

# FACING DEATH

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CONTEMPORARY PERSPECTIVES IN FAMILY  
RESEARCH VOLUME 19

**FACING DEATH: FAMILIAL  
RESPONSES TO ILLNESS AND  
DEATH**

EDITED BY

**CHRISTINA L. SCOTT**

*Whittier College, USA*

**HEIDI M. WILLIAMS**

*Virginia Polytechnic Institute and State University, USA*

and

**SIRI WILDER**

*The University of Texas at Dallas, USA*



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INVESTOR IN PEOPLE

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# ABOUT THE CONTRIBUTORS

**Sara Albuquerque** is an Assistant Professor at Universidade Lusófona. She has published several articles in scientific journals and book chapters with a focus on grief processes, individual and marital adjustment after the loss of a child, dyadic coping, post-traumatic growth, continuing bonds and, recently, on the impact of the pandemic in the grief processes, both in children and adults. She is currently the Coordinator and a Clinical Psychologist of the Grief Consultation at the PIN Clinical Center – at all stages of life (in Lisbon), whose action focuses mainly on the assessment and intervention with children, adolescents, and adults, in grief by death and chronic illnesses and divorce situations. She also gives several workshops on grief and emotional regulation.

**F. Amos Bailey, PhD, MD FACP, FAAHPM** is a Professor of Medicine at the University of Colorado, School of Medicine and the Director of the Masters of Science of Palliative Care and Interprofessional Palliative Care Certificate Programs. He moved to Colorado in the summer of 2014 to join colleagues at the Anschutz Medical Campus to develop on-line programs to bring palliative care education to healthcare providers who want to begin or expand their practice in palliative care. He studied medicine at the University of South Florida and completed a residency in Internal Medicine at the University of Vermont. In 1986, he moved to the University of Alabama at Birmingham (UAB) for a Fellowship in Medical Oncology. In 1989, he joined a practice in rural West Virginia. It was here that he began to work in Home Hospice and began to educate himself in Hospice and Palliative Care. In 1994, he returned to Birmingham and founded the Balm of Gilead Palliative Care Program, which was featured in the Bill Moyers' documentary *On Our Own Terms*. In 2001, he was recruited to establish the Safe Harbor Palliative Care Program at the Birmingham VAMC. His work in Birmingham was focused on education and training in hospice and palliative care for medical students, residents, fellows, and other clinical providers.

**Carley Barrett, M.S.**, is a Certified Child Life Specialist who supports children and families in the emergency department at St. George Regional Hospital. She received a Bachelor's degree in Child Development from The University of Akron, as well as her Master's degree in Family and Consumer Sciences with an emphasis in Child Life from Illinois State University. While at The University of Akron, she gained experience working as a Nursing Assistant on a palliative care unit at the Cleveland Clinic and supported children impacted by cancer as an intern at The Gathering Place. During her time at Illinois State University, she had the opportunity to complete child life specific clinicals in four different hospitals and assisted in teaching children at a local childcare center. Additionally, she worked

as a graduate assistant where she assisted with teaching family and consumer science courses and conducting related research.

**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.

**Jenny Ferizoviku** is a Psychologist and Psychotherapist. She has been a Psychologist at the Italian Association Amyotrophic Lateral Sclerosis (A.I.S.L.A.), and she works now at the Italian Association for the Fight Against Muscular Dystrophy (UILDM) of Milano and Monza (Italy) and at the Niguarda Hospital in Milan. Her fields of interests include disability, EMDR therapy and health psychology.

**Katelyn Y. Graves** is a Research Faculty in Behavioral Sciences & Social Medicine at the Florida State University College of Medicine. She has a background in Demography and Sociology, with an emphasis on biosocial health. She conducts demographic and statistical analyses using software packages such as Stata, and analyzes secondary data sets such as Medicare and Medicaid claims. She presently works on several evaluations assessing public health programs and improving population health. She holds a PhD and MS in Social Demography and a BS in Psychology, all from Florida State University. Follow her on LinkedIn @katie-graves-6b429569.

**Rebecca Gregory, M.S.**, is a Child Life Specialist and a current Ph.D. student in Chicago, Illinois. Her research interests include using a developmental lens to assess the cognitive understanding of traumatic events and how to best support children through trauma. Her current role as a child life specialist at the Chicago Children's Advocacy Center grants her the opportunity to help children cope with trauma related to childhood sexual abuse. In addition to being a student, she is a Teaching Assistant within the child life department at the Erikson Institute, where she works closely with Certified Child Life Specialists from a multitude of Chicago children's hospitals to teach graduate students in child life and child development.

**Karen Hoefler** received her M.A. in General Sociology at East Tennessee State University. Her thesis was on the Quality of Life of Adults Who Attempted Suicide. She is currently working on her PhD in Medical Sociology at the University of

Alabama at Birmingham. Her main focus at the moment is PTSD validation both inside and outside the military community. Her interests include loss of identity in mental hospitals, quality of life, death and dying, and mental health.

**Helle Holmgren** has an M.Sc. in Psychology from Aarhus University/Denmark and a PGDip in Psychobiology of Stress from Roehampton University/London. She received her Ph.D. from Aarhus University/Denmark in 2021. The dissertation shed light on male grief, children's experiences of losing a mother, work-life balance following bereavement and finally, what bereaved individuals themselves make of the new diagnosis of prolonged grief disorder in ICD-11. Her career combines applied research with an ongoing involvement in clinical practice. She has worked in the field of school counseling and volunteered in a shelter for battered women and their children, as well as worked therapeutically with young adults from families with drug and alcohol addictions. Her primary research interests are within the areas of psychotraumatology, bereavement, grief, family studies, and qualitative methods. She is currently working on a book project and writing scientific articles. Her recent publications appeared in *Journal of Family Issues, Illness, Crisis & Loss*, and *OMEGA – Journal of Death and Dying*.

**Katrina Kimport**, PhD, is an Associate Professor in the Department of Obstetrics, Gynecology & Reproductive Sciences and a Research Sociologist in the Advancing New Standards in Reproductive Health (ANSIRH) program at the University of California, San Francisco. Her research broadly focuses on the (re)production of inequality, with a particular emphasis on gender and sexuality-based inequality. Her more specific research interests include people's experiences of preventing pregnancy, pregnancy decision-making, and abortion care. Her work has been published in multiple journals, including the *Journal of Health and Social Behavior, Social Science & Medicine*, and *Gender & Society*. She is the author of *No Real Choice: How Culture and Politics Matter for Reproductive Autonomy* (2022, Rutgers University Press) and *Queering Marriage: Challenging Family Formation in the United States* (2014, Rutgers University Press), and co-author, with Jennifer Earl, of *Digitally Enabled Social Change* (2011, MIT Press).

**Kathryn McGrath** received her B.A. in Applied Psychology & Human Development and English from Boston College in 2019, and her M.A. in Comparative Human Development from The University of Chicago in 2020. She is interested in social psychology, with a particular emphasis on the ways social factors shape mental health outcomes. Her other research interests include interpersonal relationships, social cognition, and theoretical sociology.

**Alexandra C. H. Nowakowski** is an Assistant Professor in Geriatrics and Behavioral Sciences & Social Medicine at the Florida State University College of Medicine. They are a medical sociologist, public health program evaluator, and community advocate. Their research, teaching, and outreach focus on health equity in aging with chronic disease. They hold a PhD and MS in Medical Sociology from Florida State University, an MPH in Health Systems and Policy from Rutgers University,

and a BA in Political Science from Columbia University. Follow them on Twitter @XanNowakowski or on LinkedIn@xan-nowakowski-9a368b7.

**Lorenza Palazzo** is a Psychologist. She currently has a research fellowship at the University of Padova for “Baobab project” concerning the psychological impact of the ALS disease on children and adolescents who have a close relative affected by it. Her research interests include also grief, death education, ambiguous loss, and anticipatory grief.

**Gabriella Rossi** is a Psychologist and Psychotherapist, President of the Italian Association for the Fight Against Muscular Distrophy (UILDM) of Monza and Brianza (Italy). She has been the Coordinator of Italian Group of Psychologists of ALS disease (GipSLA) of the clinical psychology department of NeMo Clinical Center of Milano.

**Luke T. Russell, PhD, CFLE-P.**, is an Assistant Professor in the Department of Family and Consumer Sciences at Illinois State University. His research investigates how individuals living in diverse family structures (single-parent, post-divorce, stepfamilies) foster resilience and maintain family-members’ health and well-being. He also studies how broader social institutions (e.g., health care systems, schools, and government agencies) can function as supportive resources for such families. He teaches courses in communication and helping skills, public policy, and enduring issues for couples and families.

**Livia Sani, Ph.D.**, is a Clinical Psychologist, and Associate Researcher at the SuLiSoM laboratory of the University of Strasbourg (France), is an expert in emergency psychology and psycho-traumatology. Her research interests focus on post-traumatic stress disorder, bereavement, qualitative and quantitative research.

**Henk A. W. Schut** is a Clinical Psychologist and an Associate Professor of Clinical and Health Psychology at Utrecht University, the Netherlands. His research interests cover processes of coping with loss and the efficacy of bereavement care and grief therapy. He works as a trainer for professionals dealing with bereaved people and supervises post-academic clinical psychologists in research projects. He is the coauthor of scientific and professional articles and books on grief, bereavement, and death (e.g., *Handbook of Bereavement Research and Practice* (2009), with Maggie Stroebe, Wolfgang Stroebe and Bob Hansson; and *Complicated Grief: Scientific Foundations for Health Care Professionals* (2012), with Maggie Stroebe & Jan van den Bout).

**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).

**Chang Su-Russell**, PhD, CFLE-P, is an Assistant Professor in the Department of Family and Consumer Sciences at Illinois State University. Her research focuses on socializing young children in challenging social contexts. Guided by this research agenda, she has developed two lines of research. First, she has investigated how parents of young children discuss challenging social issues in the United States and how college students get prepared for challenging conversations for their future career when working with children and families. Second, she has investigated the transition to siblinghood and sibling relationships in the post-one-child-policy era in mainland China. She teaches in the Human Development and Family Science program in the Department of Family and Consumer Sciences. Her four undergraduate courses include: life-span parenting, guidance and development of infants and toddlers, multicultural family studies, and research methods in family and consumer sciences.

**J. E. Sumerau** is an Associate Professor and the Director of Applied Sociology at the University of Tampa. She is the author of over 70 scholarly articles and chapters as well as five academic books focused on the intersection of sexualities, gender, religion, health, and violence in society. She is also the author of five novels focused on LGBTQIA experiences in the United States. She holds a PhD and MS in Social Psychology from Florida State University, and a BA in Political Science from Augusta University. Follow her on Twitter @jsumerau or visit her website at [www.jsumerau.com](http://www.jsumerau.com).

**Ines Testoni** is a Professor of Social Psychology and the Director and Founder of the Master in “Death Studies & The End of Life” at the University of Padova. She is the author of numerous publications on grief, death education, gender studies, social psychology of mafia phenomena and prison, and interventions with the use of psychodrama.

**Teresa Tosatto** has completed her Master’s Degree in Clinical and Dynamic Psychology at the University of Padova, in 2021. She is currently attending her post-graduate internship. Her fields of interest are thanatology and end-of-life psychology, developmental psychology, clinical child psychology, and psychoanalysis.

**Beverly Rosa Williams**, PhD, holds a Bachelor of Arts in Sociology and History from Salve Regina University in Newport, Rhode Island, a Master of Arts in Sociology/ Anthropology from the University of Southern Mississippi in Hattiesburg, Mississippi and a Ph.D. in Medical Sociology from the University of Alabama at Birmingham (UAB). She completed a three-year NIA post-doctoral fellowship in Clinical and Behavioral Training in Gerontology and a two-year NIH Clinical Research Training Program. She has been on faculty in the Department of Medicine, Division of Gerontology, Geriatrics, and Palliative Care at the

University of Alabama at Birmingham since 2005. She is a UAB Comprehensive Center for Healthy Aging Faculty Scientist, Center for Palliative and Supportive Care Scholar, Minority Health and Health Disparities Research Center Associate Scientist, and Birmingham/Atlanta Geriatric Research, Education, and Clinical Center (GRECC) Investigator. She has expertise in qualitative methods of inquiry, analysis, and interpretation. Her research interests include bereavement, palliative and end-of-life care, health disparities, women's health, and religion, spirituality and health. She has authored or co-authored more than 75 articles in peer-reviewed journals. Her work has been supported by grants from VA Health Services Research & Development (HSR&D) and the National Institutes of Health (NIH). She and her colleagues have contributed to the literature on geriatric bereavement, expanding knowledge of the psychosocial attributes of the pre-widowhood period, examining the impact of spousal loss on morbidity and mortality, and exploring the socially isolating effect of prolonged widowhood. Her qualitative interviews with newly bereaved family members have enhanced understanding of contextual factors impacting bereavement and sensitized the field to ethical and methodological issues related to research with bereaved persons.

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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.

# SECTION 1

## COPING WITH SERIOUS ILLNESS AND THREAT OF DEATH

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# CHAPTER 1

## INTIMATE RELATIONSHIPS AS FACTORS IN ASSOCIATIONS BETWEEN INFLAMMATION AND HAPPINESS IN OLDER ADULTS: A COVARIATE ANALYSIS OF LIMITED LONGITUDINAL DATA

Alexandra C. H. Nowakowski, Katelyn Y. Graves  
and J. E. Sumerau

### ABSTRACT

*Purpose: This report analyzes relationships between chronic inflammation and quality of life (QoL). It assesses the potential role of intimate relationships in associations between inflammation, medical sequelae such as pain and disability, and QoL.*

*Design/Methodology/Approach: Limited longitudinal data from the National Social Life, Health, and Aging Project (NSHAP) were analyzed. Inflammation was assessed via the biomarker C-reactive protein (CRP). The authors examined pathwise associations between CRP levels and general happiness. The authors used ordinal logistic regression with companion OLS models, and conducted a variety of sensitivity analyses.*

*Findings: Intimate partnerships – especially marriage – appear to impact associations between inflammation and QoL. When QoL is measured*

*using general happiness, intimate relationships appear to shape directional associations between inflammation and QoL along with medical consequences of inflammation.*

*Research Limitations/Implications: Inflammation and its clinical consequences may substantially alter intimate relationship involvement and quality that in turn impact QoL. These relationships should not be viewed as unilateral explanations of the tremendous variability observed in QoL among people with inflammatory conditions, but rather as possible elements of complex causal frameworks. Further investigation using advanced methods for longitudinal modeling from limited waves of data can help to shed additional light on the nuances of happiness and QoL among people living with chronic inflammation.*

*Originality/Value: This chapter provides an overview of possible causal relationships between chronic inflammation, associated clinical and social experiences, and QoL. Researchers interested in advanced causal modeling of relationships between chronic inflammation and QoL can build on this work using novel methods and data sources.*

**Keywords:** Inflammation; intimate relationships; quality of life; happiness; NSHAP; logistic regression

## BACKGROUND

Literature on the experience of chronic disease provides a wealth of information about the potential consequences of sociomedical sequelae for the processes of forming and sustaining intimate relationships as people age throughout the life course (Nowakowski, Graves, & Sumerau, 2016). Intimate partnerships appear to exert a strong mediating influence on quality of life (QoL) for people with chronic conditions, including those involving persistent chronic inflammation (Nowakowski & Sumerau, 2015). Inflammation as measured by biomarkers such as C-reactive protein (CRP) (Nowakowski, 2014) can proxy effectively for having one or more chronic conditions due to its involvement in many core disease pathways.

C-reactive protein, often abbreviated as CRP, is a substance that circulates in the blood of individuals experiencing significant amounts of inflammation. Although it is a biomarker of inflammation rather than a direct measure of inflammation itself, CRP provides compelling evidence that inflammation from an underlying chronic condition is present. As literature proliferates on CRP itself, connections increasingly appear between the presence of this biomarker and the diverse sociomedical experiences associated with chronic illness. Such connections also appear especially important in later life.

The general phenomenon of intimate partnerships both impacting and being impacted by chronic disease is studied continuously and documented extensively. This is also especially true in late-life populations (Shaw, Krause, Liang, &

Bennett, 2007; Umberson & Karas Montez, 2010). Specifically, losing social support from intimate partners can harm QoL across multiple domains (Charmaz, 2000). People with chronic conditions may feel frustrated with relationship partners, especially if they lack a diagnosis to legitimize their illness experience (Bury, 2005; Bury & Gabe, 2013). By contrast, some people find dealing with chronic conditions brings them closer to their intimate partners (Calasanti & King, 2007).

Living with a chronic condition can also reduce people's likelihood of forging new intimate relationships and sustaining existing ones (Herzlich & Pierret, 2020). People with chronic conditions are more likely to experience separation and divorce than others (Singleton, 2012). Research likewise illuminates strong associations between chronic disease and widowhood, indicating that people with any diagnosed condition are more likely to experience spousal bereavement (Schulz, Boerner, & Hebert, 2008). Caregiver morbidity – the negative influence of caregiving on health – may mediate this association (Umberson, Williams, Powers, Liu, & Needham, 2006). A large body of research demonstrates that on average, people who get married experience higher QoL (Ross & Mirowsky, 2002). This effect is greatest when partners feel positively about one another (Hawkins & Booth, 2005). These benefits often materialize via social control (Umberson, Donnelly, & Pollitt, 2018) and support (Ross & Mirowsky, 2013). These constructs can catalyze health-promoting behaviors, which confer additional value (Ross, Hill, & Mirowsky, 2016). Marriage appears to give people access to social resources that can help them cope with adverse life experiences (Stuifbergen, Seraphine, & Roberts, 2000). It also appears to increase feelings of happiness, which independently benefit QoL (Carr, Freedman, Cornman, & Schwarz, 2014). However, people with chronic conditions marry at lower rates (Smith, 2004). This trend exists across different chronic diseases (Kleinman, 2009; Teh et al., 2009) as a potential mediator of relationships between health status and QoL (Slatcher, 2010).

Getting divorced is often independently associated with losses in QoL (Liu & Umberson, 2008) although this does depend at least somewhat on marital quality (Bourassa, Sbarra, & Whisman, 2015). Although these effects are generally strongest for the first two years (Umberson, Williams, Powers, Chen, & Campbell, 2005), divorce can exert a modest negative influence on QoL for longer periods (Cherlin, 2009). Considering that those with chronic illness are more likely to experience divorce, researchers find that this phenomena may be tied to feelings of exhaustion experienced by intimate partners (Bury, 2005), especially those who provide caregiving (Mullan, Pearlin, & Skaff, 2003). People with chronic conditions may also seek divorce because of their own negative feelings concerning partners' resentful behavior (Charmaz, 2000). Like divorce, separation occurs at higher rates among people with chronic conditions (Rendall, Weden, Favreault, & Waldron, 2011; van Wu, Penning, Pollard, & Hart, 2003). Separation can also significantly reduce QoL, though this effect is generally weaker (Umberson et al., 2005). People who separate may both grieve less and experience lower stress levels than people who divorce (Amato, 2000).

Becoming widowed also introduces grief and can thus reduce QoL markedly and for long periods (Silverstein & Parker, 2002) although happiness levels tend to rebound somewhat with time (George, 2006). These negative effects may

operate via the grief of losing a spouse, as well as feelings of isolation that can follow (Exley, 2004). People with chronic conditions are more likely to experience widowhood (Schulz et al., 2008). This may owe in part to cohort inversion in which some people get selected out of a sample through early mortality. Masculine people with chronic conditions are still more likely to die young in many cases (Rieker & Bird, 2005) although this is not universal (Bird, Lang, & Rieker, 2012). By contrast, feminine people with chronic conditions are often more likely to survive for long periods, increasing their likelihood of widowhood (Berg & Upchurch, 2007).

People who have never been married appear to experience slightly lower QoL, though this difference is not always statistically significant (Umberson et al., 2005). People with chronic conditions are more likely to remain unmarried (Smith, 2004). This trend may owe to the stigma of chronic disease, which makes people appear less desirable as intimate partners (Freund, McGuire, & Podhurst, 2003). People without chronic conditions may also find it difficult to relate to others who understand these experiences firsthand (Brown et al., 2004) or simply wish to avoid potential resentment related to their health challenges (Charmaz, 2000). Unmarried people with chronic diseases appear to experience lower QoL (Berg, 2007).

Taken together, these findings suggest that both participation in and dynamics of intimate relationships in late life may impact the overall relationship between chronic disease and happiness. In this report, we analyze potential associations between chronic inflammation, related health experiences, intimate relationships, and general happiness using limited longitudinal data on older adults in the United States. We do so by exploring the alternative hypothesis that intimate relationship factors do indeed further attenuate associations between inflammation and QoL already mediated by direct health sequelae of chronic illness. We test our findings against the null hypothesis that intimate relationship factors do not further attenuate the above associations. Results from our study consistently favor the alternative hypothesis, indicating that changes and experiences in close social relationships likely do help to explain overall associations between chronic inflammation and QoL. Specifically, these factors appear to further mediate existing pathwise causation of QoL outcomes by chronic inflammation via common health sequelae of underlying disease.

## METHODS

*Participants:* We used data from Waves I and II of the National Social Life, Health, and Aging Project (NSHAP) study. This biosocial data set provides information on physical, mental, and social health among US residents aged 57 to 85 at Wave I. The data set includes 3,005 individual cases in total. NSHAP data documentation describes the study sample as “a nationally representative probability sample of community-dwelling individuals” (Waite et al., 2007). African Americans, Latinos, males, and persons with 75 to 85 years of age are oversampled to boost statistical power (Waite et al., 2007). Data are collected via a combination of questionnaires, in-home interviews, and clinical exams.

Only two waves of NSHAP data are currently available on the original study population, making the main data essentially cross-sectional at present. There is also a Wave III that includes data on respondents born between 1948 and 1965 but does not include the exact sample for this particular study due to substantial attrition of original participants and the addition of multiple new respondents. We thus first conducted a covariate analysis using Wave I data (from the original survey implementation) to compute our final models because we did not have three waves of data to represent each timepoint in a formal mediation pathway. This strategy offered the additional advantage of facilitating comparison of our results in this study to prior work by our team (Nowakowski, 2014; Nowakowski et al., 2016). However, we did conduct a variety of sensitivity analyses using the Wave II data (from the second survey implementation with the same sample) to see if results changed using a limited longitudinal approach.

*Measures:* To assess inflammation as a proxy for living with chronic illness, we used serolevels of CRP. Our initial analytic sample contained 1,684 people whose observed CRP serolevels varied between 0 and 5.98 milligrams per liter (Nowakowski, 2014; Nowakowski et al., 2016). In applying these evidence-based inclusion criteria, we conducted a variety of sensitivity analyses to make sure that we were not introducing bias into our sample.

We focused on the NSHAP's general happiness measure as an outcome because our prior study (see Nowakowski et al., 2016) revealed significant associations between this outcome and CRP levels that appeared to be elastic to common medical consequences of inflammation. This variable (see Waite et al., 2007 data documentation) is an experiential measure of subjective well-being that assesses how frequently respondents have experienced happiness in the 12 months prior to participation. This question ("If you were to consider your life in general these days, how happy or unhappy would you say you are?") that asked participants to rate their overall happiness on a Likert scale of 1 to 5 with higher numbers indicating greater happiness. We also provide a summary of our other original outcome variable assessing happiness with relationships ("Taking all things together, how would you describe your [relationship] with [your partner] on a scale from 1 to 7 with 1 being very unhappy and 7 being very happy?") in Table 1 for context.

We engaged our measures of medical sequelae of chronic inflammation – specifically, pain and disability – from our previous study (Nowakowski et al., 2016). We operationalized physical disability by aggregating information about activities of daily living and instrumental activities of daily living with which study participants experienced difficulty, adding them into an index. We measured persistent pain using the NSHAP's variable capturing whether or not people experience pain while walking, which had real values for most study participants and offered a reasonable proxy for chronic pain across a variety of common daily activities.

We measured relationship characteristics using five different variables from NSHAP: marital status, open communication with a partner, open communication with friends, feeling able to rely on friends, and feeling able to rely on family members. We included friends and family measures for the purposes of comparison to potential mediating effects of intimate relationships. Marital status was a binary "yes/no" question indicating whether or not participants were married.

**Table 1.** Characteristics of Sample Population from NSHAP Wave I ( $n = 1,684$ ).

Construct	Variable	Units	Mean	SD	Range
Quality of life	Generally feeling happy	Points	3.61	0.86	1 – 5
	Happiness with relationships	Points	5.91	1.61	1 – 7
Chronic inflammation	C-reactive protein serolevel	mg/L	1.72	1.46	0 – 5.98
Medical sequelae	Functional disability	Points	1.10	1.75	0 – 9
	Pain while walking	Yes/No	0.38	0.49	0 – 1
Social relationship characteristics	Diagnosed chronic condition	Yes/No	0.88	0.32	0 – 1
	Marital status	Yes/No	0.60	0.49	0 – 1
	Openness with partner	Points	2.72	0.52	1 – 3
	Openness with friends	Points	2.00	0.72	1 – 3
	Relying on friends	Points	2.30	0.70	1 – 3
Chronological age	Relying on family	Points	2.57	0.66	1 – 3
	Years of age	Years	69.6	7.90	57 – 85
Sex identity	Male	Yes/No	0.50	0.50	0 – 1
	Female		0.50	0.50	
Racial background	White	Yes/No	0.75	0.43	0 – 1
	Minority		0.25	0.43	
Educational attainment	Years of education	Years	12.6	4.08	0 – 32

The Wave I & II surveys (see [Waite et al., 2007](#) data documentation) used a cluster of parallel questions to assess different feelings of satisfaction with close relationships. We created predictor variables from questions about participants feeling open with and relying on important people in their lives. Specifically, we used four different items that contributed unique value as covariates from the set of questions using “How often can you open up to [them] if you need to talk about your worries?” and “How often can you rely on [them] for help if you have a problem?” phrasing. Likert scales for these questions all ranged from 1 to 3, with higher numbers indicating greater frequency of each experience.

*Analysis:* We used ordinal logistic regression to explore possible associations between chronic inflammation, relationship characteristics, and happiness. We tested for possible mediating effects from hypothesized intervening variables first individually, and subsequently as blocks for any measures that yielded significant individual results. For all ordinal logistic models, we performed Brant tests to ensure that parallel regression assumptions were fully met. We then computed a final set of models (with corresponding Brant tests) outlining associations between chronic inflammation, its medical consequences, social relationships, and overall happiness.

We provided some limited insight about potential effect mediation by using Sobel-Goodman tests on a series of companion models computed using OLS regression. Our OLS models yielded substantively identical results to our original ordinal logistic ones, allowed us to examine the plausibility of a mediation effect from common medical sequelae of chronic inflammation, and helped us assess the apparent proportion of the predictor’s total effects mediated by the intervening variables. However, we note that these should be construed purely as a form of sensitivity analysis in assessment of covariance between our key constructs.