Building a Writing Partnership
A Narrative Focused on the Grief of Families after the Death of a Child

Joan Hagan Arnold, PhD, RN and Penelope Buschman Gemma, MS, RN PMHCNS-BC, FAAN

Introduction

This brief look at a writing partnership spanning more than 50 years highlights its development and some of the publications which resulted. It is simply a story of an evolving professional partnership and friendship. We hope it is instructive and inspires others at the start of their careers to look for ways to collaborate and sustain those relationships. This narrative is focused on selected publications to illustrate the partnership but does not include the entirety of our work. It is a legacy based on our shared passion, and we are delighted to be included in the archives of the Center of Nursing to leave this written record of work on child death and family bereavement.

Our Story

Joan and Penny reconnected at a professional workshop called 'On Caring for the Dying Child' held at the Riverside Church, New York City in 1975. Joan was an attendee and Penny was the presenter, along with Dr. John Schowalter, Head of The Child Study Center at Yale University. The focus of the conference was death in the family. Penny already had a strong clinical presence and was well respected as clinical leader in psychiatric-mental health nursing, focusing on child psychiatry.

This reunion confirmed that Joan and Penny shared a keen interest in caring for families experiencing loss, death and grief. The bond between them was forged through a common passion for reaching out to grieving families and also resulted in a lifelong friendship.

Joan and Penny's collaborative relationship actually began earlier than the dying child workshop. They had both graduated from Columbia University School of Nursing with Baccalaureate degrees in Nursing. After graduation and a Master's Degree in Child and Adolescent Psychiatric Nursing from Boston University, Penny demonstrated her clinical expertise in child psychiatry as a Clinical Nurse Specialist (CNS) at Babies Hospital, Columbia-Presbyterian Medical Center beginning in 1968. Joan was taking her clinical rotation in pediatrics at Columbia and admired Penny's stature as a CNS, a relatively new advanced nursing role which involved consulting, treating, educating, and managing an independent caseload. Penny was the sole CNS at Babies Hospital and the entire Columbia-Presbyterian Medical Center complex at the time.

In 1973, Joan was offered a position as a public health nurse/research assistant for a new project of the NYC Department of Health investigating the causes and circumstances of postneonatal mortality. Joan made home visits to families experiencing the death of an infant during the postneonatal period. The clinical findings were described in a *Nursing Forum* publication entitled "Infant Death: Nursing Interaction and Intervention with Grieving Families." This project became the forerunner for a grant to the City to establish the NYC Information and Counseling Program for Sudden Infant Death. Joan was invited to become the first Program Coordinator and establish the office in 1976, at the Office of the Chief Medical Examiner. It was the only service program devoted to families to be established at the NYC Medical Examiner's Office.

As the SIDS and Infant Mortality Program Coordinator, Joan outreached to emergency rooms throughout the City trying to establish a network of staff responsive to the needs of families affected by the sudden and unexpected death of their infants. Joan contacted Penny about setting up a liaison relationship between the Babies Hospital Emergency Department and the SIDS Program. Because of this personal relationship a standard for care was able to be established.

After publishing two articles on infant death in the 1970s, Joan was offered a book contract. The publisher asked if she would like to invite a co-author. Joan reached out immediately to Penny and that officially began their co-writing career.

Never having written a book, Penny and Joan asked the publisher how to begin! Now laughable but quite serious at the time, guidance was needed about undertaking a book once the contract was signed. Darlene Como, the publisher, suggested starting with an outline. This seems obvious now but at the time felt like a revelation. Both serious minded, Penny and Joan set to work on an outline. After multiple long meetings and 18 months, Penny and Joan produced a perfected outline. The publisher wondered if we had disappeared!

Looking back, it would have been advisable to record those meeting conversations because the book would have been written in that 18 month period. Conversations were rich and fulfilling and helped Penny and Joan delineate thinking about grief following the death of a child as a lifelong process of living with loss and living without the beloved child. Ideas were discussed in depth and synthesized and titrated and finally reduced to two perfect pages of an outline. Penny and Joan had cemented their partnership and refined their thinking and experienced a union of ideas.

But what was the next step in writing the book, now under contract? Penny and Joan called Darlene Como again and asked what to do next now that the outline was completed. Fortunately, Darlene was gentle and supportive - she indicated once an outline is complete, the next step is to select a chapter and begin writing. With an outline, any chapter could be selected. This was a further revelation to Penny and Joan. At that moment, they realized all those long discussions should have been taped. We had synthesized and reduced our ideas but now we needed to enlarge and expand them. Writing was ahead and writing was based on all the thinking, deliberating and long conversations. Writing is difficult! The end result was A Child Dies: A Portrait of Family Grief, published in 1983 by Aspen Systems Corporation. Truly a labor of love. There were many conversations that informed this book, including long late night telephone calls, and lots of yellow pads and pencils. Seems like ancient history now to write a book without the technology now available. When we received the published book in our hands it was an astonishing feeling. That small book had been years in the making. It would be impossible to communicate how much of our lives it represented and how many conversations it revealed. Much to our surprise, it was awarded Honorable Mention as a Creative and Innovative New Professional and Scholarly Book, Association of American Publishers, Professional and Scholarly Publishing Division.

Continuing to write together, Joan and Penny co-authored a chapter entitled “Grief on the Death of an Infant” in a 1991 book, edited by C. A. Corr, H. Fuller, C.A. Barnickol, & D.M. Corr, entitled Sudden Infant Death Syndrome: Who Can Help and How*,* Springer Publishing Company. It was awarded Book of the Year Award, Pediatric Nursing, by the American Journal of Nursing.

A second and revised edition of A Child Dies: A Portrait of Family Grief was published by The Charles Press, Inc. and received the Book of the Year, 1994, American Journal of Nursing Award.

In 1995, Joan completed her doctoral studies at New York University, Research and Theory Development in Nursing Science, Division of Nursing with her dissertation entitled “A Reconceptualization of the Concept of Grief for Nursing: A Philosophical Analysis.” The intent of this study was to analyze critically the foundational knowledge about grief found in the literature of nursing and to posit an alternative view of grief as a healing process not bound by time, symptomatology, or the confines of the clinical setting. A definition of grief was postulated: “Grief is a vital life function of human experience that facilitates healing and the potential for personal growth and development through the integration of loss into the self.” This sentence summed up thirteen years lived experience as a doctoral student and nurse scientist. This ‘grain of sand’ contributed to understanding the human condition but a contribution nonetheless in reconceptualizing grief as a vital life function.

Our professional lives brought us together again and again for presentations at regional and national professional conferences. We also collaborated on other works as well as published separately in the years that followed. In 2002, by invitation from the March of Dimes, we coauthored a continuing education module/monograph for registered nurses and certified nurse midwives called Loss and Grieving in Pregnancy and the First Year of Life: A Caring Resource for Nurses.

Although our careers continued on their separate but related paths, our writing partnership was strengthened. After books, articles, chapters, monographs, video presentations, agency standards - the question became: What is next?

Recognizing that our work was a reconceptualization of grief on the death of a child and the prevailing literature represented a different interpretation of parental grief, we moved in the direction of research. Our conceptualization was based on the direct accounts of families and therefore on clinical observations and clinical knowing. The relationship between theory and practice intrigued us. When theory does not really explain practice, the onus on clinicians is to extend theory from practice, in light of practice.

For us, the veracity of clinical knowledge resulted in a research study utilizing a dual approach combining quantitative and qualitative methodologies. As predominately clinicians and academics, we collaborated with an expert researcher, Dr. Linda Cushman, from the Columbia University Mailman School of Public Health. Together we formulated a way to identify a wide population through our alumni association to learn about the experience of loss over decades. The Columbia University-Presbyterian Hospital School of Nursing Alumni Association, Inc. provided access to thousands of alumni. We mailed a tear-off card which asked if fellow alumni would consider participating in the study.

As an aside, we had thousands of cards in mail bags and piled the bags into the back of a station wagon and went to the Ansonia Post Office in Manhattan where we had gained permission to mail these bags of cards to over 5,000 alumni.

With Dr. Cushman, we created a research tool to explore parental grief on the death of a child of any age. The study design resulted in a sampling frame consisting of 74 respondents reporting that they had experienced the death of a living child. With the exception of standard demographic measures, the quantitative and qualitative items in the instrument were designed specifically for this project. The content validity of the instrument was assessed by a panel of experts on grief. The research tool is available through the Center for Nursing.

The results extended the current understanding of the complex emotional response of grief. This study offered empirical support for the notion of grief as ongoing in the life of the parent whose child has died as well as significant implications for further clinical research exploring commonalities in the experience of grieving families regardless of the cause of and time since the death of their child. Most importantly for us, findings served to inform the development and provision of services for bereaved families. This study written with Dr. Cushman was published in 2005 in *Archives of Psychiatric Nursing,* entitled “Exploring Parental Grief: Combining Quantitative and Qualitative Measures.”

A few years later, in 2008, another publication called “The Continuing Process of Parental Grief” was co-authored by Joan and Penny for *Death Studies,* underscoring the lifelong nature of grief as a connection between parent and child. Theme analysis derived from qualitative findings resulted in a reformulation of parental grief.

Joan with a co-author Sherri Sheinfeld Gorin completed a book entitled Health Promotion in Practice in 2006 which soon became the preferred text for students and health professionals attempting to bridge the gap between theory and evidence based practice. Included in this work is a chapter, “Enhancing Development” authored by Penny and Joan which explores development as an ongoing and evolving process in individuals, families, groups and communities. Resilience, spirituality, and grieving are considered to be significant forces in all human systems as they develop. Loss and growth are intrinsically linked throughout life and at the time of death. Penny and Joan detailed the significance of grieving as a force in promoting health.

In 2012, an opportunity was given to us to write about Palliative Care, a particular passion for Penny. We collaborated with Dr. Marlene McHugh, an expert in palliative care and faculty colleague of Penny’s from Columbia University School of Nursing. This collaboration with Dr. McHugh resulted in our 2012 article for *Nursing Economic$: The Journal for Health Care Leaders* entitled “Nursing Leading the Response to the Crisis of Palliative Care for Vulnerable Populations.” In this article we asserted that ‘all nursing care is palliative care.’ The focus of care is the person, not the diagnosis or the setting. This viewpoint can transform health care with nurses taking the lead.

Joan’s work in Sudden Infant Death Syndrome and infant mortality traversed her professional career, inspired by her clinical position as a public health nurse conducting home visits to families who had experienced the death of their infant during the postneonatal period throughout the City of New York. This project took Joan into the homes of hundreds of families stricken by the sudden and unexpected death of their infants. Many of the babies had died at home and some in their parents’ arms. This outreach resulted in the realization that when death occurred cases were closed. This project however meant that death was the reason to begin outreach.

The project enabled Joan to not only become an advocate for grieving families, representing their grief and needs upon the death of their infant, but also to establish that care must be extended to bereft families after their loss - that outreach was mandatory.

Subsequently, Joan was invited to serve as the first coordinator of the New York City Information and Counseling Program for Sudden Infant Death, opened in the Office of the Chief Medical Examiner (OCME). This was the first human service-focused offering within the OCME. At the time, families were required to come to the OCME to identify their baby's body as part of the death investigation/autopsy protocol. Counseling services were offered to parents/families onsite and subsequently home visits to families were coordinated through the NYC Public Health Nursing Office. Educational outreach to first responders, police, fire fighters, emergency room staff, EMS was delivered by the Information and Counseling Program. The entire City was the target of outreach and education to teach about infant death and family grief.

Joan's career as an academic was always in tandem with her clinical focus on child death and family grief. Teaching was a lifelong and rich commitment for Joan, having held faculty positions with schools of nursing at Adelphi University, The College of New Rochelle, and Hunter College. She received tenure at each institution and retired with the rank of full Professor. Recognizing the necessity of demonstrated productivity in the three cardinal roles of an academic - teaching, service, and scholarship - Joan was devoted to the priorities of each institution. Outstanding teaching, dedicated service to the academic institution, the profession, the wider community, and scholarship to support clinical practice and the development of new knowledge were the hallmarks of Joan's academic life. Joan's teaching focus and expertise was largely the theory and practice of public health nursing. At Adelphi University, Joan was predominately an undergraduate educator of senior nursing students and also taught a popular college-wide elective, "Grieving and Dying in America." This elective course brought students together from every major and program. The students used this learning experience to uncover their own losses and to understand the impact of loss and grief on their lives and relationships within and outside their families. The arts were explored to further elucidate grief and loss. Students read aloud the play The Shadow Box by

Michael Cristofer and wrote letters to Viktor Frankl after reading his riveting book Man's Search for Meaning. At The College of New Rochelle, Joan developed expertise as a registered nurse educator for professionals returning to school to complete the requirements for the Baccalaureate of Science degree in nursing. This culminating theory and clinical course was based on the integration and advancement of knowledge and empowered the students to continue their education through graduate study. While at The College of New Rochelle, Joan also led the College Senate representing all faculty and staff of the College. At Hunter College, Joan was asked to coordinate special graduate programs in public health nursing and nursing administration and a post-graduate program in nursing education. Joan's life as an academic spanned almost forty years and was made meaningful through her relationship with thousands of students at all levels of study. Academic advisement was part of the faculty role that Joan took seriously. She welcomed this opportunity to get to know students individually and support them to uncover their academic and clinical paths. Sorting out the puzzles of students' lives as they interfaced with academic and clinical settings and degree requirements was complex and required skillful advocacy. Joan also coordinated clinical placements for all of her students - negotiating with hundreds of health care settings for meaningful clinical learning experiences for her students.

Joan remained a consultant to the SIDS/Infant Death Office for decades and deeply involved with the national network of other nurses, physicians, social workers, and mental health professionals closely involved with SIDS and infant mortality. A new professional organization was formed, the Association of SIDS and Infant Mortality Programs, and standards of care were developed. Research projects, program evaluation guidelines, and presentations proliferated and findings disseminated through this professional organization. Some of these publications are available through the Center for Nursing.

Joan's professional career was largely defined by her care for grieving families experiencing the death of their infant and educating health care professionals about parental grief. As a long time consultant to the NYC SIDS and infant mortality program she was often called upon to make home visits to families shortly after the death. From her earliest interaction with grieving families, Joan believed in the necessity of outreach - to bring care into the home; to knock on doors and enter the world of the family.

Penny's career began in the late 1960s as a Clinical Nurse Specialist at Babies Hospital (now the Morgan Stanley Children's Hospital). As a trailblazer in advanced clinical practice in psychiatric-mental health nursing she regularly consulted with the cross-disciplinary professional staff on complicated pediatric cases involving mental health issues. She also saw hospitalized children for therapy and carried a caseload of children and families from the community who otherwise would not have received child psychiatric care. Her approach was unique at the time - the child viewed in the context of family and the family the unit of care. Once established, Penny was an inseparable resource for the entirety of Babies Hospital. She was called upon to serve as an advocate, consultant, and educator while setting standards for care. Supporting children not expected to live and helping their families process the inevitability of impending death and tragedy in the family became a special concern. Staff also needed help to confront their feelings of helplessness and to become truly available to families and accepting of them. Caring for the dying child led to a focus on palliative care before it became a specialty.

In 1976, Penny was invited by the Columbia University School of Nursing to develop a track within the psychiatric nursing Master's program to focus on the mental health needs and care of children and adolescents. After many years of teaching as an adjunct in the program, Penny joined the full-time faculty in 1994 and continued as an academic. During that same year, Penny was elected a Fellow in the American Academy of Nursing in recognition of her clinical practice with chronically and terminally ill children, contributions to the reconceptualization of parental grief, and dedication to the prevention and treatment of child maltreatment in New York City.

Penny served as Director of the Psychiatric Mental Health Nurse Practitioner program from 1996-2016. She developed and taught courses, identified a wide range of clinical sites, and provided clinical supervision in individual and group practice with children and adults. She committed to maintaining a focus on individual, group, and family therapy while expanding the bio-physical and psychopharmacological foundation of the program. Penny served as Coordinator of Palliative and End of Life Care Subspecialties at Columbia University School of Nursing. With faculty colleagues, she developed programs in lifespan and pediatric palliative care and in 2013, the first DNP/post DNP Nursing Fellowship in Palliative Care based in a school of nursing. This fellowship continues to the present time with its graduates in clinical and educational positions of leadership. Penny oversaw the integration of palliative care knowledge and clinical skill into all levels of education at the Columbia University School of Nursing, establishing the Palliative Care Initiative with experienced and expert faculty.

In addition, Penny served as Bereavement Consultant for the Nursing Department of St. Luke's Roosevelt Hospital Center from 2002-2014, leading monthly groups for parents whose infants died during pregnancy or at birth. At the same time, Penny and a faculty colleague developed a psychiatric assessment and treatment site, St. Paul's Center on West 34th Street off 10th Avenue, with outreach to people who were homeless and mentally ill. This practice site was the first independent Nurse Practitioner (NP) run clinical center in the United States providing psychiatric assessment and evidence based treatment to the vulnerable mentally ill in danger of becoming homeless, incarcerated, and hospitalized. St. Paul's Center was supported by philanthropy during its ten years in existence as state licensure for NP practices existed then only for primary and not specialty care. During those years of operation, relationships were established with healthcare colleagues, members of the local police precinct, state and local legislators, and, of course, funders. Patient outcomes were excellent. The center served as a fine clinical setting for NP graduate students focused on the needs of the most vulnerable individuals with mental illness. Through this experience there was a recognition that palliative care was not offered to this population. This work was first published in 2016 in a chapter entitled "Communication at the Time of Death" from <u>Advanced Practice Palliative Nursing</u> and revised in a second edition.

In 2011, following the September terrorist attack on the City of New York, Penny with a psychiatric colleague, Dr. Maryann Feldstein, founded and codirected The Center for Grief which provided consultation and education to schools, community agencies, and health care professionals coping with traumatic loss and grief resulting from the attack and its aftermath. The work of this center was collaborative and based on local emergency need, the magnitude of which had not been known prior to the 9/11 attack.

Penny’s professional career was largely defined by palliative and end of life care and health professionals’ education as well as supportive care for parents following pregnancy loss and infant death. Penny’s approach was collaborative across the many disciplines of providers. She devoted much of her effort to consulting with health care providers around difficult case situations and building teams for bereavement support. Penny believed in the importance of creating a system of care so that bereft families would be assured of needed support. Her advanced psychiatric-mental health preparation permits ongoing consultation to hospital staff and psychiatric providers for complicated grief in children and families and guidance on how to work with families.

Our final collaboration was to turn our attention to sibling grief. Always impressed with the impact of child death on the family, we were intensely aware of the lifelong nature of grief for siblings of the dead child. In our own lives, we each lost an adult sibling and felt first hand the impact for us and our families. Having received a small grant, we were able to retrospectively study sibling grief across the lifespan. Tool development ensued with the consultation of Dr. Mark Spellman. This study was presented at the Eastern Nursing Research Society and finally at our own Columbia University School of Nursing Alumni Reunion. An illuminating PowerPoint presentation is viewable through the Center for Nursing.

So, if life is an ‘expanding spiral’ (Martha E. Rogers) - our partnership and friendship illustrate the incredible power of evolving. We began our nursing education and friendship through Columbia University School of Nursing and our final joint presentation was at our alumni reunion. The spiral of this circular evolving motion is infinite. It is our hope that our small contribution to the understanding of grief as transformative and an ever enfolding and unfolding experience of learning to live with loss and live without those we love will persist and nurse clinicians and scientists will expand understanding resulting in informed care for families.

Writing collaboratively has provided greater insight and meaning into the study of child death and family grief. Our career paths provided crossover and yet were uniquely different. But learning from the families was key to both of us and writing united us. We viewed our clients as our teachers, ever informing us about the unknowable nature of grief. We recognized that they could only communicate the fringes of their experiences because the very core of grief is unspoken - there are no words. Working together we were able to validate our insights and shape a conceptualization of grief that reflected the pain and suffering shared with us, respecting the depth which could not be communicated. There is no language for grief. We learned that acceptance and validation were the most important forms of support to offer individuals and families. We learned about our role in fostering communication within the family. We learned that the spotlight must always be on the family, not on ourselves. Working with families experiencing the death of a child is a humbling experience - a privilege. Who willingly heads into pain and suffering - yet in order to support families one must do just that. Writing was a catharsis and helped shape ideas. When one writes, knowledge is discovered. The process of writing is not only a creative experience but also a discovery process. When one writes, it is a journey through an open window - but you are never sure what you will see. And you see more and more as you write. There is no expected outcome because the path is uncharted and the results are revealing. As writing partners, Joan and Penny sought to uncover personal experiences of parental grief and to represent the families who had shared their stories. It was a gift and a responsibility to be included in their stories and to witness their human suffering. The families taught us how to be supportive. Translating that knowledge into care standards was an obligation. Our written work elucidated what families had taught us - and memorialized their children.

We urge you to write and to write with a partner whenever possible. The joys of collaboration are many. You can laugh together. When one is feeling drained, the other can provide inspirations. When one needs to give up for a period of time, the other understands and supports. Each provides a sense of strength for the other. There is a balance in the relationship - never even but always available. The most important reason to write with a partner is that knowledge and understanding evolve through dialogue as the partnership deepens. Together, you hone the written word so that others may gain a deeper understanding of your meaning.

For their support and encouragement, special thanks are given to:

Deborah Elliott, MBA, BSN, RN, Executive Director, Center for Nursing, Foundation of New York State Nurses, Inc. and Nurses House, Inc.

Cathryne Welch, EdD, RN, Dedicated Volunteer, Center for Nursing

Susan Birkhead, DNS, MPH, RN, CNE, Dedicated Volunteer, Center for Nursing

Summer 2021

Joan Hagan Arnold, PhD, RN & Penelope Buschman Gemma, MS, RN, PMHCNS-BC, FAAN

Our Selected Publications and Educational Materials on Loss, Grief and Child Death

Doctoral Dissertation:

Arnold, J. (1995). *A reconceptualization of the concept of grief for nursing: A philosophical analysis*. (9609382) [Doctoral dissertation, New York University]. Proquest Dissertations Publishing.

Books:

Arnold, J.H., & Buschman Gemma, P. (1994). *A child dies: A portrait of family grief* (2nd ed.). The Charles Press. Publishers, Inc.
Book of the Year, 1994, American Journal of Nursing.

Arnold, J.H., & Buschman Gemma, P. (1983). *A child dies: A portrait of family grief*. Aspen Publishers, Inc.
Honorable Mention as a Creative and Innovative New Professional and Scholarly Book, Association of American Publishers, Professional and Scholarly Publishing Division.

Chapters:

McHugh, M., & Buschman, P.R. (2016). Communication at the time of death. In Dahlin, C., Coyne, P., & Ferrell, B. (Eds.). *Textbook of advanced practice palliative nursing*. Oxford University Press.

Buschman Gemma, P., Farley, J.M., & Rushton, C.H. (2012). Chronic and palliative care of pediatric populations. In E. Yearwood, G. Pearson, & J. Newland (Eds.). *Child and adolescent behavioral health: A resource for advanced psychiatric and primary care nurse practitioners*. Wiley-Blackwell.

Buschman Gemma, P., & Arnold, J. (2006). Enhancing development, In Gorin, S.S. & Arnold, J. (Eds.). *Health promotion in practice*. Jossey-Bass.

Arnold, J., McClain, M., & Shaefer, S.J.M. (1997). Reaching out to the family of a SIDS baby. In J.R. Woods, Jr. & J.L. Esposito Woods (Eds.). *Loss during pregnancy or in the newborn period: Principles of care with clinical cases and analyses* (pp. 159-187). Jannetti Publications, Inc.

Buschman, P.R. (1996). Helping adolescents deal with death on an inpatient unit. In *Group therapy with children and adolescents*. American Psychiatric Press.

Arnold, J., & Buschman Gemma, P. (1991). Grief on the death of an infant. In C.A. Corr, H. Fuller, C.A. Barnickol & D.M. Corr (Eds.). *Sudden infant death syndrome: Who can help and how* (pp. 45-56). Springer Publishing Company.
Book of the Year Award, Pediatric Nursing, American Journal of Nursing.

Arnold, J.H., & Buschman Gemma, P. (1987). The loss of a child and parental grief. In A. Kutscher (Ed.). Advances in Thanatology, 6(1); and In P. Buschman, J. Schowalter, & A.H. Kutscher (Eds.). *The pediatric nurse and the life-threatened child*. NY: The Foundation of Thanatology.

Gilder, R., & Buschman, P. (1980). Approaches to the dying child. In J.R. Bemporad (Ed.). *Child development in normality and psychopathology* (pp. 509-531). Brunner and Mazel, Inc.

Arnold, J.H. (1981). Infant death. In J.A. Fox (Ed.). *Primary health care of the young*.

McGraw-Hill Book Company.

Buschman, P.R. (1973). Care of the dying adolescent. In P.R. Patterson, C. Denning & A.H. Kutscher (Eds.). *Psychosocial aspects of cystic fibrosis*. Columbia University Press.

Sheets, S., Buschman, P.R., & Wharton, A. (1973). Use of psychopharmacologic agents in the care of terminally ill child. A nursing position paper. In I.K. Goldberg, S. Malitz, A.H. Kutscher (Eds.). *Psychopharmacologic agents for the terminally ill and bereaved*. Columbia University Press.

Articles:

McHugh, M.E., Arnold, J., & Buschman, P.R. (2012). Nurses leading the response to the crisis of palliative care for vulnerable populations. *Nursing Economic$: The Journal for Health Care Leaders*, *30*(3), 140-147.

Arnold, J., & Buschman Gemma, P. (2008). The continuing process of parental grief. *Death Studies*, *32(7)*, 658-673.

Arnold, J., Buschman Gemma, P., & Cushman, L. (2005). Exploring parental grief: Combining quantitative and qualitative measures. *Archives of Psychiatric Nursing*, *19*(6), 245-255.

Arnold, J., & Fernbach, K. (2000). Sudden infant death syndrome: Unpredictable and unpreventable, but risk can be reduced. *Advances for Nurse Practitioners*, *8*(2), 73-74.

Arnold, J. (1996). Rethinking grief: Nursing implications for health promotion. *Home HealthCare Nurse*, *14*(10), 777-783.

Gaines, J., Arnold, J., Jessop, D.J., Burke, D., Donahue, C., & Rosenbluth, L. (1996). Home visits to bereaved families subsequent to sudden infant death: A demonstration project. *Journal of Sudden Infant Death Syndrome and Infant Mortality*, *1*(1), 33-44.

Feldstein, M.A., & Buschman Gemma, P. (1995). Oncology nurses and chronic compounded grief. *Cancer Nursing*, *18*(3), 228-236.

Arnold, J. (1990). Grieving. *Imprint: Journal of the National Student Nurses Association*, 37(1) 43-48.

Arnold, J. (1980-1981). Child death and family bereavement: An exploration through the arts. In J.R. Hott, P. Woog, R. Hyman, P. Brown, & L. Knuth (Eds.). *PRN: The Adelphi Report - Project for Research in Nursing, Adelphi University School of Nursing*, 33-43.

Arnold, J.H., & Ramsey, D.E. (1979). Infant death: An approach to nursing interventions for poverty-level Black and Hispanic families. *Health Values: Achieving High Level Wellness*, *3*(3), 171-174.

Arnold, J.H. (1979). When their baby dies. *Archives of the Foundation of Thanatology*, *7*(3), 29.

Gilder, R., & Buschman, P.R. (1978). Group therapy with parents of children with leukemia. *The American Journal of Psychotherapy*, *32*(2), 276.

Buschman, P.R. (1976). Group support for parents. *The American Journal of Nursing*, *76*(7), 1121.

Hagan, J.M. (1974). Infant death: Nursing interaction and intervention with grieving families. *Nursing Forum*, *13*(4), 371-385.

Research Tool:

Arnold, J., Buschman Gemma, P., & Cushman, L.F. (2000). *Grief Over a Lifetime: A Study of the Lifelong Effects of Child Death on Parents*.

Modules/Monographs:

Okun, A., Buschman, Pl, McNamara, L., Battista, V. (2015). Quality of life for children living with severe neurological impairment and their families: How can we understand it better and whose lives are we talking about? Abstract in *Journal of Pain and Symptom Management*, *49*(2), 371.

McClain, M., Arnold, J., Longchamp, E., & Shaefer, J. (2004). *Bereavement counseling for sudden infant death syndrome (SIDS) and infant mortality: Core competencies for the health care professional*. Association of SIDS and Infant Mortality Programs.

Longchamp, E., Hall, D., & Arnold, J. (2004). *A case study of faith based outreach in New York City: Lessons learned from a risk reduction initiative*. US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Contract #02-MCHB-65A.

Wulff, L.M., Arnold, J., & Fernbach, K. (2003). *Pilot of ASIP SIDS and other infant death program evaluation plan: Final report*. US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Contract #01-MCHB-73A.

Buschman Gemma, P., & Arnold, J. (2002). *Loss and grieving in pregnancy and the first year of life: A caring resource for nurses. Continuing education for registered nurses and certified nurse-midwives*. March of Dimes Nursing Module. March of Dimes.

Buschman, P.R., et.al. (1997). *End of life care in children and their families. Ethical Dimensions, A Continuing Education Monograph for Nurses*. Glaxo Wellcome, Inc.

Hagan, J.M. (1976). Nursing interaction and intervention with grieving families. *After Our Baby Died: Instructors's Guide for a Film on the Sudden Infant Death Syndrome*. US Department of Health, Education and Welfare, Public Health Service, HSA, Department of HEW Pub No. (HSA) 1976-5141, 7-13.

Agency Standards:

Association of SIDS and Infant Mortality Programs. (2001). *SIDS and other infant death program evaluation plan*. J. Arnold, co-authored with ASIP Research Committee members, for national and international distribution.

Association of SIDS and Infant Mortality Programs. (2001). *Database templates: Case Management, reporting inventory of case and program activity, outreach education, epidemiology.* J. Arnold, co-authored with ASIP Research Committee members, for national and international distribution.

The Sudden Infant Death Syndrome Alliance, Family Services Advisory Council. (1991). *Standards of service to families*. J. Arnold, & K.L. Fernbach, for national distribution.

Selected Poster/PowerPoint Presentations:

Arnold, J., & Buschman, P. (2014). *Sibling Grief: A retrospective exploration*. Notebook with PowerPoint presentation slides prepared for alumni reunion (Columbia University-Presbyterian Hospital School of Nursing Alumni Association, Inc., and Columbia University School fo Nursing Alumni Association.

Arnold, J. & Buschman Gemma, P. (2013). *A retrospective analysis of sibling grief across the lifespan*. Eastern Nursing Research Society, Nursing Research: A Bridge to the Future of Healthcare. Boston, MA.

Arnold, J., Ostfeld, B.M., Esposito, L., McClain, M., Coutant, S., Hall, D., Longchamp, E., Corwin, M., & Hegyi, T. (2012). *Measuring parental perceptions of the evolution of grief* *after a sudden infant death: A pilot study.* Eastern Nursing Research Society, From Cell to Society: The Intersection of Nursing Research, Practice and Policy. New Haven, CT.

Arnold, J., & Buschman Gemma, P. (2011). *Exploring parental grief: Practice and policy implications*. Eastern Nursing Research Society, Informing Health Policy through Nursing Science. Philadelphia: PA.

Arnold, J., Ostfeld, B., Corwin, M., Coutant, S., Esposito, L. Hall, D., Longchamp, E., McClain, M., Cushman, L., & Hegyi, T. (2009). *Measuring the evolution of parental grief after sudden infant death*. Pediatric Academic Societies, Society for Pediatric Research.

Arnold, J., Buschman Gemma, P., & Cushman, L. (2007). Parental grief research: Combining quantitative and qualitative measures. Breaking Barriers: Changing Policy and Practice with Evidence, American Academy of Nursing, 34th Annual Meeting and Conference. Washington DC.

Arnold, J., Buschman Gemma, P. (2002). *Loss and grieving in pregnancy and the first year of life: A caring resource for nurses*. 25th Annual Perinatal Nurses Conference, Greater New York March of Dimes.

Arnold, J., Chandick, M., DeCoster, M., Esposito, Longchamp, E., & Wright, K. (2002). *The nursing role in safe infant care practices*. The Continuing Challenge of Infant Mortality: Spotlight on Research and New Practice Models. ASIP Fifteenth Annual Conference, Association of SIDS and Infant Mortality Programs. Cambridge, MA.

Arnold, J., Buschman Gemma, P., & Cushman, L.F. (2002). *Grief over a lifetime: A study of the lifelong effects of child death on parents*. The Continuing Challenge of Infant Mortality: Spotlight on Research and New Practice Models. ASIP Fifteenth Annual Conference, Association of SIDS and Infant Mortality Programs. Cambridge, MA.

Arnold, J. Longchamp, E., & Hall, D. (2002). *Faith-based SIDS risk reduction outreach and education in New York City: Reaching African American grandparents and caretakers.* The Continuing Challenge of Infant Mortality: Spotlight on Research and New Practice Models. ASIP Fifteenth Annual Conference, Association of SIDS and Infant Mortality Programs. Cambridge, MA.

Arnold, J., & Buschman Gemma, P. (2001). *A child dies: A portrait of family grief*. Creative and Expressive Arts in Nursing: The HeART of Nursing, 36th Biennial Sigma Theta Tau InternationalInternationalInternationalInternationalInternational Honor Society of Nursing Convention. Indianapolis, IN.

Arnold, J., & Buschman Gemma, P. (2000). *Grief over a lifetime: A study of the lifelong effects of child death on parents*. 23rd Annual Greater New York March of Dimes Perinatal Nurses Conference, Aim Higher Towards…Opportunity, Caring, Knowledge, Research.

Pamphlets/Newsletters/Teaching Tools/Book Reviews:

Arnold, J. & Buschman Gemma, P. (2014, Fall). Sibling grief research report. T*he Alumni Newsletter, Columbia University-Presbyterian Hospital School of Nursing Alumni Association, Inc.*, 18(2).

Buschman Gemma, P., et.al. (n.d.). Informational pamphlets: *What can you do? Helping loved ones deal with the death of their baby*; *From hurt to healing: Dealing with the death of your baby*; *When you want to try again: Thinking about pregnancy*. March of Dimes.

National SIDS Resource Center (n.d.). *The death of a child, the grief of parents: A lifetime journey*.

Arnold, J., & Hall, D. (2006). *When a baby dies late in pregnancy or at birth*. New York City Satellite Office/MHRA, New York State Center for Sudden Infant Death.

Arnold, J., Buschman Gemma, P., & Cushman, L.F. (2006). *Excerpts from exploring parental grief: Combining quantitative and qualitative measures*. The Alumni Newsletter: Columbia University-Presbyterian Hospital School of Nursing Alumni Association, Inc., 2(1), 3.

Hall, D., & Arnold, J. (2005). *Training module and peer educator presentation guide. SIDS risk reduction: A peer education program for African American grandparents and infant caretakers*. Funded by the Bureau of Maternity Services, NYC Department of Health & Mental Health.

Arnold, J., & Longchamp, E. (2004). *Reducing the risk of SIDS*. Nursing Spectrum, 12-13.

Arnold, J. (2003). *Explaining death and grief to children*. Center for Parents and Children Winter Newsletter.

Arnold, J., Chandick, M., DeCoster, M., Esposito, L., Longchamp, E., & Wright, K. (2001). *The nursing role in safe infant care practices* (bookmark). Region II Nursing Summit, Health Resources Services Administration, USDHHS.

Webcasts:

Arnold, J. (2004). *Parental grief on the death of an infant*. Clinical Directors Network,, Inc. (CDN).

Arnold, J. (2005). *Community outreach for SIDS risk reduction*. Clinical Directors Network Inc. (CDN).

Non-Print:

Arnold, J., & Buschman Gemma, P. (1988). *A child dies*. Video produced by the American Journal of Nursing Company and the Hospital Satellite Network.

Arnold, J., & Buschman Gemma, P. (1988). *A grieving family*. Video produced by the American Journal of Nursing Company and the Hospital Satellite Network.