FACING DEATH

Familial Responses to Illness and Death

Edited by Christina L. Scott, Heidi M. Williams and Siri Wilder

CONTEMPORARY PERSPECTIVES IN FAMILY RESEARCH

VOLUME 19

FACING DEATH

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FACING DEATH: FAMILIAL RESPONSES TO ILLNESS AND DEATH

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SECTION 3
FACING DEATH AND BEREAVEMENT

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Kathryn L. Burgio, PhD, is a Behavioral Psychologist and Clinical Investigator with 40 years of experience in behavioral medicine, gerontology, and geriatric medicine. She completed her doctoral training at the University of Notre Dame and a fellowship in Behavioral Medicine at the National Institute on Aging, NIH. During her tenure at the University of Alabama at Birmingham (UAB), she has served as the Director of the Social and Behavioral Sciences Section in the Division of Gerontology, Geriatrics, and Palliative Care and Founding Director of the UAB Continence Program. She also served as an Associate Director for Research at the Birmingham/Atlanta VA Geriatric Research, Education, and Clinical Center (GRECC) and the Director of the GRECC Fellowship in Advanced Geriatrics. Currently, she is a Professor of Medicine (Emerita) and an Assistant Director of the Deep South Resource Center for Minority Aging Research (RCMAR). Her research agenda has focused on genitourinary disorders, particularly urinary incontinence, and has included investigations of its prevalence and risk factors and clinical studies of the effectiveness of behavioral treatments with a variety of populations. She has completed several clinical trials investigating various interventions for incontinence funded by the National Institutes of Health and the Department of Veterans Affairs. She has published extensively in the field and is an international expert on behavioral interventions. Beginning in 2001, her research interests extended to palliative medicine and interventions to change provider behavior and improve end-of life care. She has led several team projects related to implementing palliative care education interventions, including the multi-site, "Best Practices for End-of-Life Care for Our Nation's Veterans" (BEACON) project funded by the Department of Veterans Affairs.

Asuman Buyukcan-Tetik is an Assistant Professor in the Psychology Program of Sabanci University, Turkey. Her research investigates the relational processes and interdependence between family members after major life events such as losing a significant other, marriage, and transition to parenthood. She aims to integrate the theoretical and methodological approaches of social, family, clinical, and developmental psychology. Most of her papers include dyadic, family-level, and (intensive) longitudinal studies. Currently, she collects data from bereaved parents using a diary method to examine the effects of relationship quality and positive emotions on grief adjustment.

Patricia Drentea, PhD, is a Professor in the Department of Sociology at the University of Alabama at Birmingham (UAB). Her interests include aging, end-of-life issues, caregiving and mental health, debt, and the effects of debt on health and well-being. She wrote the book *Families and Aging* in 2019 (Rowman & Littlefield). The book examines how social changes in families in the United States, such as delayed childbearing, divorce, being single, and so on affect families and individuals as they age. The book is written with an emphasis on helping a younger audience understand how families will be in the future with social trends

such as increasing numbers of multiracial families, same-sex couples and women starting families later in life. She examines topics such as caregiving, work and retirement, activities, and health. Her recent work examines caregiving and end-of-life issues, grandparenting, and the emotional labor of nurses. She also works on research about debt and mental health. She has published in multiple journals including *The Gerontologist, The Journal of Health and Social Behavior, Aging and Health, Contexts, the Journal of Palliative Care, and CANCER*. She is currently on the editorial board of *Society and Mental Health*.

Maarten C. Eisma is an Assistant Professor of Clinical Psychology at the University of Groningen. His research interests include the assessment, etiology and (internet-based) cognitive-behavioral treatment of complicated grief. Over the past decade, he has published more than 60 peer-reviewed scientific articles and book chapters. In 2019, he received a prestigious Dutch Research Council VENI Grant to investigate loss-related approach and avoidance behaviors in complicated grief. He is an editorial board member of *Death Studies* and a member of the Dutch/Flemish Research School Experimental Psychopathology.

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Margaret S. Stroebe is a Professor Emerita (Utrecht & Groningen Universities, NL). She has long specialized in the bereavement research field. With Henk Schut she developed the Dual Process Model of Coping with Bereavement. Her books include *Bereavement in Later Life*, with Robert Hansson; the and *Handbook of Bereavement Research and Practice*, with Robert Hansson, Henk Schut and Wolfgang Stroebe. She edited *Complicated Grief: Scientific Foundations for Health Care Professionals*,

with Henk Schut and Jan van den Bout. Her honors include an Honorary Doctorate (University of Louvain-la-Neuve, Belgium), Scientific Research Award (ADEC, U.S.A.), and title: Officer of the Order of Orange Nassau (NL).

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FOREWORD

Death is one of the rare certainties of life. While rituals surrounding death may vary by geography, culture, and time, suffering the loss of a loved one is a universal experience. However, the ongoing COVID-19 pandemic has increased global awareness of and proximity to serious illness and death. Since the outbreak of the virus in 2019, hundreds of millions of individuals have been infected and the SARS-CoV-2 virus has been directly implicated in millions of deaths worldwide. Societal changes, related to social distancing requirements and city-wide lockdowns attempting to slow the spread of disease, have made it more difficult for individuals to find support in their grieving process. As a result, those coping with the death of a loved one have often found themselves caring for family members and managing the bereavement process in isolation. Facing daily death tolls and constant efforts to avoid infection has kept death in the forefront of our collective awareness. As a multidisciplinary endeavor, the current volume of *Contemporary Perspectives in Family Research* includes contributions from a variety of methodologies and contexts to provide a timely exploration of familial responses to illness and death.

Coping with Serious Illness and Threat of Death

While the physical toll of long-term illness is widely acknowledged, the negative psychological effects are less obvious. Both the affected individual and their loved ones may suffer distress and anxiety dealing with the day-to-day impact of chronic health conditions. However, familial relationships can also be sources of comfort and provide opportunities to initiate difficult, but necessary discussions about death.

Chronic illnesses can follow us through our lifetime, but they may have a more profound effect on the quality of life of older adults. Supportive personal relationships play an important role in buffering against the negative psychological effects of those coping with long-term illness, especially later in life. In "Intimate Relationships as Factors in Associations Between Inflammation and Happiness in Older Adults: A Covariate Analysis of Limited Longitudinal Data," authors Alexandra C. H. Nowakowski, Katelyn Y. Graves, and J. E. Sumerau discuss the positive role of intimate relationships in attenuating the relationship between chronic illness and quality of life. Using biosocial data from the *United States' National Social Life, Health, and Aging Project*, the study utilizes ordinal logistic regression analyses to examine associations between chronic illness and well-being. The chapter concludes that marital relationships appear to mediate the relationship between chronic inflammation and quality of life, providing further evidence regarding the positive effects of social support in the lives of individuals experiencing chronic health conditions.

The ongoing COVID-19 pandemic has heightened anxiety about illness and death, but families who were already coping with serious health conditions may have been affected more severely. "Facing Amyotrophic Lateral Sclerosis Under Lockdown," by Ines Testoni, Lorenza Palazzo, Teresa Tosatto, Livia Sani, Gabriella Rossi, and Jenny Ferizoviku, considers the impact of Italy's social isolation measures (designed to prevent the spread of the virus) on children of parents with ALS. The research also explores children's feedback regarding a psychological intervention to help them manage stress surrounding their parents' diagnosis during lockdown. Thematic analysis was used to identify several categories of responses from qualitative data obtained during interviews with minor children. Results highlight the beneficial emotional, behavioral, and educational impacts of psychological intervention, difficulty involved with talking about future parental death, positives and negatives of COVID-19 stay at home orders, and the children's advice for peers in similar situations.

Explaining the abstract concept of death to young children can be daunting for any parent or family member. Rebecca Gregory, Chang Su-Russell, Luke T. Russell, and Carley Barrett approach the complexities of this process in "Navigating Discussions of Death with Young Children: Variable Strategies of Protection." Guided by grounded theory, interviews with parents of young children were conducted to determine how parents may approach discussions of death. The results indicate that parent-child discussions of death tend to revolve around protecting the child's innocence with age-appropriate conversation or preparing them for eventual exposure to death with in-depth engagement. Notably, parents' preferred strategy appears to hinge on a combination of factors, including their experiences with death, the child's level of understanding, and their cultural and religious values.

Decisions Surrounding Serious Illness and End-of-Life

Family members are often responsible for making determinations regarding end-of-life care and the dying process. This experience can be overwhelming, as they are tasked with understanding and responding to complex medical information, while at the same time managing their own emotions and honoring the wishes of their loved ones.

For many families, facing end of life in a hospital setting can be especially dysregulating. In "Familial Responses to Death in Veterans Affairs Medical Centers: Losing Control and Holding On," authors Patricia Drentea, Beverly Rosa Williams, Karen Hoefer, F. Amos Bailey, and Kathryn L. Burgio utilized qualitative data from the *United States' Best Practices for End-of-Life Care and Comfort Care Order Sets for Our Nation's Veterans* study to examine familial responses to the death of a loved one in the care of Veterans Affairs Medical Centers. The chapter maintains focus on the importance of a "good death" to veterans and their families, addressing the realities and challenges of hospital life as well as the complex interplay of family relationships within the hospital environment. Data analysis identified the dual themes of "losing control" and "holding on" expressed by veterans' family members, encompassing their struggle to maintain the dignity and comfort of their critically ill loved ones through the experience of end-of-life care in the hospital setting.

While most expectant parents associate the hospital setting with the birth of a baby, for some it is a place where they must navigate painful choices surrounding the viability of the fetus. Katrina Kimport's "Choosing Abortion for a Serious Fetal Health Issue: From Medical Information to Values" examines the difficult process of deciding to end a pregnancy due to serious fetal illness. Women who had experienced abortion after the twenty-fourth week of pregnancy due to serious fetal health problems were interviewed using a semi-structured approach. Qualitative coding focused on identifying behaviors and emotions associated with the limitations of medical knowledge surrounding fetal diagnoses and the unexpected termination of the pregnancy.

Facing Death and Bereavement

The devastating effects of losing a loved one are almost unimaginable. The cause and circumstances surrounding the death can affect the already difficult grieving process, and support from friends and family can be of vital importance as they navigate daily life after the loss.

Helle Holmgren identifies the specific support needs of bereaved individuals in "Social Support in Bereavement: The Experiences of Support Following Spousal Loss in Families with Dependent Children." Qualitative survey responses from bereaved Danish spouses with minor children described many sources of support post-loss, from professional sources, such as bereavement organizations, to personal connections, including support groups and in-laws. However, thematic analysis revealed that families often felt adrift and isolated as the support they received dissipated while their grief remained. The chapter includes a comprehensive overview of what types of support bereaved individuals identified as necessary (and lacking) following their loss, providing concrete information that could strengthen support programs for grieving families going forward.

Close family relationships can be essential sources of understanding and solace during the grieving process. Coauthored by Asuman Buyukcan-Tetik, Sara Albuquerque, Margaret S. Stroebe, Henk A. W. Schut, and Maarten C. Eisma, "Grieving Together: Dyadic Trajectories and Reciprocal Relations in Parental Grief After Child Loss" addresses the devastating impact of child loss on Dutch parents and the interrelatedness of parents' grief. Using longitudinal data, the authors conducted latent growth curve and cross-lagged panel analyses examining individual and dyadic patterns of parental grief following the loss. Deepening our understanding of the enduring emotions experienced by parents who have lost a child, the authors' findings highlight the process by which each parent's grief affects the other's and the persistence of intense grief across time.

In "Suicide Bereavement and Social Relationships: A New Application of Durkheim," Kathryn McGrath examines the uniquely complicated experiences of individuals who have experienced the death of a loved one due to suicide through the lens of Durkheim's theory of social integration (Durkheim, 1897/1966). Using archival interview data, this qualitative analysis sought to distinguish the range of emotions and opinions experienced by loved ones left behind after a suicide. Participants' responses reveal the variety of conceptualizations and judgments associated with suicide, each of which influences the suicide-bereaved individuals'

emotional reflection on the impact of the death. The findings illustrate how individuals' perceptions of suicide directly influence their framing of the loss in relation to a larger social context.

A rapid increase of global connectedness in recent times has allowed individuals worldwide to connect and share information on an unprecedented scale. As the COVID-19 pandemic stretches on, death continues to be a daily concern that transcends geographic and cultural boundaries. *Facing Death: Familial Responses to Illness and Death* provides an avenue to analyze, understand, and process death from a variety of perspectives, and we are deeply appreciative of each author who has contributed their time and expertise to this volume. We also want to extend sincere thanks to the members of the editorial board, the external reviewers, and the Emerald Publishing staff for their contributions.