

- ◆ Participants were recruited 3 sources: 98 from advertisements placed in the state newsletters of Stillbirth and Neonatal Death Support (SANDS) Australia, 20 questionnaires were distributed at SANDS support group meetings and 20 by word of mouth
  - ◆ 109 women, 78 of whom had experienced stillbirth and 31 who had experienced neonatal death with an average age of 34.5 years. Participants came from all states in Australia and both rural and metropolitan areas. 83% were married. 37% had university degrees. Number of months post loss ranged from 2 to 207 months, 33% within 12 months.
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### **Selected Measures**

- ◆ 5-item scale measured perceived social support
- ◆ 2 open-ended questions asked participants to recount the important aspects of their personal grief experience and to comment on their current situation
- ◆ Extent to which participants participated in SANDS group and/or professional counseling
- ◆ Attachment in Perinatal Bereavement Scale (APBS), a 20-item scale designed for this study; assessed aspects of the phenomenological experience of perinatal death. APBS yields 4 subscales: numbness, disorientation, yearning and despair
- ◆ 5-item scale measured the extent to which participants experienced a continuing relationship with their baby
- ◆ Two questions asked about the participants' current search for meaning; respondents were asked how often they were troubled by the question, "Why me?" and how often they found themselves "searching for some reason, meaning or way to make sense out of their experience of the death of their baby"
- ◆ Spiritual Orientation Scale (SOS) 6-item version of the subscale measuring general spiritual beliefs in McIlwain's SOS. Higher score indicates greater spiritual orientation
- ◆ Perinatal Grief Scale (PGS), 33-item grief measure devised by Potvin, Lasker and Toedter. Assesses current loss-related thoughts and feelings. Low scores indicate greater grief acuity. Yields 3 subscales: active grief; difficulty coping; despair
- ◆ Psychological distress was assessed using the Brief Symptom Inventory (BSI), a 53-item symptom checklist. Yields the Global Severity Index (GSI). A higher score indicates poorer global health
- ◆ Impact of Event Scale Revised (IES-R), included 22 items and measured the level of three typical symptomatic responses to trauma: intrusion; avoidance and hyperarousal
- ◆ Sense of Coherence Scale (SOC) 3 components: comprehensibility, manageability and meaningfulness in a 29-item High scores indicate high sense of coherence
- ◆ Adult Attachment Scale (AAS) was used to measure attachment as a trait-based tendency. The AAS has 2 factors high score on one factor (closeness) related to high comfort with closeness (or high security of

attachment) and a high score on the other factor (anxiety) relates to high anxiety over abandonment (or low security of attachment)

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### **Selected Outcomes**

- ◆ There were no significant effects for type of death (stillbirth vs neonatal) but there was a significant group effect for source of enrollment; all analyses adjusted for source of enrollment
  - ◆ 84 (77%) participants saw the death of their baby as causing a marked decline in their ability to function; 91% of participants claimed their baby's death to be "the worst thing that's ever happened to me"
  - ◆ Factor analysis of the APBS revealed 4 factors that accounted for 65% of the total variance. Overall, factor analysis supported the existence of the discrete dimensions to perinatal bereavement predicted by attachment theory. Mean scores on the APBS suggested that most participants had experienced numbness, disorientation, yearning and despair at least moderately
  - ◆ The majority of participants identified phenomena consistent with an ongoing relationship with the baby. The majority of mothers did not expect feelings of closeness to their baby to abate with time
  - ◆ The search for meaning significantly attenuated over time. At the time of their baby's death, 61% of participants claimed to have been troubled by the question "Why me?" very often or always at the time of their baby's death. At the time of the study, 72% reported being troubled no more than occasionally. Similarly, 81% of respondents at the time of their baby's death reported they very often or always found themselves searching for meaning. At the time of the study, 58% reported that they occasionally still searched for meaning. 20% of the sample claimed never to be troubled by the question "Why me?" and 13% claimed they currently never search for meaning. 26% claimed they had found at least a considerable amount of meaning in their experience and 33% failed to find any meaning whatsoever
  - ◆ 87% of respondents identified with experiencing a change in identity. 68% were able to attribute something positive to the experience. 55% of participants claimed to have made downward comparisons to others; 86% examined their own role in the perinatal death; 8% saw themselves as wiser. These findings support Janoff-Bulman's assumptive world model
  - ◆ All predictor variables were significantly correlated with PGS except for degree of spiritual beliefs and the extent to which spiritual beliefs helped one to cope. Both were positively related to the degree of meaning found and therefore indirectly related to grief acuity
  - ◆ Unadjusted, the best predictors of PGS were: Sense of Coherence Scale (SOC) (inverse), current psychological distress (GSI), 2 subscales of the IES-R, intrusion and hyperarousal, and the present search for meaning (inverse)
  - ◆ The fact that variables measuring attachment were more strongly associated with SOC than the variables measuring meaning supports the view that meaning is a second-order function
  - ◆ The reduced regression model included 5 predictor variables including time since loss, intrusion, GSI, present search for meaning and SOC and accounted for 72% of variance in PGS. SOC remained the strongest predictor of PGS
  - ◆ Results highlights grief as an interpretive phenomenon and suggest that, within a bereavement context, a child's inaccessibility precipitates extreme attachment behavior on the part of the mother
-

## **SELECTED EVIDENCE**

### **Health Outcomes**

Qualitative

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### **Principal Investigator(s)**

Van P and Meleis A. (2002). Coping with grief after involuntary pregnancy loss: perspectives of African American women

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### **Study Design**

Semi-structured interview

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### **Sample Description**

- ◆ African-American women who spoke English and had a history of IPL within the past 3 years were recruited from group meetings in health care settings, social service agencies, church activities and organization community-based function such as health fairs in the western US
  - ◆ 74 women completed a questionnaire. First 10 women who completed a questionnaire participated in a semi-structured, audio taped interview. Another 10 from the remaining 64 were interviewed based on purposive sampling according to gestational age at loss and elapsed time since the loss
  - ◆ 20 respondents had an average age of 31.8 years; 60% were married or living with a partner; 75% lived in CA; 60% graduated from college; 45% reported Baptist as their religious affiliation. Mean elapsed time since the loss was 23 months. 70% were in their first trimester at the time of the loss. At the time of the interview, 70% were living with children
- 

### **Selected Measures**

- ◆ Coping strategies, i.e., *Please share the things that were helpful and not so helpful to you after the loss of your pregnancy (or baby)*
- 

### **Selected Outcomes**

- ◆ Participants viewed their IPLs as the death of their baby, as opposed to the loss of their pregnancy
  - ◆ Responses regarding coping were categorized into 1) personal reactions and responses after IPL; 2) reactions of other; 3) memories of the baby and 4) subsequent pregnancies
  - ◆ The respondents used inner resources to develop self-help strategies to cope with their IPLs by deliberately connecting with others and with their religious and spiritual beliefs and practices
  - ◆ Respondents reported many incidents of insensitivity from other persons who were not their husbands, partners, or best friends. In most cases, the women chose to ignore their remarks or forgive them, rationalizing that the responses were due to lack of knowledge about how to support a person after an IPL
  - ◆ Participants reported that memories of the baby were healing and helped them deal with their grief
  - ◆ Women who became pregnant after IPL experienced pregnancy-related anxiety and low levels of attachment to their unborn fetus until they passed the point at which the previous loss occurred or in some cases, until they delivered a healthy newborn
  - ◆ Nursing assessment of the woman's religion and spirituality should be conducted on two levels, cognitive and behavioral.
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Longitudinal

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### **Principal Investigator(s)**

Walsh K, King M, Jones L, Tookman A and Blizard R. (2002). Spiritual beliefs may affect outcome of bereavement: prospective study

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### **Study Design**

Questionnaires administered 1, 9 and 14 months after the death of their relative or friend

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### **Sample Description**

- ◆ Participants were recruited from a Marie Curie centre for specialist palliative care in London. Staff referred the relative or friend they thought was the closest to the patient
  - ◆ 216 people were eligible for the study, 153 (71%) agreed to be interviewed
  - ◆ There was no significant difference in sex of people agreeing or refusing to participate
  - ◆ 135 (88%) took part in the baseline interviews. 67% were women. 129 patients (96%) died within the time available for follow-up. Relatives and friends of these 129 comprised the study. 95 (74%) completed the follow-up assessments
  - ◆ There were no significant differences between non-respondents, respondents with incomplete data and those with complete data, although there was a tendency for people with no spiritual beliefs to fail to complete all follow-up assessments
  - ◆ 40% of participants were the spouse or partner of the dying patient, 40% were their adult children, 7% were friends and 13% were other relatives
  - ◆ 56% of patients died within one month of the baseline interview, 29% died within 3 months
- 

### **Selected Measures**

- ◆ The Royal Free interview for religious and spiritual beliefs assessed the nature and strength of spiritual beliefs and practice. High scores indicate strongly held beliefs that play a major part in a person's life. Strength of spiritual belief is considered independently of religious observance
  - ◆ Intensity of grief was measured by the core bereavement items scale
  - ◆ Hospital anxiety and depression scale is a brief measure of emotional status
  - ◆ The Close Persons Questionnaire measured social support. High scores indicate strong social ties
  - ◆ Locus of Control of behavior scale is a measure of the extent to which people perceive events as being a consequence of their own behavior and under personal control. Low scores indicate an internal locus of control and high scores indicate an external locus of control
- 

### **Selected Outcomes**

- ◆ 16% of respondents reported no religious or spiritual belief; 41% reported spiritual beliefs of low intensity; 43% reported strongly held beliefs
- ◆ Marital status and ethnic origin were significantly related to spiritual belief. People with partners had stronger beliefs and whites had low levels of spiritual beliefs

- ◆ Of the 95 participants who completed all assessments, participants with strongly held spiritual beliefs had a linear pattern of recovery from bereavement (as measured by their score on the core bereavement items scale), whereas those with low strength of belief showed little change by 9 months but recovered rapidly thereafter. Participants with no spiritual beliefs showed a temporary decline at 9 months but their symptoms of grief intensified at 14 months
  - ◆ Strength of spiritual belief remained marginally related to bereavement after adjusting for sex, closeness to the deceased, hospital anxiety and depression at baseline
  - ◆ At 14 months, the difference between the group with no beliefs and the combined low and high belief groups was 7.30 points on the core bereavement items scale. Adjusting for confounders in the final model reduced this difference to 4.64
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## **SELECTED EVIDENCE**

### **Health Outcomes**

Quantitative  
Cross Section

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### **Principal Investigator(s)**

Wayment H and Vierthaler J. (2002). Attachment style and bereavement reactions

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### **Study Design**

Questionnaire via mail

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### **Sample Description**

- ◆ Participants were recruited from 8 hospices in AZ and CO. To be eligible participants had to be at least 18 years old and had to have experienced the loss of a spouse, family member or close friend in the previous year. 60% of questionnaires were completed and returned. 91 individuals, 70 women and 21 men, participated in the study
  - ◆ 86% of the sample was white and highly educated, 58% had at least a college education. Participants ranged in age from 21 to 86 years with a mean age of 54. 48% of the sample reported losing a spouse or life partner, 31% a parent, 7% a sibling, 5% a child, 6% a friend and 5% other family member. 59% of patients had died from cancer. 63% reported the time since death as the past 6 months
  - ◆ Data for men and women were combined for all analyses
- 

### **Selected Measures**

- ◆ Degree of attachment to the deceased rated on a 5-point scale with 1, “not very close at all” to 5 “closer than any relationship I’ve ever had before or since”
  - ◆ 3 items asked about the suddenness of death, expectedness of the death and duration of illness. They were summed to form one “suddenness of death” variable, with higher scores indicating the death having been more sudden
  - ◆ 5 adult attachment styles were assessed using the Attachment Style Questionnaire including 2 types of anxious-ambivalent attachment styles, 2 types of avoidant attachment styles and 1 type of secure attachment style. Items were summed so that higher scores indicated greater levels of attachment style. Three attachment style measures, secure, anxious-ambivalent and avoidant, were derived from this measure
  - ◆ A shortened version (20 items) of the Marlowe-Crowne Social Desirability Scale was used to control for socially desirable responses. Higher scores indicated that the individual responded in a socially desirable manner, therefore exhibiting a desirable bias
  - ◆ Intensity of grief reactions was assessed by the 13-item Texas Revised Inventory of Grief (TRIG)
  - ◆ The Symptom Checklist-90-Revised (SCL-90-R) measured negative affective states. Respondents were asked to report the magnitude to which they were distressed by symptoms of depression (13 items), anxiety and somatization (12 items) during the prior 2 weeks
-

## **Selected Outcomes**

- ◆ Individuals who reported that the death was sudden and those who reported having a closer attachment to the deceased reported more grief
  - ◆ Individuals with higher anxious-ambivalent attachment style reported more depression
  - ◆ Individuals with higher avoidant attachment style reported more somatic complaints. These findings appear consistent with other research suggesting that avoidant individuals are either able to avoid experiencing emotional distress or may be at greater risk for their emotions to work themselves out in physical complaints
  - ◆ A secure attachment style was not significantly related to grief but was significantly related to less depression, suggesting that the mental models secure individuals have of themselves and others are protective during times of loss. Securely attached individuals may be the most likely to display what is considered a “normal” reaction to grief, intense grief following a loss with the gradual incorporation of the loss into their sense of self, while being less susceptible to more pathological reactions such as depression
  - ◆ Social desirability responding bias increased reports of grief, perhaps reflecting a cultural bias that grief is normal and expected
  - ◆ More time passing since the death was significantly associated with lower levels of depression but not grief, suggesting that grief and depression may be distinct types of reactions.
  - ◆ Individuals with greater education report significantly more depression
  - ◆ Older bereaved respondents reported significantly fewer somatic complaints
  - ◆ Data provide support for the idea that grief, depression and somatization following bereavement are distinguishable and have unique predictors
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## **APPENDIX B**

### **EVIDENCE SUMMARIES FOR CHAPTER 6 HEALTH CARE PROFESSIONAL AND HEALTH SYSTEMS ISSUES**

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Allen H and Miller D. (1988). Client death: A national survey of the experiences of certified rehabilitation counselors

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### **Study Design**

Self-administered questionnaires via mail

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### **Sample Description**

- ◆ 1,496 rehabilitation counselors certified by the Commission on Rehabilitation Counselor Certification (CRCC), randomly selected from 10,000 CRCC membership (15%), were mailed questionnaires
  - ◆ 867 returned questionnaires, only 627 usable (42% response). 16% of questionnaires returned were not usable because: a) persons felt that the research was not relevant to them; b) persons no longer worked in the field or retired; c) mailings overlapped and responses were duplicated; d) persons did not have a caseload; e) research project was not approved by their agency; f) persons refused to participate
  - ◆ 40% of respondents were counselors and 22% were administrators who served mainly in state (31%) or private (30%) rehabilitation settings
  - ◆ 339 women and 288 men with mean age of 39.7 (SD=8.9) and mean number of years experience of 10.7 (SD=7.8)
  - ◆ 76% of respondents had a Masters degree; 64% had earned their highest degree in rehabilitation
- 

### **Selected Measures**

- ◆ Used revised version of instrument designed by Allen and Jaet (1982)
  - ◆ Extent worked with terminally ill clients and the impact of death of a client on work-service role and personal life including new questions regarding the impact of a client's death on the empathy level of the counselor (results not included in this study)
- 

### **Selected Outcomes**

- ◆ 151/627 (24%) served persons who had a terminal illness between 1982-1985; 40% of direct service providers
- ◆ 226/627 (36%) had experienced the death of at least one client between 1982-1985; 61% of direct service providers
- ◆ 71% of respondents did not have any special training in serving persons with terminal illnesses; 91% believed that special training is needed to effectively serve these people
- ◆ 54% reported no special training in dying, death and bereavement issues; 99% believed training was needed in this area
- ◆ 242/627 (39%) CRCs responded to a group of items concerning the immediate and delayed emotional impact of a client's death; 81% reported an immediate sense of loss; 40% reported a prolonged sense of loss (up to 3 months). 86% reported an immediate sense of grief with 37% experiencing a prolonged sense of grief

- ◆ Small number reported having a physical reaction to the death of a client: 12% reported sleep loss; 6% general sense of fatigue; 3% decrease in appetite; 2% stomach problems; 3% increased use of alcohol and drugs
  - ◆ 51% reported their efficiency was immediately affected at work; 59% stated that their level of energy and vitality at work was initially affected. Frustration tolerance was immediately affected for 42% and the concentration level was initially affected for 60%
  - ◆ CRCs often felt the event of death heightened their facilitative skill level: 64% reported their capacity to empathize with other clients was immediately heightened; 50% still noted it 3 months later; 60% reported heightened capacity to be warm and caring, 47% noted it 3 months later
  - ◆ 72% reported an impact on their sense of appreciation of life immediately after the client's death. 74% reported a heightened sense of appreciation for significant others in their life, with 45% stating that the impact lasted 3 months after the event
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## **SELECTED EVIDENCE HEALTH CARE SYSTEM**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Barclay S, Wyatt P, Shore S, Finlay I, Grande G and Todd C. (2003). Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales

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### **Study Design**

Self-administered questionnaire via mail

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### **Sample Description**

- ◆ 590 randomly selected general practitioners from the lists of the Health Authorities covering Wales
  - ◆ Over sampled the Valleys of South Wales, underprivileged areas with high chronic illness
  - ◆ Overall 68% response rate; 71% in the non-Valleys; 61% in the Valleys
  - ◆ Average age of respondents 43.8; average years qualified 19.9; average years as GP principal 12.5; average number of partners 4.5
  - ◆ GPs that did not complete a questionnaire were less likely to be trainers, UK graduates, members of the Royal College of General Practitioners and were more likely to have qualified recently to work in the Valleys and in small practices
- 

### **Selected Measures**

- ◆ Training received during four career stages (clinical medical student, junior hospital doctor, GP registrar [trainee] and GP principal) in five areas of palliative care: pain control, control of other symptoms, use of syringe driver, communication skills and bereavement care
- 

### **Selected Outcomes**

- ◆ As medical students 75% reported no training in bereavement, 53% no training in communication; 27% did not receive any training in palliative care
  - ◆ As junior hospital doctors, 77% reported no training in either bereavement or communication; 26% did not receive any training in palliative care
  - ◆ Combined six or more years of training as medical student and junior hospital doctors, 64% reported no training in bereavement, 45% no training in communication and 16% reported no training in palliative care.
  - ◆ As GP registrar, 30% received no training in bereavement, 15% reported no training in communication; less than 10% received no training in palliative care. Registrar year covered all areas more commonly than previous six years of training
  - ◆ As GP principal responsible for own training; two thirds report they have covered all five areas
-

## SELECTED EVIDENCE

### Health Care System

Quantitative  
Survey  
Cross section

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### Principal Investigator(s)

Behnke M, Reiss J, Neimeyer G and Bandstra E. (1987). Grief responses of pediatric house officers to a patient's death

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### Study Design

Self-administered questionnaire

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### Sample Description

- ◆ 25 out of 30 residents involved in postgraduate pediatric specialty training at a tertiary hospital. All had graduated from medical school between 1972 and 1981
  - ◆ 14 males, 11 females, ages 24-37, mean age 29
- 

### Selected Measures

- ◆ 14 behavioral and 20 psychophysiologic responses to two hypothetical patients' deaths. The two hypothetical cases differed as to the degree of involvement of the physician (low and high attachment). Each rated on a 5-point Likert scale with 1 *very uncommon* and 5 *very common*
  - ◆ Expected reactions rated for self and "ideal" physician
- 

### Selected Outcomes

- ◆ For high attachment case, residents perceived an ideal MD to be significantly more likely to review medical records for a clue as to the cause of death; more likely to seek professional help to cope with the death; and less likely to be preoccupied by recurring thoughts of the dead child than they perceived themselves
  - ◆ For high attachment case, male residents reported being significantly more likely to remain unaffected by the death than female residents. Female residents were significantly more likely to experience body aches; feelings of guilt; sleep pattern changes; disturbances in time perception; a sense of unreality; a decreased interest in daily activities; feelings of emotional isolation from others; feelings of worthlessness; despair; shock and emotional numbness; and were more likely to seek professional help in coping with the death than male residents
  - ◆ For low attachment case, there were no significant differences by sex or self vs. ideal
  - ◆ Reported reactions were found to be similar to grief responses experienced with the death of a loved one
  - ◆ Perceived discrepancy and ambivalence between reaction of self and ideal MD may account for some of the stress that accompanies a patient's death
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Comparative  
Survey

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### **Principal Investigator(s)**

Carr M and Merriman, M (1996). Comparison of death attitudes among hospice workers and health care professionals in other settings

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### **Study Design**

Survey

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### **Sample Description**

- ◆ Convenience sample of hospital and hospice workers in a large Florida city
  - ◆ Sample population included registered nurses, licensed practical nurses, social workers, chaplains and home health aides
  - ◆ Participants were grouped by setting and then by discipline
  - ◆ Hospice personnel: n = 106; modal age range 41 – 55 years of age; 55% had worked in hospice for more than 7 years; 26% white, 25% African-American, 16% Hispanic; 41.5 % live in nuclear families; 83% describe their value system as sacred rather than secular
  - ◆ Hospital personnel: n = 76; modal age range 20 – 40 years of age; 75% had worked in their profession for more than 7 years; 38% white, 30% African-American; 47.4% live in nuclear families and 72.4% describe their value system as sacred rather than secular
- 

### **Selected Measures**

- ◆ Death attitudes (using Death Attitude Index [DAI]) and death anxiety (using Templar Death Anxiety Sale [DAS]) of hospice personnel
  - ◆ Compare death attitudes of hospice personnel with health care professionals in acute care and hospice settings
  - ◆ Comfort in dealing with dying patients is a product of personal beliefs and experience
- 

### **Selected Outcomes**

- ◆ Significantly higher score on death attitude index for hospice compared to hospital personnel – higher score indicates more comfort with death
  - ◆ Nurses aides had the lowest death attitude scores and highest DAS -- higher scores indicates higher death anxiety scores in both settings – there is a correlation between lower education level and increased anxiety
  - ◆ Personnel who had received seminar or training on death and dying had higher DAI scores compared to those who did not
  - ◆ Nurses in hospital settings were not as comfortable dealing with dying patient as those in hospice, despite similarities in their beliefs about life
-

**SELECTED EVIDENCE**  
**Health Care System**

Qualitative

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**Principal Investigator(s)**

Cohen M and Sarter B. (1992). Love and work: Oncology nurses' view of the meaning of their work

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**Study Design**

In-depth interviews and participant observation

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**Sample Description**

- ◆ 23 oncology nurses working in a medical center specializing in cancer care. 6 were charge nurses, the rest were staff nurses. The nursing director identified participants
  - ◆ All women, ranging in age from 25 to 62 years (mean age 42)
  - ◆ Nursing experience ranged from 1 to 40 years (mean 13 years); amount of time in cancer nursing at this hospital ranged from 3 months to 27 years (mean 7)
  - ◆ 22% had Baccalaureate degrees, 39% had Associated degrees; 39% were high school graduates
- 

**Selected Measures**

- ◆ Nurses were asked to describe a critical incident that captures the essence of oncology nursing for them, a typical day, an unusual day, how their career with patients with cancer began, what it is like to work with cancer patients, difficult aspects of their job, rewarding aspects of their job, their future career plans and goals
- 

**Selected Outcomes**

- ◆ Oncology nurses appear to be driven by a deep concern for patients and families that creates tremendous stress when conditions such as poor staffing, excessive use of registry nurses and unexpected crises occur. The task orientation of these nurses also seems to be based on their fundamental concern for patient welfare. These particular findings suggest the need to provide nurses with support and an opportunity to discuss their work
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Dean R. (1998). Occupational stress in hospice care: causes and coping strategies

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### **Study Design**

Self-administered questionnaire

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### **Sample Description**

- ◆ 33 nurses from 3 hospice services in a large midwestern city
- 

### **Selected Measures**

- ◆ Causes of and responses to difficult or demanding work-related situations, i.e., situations where the nurse experienced uncertainty as to whether the available resources would be sufficient to enable a therapeutic response
  - ◆ Self Inventory of Situational Responses -TC (SISR-TC) assessed whether a subject perceived a situation to be a challenge or a threat
  - ◆ Spielberger State Anxiety Inventory (SSAI) included 22 items designed to isolate feelings of apprehension, nervousness, tension and worry
  - ◆ Questionnaire designed for this study had participants rank order 4 causes of difficult or demanding situation including: intractable symptoms, communication issues, death/loss, administrative issues and other
- 

### **Selected Outcomes**

- ◆ Predominant response to SISR-TC was an appraisal of the difficult or demanding situation as a challenge rather than a threat
  - ◆ 42% of respondents ranked intractable symptoms in first place. 50% ranked communication in second place. 48% of respondents ranked death/loss in <sup>third</sup> place or lower
  - ◆ Respondents had statistically significantly higher levels of anxiety than the norm for working females
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Dickinson G and Field D. (2002). Teaching end-of-life issues: current status in United Kingdom and United States medical schools

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### **Study Design**

Self-administered questionnaire via mail

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### **Sample Description**

- ◆ 23 preclinical deans or directors of medical education at UK medical schools (100% response) and 112 academic deans at US medical schools (92%) completed questionnaires
- 

### **Selected Measures**

- ◆ Information on the medical schools' dying, death and bereavement education including: extent of offerings on palliative care; end-of-life topics covered in the curriculum; background of the instructor(s); whether a terminally ill patient addressed the class; whether students had a continuing relationship with a terminally ill patient and extent to which students spent time with hospice patients
- 

### **Selected Outcomes**

- ◆ All but one school in the UK reported some exposure to the topic. 13% of UK schools and 18% of US schools offered a separate course on death and dying. 13% of schools in both countries covered the topic in one or two lectures. Death and dying offered as a module of a larger course was more frequent in US schools (49%) than UK (26%)
  - ◆ Mean number of teaching hours was 20 in UK and 14 in US
  - ◆ Multidisciplinary team approach was used to teach material in both countries; physicians were the majority of instructors
  - ◆ 25% of respondents in UK and 29% in US indicated that a terminally ill patient addressed the class. Only 1 school in the UK reported all students had an extended relationship with a terminally ill patient, 6 schools reported some or most students had. 24% of US medical school said that students had a continuing relationship with a terminally ill patient lasting several weeks
  - ◆ 92% of schools in the UK included hospice participation as part of the program, compared to 56% of US schools. 35 schools in the US said hospice participation would be part of the curriculum in the future
  - ◆ All of the schools in the UK and 87% in the US said their curriculum directly addressed the topic of palliative care
  - ◆ Over 70% of schools in both countries covered the following end-of-life topics: attitudes toward dying and death; communication with dying patients and their families; grief and bereavement; psychological aspects of dying; analgesics for chronic pain; and advance directives. 13 out of 19 topics were covered in at least 75% of UK medical schools
-

## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative

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#### **Principal Investigator(s)**

DiTullio M and MacDonald D. (1999). The struggle for the soul of hospice: stress, coping, and change among hospice workers

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#### **Study Design**

115 hours of participant observation; semi-structured interviews and 3 collaborative group discussions with participants

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#### **Sample Description**

- ◆ 38 hospice workers from a Medicare-certified, nonprofit hospice in upstate NY
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#### **Selected Measures**

- ◆ Experience of performing hospice work
- 

#### **Selected Outcomes**

- ◆ Authors chose the metaphor of “cramping” to characterize the sense of progressive constriction on available time and the resulting shrinkage of opportunity for emotional processing and professional autonomy. 71% of study participants cited “time cramping” as a primary source of work stress. 55% expressed “emotional cramping” (lack of time for one’s emotional self care) and “policy cramping” (restriction or demands imposed by federal health care policy) as major contributors to occupational stress
  - ◆ Increased work volume and complexity and a consequent rise in crisis-driven intervention were distinct sources of stress. 55% of study participants indicated that inadequate communication was a major source of stress. 32% said lack of support and appreciation by both management and co-workers was a source of stress
  - ◆ Organizational coping resources provided within the hospice include the creation of an employee assistance program, weekly support groups for direct-service staff, staff memorial services, in-service education and mutual informal support
  - ◆ Coping resources and strategies most frequently employed by participants included relaxation, meditation, and self-soothing behaviors such as smoking and overeating (62%); supportive relationships outside of hospice (44%); behaviors directed towards maintaining inner-balance and acceptance (44%); and supportive relationships with hospice co-workers (42%)
  - ◆ Based on participants’ reports, organizational and personal coping resources and strategies were not adequate to reduce stress. On the theoretical continuum of strain-stress-burnout, the hospice workers interviewed generally appeared to be somewhere between stress and burnout
  - ◆ Support appeared repeatedly in the interviews as a major reward of hospice work, as a major stressor when perceived to be absent or insufficient and as a major device for coping with stress
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Feldstein M and Gemma P. (1995). Oncology nurses and chronic compounded grief

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### **Study Design**

Self-administered questionnaire via mail

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### **Sample Description**

- ◆ 95 questionnaires were distributed to oncology nurses at two research sites; 50 responded (53%)
  - ◆ 48 women, 2 men; 46% white, 27% African-American, 27% other race; 46% had a Bachelors degree; 18% had a Masters degree; 58% were not married
  - ◆ On average, nurses were employed 7.5 years at hospital; had 5.2 years in the position and had 11.3 years in nursing. 75% worked the day shift
- 

### **Selected Measures**

- ◆ Job status, e.g. leave oncology nursing (n=8) and stay in oncology nursing (n=42)
  - ◆ Shortened version of the Grief Experience Inventory (GEI): 102 statements found to be frequently associated with grief and bereavement. GEI yields scores for 9 scales including 3 validity scales (denial, atypical responses and social desirability) and 6 research scales (despair, anger/hostility, social isolation, loss of control and somatization). T scores used in study
  - ◆ Demographic characteristics including professional, personal and supportive influences that might have affected grief experience, e.g. death in family, cancer in family, illness in family, recent divorce, number of patient deaths this year, number dying patients this year, support available from close friend, spouse, colleague
- 

### **Selected Outcomes**

- ◆ There were no significant differences between nurses who stayed in oncology and nurses who left oncology in terms of their personal grief, although nurses who left had a higher incidence of recent divorce or in terms of their support
  - ◆ There were no significant differences between nurses who stayed and nurses who left in terms of their GEI scores
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Medium

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### **Principal Investigator(s)**

Foliat D, Clausen, M and Siljestrom, C. (2001). Bereavement practices among California Hospices: Results of a Statewide Survey

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### **Study Design**

Survey

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### **Sample Description**

- ◆ 131 (of 160) hospices returned via fax (to all hospice directors) the survey, 82% response rate, slighter higher response rate among the larger hospice centers compared to small
  - ◆ large hospice annual expense > \$1M, mid-size hospice annual expense \$100K to \$1M and small hospice annual expense < \$100K
  - ◆ average daily census of patients 30 patients
  - ◆ median average duration of care 39 days
  - ◆ median percentage of cancer patients 73%
  - ◆ information on training was provided for 480 individuals
- 

### **Selected Measures**

- ◆ Content of bereavement programs related to the size of the hospice – larger hospices provide more services including support groups and workshops
  - ◆ Determine training of those involved in bereaved services among different size hospices and cost of services
- 

### **Selected Outcomes**

- ◆ All hospices provide telephone support, scheduled mailings, grief brochures, and pastoral care
  - ◆ Individual and family counseling is provided by most hospices
  - ◆ Not all large hospices have comprehensive bereavement programs
  - ◆ Volunteers comprise almost one third of bereavement staff at small hospices
  - ◆ No clear relationship was found between the size of the hospice and the bereavement services offered
  - ◆ Small percent of staff are consultants that provide mental health counseling
  - ◆ Larger hospices had a greater percent of MSWs than small hospices (35% compared to 17%) and a smaller percent with high school degrees (5% compared to 19%)
  - ◆ In small hospices nurses play a large role in bereavement services (20% compared to 1%)
  - ◆ Pastoral care and visits by volunteers were the most common components of bereavement services
  - ◆ Clergy were involved in bereavement services in all size hospices
  - ◆ Most hospices (89%) provided bereavement services at no charge
  - ◆ Some services such as workshops, professional counseling or supports were associated with a small fee (\$50 or less)
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## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative

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#### **Principal Investigator(s)**

Irvin S. (2000). The experiences of the registered nurse caring for the person dying of cancer in a nursing home

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#### **Study Design**

Case study (1 nursing home), using reflective journals and unstructured, in-depth interviews

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#### **Sample Description**

- ◆ Five registered nurses employed in 1 nursing home for at least 12 months working in this setting
  - ◆ Four had at least seven years gerontology experience
- 

#### **Selected Measures**

- ◆ Description of the experiences of the RN working in a nursing home in caring for the resident dying of cancer.  
Four themes:
    - 1) Exclusivity of relationships
    - 2) Difficulties in measuring pain
    - 3) Expectations of the RN
    - 4) Impact of caring on the RN
- 

#### **Selected Outcomes**

- ◆ The relationships between nurses and residents were exclusive in that they evolved from the provision of nursing care to ones that were more intimate, personal and committed
  - ◆ Nurses' personal and past experiences of the death of a family member often affected the relationship with the resident and, in turn, enhanced the resident's care
  - ◆ Limited workplace support such as counseling or lack of recognition of the special relationships that can develop between a member of the nursing staff and a resident potentially places the RN at an emotional risk from burnout and complicated bereavement
  - ◆ All nurses described clinical difficulties in achieving symptom control, particularly pain
  - ◆ The nurses had high expectations of the care that they felt should provide to residents who were dying. All described their expectations of providing the resident with a "good" death
  - ◆ Nurses clearly articulated that caring for a dying resident had both a positive and negative impact. Forming a meaningful relationship with the resident was important to the nurse. Nurses described feelings of frustration with MD's attitudes, the lack of time and other organizational constraints to achieving what they perceived to be optimal care. All described the experience of caring for dying residents as personally confronting. All experienced a need for support as a way of coping
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## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative  
Model  
Interview

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### **Principal Investigator(s)**

Kaplan L. (2000). Toward a model of caregiver grief: nurses' experiences of treating dying children

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### **Study Design**

Structured Interview

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### **Sample Description**

- ◆ 15 American nurses who were licensed practical nurses or registered nurses; worked as nurse for 2 or more years; had a primary practice in clinical nursing; treated primarily pediatric patients; and cared for terminally ill pediatric patients
  - ◆ interviewed only nurses who worked directly with patients
  - ◆ age range 28 – 52 years old; 14 women, 1 man; all white
  - ◆ 8 had Bachelors degree, 2 had a Masters degree, 2 had an Associates degree, 2 had a diploma, and 1 an LPN
  - ◆ participants worked for inpatient hospitals, outpatient clinics, private practice and hospice
  - ◆ 14 participants worked with hematology/oncology patients
- 

### **Selected Measures**

- ◆ Understand emotional reactions of nurses who work with dying children
  - ◆ Asked questions about the:
    - subject's emotional experience
    - nature of relationships
    - subject's attitudes and reactions to the dying process
    - meaning held regarding the subject's career in pediatric nursing
- 

### **Selected Outcomes**

- ◆ Participants experience intense emotions working with terminally ill children
  - ◆ Expressed that no formal support system existed to help them deal with the emotional intensity of their work
  - ◆ Managing their emotions involved finding ways to express their emotions and balance between the use of emotion to connect with patients and families and to restrain their emotions to maintain professional role -- this balance is key to allowing them to continue in this profession (avoid burnout and depression)
  - ◆ Full expression of feelings is critical to maintaining mental and physical health and continuing with their work
  - ◆ Participants expressed their emotions in different ways and in different places – mostly in private
  - ◆ Ten of 15 subjects described their emotion with the death of a patient as grief – the grief was influenced by the kind of relationship they had with the family and the patient
  - ◆ Participants expressed the importance of bringing closure to the death of their patient
  - ◆ After a patient dies there is often another patient to care for so there is not time for grieving
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative

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#### **Principal Investigator(s)**

Kirchberg T, Neimeyer R and James R. (1998). Beginning counselors' death concerns and empathic responses to client situations involving death and grief

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#### **Study Design**

Questionnaire and written response to 8 videotaped enactments of client situations involving death and non-death presenting problems (e.g. death of a child, death of a spouse versus job loss, recent physical disability)

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#### **Sample Description**

- ◆ 58 Masters-level counseling students at University of Memphis
  - ◆ 51 women, 7 men; 9 African-Americans, 49 whites, ranging in age from 22 to 56 years with median age of 34 years
  - ◆ Years of counseling experience ranged from 0 to 7 but modal number of years experience was 0
- 

#### **Selected Measures**

- ◆ Multidimensional Fear of Death Scale (MFODS): 42 statements pertaining to various death and dying situations. Respondents indicate their level of agreement/disagreement on a 5-point Likert scale. Scale divides into 8 factors: fear of dying process; fear of the dead; fear of being destroyed; fear for significant others; fear of the unknown; fear of conscious death; fear for the body after death; fear of premature death
  - ◆ Threat Index (TI): the degree to which a respondent "splits" ratings of self and personal death on a sample of contrasting construct scales (e.g. self is viewed as "hopeful" and death is associated with "no hope"). Index yields global factor and three subfactors: threat to well being; uncertainty and fatalism
  - ◆ Self-report of comfort level with counseling scenario rated on a scale of 1 (very uncomfortable) to 9 (very comfortable)
  - ◆ Carkhuff Rating Scale for empathic understanding: coded from written responses to videotaped client. Higher score indicates more empathic response
- 

#### **Selected Outcomes**

- ◆ Beginning counselors reported significantly greater discomfort in responding to situations involving death and dying than to other serious, but non-death-relevant situations. Counselors acknowledged greater discomfort when faced with a videotaped client presenting with AIDS, life-threatening cancer and to a slightly lesser extent grief over the death of a child
- ◆ The overall MFODS score was predictive of discomfort in death and dying situations but the TI was not. Thus, as personal fear of death increased, beginning counselors became more uncomfortable with counseling situations involving death and dying
- ◆ Fear of the Dead subfactor alone predicted comfort in death and dying counseling situations. As counselors reported more Fear of the Dead, a factor assessing phobic avoidance of corpses and other vivid reminders of death, their discomfort in death-relevant situations intensified

- ◆ Beginning counselors were slightly more empathic in responding to client situations involving death and dying than to other serious but non-death-relevant situations. However, the overall level of empathy displayed by beginning counselors to all client situations was low
  - ◆ As counselors scored higher on fatalism, empathy scores decreased. Items loading on the Fatalism subfactor are suggestive of despair in the face of death and include learning/not learning, hope/no hope, useful/useless, productive/unproductive
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## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative  
Quasi-experimental  
Evaluation

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### **Principal Investigator(s)**

Larson D. (1986). Developing effective hospice staff support groups: pilot test of an innovative training program

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### **Study Design**

Pre- and post-test, self-administered questionnaires

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### **Sample Description**

- ◆ Two CA-based hospice organizations
  - ◆ Group A: 9 volunteers and the director of volunteers. 5 men and 5 women, with a median age of 41 and a median of 11 months experience in hospice work
  - ◆ Group B: 10 staff members, 4 nurses, 4 home health aides, 1 physical therapist and the hospice program manager. They had a median age of 45 and a median of 51 months experience in hospice work
  - ◆ All participated in a 12-week pilot test of the Common Concern program specialized for hospice and oncology workers
- 

### **Selected Measures**

- ◆ Pre- and postgroup measures of burnout and coping strategies
    - Pines & Aronson (1981) burnout measure consisting of 21 items covering aspects of the physical, emotional and mental exhaustion
    - Jenkins Means of Coping Checklist adapted from Lazarus' Ways of Coping, contains a list of 74 coping strategies
  - ◆ Pregroup questionnaire included items on expectations of the group experience
  - ◆ Postgroup questionnaire included items on feelings about the group (satisfaction, support received) and perceptions of how the group had worked (importance of advice, catharsis, helping others, self-exploration)
- 

### **Selected Outcomes**

- ◆ Pregroup expectations about the self-led and audiotape dimensions of the group experience were mixed, postgroup evaluations of these features were positive
  - ◆ Participants liked their groups, felt included and emotionally involved, experienced psychological safety and indicated they had made progress toward their personal goals
  - ◆ 19 out of 20 would recommend this experience to other hospice workers
  - ◆ Pre- and postgroup burnout scores did not differ significantly in either group
  - ◆ Discussing a situation with a peer or team member was the coping strategy most frequently endorsed as effective (47%)
-

**SELECTED EVIDENCE**  
**Health Care System**

Quantitative  
Survey  
Cross section

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**Principal Investigator(s)**

Lattanzi-Licht M. (1989). Bereavement services: Practice and problems

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**Study Design**

Self-administered questionnaire via mail

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**Sample Description**

- ◆ Questionnaire mailed to the 439 provider members of the National Hospice Organization
  - ◆ 268 (61%) completed and returned the questionnaire
  - ◆ Average age of the responding hospices was 5.3 years; Average age for bereavement service programs was 4.5 years, a 9-month differential from the onset of the hospice
- 

**Selected Measures**

- ◆ Form and function of hospice bereavement services, e.g. size, coordination of services, training, services provided, referrals, clients, funding, data collection
- 

**Selected Outcomes**

- ◆ One of the major factors regarding bereavement services is the size/number of deaths per year of the hospice
- ◆ Social work primary discipline involved in the coordination of bereavement services (36%), followed by nursing 25%
- ◆ 85% of bereavement coordinators salaried at some level and spend an average of 11.5 salaried hours per week on coordination of bereavement services
- ◆ Ratio of over 4 to 1 of volunteers to staff in bereavement care
- ◆ Few hospices, 11%, use the services of students
- ◆ 93% of hospices reported offer initial general training for all caregivers averaging 16 hours
- ◆ Participating hospices reported that 89% of bereaved family members received personal contacts. Phone calls by bereavement personnel (88%) and phone calls by the nurse involved prior to death or visits to the bereaved by bereavement personnel (83%) were the most prevalent hospice bereavement services offered.
- ◆ Top service priorities, visits to the bereaved listed by 47%, followed by phone calls to the bereaved 24% and groups meetings 22%. Group meetings were also the service that most bereavement programs indicated they would wish to increase if time and money were no object (31%)
- ◆ Hospice bereavement programs make few referrals to outside counseling (an average of 7% of their clients sought or were referred to outside counseling)
- ◆ 77% of hospices reported the use of a bereavement assessment process to identify high risk individuals (most often a written form 58%)
- ◆ Little inclination to provide bereavement services only to high risk individuals

- ◆ Greatest obstacle to delivery of bereavement services selected was the lack of staff time (30%), followed by lack of personnel (22%), funding pressures (15%), staff/volunteer burnout (10%)
  - ◆ While a significant number of respondents indicated that bereavement services were not specified or separated out in the hospice budget, bereavement services at 87 hospices averaged 7% of hospice budget. 100 hospices budgeted an average of \$13,014 for bereavement services
  - ◆ 60% of responding hospices were not involved in collection of data on their bereavement services
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Longitudinal (quasiexperimental)  
Comparative  
Low

### **Training**

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### **Principal Investigator(s)**

Lev E. (1986). Effects of course in hospice nursing: attitudes and behaviors of Baccalaureate school of nursing undergraduates and graduates

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### **Study Design**

Longitudinal quasiexperimental

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### **Sample Description**

- ◆ n = 6 nursing students and n = 69 graduates
  - ◆ Sample from 2 accredited schools of nursing in Northeast
  - ◆ Control group (n = 42) included only students who would be interested in attending the course
  - ◆ Test group (n = 33) received training
  - ◆ Median age = 21
- 

### **Training(s) (if appropriate)**

- ◆ Course in hospice nursing – 3 credits, 14 weeks – included a clinical component of visits to the dying patient and family
- 

### **Selected Measures**

- ◆ Attitude - fear of death and dying (Colett-Lester Fear of Death Scale)
  - ◆ Behavior - measures of social distance people place between themselves and other avoidance producing groups
- 

### **Selected Outcomes**

- ◆ There was less fear of death and dying in the trained group
  - ◆ There was less avoidance behavior in the trained group
  - ◆ There was less avoidance behavior toward psychiatric patients, alcoholics and persons with AIDS in the trained group
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## SELECTED EVIDENCE

### Health Care System

Quantitative  
Survey  
Cross section

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### Principal Investigator(s)

Llamas K, Llamas M, Pickhaver A and Piller NB. (2001). Provider perspectives on palliative care needs at a major teaching hospital

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### Study Design

Self-administered questionnaire distributed by internal hospital mail

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### Sample Description

- ◆ Convenience sample of all Jericho Metropolitan Hospital (JMH) clinical oncology staff, n=267. JMH is a 700-bed tertiary referral teaching hospital
  - ◆ 221 completed the questionnaire (83% overall response). 78% response from nurses; 84% medical staff; 86% radiation therapists and 95% of allied health
  - ◆ 51% of sample was nursing staff; 9% medical staff; 23% radiation therapists and 17% other allied health professionals. 52% were 30-49 years old. 11% had less than 1 year experience in palliative care; 36% had 1-5 years; 21% had 6-10 years and 32% had over ten years. 76% said 50% or less of their work is palliative care
- 

### Selected Measures

- ◆ Questionnaire based on a survey developed by Sellick
  - ◆ Staff perceptions of palliative care needs of cancer patients and degree to which existing services were meeting those needs, as well as staff educational and support needs
- 

### Selected Outcomes

- ◆ 91% believed that palliative care, as defined by WHO, should be an integral part of the care of cancer patients
  - ◆ 45% reported a need for emotional and/or spiritual support in dealing with their own issues arising from the provision of care to terminally ill cancer patients *at least once in the past 6 months*
  - ◆ 31% perceived that they had access to any formal mechanism of staff support including a staff counselor, team or ward meetings, debriefing sessions, peer support and in-service sessions related to grief. There did not appear to be a uniform perception about availability and/or applicability of some of the identified supports, e.g., majority of oncology staff are either unaware of staff counseling service or do not perceive it as a source of support
  - ◆ 79% believed that there was need for improved formal mechanisms of staff support at JMH. Medical staff was significantly less likely to report need than other staff groups. 66% rated inadequate palliative care education as a critical problem. 24% of respondents reported having any formal palliative care education. 93% of respondents believed they needed to increase their palliative care knowledge and/or skills
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative

#### **Services**

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#### **Principal Investigator(s)**

Lloyd M. (1997). Dying and Bereavement, Spirituality and Social Work in a Market Economy of Welfare

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#### **Study Design**

Postal Questionnaire and Interviews

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#### **Sample Description**

- ◆ 99 hospital social workers in England and London
  - ◆ Follow-up interviews with 4 of the above
  - ◆ Semi-structured interview with 14 bereaved and 9 dying patients
- 

#### **Selected Measures**

- ◆ Do social workers have a role to play in the care of people who are dying or bereaved
- 

#### **Selected Outcomes**

- ◆ Social workers reported their roles to be supportive (75%) and counseling (57%) and the primary skills that they used to be listening/counseling (94%)
  - ◆ 13 of the 23 clients' reports on the help they received were not specifically related to social work support; however there was an overall feel that what they valued most was the ability of the social worker to relate to them in a particular situation
    - 4 interviewees identified practical or tangible help
    - most respondents non-practical (caring and support) help was most significant
  - ◆ Social workers indicated that they encountered barriers to effective function including organizational constraints and denial of death (personal, professional and societal)
  - ◆ Social work is a narrowly defined discipline which may need to expand
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## **SELECTED EVIDENCE**

### **Health Care Systems**

QL=Qualitative

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#### **Principal Investigator(s)**

Main J. (2000). Improving management of bereavement in general practice based on a survey of recently bereaved subjects in a single general practice

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#### **Study Design**

Semi-structured interview conducted at home by the author (the practice nurse employed by the GP)

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#### **Sample Description**

- ◆ Bereaved persons were identified from practice records (no death registry) and were eligible to participate if they were over 18 years old, had been bereaved at least 6 months and did not have health problems associated with their bereavement (from medical records)
  - ◆ 36 patients were identified; 23 agreed to participate. 74% women. All were over 60 years old
- 

#### **Selected Measures**

- ◆ Individual experience of bereavement
  - ◆ Intervention of the health care services at the time
  - ◆ Expectations of the health care services regardless of their actual experiences
  - ◆ Reaction to several suggestions for possible improvement
- 

#### **Selected Outcomes**

- ◆ Five themes or categories were identified:
  - Satisfaction with the service: 10 respondents who expressed complete satisfaction all had relatives who had been ill for some time. 13 respondents voiced some dissatisfaction with the service they had received. Those who mentioned that there had been no contact with the surgery felt that this was an important job of the GP or a member of his team. Contact in any form would have been appreciated and they had expected it to happen
  - Quality of Information Given (GP and hospital): Prior to death, those respondents who felt fully informed at every stage of their relative's illness told of the "kindness" of hospital staff, the "marvelous" GPs and the "excellent" care their relatives received. Others felt they had not been fully informed. After death, some subjects who had expressed some dissatisfaction at not feeling fully informed prior to the death were happy that the GP/hospital explained to their satisfaction the reasons for the death. Others were unhappy because, even up to 3 years later, they did not fully understand the cause of death or circumstance surrounding it
  - Adequacy of Communication (GP and hospital): The majority of respondents had no problems in this area. Most only recalled that the manner of health service staff had been comforting and supportive. Those who reported problems in communication could recall exact remarks made at the time and were still upset about them
  - Differing Expectations of the GP Service: The majority of respondents felt that contact and communication with people who had recently been bereaved was important and something that ought to

happen. The need for the GP to be aware of bereavement and to acknowledge it during routine consultations was thought to be important by some respondents. Several were upset when their bereavement was not mentioned as they had questions they wanted to ask but felt unable to raise the subject as the GP had not mentioned it. The majority of those whose bereavement had been acknowledged by their GP appreciated it and felt it proper that it had been

- Development of the Service: Letter of Sympathy, majority said yes; Visit from GP/Nurse, few believed it to be necessary, although most would have appreciated it; Tagging of Notes, those who expected awareness and acknowledgement reacted enthusiastically, while the few who had reservations were those concerned about the trivialization of physical symptoms; Record of Death within the practice was generally well received
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Quasi-experimental  
Cohort  
Evaluation

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### **Principal Investigator(s)**

Mason C and Fenton G. (1986). How successful is teaching on terminal care?

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### **Study Design**

Self-administered questionnaire given out to students at the beginning of a symposium and collected before the symposium began

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### **Sample Description**

- ◆ Fourth year students at Dundee Medical School, Scotland (84/85 academic year)
  - ◆ 74 out of 103 students (72%) present on day of symposium completed a questionnaire
  - ◆ 45 males, 27 females, 2 did not respond; 48 (65%) had personal experience of bereavement, 2 did not respond; 21 (28%) had attended special seminars on terminal care, 32 (43%) had not attended, 19 (26%) could not remember if they attended, 2 did not respond
- 

### **Selected Measures**

- ◆ Factual information on terminal care and bereavement presented during 2<sup>nd</sup> year
  - ◆ Symptoms of abnormal grief presented during the 4<sup>th</sup> year
  - ◆ Pain control
  - ◆ Attitudes about the subjects of dying and bereavement, i.e., showing personal feelings of grief in front of relatives; need for special training in hospice to deal with terminal illness; notification if suffering from terminal illness; most/least satisfying aspects of care; most/least worrying; alternative strategies of management of terminal illness
- 

### **Selected Outcomes**

- ◆ 88-100% of students answered factual questions on terminal care presented during 2<sup>nd</sup> year correctly (class mean 8.07 out of 10)
- ◆ 6 of 10 questions on abnormal grief were answered correctly by more than 80% of the respondents (class mean 7.45 out of 10)
- ◆ Questions on pain control were answered incorrectly by 50% or more of the respondents (class mean 2.45 out of 5)
- ◆ 26% agreed that MDs should not show personal feelings of grief in front of relatives when patients die; 30% agreed that special training in hospice for MDs to know how to deal with terminal illness; 92% would want to know if they were suffering from a terminal illness

- ◆ 12.3% rated *looking after a terminally ill patient* high on satisfaction (7 out of 10) but 42.3% rated it high on worry (4 out of 10). Similarly, 11.1% rated *speaking with the relatives of those with incurable cancer* high on satisfaction (9 out of 10) but 65.3% high on worry (1 out of 10)
  - ◆ No respondents chose the strategy “withhold information about prognosis from patient for as long as possible”
  - ◆ There were no significant differences between men and women, between those who experienced personal bereavement and those who did not and those who attended the 2<sup>nd</sup> year seminars and those who did not in terms of their knowledge or attitudes
  - ◆ Results highlighted the need for specific education on pain control. Additionally, despite acceptable knowledge, terminal care was rated by the majority of students as low on satisfaction and high on worry
-

## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey

#### **Services**

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#### **Principal Investigator(s)**

Murphy K, Hanrahan P, and Luchins D (1997). A survey of grief and bereavement in nursing homes: The important of hospice grief and bereavement for the end-stage Alzheimer's disease patient and family

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#### **Study Design**

Telephone survey

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#### **Sample Description**

- ◆ n = 111 nursing homes in the lower peninsula of Michigan
  - ◆ respondents included either the social work or Director of Nursing
- 

#### **Selected Measures**

- ◆ What on-site grief and bereavement services are offered
  - ◆ What services are routinely offered by licensed hospice agencies
  - ◆ Specific questions asked:
  - ◆ Does anyone at your facility usually send a sympathy card (> 50% of the time) to each family after the patient's death?
  - ◆ Does your facility provide the family with materials on the grieving process and bereavement before or after the death?
  - ◆ Does anyone at your facility send a letter after the death inviting the family member to attend a monthly bereavement support group meeting either at the nursing home or in the community?
  - ◆ Does anyone at your facility have the opportunity to offer a referral to a counseling or psychiatric professional when bereavement intervention is deemed appropriate?
  - ◆ Does anyone at your facility usually (>50% of the time) visit the family at the funeral home during visitation or attend the funeral?
  - ◆ Does anyone at your facility visit, make phone calls or provide written communication including bereavement newsletters within the first 13 months of death?
- 

#### **Selected Outcomes**

- ◆ 55% of homes sent sympathy cards to family members after the death
- ◆ 99% of the facilities did not provide materials to the family or to the primary caregiver on the grieving process or bereavement after death
- ◆ 99% of the facilities did not send a letter after the patients death informing them of local community or on-site bereavement support group meetings

- ◆ 76% of the homes were unable to offer a referral to a counseling or psychiatric professional when bereavement intervention was deemed appropriate
  - ◆ 44% of the homes usually went to the funeral home or the funeral of a patient who died the facility
  - ◆ 99% of the nursing homes neither visited, made phone calls or provided written materials to the family members after the patient's death
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## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative  
Interview  
Model

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### **Principal Investigator(s)**

Papadatou D. (2000). A proposed model for health professionals' grieving process

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### **Study Design**

In-depth interviews, professional experience

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### **Sample Description**

- ◆ n = 63 nurses (caring for dying children)
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### **Selected Measures**

- ◆ Propose a model conceptualizing how health care professionals deal with multiple loss of patients and their reaction to loss and to shed light on the private pain they experience
  - ◆ How teams function in the face of loss
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### **Selected Outcomes**

- ◆ Health professionals' grieving process occurs as a fluctuation between focusing and experiencing the loss (report depression, sorrow, anger, guilt) and avoiding or moving away from the loss (refraining from experience, denial – shutting off feelings, numbing – avoiding contact with family – dehumanizing the dying patient); this fluctuation is described as healthy, necessary and adaptive
  - ◆ Lack of fluctuation may result in difficulties such as feeling overwhelmed or repressing the experience
  - ◆ Fluctuation allows the health care professional to create meaning out of the death and to reinvest in life
  - ◆ Team meaning-making is when teams such as a health care unit make meaning out of patients death together and symbolically share this
  - ◆ Health care professionals seek active search for support from colleagues – sometimes support is not found
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey

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### **Principal Investigator(s)**

Puntillo K, Benner P, Drought T, Drew B, Stotts N, Standard D, Rushtin C, Scanlon C and White C. (2001). End-of life issues in intensive care units: a national random survey of nurses' knowledge and beliefs

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### **Study Design**

Survey developed by investigators who are experts in critical care, pain, ethics and quantitative and qualitative research -- stratified random sample sent to 3000 direct care provider nurses through the American Association of Critical-Care Nurses

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### **Sample Description**

- ◆ 906 respondents (30%)
  - ◆ mean age 42
  - ◆ 95% female; 89% white; 49% Bachelors degree
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### **Selected Measures**

- ◆ Access to consultation services including pain management, ethics, and hospice consultation
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### **Selected Outcomes**

- ◆ Consultations were available to less than one third of the nurses
  - ◆ Ethics and hospice consultations were available to half of the nurses
  - ◆ Consultations with all 3 types of specialists were unavailable
  - ◆ Most of the respondents noted that unit-level conferences that focused on grief counseling and debriefing for the staff after a patient died either rarely (38%) or never (49%) occurred
  - ◆ 13% of respondents reported that they had access to unit-level grief counseling and debriefing
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## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative  
Survey  
Very Low

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### **Principal Investigator(s)**

Raudonis B and Kirschling M. (1996). Family caregivers' perspectives on hospice nursing care

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### **Study Design**

Naturalistic -- qualitative – bereaved care givers were interviewed upon consent by the study authors

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### **Sample Description**

- ◆ n = 9 bereaved caregivers, bereaved at least six months prior to study
  - ◆ 5 men and 4 women
  - ◆ Mean age = 70.3 years
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### **Health Care Setting (s)**

- ◆ Hospice – focus on nurses
- 

### **Selected Measures**

- ◆ Describe the family caregiver's relationships between the hospice patient, the nurse and themselves
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### **Selected Outcomes**

- ◆ Family caregivers perceived hospice nurses as part of the family and described them as being caring, kind, and clinical experts
  - ◆ Further study is needed to determine whether or not nurses perceive themselves as part of the family? Is being part of the family an empathetic relationship toward the caretaker? To determine the outcomes of specific nursing intervention in hospice care?
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## SELECTED EVIDENCE

### Health Care System

Quantitative  
Qualitative  
Cross section

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### Principal Investigator(s)

Redinbaugh E, Sullivan A, Block S, Gadmer N, Lakoma M, Mitchell A, Seltzer D, Wolford J and Arnold R. (2003).  
Doctors' emotional reactions to recent death of a patient: cross sectional study of hospital doctors

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### Study Design

Semi-structured interview and self-administered questionnaire

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### Sample Description

- ◆ Index patient cases randomly selected from patients at two academic teaching hospitals who had a minimum stay in the hospital of 24 hours; died on a general medicine unit or intensive care unit and case involved hospital doctors in patient's care. 81 patient cases identified. 13 cases were excluded due to insufficient data (only 1 doctor completed an interview)
  - ◆ 251 doctors cared for 81 patients; 246 eligible to participate. 188 completed an interview (76% response rate).
  - ◆ Doctors who did not participate in the study or who were excluded from the study did not differ significantly from those who participated in terms of their level of training, race, marital status or age. Jewish doctors were more likely to be non-participants/excluded
  - ◆ Only 2 medical students were involved in patient care and were combined with interns. There were no significant differences between primary care physicians and attending physicians in intensive care and general medicine in terms of their age, sex, marital status or race. All attending doctors were combined in one group
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### Selected Measures

- ◆ Doctor's level of training
  - ◆ Doctor's experience in providing patient care included 7 items on questionnaire that assessed doctors' satisfaction with patient's symptom management and 4 questions during the interview that assessed satisfaction with caring for patient, closeness of relationship with patient, conflict regarding patient care and amount patient suffered
  - ◆ Doctor's emotional reactions to patient's death: 14 grief symptoms; 6 items from impact of even scale that assessed doctors' intrusive thoughts and avoidant behavior during week after patient's death; and 2 questions during interview, *How disturbing was this death? How emotionally powerful was this death?*
  - ◆ Doctors' use of coping resources after the death: 5 coping items on situational COPE scale that assess how doctors coped with patient's death during week after patient's death; 15 yes/no question that assessed people doctor talked to about patient's death and the content of the conversation and 1 question that identified person who was most helpful in providing doctor with social support; 2 questions during the interview, *How much support from colleagues to cope with patient death? How much support received from colleagues regarding patient death?*
-

## Selected Outcomes

- ◆ 82% of doctors had not cared for the patient before the final admission to the hospital. 36% knew the patient for 3 days or less; 36% for 4-7 days and 28% reported caring for the patient longer than a week. 11% reported feeling very close to the patient
  - ◆ 74% of doctors reported taking care of the patient as a *very satisfying/satisfying* experience
  - ◆ 55% said the patient's death disturbed them very little, 23% said it was very disturbing. The differences in emotional reactions by level of training were not significant
  - ◆ On average, doctors reported experiencing 2 (out of 14) grief symptoms. Female doctors reported more symptoms of grief than male doctors. The most common was feeling upset when thinking about the patient
  - ◆ Duration of care was associated with more satisfying experience and greater feelings of closeness to the patient but also finding the death more disturbing and emotionally powerful as well as more reported symptoms of grief
  - ◆ On average, doctors reported 2 coping strategies (out of 5) to manage the emotions associated with the patient's death. Female doctors used more coping strategies than males. Residents used more coping behaviors than interns or attending physicians
  - ◆ 83% of doctors reported needing little emotional support from colleagues. Interns reported needing more emotional support than attending physicians. Female doctors reported needing more emotional support than males. 35% of all doctors said their needs had gone unmet
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey

### **Services**

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### **Principal Investigator(s)**

Richman J. (1990). Group work in a hospice setting

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### **Study Design**

Telephone survey

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### **Sample Description**

- ◆ Stratified random sample of hospices in North Carolina
  - ◆ 44 state hospices including rural and urban and various sizes
  - ◆ Hospice representative (usually the director) was interviewed
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### **Selected Measures**

- ◆ What groups are currently using the provision of services to clients and families?
  - ◆ What groups provide training, operation and support of hospice volunteers and staff?
  - ◆ Who leads or conducts each group and how often do these groups meet?
- 

### **Selected Outcomes**

- ◆ 100% (44) conducted staff meetings, often led by nurses, and discussed daily operations and nature and needs of clients – provides an opportunity for the staff to share perspectives and information (noted -- there is a multidisciplinary approach to hospice – there is often a blurring of professional roles – the staff member with the best relationship with the client may provide counseling, e.g., the aide rather than the social worker)
  - ◆ 100 % (44) has interdisciplinary team meetings – all members of the team, paid and unpaid are present – this is when the care plan is developed
  - ◆ 75% (33) provided bereavement groups often led by the bereavement care coordinator or chaplain – typically free and may be time limited
  - ◆ 30 (65%) provided training and support groups for their volunteers -- facilitated by volunteer coordinators and hospice staff, sometimes community professionals
  - ◆ 17 (38.6%) provided staff support group, 5 were planning them – facilitated by an outside consultant
  - ◆ 75% (33) provided bereavement groups often led by the bereavement care coordinator or chaplain – typically free and may be time limited
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Quasi-experimental  
Cross section

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### **Principal Investigator(s)**

Richman J and Rosenfeld L. (1987). Stress reduction for hospice workers: A support group model

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### **Study Design**

Self-administered questionnaires, sent to and distributed by hospice directors

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### **Sample Description**

- ◆ Members of hospice teams throughout the state of NC, questionnaires were mailed to 54 state hospice directors; 94 questionnaires were returned, 83 (54%) were usable
  - ◆ 78 females, 5 males with a mean age of 39 and with an average of five years hospice work experience
  - ◆ 36% of respondents were nurses; 24% hospice directors; 15% social workers; 13% office staff and 12% volunteer coordinators
  - ◆ Respondents were separated into two groups: respondents with stress scores below the median and those with scores above the median. There were no significant differences between the two groups in terms of age and years in hospice work
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### **Selected Measures**

- ◆ Stress as measured by The Tedium Questionnaire, 21 phrases relating to personal experiences rated 1 to 7. Measured aspects of stress including: unhappiness; exhaustion; self-rejection. Summative score was used
  - ◆ Social support as measured by The Support Functions Questionnaire, includes 6 types of social support-- listening, technical appreciation, technical challenge, emotional support, emotional challenge and shared social reality. Respondent asked to provide the name and relationship of persons who provide each type of support
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### **Selected Outcomes**

- ◆ Respondent's involvement in a support group had no effect on his/her reported level of stress
  - ◆ From Tedium Questionnaire, hospice workers experience exhaustion most intensely, unhappiness next and self-rejection only slightly
  - ◆ Social support, external to the work setting, bore no direct relationship to the respondents' reported levels of stress
  - ◆ Results suggest that effective support groups for hospice workers are characterized by their technical challenge, shared social reality and emotional challenge. They de-emphasized listening support as a goal. Technical appreciation and emotional support did not distinguish effective from ineffective support groups
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## **SELECTED EVIDENCE**

### **Health Care System**

Quantitative  
Survey  
Cross section

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### **Principal Investigator(s)**

Robbins R. (1991). Death anxiety, death competency and self-actualization in hospice volunteers

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### **Study Design**

Self-administered questionnaires completed as part of hospice program

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### **Sample Description**

- ◆ 248 volunteers from 6 hospices in PA, two from large cities and 4 from small cities
  - ◆ 212 women, 36 men, with an average age of 50.6 years. Their length of time as hospice volunteers averaged 43.1 months
  - ◆ Respondents from various hospices did not differ on demographic characteristics or on personality variables
- 

### **Selected Measures**

- ◆ Self-actualization as measured by the Personal Orientation Inventory: self-actualization
  - ◆ Death anxiety as measured by the Templer/McMordie revision of the Templer Death Anxiety Scale
  - ◆ Death-preparatory behaviors as measured by Bugen's Coping with Death Scale
  - ◆ Death self-efficacy as measured by a 45 item Self-Efficacy Scale designed for this study
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### **Selected Outcomes**

- ◆ Death anxiety was negatively associated with Time Competence, Inner-Directedness, Self-regard and Self-acceptance on the Personal Orientation Inventory
  - ◆ After adjusting for the effects of age, coping with death was positively associated with Time Competence, Inner-directedness, Self-actualizing Value, Existentiality, Spontaneity, Self-regard, Self-acceptance, Acceptance of Aggression and Capacity for Intimate Contact
  - ◆ The Death Self Efficacy Scale was positively associated with 11 of 12 scales of the Personal Orientation Inventory (Synergy was not significant)
  - ◆ Death competency or coping with death or death self-efficacy may be more useful than the concept of death anxiety in conceptualizing people's emerging self-actualization in the process of confronting mortality
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**SELECTED EVIDENCE**  
**Health Care System**

Qualitative

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**Principal Investigator(s)**

Saunders J and Valente S. (1994). Nurses' grief

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**Study Design**

Self-administered questionnaires and interviews

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**Sample Description**

- ◆ 300 oncology and hospice nurses who attended bereavement workshops over a 7 year period
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**Selected Measures**

- ◆ Personal and professional experiences with bereavement
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**Selected Outcomes**

- ◆ Most nurses reported that they felt they managed their grief effectively if they helped the patient die a *good death* which included: a) relieving patient's distress and symptoms to the extent allowed by current knowledge and technology; b) patients had a chance to complete tasks related to their important relationships; c) believing that he/she had delivered the best quality of care possible for the patient; d) person's death did not violate the natural order; e) patient's death was contextually appropriate (e.g., natural deaths in oncology)
- ◆ When nurses reported that they had not been able to help a patient die a *good death* for whatever reasons or when they were off duty when the patient died, they said their grief was more difficult
- ◆ Although their grief after the patient's death took longer than many nurses anticipated, they were proud of managing symptoms and facilitating family communication and this comforted them in their own grief
- ◆ Many nurses identified their knowledge of the grief process was derived from personal experience and listed few role models or knowledge bases that were helpful

## **SELECTED EVIDENCE**

### **Health Care System**

Qualitative

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#### **Principal Investigator(s)**

Vachon M. (1987). Team stress in palliative/hospice care

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#### **Study Design**

Individual semi-structured interviews; group interviews and informal discussions

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#### **Sample Description**

- ◆ Sample drawn from larger study of 581 caregivers in Canada, USA, Europe and Australia
  - ◆ 60 hospice workers drawn from an international convenience sample of 100 (60%) participated in 23 individual semi-structured interviews; 11 group interviews involving 51 caregivers and 23 informal discussions
  - ◆ 38% of participants were MDs, 42% nurses, 13% social workers, 2% clergy, 3% volunteers, 3% physiotherapists and 9% others
  - ◆ 45% of participants were between 30 and 45 years old; 52% were over age 45
  - ◆ 63% of participants were from Canada, 13% of USA, 22% from GB, Australia and South Africa and 2% from non-English speaking countries
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#### **Selected Measures**

- ◆ Subjects were asked to describe the sources of stress they experienced in working with the critically ill, dying and bereaved. They also were asked to: comment on factors from their personal lives which made them more or less vulnerable to these stressors; discuss the symptoms of stress they experienced; comment on personal and environmental coping techniques they used to deal with these stressors
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#### **Selected Outcomes**

- ◆ 527 incidents of stressors mentioned by 60 individual and group interviews with palliative care staff members represented 8.78 stressors reported per interview. This response rate was less than the average number of stressors for total group of caregivers. Rate was less than that reported by staff working in ER, OB, ICU and chronic but more than oncology, pediatric chronic care or pediatric intensive care
- ◆ Major source of work stressors reported by those in hospice were work environment (48%), occupational role (29%), patient/family (17%) and illness (7%)
- ◆ Rank ordering of stressors showed following ten accounted for 73% of stressors reported: communication problems with others in the system (13%); role ambiguity (10%); team communication problems (7%); communication problems with administration (7%); role conflict (6%); nature of the system (6%); inadequate resources (5%); unrealistic expectations (5%); patient/family communication problems (5%); patient family coping or personality problems (4%)
- ◆ Hospice caregivers had more difficulty with communication within the hospital and/or community than did any other specialty — much reflected initial justification for a hospice program
- ◆ In hospice work the team, which is thought to be a major source of nurturance is a major source of stress. Team communication stressors mentioned by caregivers included: difficulty developing trust within an interdisciplinary team; difficulty with communicating information; power struggles; handling conflict; “incest” on the health care team; and ensuring longevity beyond the life of the original team

- ◆ Communication problems with administration often polarize: overinvestment and an inability to loosen the reins on a potential showcase service to lack of interest or resistance to the service
  - ◆ The length of time clients were in the program often impacted on the degree of stress staff felt when the patient died
  - ◆ The major manifestations of stress among respondents were: staff conflict; feelings of depression, grief and guilt; job/home interaction; and feelings of helplessness and insecurity
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