CONTENTS

Issues & Commentary
“We Wanted to Include Him”: Personhood in One Hispanic Family’s Experience of the Genetic Illness and Loss of Their Son
Deborah D. Blake 323

Theory & Research
Investigating Religious and Spiritually Oriented Coping Strategies in the Swedish Context: A Review of the Literature and Directions for Future Research
Fereshteh Ahmadi Lewin 336

The Process of Acculturation in Israel among Elderly Immigrants from the Former Soviet Union
Pnina Ron 357

Principles & Practice
Communicating with Parents Who Experience a Perinatal Loss
Karen Kavanaugh and John B. Paton 369

A Personal Journey through Grief
Mary Ann Pathy 381

Reviews & Resources
Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers, edited by Therese A. Rando
Richard Gilbert 395

Instructions for Authors 399
Index 402
“We Wanted to Include Him”:
Personhood in One Hispanic Family’s Experience of the Genetic Illness and Loss of Their Son

Deborah D. Blake
Regis University

This article draws from an ethnographic study to examine the understanding of personhood that emerges as a Hispanic family from Southern Colorado responds to the diagnosis, illness, and loss of a child with a severe genetic disorder. The focus of this article is on the cultural/religious ethos that shaped this family’s resistance to the ideologies and practices that threatened to define their son by his genetic disorder and to diminish his value as a person. The case study exemplifies, and is consistent with, other families in the larger study. The concept of personhood that emerges stands in sharp contrast to, and as a critique of, the ideologies and practices of “geneticization” that define and diminish the value of a person with a genetic disorder.

In a room filled with family and friends celebrating his mother’s fortieth birthday was a display of family photos that included a photo of Antonio, his mom and dad, and his older brother. “We wanted to include him,” his father told me. “He’s looking down on us. He’s saying, ‘You did good.’ . . . He would have been sixteen.’” Born in 1984, in the early days of the genetic revolution, Antonio would eventually be diagnosed with Recombinant 8 Syndrome. He passed away when he was twenty-two months old, following heart surgery.

The focus of this article is on the cultural/religious ethos that shaped his family’s resistance to the “geneticization” of Antonio, resistance to the ideologies and practices that threatened to define Antonio by his...
genetic disorder and to diminish his value as a person (Lippman 1998). A concept of personhood that challenges the emerging ideology of geneticization and understanding of personhood in the dominant culture emerges from the narrative accounts of his birth, life, family, “problems,” care, and the loss his family felt when he left them. This narrative draws on data from an ethnographic study of the influence of religious and cultural traditions of Hispanic families from New Mexico and Southern Colorado on their decisions about access and use of medical genetics services. Analysis provides insights into the fundamental values of this family and community, particularly their understanding of personhood. This understanding is manifest in everyday life (Geertz 1973, 362); personhood is socially constructed (Berger and Luckmann 1966). The narrative provides positive affirmations of personhood, as well as a kind of *via negativa*, incidents and constructions of identity in which personhood is denied or marginalized. This family does not seem to be unique except, perhaps, in relation to the character of the dominant culture. And that difference is the contribution that they make to our considerations about the care of children and families who deal with the illness, crises, and death of a child with a severe genetic disability.

In this community, the understanding of personhood is developed within the context of a particular Roman Catholic religious tradition. The meaning of personhood can be advanced through the interpretive, symbolic analysis practiced by, among others, Clifford Geertz (1973). Moving us beyond “mere descriptivism,” Geertz points us to “a traffic of significant symbols” of the community, to “ordered clusters of significant symbols” that perform a “constructive role” in understanding what characterizes personhood in this community. Geertz points to symbols as “material vehicles of thought that embody meaning.” In contrast to theoretical discourses on the concept of personhood, this idea of personhood is presented in “the half-formed, taken-for-granted, indifferently systematized notions that guide the normal activities of ordinary [people] in everyday life” (pp. 362-363).

Antonio provides a tangible link between the sense of personhood identified through the recollection of those who knew him and “significant symbols [in his community] . . . upon which men [and women] have impressed meaning” (Geertz 1973, 362), including the meaning of personhood. In his mother’s hometown, the people of the parish have built a shrine on the hillside, the Shrine of the Stations of the Cross. While walking the stations I found Antonio’s name on a memorial plaque. It was not a trivial coincidence. The stations are important symbols in this community, where religion is a central feature of this community’s culture rather than an add-on or compartmentalized dimension of an otherwise secular life. Following Geertz (1973, 362), attention will be given to “the conceptual structure embodied in symbolic forms,” to the idea of
personhood that is embodied in the stations of the cross and the concur-
dant values that shape and support this community’s understanding
and response to illness, crisis, and loss.

BACKGROUND

Antonio was diagnosed with Recombinant 8 Syndrome (Rec 8). This
syndrome has been described in thirty-six kindreds, all of whom are His-
panic and “appear to have descended from a single seventeenth or eight-
teenth century Spanish immigrant to New Mexico” (Williams et al. 1984,
1080). Historian Angelico Chavez (1974, xi-xi) noted,

Although we are truly Hispanic in blood, language, religions and cus-
toms, we [are] no longer Spaniards like the clergyman from Spain…. Nor
[are] we really Mexicans, as our North European-derived neighbors
[choose to call us]. The differences . . . [are] all a matter of cultural and lin-
guistic development from a parting of the ways with both Hispanic
Europe and Hispanic Middle America down [four] centuries.

A unique sociocultural border binds this region and this people.
This genetic syndrome is rare. It is a chromosomal abnormality that
results in multiple anomalies: congenital heart disease, facial
dysmorphology, urinary system anomalies, and developmental delay
are present in all cases. The oldest known person with Rec 8 died at age
thirty-four; the mortality rate for the first three years of life is 71 percent.
The syndrome results in 6.2 percent of pregnancies when one parent is a
carrier. The carrier parent is unaffected phenotypically but carries a
centromeric inversion on chromosome 8. The affected child carries both
the inversion and a recombination (Smith et al. 1987; Sujansky et al. 1993;
Williams et al. 1984).

METHOD

Over a six-year period, ethnographic fieldwork provided data con-
sisting of field-based observations of families and communities in which
each family is located; interviews with members of extended families,
clergy, community members, and relevant health care providers; and
examination of archival materials (church baptism and marriage
records, and materials held by families that include medical records and
medical bills, family photos, journals, and memory books).

Research participants included four extended families and their lin-
eages, as well as health care providers, clergy, and community members
involved with the family. The presence of Recombinant 8 Syndrome pro-
vided an initial parameter for selection.
ANTONIO’S STORY

After several years of getting to know Antonio’s family, his parents sat down with me and told Antonio’s story in August 1998. The story began with a reference to a place, the San Luis Valley in Southern Colorado. His father, Manuel, had grown up in the largest city in the Valley with a population of ten thousand, and his mother, Dolores, in a small village. After graduation from the local college, they packed up and drove with their son Jacob to the University of Wisconsin, where Manuel began graduate studies. Dolores recalls,

"When you come from a (pause) well for me from San [Fernando] which is 99 percent Hispanic and then moving to [Adams] which is probably 50/50 and then going to somewhere where the minority is really the minority (laugh) there and so that was a real culture shock for me. Because they were Puerto Ricanos and Cubanos and first generation Mexicanos and I mean they couldn’t even believe how long our ancestors had been in the Valley."

Manuel added, “We started explaining that, you know, we were kind of the first settlers . . . and we are fifth generation.”

This aspect of Antonio’s personhood, rooted in a history of a people that extended back four hundred to five hundred years (Chavez 1974; Lopez-Tushar 1992), preceded him. Although he was born in Wisconsin, Antonio will always be from the Valley. He was from a “prominent family,” as a local public health nurse described them in an interview in September 1999. This distinction was based not on material resources, but on one’s family name, paternal and maternal descendents of Spanish conquistadors, the prominence of the town one’s family is from, and the leadership roles that family members have assumed in the community and the contributions that they have made. Antonio’s mother came from a town that was “99 percent Hispanic,” where her experience was that of pride in Hispanic leadership and ownership and self-determination. Antonio is deserving of respect because of who he is and where he is from. His personal identity is intimately tied to the family and place that preceded him.

Dolores’s pregnancy was unexpected, but not unwelcome. It was also uneventful. Their first child was born prematurely, by cesarean section. They wanted their second child to be born naturally. The pregnancy was carefully monitored, although it did not include amniocentesis. But, “[Just] in case . . . we were all prepared for [an emergency],” noted Dolores. “So all that becomes interesting when we found out what was going on with Antonio because we had all this testing done and we were so careful and why didn’t something come up before,” observed Manuel.
In the fall of 1984, Dolores went into labor. The delivery was normal. Manuel asked about the Agpar score. It was nine, and then ten, even though they said that Antonio had a heart murmur. Manuel heard the nurse:

She said something about, oh, his testes hadn’t descended into the scrotum. And I know my eyes lit up but I didn’t say anything. Well, I did say, “What does that mean?” And she said, “Oh don’t worry about it.” ... And then I heard her say, “Oh, he’s got a cleft palate.” . . . She showed me . . . and . . . she said, “It’s just a little notch, it’s not bad.”

And so, we knew then there was something but we didn’t know a whole lot. Actually, I wasn’t that concerned.

They took Antonio “to work on him” and took Dolores to her room. She waited and waited, and she kept asking the nurse about Antonio. She would have to wait until the doctor came by. Manuel had gone home to rest and to get their other son and bring him back to the hospital. He had not been home long when Dolores called. She was crying; something was wrong with the baby. By the time Manuel got there, he saw Antonio and he was just a totally different person than I had left, because he was hooked up to all these monitors and he . . . it just looked like a crib with a baby in it with tubes everywhere.

Antonio had a serious heart defect.

The monitors and tubes changed Antonio; the person he was at birth was lost in the medical machinery. The first thing that his father identified was the crib “with a baby”—Antonio was at risk of being defined by his medical condition and treatment rather than by his place in his family. His role was changing, from second-born son to sick son. Throughout his short life, his parents would sustain his place in his family as a normal participant in family life and not as a sick son, a son who was somehow medically or genetically abnormal.

Antonio was transported to Children’s Hospital. Manuel recalls, “[The EMT] looked at me and what I saw in her face was horror. . . . She said, ‘In the event that your son does not make it . . . would you like to have him baptized?’ . . . I thought, Oh my God. He’s going to die.” Antonio was baptized. During his baptism, Antonio’s identity was now tied to the faith and religious traditions of his parents. A few months later he would be baptized again at the local church, with his aunt and uncle as padrinos (godparents) and his grandmothers. Theologically, a second baptism was not necessary, or appropriate. Yet, the second baptism was necessary and appropriate for the family; it involved the family in a place that they chose, in the church.

Manuel and Dolores met with genetic counselors who suspected that Antonio had some kind of genetic syndrome. In an interview in August
1998, Antonio’s great-grandmother would recall that “he was born with a lot of problems.” His heart “problem” was tetralogy of fallot; he had a cleft palate, undescended testes, developmental delay, and a diagnosis of moderate mental retardation. Manuel would track down the identity of the syndrome; he recalled a story in his hometown newspaper about a genetic syndrome unique to Hispanic families of the region. However, Antonio did not become the syndrome; in six years I have never heard his mother or father identify their son as a Rec 8 child.

A week after his birth, Antonio left the hospital. The next spring he would go “home” to the Valley, after his father received his master’s degree. By then, his parents had a routine. Dolores fed him, measuring “intake” and “outake,” trying every nipple she could find and finally using a dropper because of the cleft palate. During Tet-spells, “He could turn so blue, his lips and his fingers.” To calm him they would tuck his legs up under him and hold him or they would get into a warm tub of water and play with him; the water seemed to calm him. Every day Antonio and his mom would get up and do his exercises to strengthen his gross motor skills. Although the doctors had told his parents that it would be futile, Antonio learned sign language, especially “cookie,” “more cookie,” and his name (field notes, 18 August 1998). Later, he would verbalize his words. “I think his first word was ‘mama.’ . . . He was a little happy boy,” recalls Dolores. Antonio would have problems and they shaped the activities of his day, but they would not define him. His personhood was not medicalized or geneticized.

“He was just a regular little kid,” recalls his aunt Emily. “We loved him like the rest of the kids” (interview, 20 August 1998). His brother remembers Antonio’s excitement opening Christmas packages, and then playing with the boxes and wrapping papers (interview, August 1998). When he visited his grandfather, he would be lifted into the air, danced through the house, and treated to a special piece of “contraband” licorice. He would gurgle and move his hands, and “make some sounds because he was so excited to see his grandpa” (interview, 21 August 1998). “He was a smart kid,” recalled his father.

He was interested in a lot of things. [His older brother] had . . . a little three-wheel cart that he would drive and Antonio . . . tried to figure out how it worked because he kept looking underneath it to see what made it go. . . . He would get on it and he’d even make the noise that it would make.

The other thing that made me . . . know that he was intelligent was that he had enough of doctors [and] hospitals, because every time he was hospitalized he would look at the cribs and he knew that either meant shots or that meant yucky stuff or whatever but he would look at it and start to get irritable and cry.
He had a little mechanical dog that you “wind up and they flip over”—“he would look, he would just laugh and laugh and laugh and his whole body would shake when he’d laugh and chuckle.” And everyone remembers him signing for a cookie, especially for a second cookie. Antonio did normal things that any child would do: laugh, giggle, negotiate for a second cookie, investigate the world around him, and experience the playfulness of his grandparents. He also identified and resisted things that he found uncomfortable or undesirable.

He was also a special kid. “Antonio enriched my life,” recalls his aunt Barbara, “and all our lives you know” (interview, 21 August 1998). Antonio’s father works with children who are developmentally disabled and his mother is an elementary school teacher; “I think [he influenced] how we view kids like that and how we deal with them and our sensitivity towards those children.” Antonio taught his family “kindness and caring” (interview, 19 August 1998). He made his young parents grow up and look at life differently, and “appreciate life.” His grandmother reminded me that, “To everybody [who] knew him [he] was a little person from heaven” (interview, 18 August 1998). Antonio’s problems did not make him “deficient” or “defective” or “abnormal”; they did not diminish his personhood. Rather, his problems allowed him to contribute in a special way to his family and to those around him.

Antonio and his parents would make regular visits to see specialists at the Children’s Hospital in Denver. It took over four hours to drive there, and they would spend the whole day at the clinic. Antonio’s parents agreed to “participate in helping” the medical geneticists understand Recombinant 8 Syndrome during those visits. They recall pictures of their son being taken, both “front-view and side-view.” The clinicians “always ask[ed] us are you sure this is ok, this isn’t too much for us.” His parents appreciated that. They were willing to help—“maybe hoping for a cure or something”—but another part of them said, “Enough is enough.” Dolores remembers thinking,

This is my child and he’s not a guinea pig. . . . It was reality check and realizing that he really does have all these little things that are wrong with him that I don’t view it that way.

While Dolores and Manuel were willing to participate in the early research on Recombinant 8 Syndrome, especially with the hope that others could be helped, they were also protective of their son and how he was viewed. His parents were uncomfortable when Antonio became an object of study. They did not see him as a child with a “lot of little things wrong with him.” Here, again, his personhood was at risk of being medicalized or geneticized. Yet his personhood was linked to his
contribution to a community so that other families could better understand Recombinant 8 Syndrome; contributing to others and to the community is part of what it means to be a person in Antonio’s community.

That next summer, Antonio had surgery for his heart problems. While the surgery was routine for most children, his parents knew that his chances were “real slim.” For them, the hardest thing was to “walk with him down to surgery” and hold him and then to let him go. “Antonio just looked at us and started crying. He knew something was up. He didn’t want to go.”

Following surgery, the doctor told them that “everything went fine.” “We heard his heart and everything looked good,” recalls Manuel. Two days later, Antonio was unconscious. They put him on a “heart-lung bypass machine . . . to rest and to heal,” and “they were giving him massive doses of everything,” remembers his mother. “Then he kind of went downhill from there.” Everyone waited. It was time to make a decision.

Antonio was placed in his mother’s arms. “They turned off the machines and stopped the medicines and gave him to me.” His parents talked to him. “It was okay, we’ll let him go.” Manuel noted, “His body had gone through so much.” “What their bodies go through,” responded his mother. “It didn’t even look like him at the end,” observed his father. The physician asked if the family would allow an autopsy. Dolores said, “I couldn’t do it . . . . His chest cavity had been open the whole time.” Manuel continued, “I mean his skin just split because he was so puffy and swollen. . . . It was just awful to see that. I just told them under any other circumstance I would probably do that, but he’s been through enough and we don’t want it.” Antonio’s parents chose to stop the distortion and intrusion of his body and to regain their son.

His brother was sad and angry and cried. Why had his parents taken Antonio to the hospital and to those doctors? His father remembers,

My thoughts were Antonio has a heart defect and he has all these things because that’s who he is and the reason he didn’t survive is because we tried to fix something and his heart needed to be that way.

Antonio’s body was a part of who he was; it was a manifestation of his person. His physical problems and his genetic makeup were not defects, but a normal part of Antonio. His illness was a part of who he was as a person. His mother reflects,

We look back on it now and I think [of] all the things that we went through with him and his time with us and I think he was just given to us. . . . I look back at it as we were like children you know, given the opportunity to care for him . . . kind of like a little loan from God and a little angel that we were responsible for, and to do the best that we could do for him.
Dolores and Manuel would not have any more children of their own, although they would adopt another child. It was not because of the challenges and hardships of raising a child with severe disabilities, but because of the fear and pain of losing another child (archive, essay, 19 August 1998).

Antonio was buried with two cookies, one in his hand and the other in the pocket of his little pacheras (overalls). At the rosary service, the evening before the funeral, Antonio was on a little bed with the sheepskin blanket that he slept on because “he would get so cold.” “When the kids came in they were looking under his pant legs and checking him out . . . [his cousins] were all the way around,” recalls his mother. “It was different from a regular funeral; it was real kid oriented.” Instead of a traditional prayer, his remembrance card had a special version of his favorite poem:

Twinkle, twinkle little star
God has placed you where you are . . .
Twinkle, twinkle, little star,
I can’t reach you in a car;
But someday by Jesus’ might
I’ll fly to visit you each night. (archive, memorial card, 5 May 1998)

At the cemetery they released balloons. “Even though we were hurting and sad and everything, we wanted it to be a happy time too,” recalled Manuel. His tombstone reads, “’C’ is for cookie, that’s good enough for me.” Antonio’s life was celebrated in the town where his mother grew up, in the parish church where his parents were married, surrounded by family and friends, with rituals and symbols, both new and old.

COMMUNITY SYMBOLS AND PERSONHOOD

Whenever I ask about the religious and cultural traditions of the Valley, I am referred to his mother’s hometown and to the Shrine of the Stations of the Cross, built by the people of the parish as a conscious expression of their identity (archive, stations pamphlet, no date). The stations serve as “material vehicles” that embody meaning, including the meaning of personhood (Geertz 1973, 362-63). An analysis, or “unpacking,” of this “cluster” of symbols confirms and enhances the idea of personhood that has been disclosed in Antonio’s story.

The stations of the cross depict the last hours of Christ’s life, his suffering, crucifixion, and death in the traditional fourteen stations, and his resurrection in the fifteenth station. Here the almost life-size bronze sculptures also reflect the faces of the people from the Valley. Antonio’s
grandfather, like many others, walks the stations daily, climbing one mile to the top of the mesa.

Antonio’s name is found halfway through the stations among the names of his grandmother, cousin, great-grandparents, and aunts and uncles who preceded him, with whom he is remembered in a place that is important to his family. The names are accompanied by two biblical passages (archive, photo):

Come, all who pass by the way, look and see whether there is any suffering like my suffering, suffering with which the Lord has afflicted me on the day of his blazing wrath. At this I weep, my eyes run with tears; far from me are all who could console me, far away are any who might revive me. (3 Lam. 12 and 16)

There was following Jesus a great crowd of people, and among them were some women who were bewailing and lamenting him. Jesus turning to them said, “Daughters of Jerusalem, do not weep for me, but weep for yourself and for your children.” (23 Lk. 27-28)

I later asked Antonio’s parents about the station and they said that it did not seem to be anything special or extraordinary; they would, of course, always remember family members who had died.

As religious symbols, the stations of the cross have a central place in a more encompassing lay spirituality that developed in Nuevo Mexico (now New Mexico and Southern Colorado) during the late eighteenth and nineteenth centuries. The villages of Nuevo Mexico were outposts of Spanish colonial settlement and isolated geographically. A lay brotherhood, Hermandad de Nuestro Padre Jesus Nazareno (the Brotherhood or penitents) developed and filled the religious, economic, and political void created by isolation. According to anthropologist Marta Wiegle (1976, 179-180), the brothers preserved longstanding Hispanic Catholic traditions by “appropriat[ing] orthodox forms of worship and adapt[ing] them into vital, significant religious and social expressions. … These rites provided the setting for individual religious experiences and served to consecrate and confirm basic communal ties.” These rites exist today and continue to maintain communal ties; they also embody and sustain values central to the community.

The yearly passion play, which was based on the stations of the cross, dramatizes what the stations embody (Steele 1994, 88).

In the unfolding events of the Lenten drama [one finds] the meaning of the irony and tragedy he faces in his own life. … Without placing a high value on his own life, [there] would [be] no meaning in his reenactment of the tragic events that inevitably led to Calvary. … The prerequisite for tragedy is that a high value be placed on human life. (Tate 1968, 2)
The passion and death of Jesus are the source of human dignity. In one of the alabados, or hymns of the Passion play, the community sings, “There is no one now / Who is not worth something; / Christ is already dead.” Alternatively translated, “There’s none unworthy / Since Jesus died” (Steele 1994, 99, 101).

The stations of the cross point to an incarnational theology that emphasizes the Jesus of the cross underscoring the incarnation, the human life of Jesus, and the humility of the passion, crucifixion, and the resurrection. It is a basic theology and ethics of a believing community that prayed and worshipped in common, doing rituals together that implicitly but very effectively committed the faithful to live out in their daily lives what they acted out in rituals, to walk in the footsteps of Jesus not only during Holy Week but all the days of the year. (Steele 1994, 108)

Religion is not a compartmentalized dimension of an otherwise secular life; it infuses one’s life every day and is a central expression of the identity of the community.

It is also important to recognize that the underlying ethos of this community is informed and shaped by performative traditions, by experiential ritual, rather than legalistic proscription. Whenever I have explored the link between a person’s faith and an ethical position, pregnancy termination in particular, there may be mention of God’s will, but I have never recorded anyone supporting his or her claim by referring to the authority of official Church teaching. The ethos of this community is expressed in a deep abiding character of the community that is faithful to a consciously constructed identity rather than a pattern of obedience to an external authority. Although the authority of the clerical hierarchy is respected, it is the lay leadership and the communal structures of participation that have sustained and defined the Catholic religious traditions, faith, and practices of this community. This is not an abstract or legalistic Catholicism. The ethic of the community is one of character rather than a legalistic ethic.

The stations of the cross also point to a theology of accompaniment (Goizueta 1995). When visiting the stations, or in the procession on Good Friday, one accompanies Jesus. This is not so much an exaltation of suffering or a sense of fatalism. Rather, it is a sense of acceptance of, and faithfulness to, the person who is suffering. It doesn’t “fix” the suffering, but accepts the reality of the suffering while being present, maintaining the dignity of the person through acceptance and accompaniment. This is what is lived out in everyday life. This theology emphasizes relationships; one accompanies the child with Rec 8 and his or her family in the
events of daily life—celebrations of baptisms and birthdays, visits with grandparents and aunts and uncles and cousins, surgeries and illnesses. One also accompanies the child at the end of his or her life, as his family and friends accompanied Antonio.

CONCLUSION

When I have shown photos of Antonio to those who did not know him, they comment that they cannot quite tell that he is sick or what the physical characteristics of the syndrome are. “He looks like a normal kid.” He was a normal kid, although he had some problems. The cousins at his funeral treated him like a normal kid; they were not afraid of him—they “checked him out.” And he was there with the normal things from his life: his cookies, the sheepskin from his bed, his cousins, and his family, community, and church. Antonio was not stigmatized or ostracized, nor were his parents, although they did wonder what would have happened had Antonio gone to school. The problems that he had, rooted in his genetic makeup, set some parameters for his development of communication and speech, physical development, and eventually the length of his life, but they did not define him. Antonio’s world was relational; his personhood was very much defined by relationships to family and community, to a particular history and place, and to distinct religious and cultural traditions.

Competitive performance, cognitive and physical development, or genetic “perfection” does not delimit personhood in this community. Personhood is not an individual attribute. In Antonio’s world, personhood is intimately linked to community; one cannot be fully human outside of relationships and participation in family and community. His recognition as a person precedes him because he is part of a family and is tied to a particular place or community. Respect and dignity is presumed, based on the knowledge of the family within the community and on “the high value placed on human life” in the religious tradition of the community—the passion, death, and resurrection of Jesus. This understanding of personhood is supported and sustained by the significant symbols and rituals in his community, notably by the stations of the cross. Participation in this symbol system sustains the ethos of the community and “guides the normal activities of ordinary people in everyday life” (Geertz 1973, 362). Religion infuses everyday life.

In Antonio’s family and community, “There is a place for everyone” (field notes, 18 March 1999). Everyone is “worthy.” Everyone is included. And fourteen years after his death, at the celebration of his mother’s fortieth birthday, Antonio’s father told me, “We just wanted to include him.”
NOTE

1. Pseudonyms are used for proper names and places, as appropriate.

REFERENCES


Deborah D. Blake, Ph.D., is an associate professor of Religious Studies (Religion and Culture, Ethics) at Regis University, Denver, CO. Her research focuses on issues of cultural diversity and healthcare ethics, rural healthcare ethics, and the appropriation of qualitative theory and method for Christian ethics and healthcare ethics.
Investigating Religious and Spiritually Oriented Coping Strategies in the Swedish Context: A Review of the Literature and Directions for Future Research

Fereshteh Ahmadi Lewin
Uppsala University, Sweden

There has not been much systematic research in Sweden examining the existential and spiritual aspects of coping with serious illnesses. Taking one step toward redirecting attention on this research area, this article discusses some findings and barriers that are important when investigating the religious and spiritually oriented coping strategies among ill persons in the context of Swedish culture. The article concludes that a new alternative scale measuring spirituality among ill persons and new models of meaning and importance of religious and spiritual coping with serious illness should be developed from perspectives that consider the cultural context of societies such as Sweden, where people practice “religion” in a spiritual, subjective, and/or nonorganizational way rather than an organizational way and that, therefore, practicing organizational religiousness is not an important health-related measure. The Religious Orientation Scale and Spiritual Assessment Inventory seem to be appropriate methods on which new models can be based.

This work was stimulated to a great extent by seminars within the social gerontological group at the Department of Sociology, Uppsala University. The social gerontological group is composed of, in addition to the author, Lars Tornstam, professor and chair of social gerontology; Gunhild Hammarström, Ph.D., professor; Peter Öberg, Ph.D.; Marianne Winqvist, Ph.D., certified psychologist; Sang-Hoon Ahn, M.SSc.; Sandra Torres, M.SSc.; and Torbjörn Bildgård, B.A. This work was funded by the Swedish Council for Social Research and the Faculty of Social Science, Uppsala University. Address correspondence to Fereshteh.Ahmadi_Lewin@soc.uu.se.
Although there is a voluminous literature examining how people cope with different serious illnesses, the existential and spiritual aspects have largely been neglected (Dein 1997; Levin 1994). There has not been much systematic research on this topic, either in hospitalized or general practice patient samples (Dein 1997; Koenig, Moberg, and Kvale 1988; King, Speck, and Thomas 1994). This is the case despite the fact that there are some suggestions that religious attitudes and beliefs and spiritually based feelings may influence help-seeking behavior (Dein 1997; Koenig 1994a; Ellison 1994) and that religion and spirituality may make, with regard to questions of health, morality a source of aid when dealing with the uncertainties of aging and illness (Levin and Schiller 1987; Poloma and Pendleton 1989; Kaldestad 1996).

While certain investigations provide some evidence of a relationship between age and religious coping (Gurin, Veroff, and Feld 1960; McCrae 1984), there are other studies that do not give any evidence of a relationship between age and the degree of religious involvement in coping (Pargament, Van Haitsma, and Ensing 1995, 53). As Pargament, Van Haitsma, and Ensing (1995) maintained, while the literature “indicates that religion is an important part of the way the elderly deal with difficult times, it does not say that the elderly use religious coping methods more than their younger counterparts” (p. 52).

On the other hand, some studies—among others, the Project of Religion and Coping—have found support for the idea that it is the kind of religious coping rather than the amount of religious coping that changes with age (Pargament, Van Haitsma, and Ensing 1995, 53). For example, Pargament, Van Haitsma, and Ensing (1995) found that “old people were more likely to use spiritual-based ways of coping” (p. 53).

Besides, there are hypotheses that religious and spiritual approaches to coping may be more helpful to some kinds of elderly people than to others and that some kind of religious and spiritual coping strategies are more helpful for the elderly than for others (Kurlychek 1976; Pargament, Van Haitsma, and Ensing 1995).

The various ways in which the elderly cope with different illnesses have been major topics of interest in gerontologically oriented health research in Sweden during past decades. However, the roles of religion and spiritually oriented coping mechanisms have remained an unresearched issue in this country. One reason for this might lie in the antipathy toward religion inherent in the modern scientific worldview, especially in countries such as Sweden where secularism and individualism are deeply internalized in the ways of thinking of scientists in general. For many scientists, religion and spirituality are not seen as relevant to the human condition. Perhaps this is due to the fact that Western
sociomedicine is still wrestling with a body-mind dualism that defies consensus; thus, for many researchers in this field, any resolution of body-mind-spirit pluralism is simply beyond consideration. Yet, despite such an antipathy toward scientific research on religion and spirituality, especially in the field of sociomedicine, there have been some attempts by social scientists to integrate religious and spiritual phenomena within mainstream theoretical perspectives in certain countries (e.g., Atchley 1997; Jenkins and Pargament 1995; Coleman 1992; Benson, Beary, and Carol 1974; Byrd 1988; Ellison 1991; Hunsberger 1985; Bearon and Koenig 1990), but in Sweden, these models have received limited or almost no attention in the research. Despite the importance of such studies on religious and spiritually oriented coping with different diseases, I have been unable to find any research on this topic in Sweden. To get past this problem, we need to redirect our attention toward the empirical research linking religiosity and spirituality to an assortment of health outcomes, notably physical health status and mental illness. Taking one step toward this goal, this article discusses some findings and barriers that are important when investigating the religious and spiritually oriented coping strategies among elderly ill persons in Sweden; it is hoped that this will give rise to serious discussion of the issue.

The first section of this article is devoted to an introduction of some theoretical and empirical research on religious coping. The second section discusses the shortcomings of these studies, which are limited with regard to investigating religious and spiritual coping behaviors in the context of cultures such as the Swedish one, where people practice their “religion” in a spiritual, subjective, nonorganizational way rather than an organizational way.

The article concludes that a new alternative scale for measuring spirituality and new models of the meaning and importance of religious and spiritual coping with serious illness should be developed from perspectives that consider the cultural context of societies such as Sweden where self-definitions as religious beings are not chiefly a function of individuals’ religious actions (what I do or have done), and therefore, practicing organizational religiousness is not an important health-related measure. The article does not aim at providing any prescriptions for future research but rather provides some underlying principles for its development.

The topics discussed in this article are (1) religiosity, spirituality, and the practice of coping; (2) religious and spiritually oriented coping strategies in the Swedish context; and (3) directions for future research: a methodological approach.
RELIGIOSITY, SPIRITUALITY, AND THE PRACTICE OF COPING

Lazarus and Launier (1978) defined coping as efforts, both action-oriented and intrapsychic, to manage (i.e., master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them that tax or exceed a person’s resources. Researchers usually suggest that religious beliefs and spiritual experiences may take on a larger role as a personal resource/support with increasing age (see, e.g., Koenig, Kvale, and Ferrel 1988; Ellison 1991). This is in line with the popular view that religious faith becomes stronger as frailty increases and death approaches. But is this true? Do religion and spirituality always positively affect well-being in later life, and can religion and spirituality be considered coping mechanisms for all elderly people?

Spiritual support may act through “cognitive mediation,” by contributing to a positive cognitive appraisal of the meaning and implication of negative life events (Coleman 1992) or by enhancing perceptions of being valued, loved, and cared for by God, consequently increasing self-esteem and reducing negative affect (Dein 1997, p. 295). There are studies, especially among the elderly, that indicate that religious belief is related to physical health and well-being and that religion is a powerful cultural force in the lives of older medical patients (Koenig, Cohen, and Blazer 1992; Koenig, Kvale, and Ferrel 1988; Pressman et al. 1990). Using the Index of Religiousness, Pressman et al. (1990) looked at religion as a coping mechanism in elderly women with fractured hips and found religious beliefs to be associated with lower levels of depressive symptoms and better ambulatory status. The most comprehensive study carried out on religious coping and depression among medically ill men is that by Koenig, Cohen, and Blazer (1992), who administered a three-item index of religious coping to a sample of 850 men older than 65 with a range of physical diagnoses. He found that religious coping was a common behavior that was inversely related to depression in hospitalized elderly men.

As Koenig (1994b) maintained on the basis of many studies conducted in the United States, religion is often mentioned spontaneously when the elderly answer open-ended questions such as “What enables you to cope; what keeps you going?” Yet, the relationship between measures of religiousness and psychological well-being is not consistent. Most studies, but not all, have found a positive correlation between religiousness and subjective well-being (Ellison 1991). Many studies have also found religiousness to be positively correlated with both global and
specific health measures, but again, this is not true of all studies (Atchley 1997; Levin 1994; Koenig 1995).

One way religion may benefit people is in terms of the attributions it provides. An important attribution is the selective incidence or “Why me?” question. Sickness may be seen as the result of God’s will and therefore accepted, or as in the story of Job, it may be seen as an educational theodicy (Dein 1997). Perhaps religion functions by taking away responsibility from the sick person, lessening self-blame and consequently leading to a better psychological outcome (Gotay 1985; Linn, Linn, and Stein 1982). However, the reverse may also be the case: patients may feel that God has let them down or become angry with them, leading to a worsened psychological prognosis (Litwood and Dein 1995). As Coleman (1992) maintained, with regard to people growing into old age, religion “may gain in meaning for some, but lose it for others. For some the struggle between doubt and faith may become more intense” (p. 23). In a study (McCulloch 1985) conducted among elderly people in Southampton, United Kingdom, almost half of the sample of 100 people said that they found it difficult to maintain the traditional religious beliefs they had been brought up with. The experience of religious questioning among the elderly is also considered in other studies (Coleman 1992).

Although it has been suggested that religion can sometimes positively affect elderly people’s well-being (Ellison 1994; McFadden 1995), some empirical studies find a negative effect of religion on individuals’ well-being. Baider and Sarell (1983) found that Israeli breast cancer patients who had fatalistic religious explanations for their disease coped less well than did those who had more scientific worldviews. Weisman and Worden (1976) found that church attendance was positively correlated with vulnerability to problems of adjustment.

In a study focusing on the role played by religious beliefs and practices in the aging experience of the very old (ages 70 to 85) in Singapore, Muslims and the Indian Community comprising Hindus, Sikhs, Christians, and a Jain were compared (Mehta 1997). Although this research demonstrates the positive influence of religion on the adjustment process in later life and on coping with different illnesses, it showed that in each ethnic group, there were individuals who did not feel that religion had an important part to play in their lives. One of the negative impacts of religious beliefs observed in this study was the common practice of using explanations “which indicate use of external locus of control such as Fate and Karma in the Malay and Indian communities respectively” (Mehta 1997, 112). There were cases in which the use of such explanations discouraged the elderly from seeking appropriate forms of assistance. This was especially true in the area of health services and counseling (Mehta 1997, 112).
In another study, longitudinal data were used to examine whether the subjective importance attached to being a religious person at one point in time influenced health or psychological well-being fourteen years later (Atchley 1997). The study indicated that religious affiliation and frequency of attending religious functions are unrelated to health or psychological well-being (Atchley 1997, 131).

Religious and spiritually oriented coping may seem to be highly individual projects; some studies (Mehta 1997; Thomas 1997; Atchley 1997; McFadden 1995; Coleman 1992) indicate the importance of the social and cultural aspects of these processes. For instance, research on religion and health shows that the negative or positive impact of religion on elderly people's well-being as well as the possibility of using religion as a coping mechanism may depend on certain factors: among others, gender, ethnicity and culture, income, educational levels, and marital status.

The crucial question is not, however, as Pargament, Van Haitsma, and Ensing (1995) maintained, whether religion is lived or used but how religion is used and to what ends. In line with thinking about religion as "means and ends" rather than "means or ends," coping theory describes religious ways of understanding and dealing with critical life events in the search for a variety of significant ends, spiritual and mundane (Kaldestad 1995).

There are certain assumptions about the ways in which religious cognitions and practices are fashioned into patterns regarding stress managing, physical and mental well-being, personal mastery, and internal locus of control, especially in the cases of individuals who are facing certain life events and difficult conditions. Event specificity and religious role taking are the most dominant assumptions in the field.

Concerning the event specificity assumption, it is suggested that certain life events are particularly likely to elicit religious coping responses, including illness and physical disabilities (Jenkins and Pargament 1988; Pargament and Hahn 1986). There is a hypothesis about why religious coping should be particularly effective in response to specific conditions. One of them, as Ellison (1994) described, suggests that "individuals continually struggle to maintain the perception of a 'just' world, a world in which good fortune comes to good people and bad people get what they deserve" (p. 104). Events and situations such as serious illness, unyielding pain, and sudden death often violate such assumptions. According to Ellison (1994), "by reframing these events in broadly religious terms, individuals may be able to manage their emotional consequences while still salvaging their belief in a just world" (p. 104).

According to the religious role taking assumption, through the identification with various figures portrayed in religious texts, individuals may experience a divine personification (Pollner 1989). As Ellison (1994) explained, "individuals may resolve problematic situations more easily
by defining them in terms of a biblical plight and by considering their own personal circumstances from the vantage point of the ‘God role’ ” (p. 105). This being the case, facing serious illness may make the elderly draw on scriptures and devotional practices to confront specific stressors.

There are studies that focus on the different styles of religious and spiritually oriented coping. Pargament et al. (1988) developed the concept of the “religious coping style.” They identified three broad styles of religious coping. First is “a ‘deferring’ religious problem-solving style in which the individual passively waits for solutions from God” (Kaldestad 1996, 214). Deferential religious copers seek control over problematic situations through a divine other, who then becomes a psychological crutch. This seems to be part of an externally oriented religion and is associated with lower levels of competence. In contrast, the second style, a “collaborative” religious problem-solving style, involves active personal exchange with God (Kaldestad 1996, 214). Collaborative religious copers, as Ellison (1994) explained, “perceive themselves as being actively engaged in dynamic partnership with a divine other” (p. 105). The collaborative religious coping style appears to be part of an internalized committed form of religion, one holding positive implications for the competence of the individual. Finally, there is the “self-directed” religious style in which the individual does not lean on God. “Self-directed religious copers employ religious cognitions and activities only sparingly in response to stressors” (Ellison 1994, 105).

I have reviewed some important studies on religious coping. In the following section, I will discuss the shortcomings of these studies, which are limited with regard to investigating religious and spiritual coping behaviors in the context of Swedish society, where people mainly do not practice their “religion” in an organizational way, but in a spiritual, subjective, and nonorganizational way.

**RELIGIOUS AND SPIRITUALLY ORIENTED COPING STRATEGIES IN THE SWEDISH CONTEXT**

Much of the research on which the above-mentioned assumptions are formulated is conducted in the United States where, as studies show, church involvement as the organizational component of religiousness is an important health-related measure (Krause 1997; McAuley, Pecchioni, and Grant 1998). As some researchers maintain, at least among white Americans, there exists a tendency to refer to a divine other in terms that are more impersonal and abstract. Studying how religion and God are incorporated into white elderly Americans’ health belief system, McAuley, Pecchioni, and Grant (1998, 9) maintained that white respondents tended to speak about their religious lives primarily in terms of
their organizational religiousness (e.g., attending services, being involved in church meals, playing piano at church). Accordingly, self-definitions as religious beings were chiefly a function of their religious actions (what I do or have done) (McAuley, Pecchioni, and Grant 1998, 9).

It seems the Swedes show a different tendency with regard to this question: the social and cultural backgrounds of Swedish society are different in many respects from those of many other Western countries, especially from the those of the United States. As research conducted among 2,003 Swedes in 1993 shows (Kallenberg, Bråkenhielm, and Larsson 1996, 54), 33 percent of Swedes belong to a major group that can be categorized as privately spiritual (see Table 1). In comparison with other European countries, Sweden stands at the lowest level with regard to Church Christians and private Christians. Regarding those who are categorized as Church spiritual and privately spiritual, Sweden is among those countries occupying the highest places (Kallenberg, Bråkenhielm, and Larsson 1996, 53).

As Table 2 indicates, if we take into consideration only those with a religious and/or spiritual tendency, 64 percent of studied people consisted of spiritually oriented individuals who are not used to attending church, that is, those who are privately spiritual.

According to another investigation into the conception of life among Swedes, traditional metaphysical ideas about the world as either a materialistic-probabilistic construct or as a world created and endowed with spirituality are not in the forefront of most people's thinking. Many people do consider these issues, but holders of decisive views are a minority. This is one of the many ways people interpret Christian in their own ways (Jeffner 1988).

With regard to the fact that Swedes are more likely to describe their religious lives in spiritual terms, it seems appropriate to talk of the existence of a kind of spirituality rather than religiosity among Swedes.

Concerning this point, we have good reason to question some assumptions about religious and spiritually oriented coping strategies, which are presented in the first section of this article. For instance, we can ask if event specificity and religious role taking assumptions can explain a possible use of religious and spiritually oriented coping mechanisms among elderly Swedes. Or, concerning the very secular character of Swedish society and the fact, mentioned before, that spirituality is more prevalent among Swedes than religiosity, we can suppose that besides those styles of religious coping that are introduced above, there possibly are other styles used by Swedes. Research needs, therefore, to find more culturally appropriate assumptions that can explain the religious and especially spiritually oriented coping mechanisms that Swedes (or maybe other peoples among whom spirituality is more...
TABLE 1 View of Religion (total)

<table>
<thead>
<tr>
<th>Belief</th>
<th>Church Attendants</th>
<th></th>
<th>Church Nonattendants</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a personal God</td>
<td>Church Christian</td>
<td>111 6</td>
<td>Privately Christian</td>
<td>193 10</td>
<td>349</td>
<td>16</td>
</tr>
<tr>
<td>There is some kind of spiritual being or vital power</td>
<td>Ecclesiastically spiritual</td>
<td>49 2</td>
<td>Privately spiritual</td>
<td>647 33</td>
<td>696</td>
<td>35</td>
</tr>
<tr>
<td>I do not know what to believe</td>
<td></td>
<td></td>
<td>Agnostic</td>
<td>548 28</td>
<td>561</td>
<td>29</td>
</tr>
<tr>
<td>I do not actually believe that there is any kind of spiritual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>being, God, or vital power</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>173 9</td>
<td></td>
<td>1,789 91</td>
<td>1,962</td>
<td>100</td>
</tr>
</tbody>
</table>


TABLE 2 View of Religion (partial)

<table>
<thead>
<tr>
<th>Belief</th>
<th>Church Attendants</th>
<th></th>
<th>Church Nonattendants</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a personal God</td>
<td>Church Christian</td>
<td>111 11</td>
<td>Privately Christian</td>
<td>193 19</td>
</tr>
<tr>
<td>There is some kind of spiritual being or vital power</td>
<td>Ecclesiastically spiritual</td>
<td>49 5</td>
<td>Privately spiritual</td>
<td>647 64</td>
</tr>
</tbody>
</table>


NOTE: N = 1,000 (100 percent).
prevalent than religiosity) possibly use. Such research can result in the identification of new and unknown religious and spiritually oriented coping strategies and styles.

As L. H. Robinson (1986) mentioned, the religious orientations (the extrinsic, intrinsic, and quest orientations) that are related to the above-mentioned coping strategies and styles are comprehensive theoretical constructs that differentiate important aspects of religiosity. It is therefore necessary that we take into consideration different doctrinal beliefs, forms of morality, religious attitudes, and religious activities when we inquire into different religious coping styles among the elderly in Sweden. Adding to the complexity of studying religious and spiritually oriented coping with acceptable cultural relevance is “the diversity inherent in older adults and in factors that contribute to their mental health” (Reed 1991). In this respect, it may be necessary to develop alternatives to traditional methods and types of methodological approaches with a uniquely cultural and gerontological focus as we explore the experience and expression of spirituality among elderly ill persons in Sweden. In the following section, without aiming to provide any prescriptions for future research, I discuss a methodological approach that may help to study religious and spiritual coping behaviors in the context of those cultures, such as the Swedish one, where people practice their “religion” in a spiritual, nonorganizational way.

DIRECTIONS FOR FUTURE RESEARCH:  
A METHODOLOGICAL APPROACH

CONCEPTUALIZATION OF RELIGIOSITY

Religion is difficult to define, and no consensus has been reached about what particular empirical measures should be used. Definitions of religiousness have ranged from “a system of beliefs in a divine or superhuman power, and practices of worship” (Argyle and Beit-Hallahmi 1975) to “feelings, acts and experiences of individual men in their solitude, so far as they apprehend themselves to stand in relation to whatever they may consider the divine” (James 1961, 42). One of the problems involved in introducing religion as a variable in medical and sociological research concerns the way in which it is operationalized.

There are, however, certain methods that have allowed sociomedical researchers to successfully conceptualize religion. There are one-dimensional as well as multidimensional measures of religion.

Unidimensional measures of religion. In some research on religion and health (Levin and Schiller 1987; Larson et al. 1986), religious affiliation is the most commonly used measure of religion. Regarding this kind of
measuring of religiousness, as Williams (1994) pointed out, “how to group together different denominations that share common characteristics has received extensive attention from sociologists of religion” (p. 127). The distinction between church and sect is one of the most influential typologies in the field (Williams 1994, 127). This kind of measurement is, however, inadequate and does not capture the great variations that exist among religious groups (Williams 1994, 127).

Frequency of religious attendance is another unidimensional measure of religion that is used in health research (Larson et al. 1986; Levin and Schiller 1987). There are, however, certain problems associated with the use of religious attendance as a measure of religious involvement. Among others, there is the fact that religious attendance “is frequently a badge of social status, secular in character, and of no greater religious significance than participation in other community organizations” (Williams 1994, 129). Another problem is that as research concerning elderly people shows (Levin and Markides 1986), public participation in religious activities requires a certain degree of physical health. Furthermore, it is not clear that religious attendance per se is indicative of anything intrinsically religious (Williams 1994, 129). Concerning the fact that among the elderly, the intrinsic dimension of religiosity is often stronger than the extrinsic dimension, this problem becomes more serious.

On the basis of the problems associated with the use of unidimensional measurement of religious involvement in health research, especially among the elderly, and with regard to the fact that church involvement is not an important aspect of religiousness and spirituality among Swedes,4 it seems appropriate to apply multidimensional measures of religion when inquiring into religious and spiritually oriented coping strategies in Sweden.

Multidimensional measures of religion. To capture the quality of the impact of religious ritual and symbolism on elderly people’s health, especially when dealing with serious illness, what is needed is a comprehensive but parsimonious set of conceptually based measures of religious involvement. The use of multidimensional measures of religious involvement becomes still more obligatory when a sociological approach is supposed to be applied. There are, however, different types of multidimensional measures of religious involvement.

A commonly used scale in research on religion is the Index of Religiousness, which contains a three-item measure asking about frequency of attendance at services, perceived religiousness, and degree to which religion is a source of comfort (Zuckerman, Kasl, and Ostfield 1984; Pressman et al. 1990). The Index of Religiousness scale seems, however, to be useless in research on religious and spiritually oriented coping
strategies in Sweden since it focuses mainly on the organizational components of religiousness. As explained before, in Sweden, we deal with people who practice their “religion” in a spiritual, subjective, and/or nonorganizational way rather than an organizational way.

Another scale is Glock’s multidimensional measurement model of religion (Glock and Stark 1965). Glock and Stark (1965) devised a scale for measuring religiosity based on five dimensions of religion: experiential (religious feelings), ritualistic (religious practice), ideological (religious beliefs), intellectual (religious knowledge), and consequential (generalized effects of religion in an individual’s life). The latter dimension examines how the first four are applied to real life.

In research on religious and spiritually oriented coping strategies, a multidimensional conceptualization of religious and spiritual involvement based on profiles of religious sentiments and activities and differential sociodemographic factors is of tremendous importance. Yet, as mentioned before, the social and cultural backgrounds of Swedish society are, in many respects, different from those of many other Western countries, especially from those of the United States, where Glock’s scale (Glock and Stark 1965) was developed and examined. Therefore, we need to develop a constructive alternative to Glock’s multidimensional measures of religiosity in such research. In doing this, the basic concepts used in Glock’s typology should be operationalized with regard to the cultural specificity of Swedish and, in general, Nordic societies.

On the other hand, Glock’s five-dimensional model (Glock and Stark 1965) does not fully capture spirituality as the subjective dimension of religiosity. There are also measures that include indicators of the subjective dimensions of religiosity. The ensuing discussion of the consequences of religion in terms of subjective religiosity extends the conceptualization of religious involvement.

As a concept applicable to individuals, religiousness is composed of both internal and external dimensions. Internally, people can have religious identities; goals for religious development; and religious attitudes, values, and beliefs. The psychological salience of religious ideas and behavior varies enormously across individuals and across cultures. Externally, religiousness can be expressed by religious affiliation, devotional practices, membership in a religious community, or attending religious functions. For some people, religion and spirituality are synonyms; for others, spirituality is a broader term that may include the behavioral, cognitive, and organizational elements of religion but also may include broader, more mystical experiences as well.

King, Speck, and Thomas (1994) described religion as the external practice of spiritual knowledge and/or the framework for a system of beliefs, values, codes of conduct, and rituals. Spirituality refers to a belief in a higher power outside oneself that may influence a person’s life. This
higher power may or may not be given the word *God*. The term spiritual may be used in another way, as relating to the search for existential meaning within any life experience. Those who are spiritual do not always describe themselves as religious.

Spirituality points to an element of transcendence, of meaning in life and a concept of self that goes beyond societal expectations or definitions. Dudley and Helfgott (1990) talked of the spiritual dimension as “[encompassing] the need to find satisfactory answers to the meaning of life, illness, and death, as well as seeking a deeper relationship with God, others, and self” (p. 287). Spirituality is thus different from religion, which is a social institution. “Spirituality does not necessitate association with formal religion” (Pastorello and Wright 1997). Emphasizing this distinction and attempting to understand the difference is important in an inquiry into religious and spiritually oriented coping strategies in Sweden since, as mentioned before, it is supposed that Swedes are more spiritual than religious. One of the most important tasks is, therefore—besides the conceptualization of nonorganizational religiousness—the conceptualization of spirituality.

**CONCEPTUALIZATION OF SPIRITUALITY**

Although the distinction between the spiritual and the religious is vague, spirituality has been likened to intrinsic, as opposed to extrinsic, religiosity, assuming a sort of continuum. Spirituality is a multidimensional phenomenon and may be observed or expressed through a variety of behaviors. There are, thus, certain problems in the conceptualization, definition, and measurement of spirituality. Generally, spirituality is conceptualized as an orientation to life and death, as that which provides meaning in life. Definitions of spirituality are, however, diverse. Spirituality has been defined as “the human response to God’s gracious call to a relationship with himself” (Benner 1989, 20), “a subjective experience of the sacred” (Vaughan 1991, 105), and “that vast realm of human potential dealing with ultimate purposes with higher entities, with God, with love, with compassion, with purpose” (Tart 1983, 4).

Although interest in spirituality has increased during the past two decades, there are few measures of subjective religiosity, a majority of them designed especially for psychotic illness (e.g., The Spiritual Well-being Scale, Ellison 1983; The Ethical Principles of Psychologists and Code of Conduct, American Psychiatric Association 1992; Self-Related Religiousness and Spirituality, Zinnbauer et al. 1997). There are, however, two widely used measures of spirituality that are useable with patients with physical diseases.
Religious Orientation Scale (ROS). Gordon Allport’s scale (Allport 1950; Allport and Ross 1967; Batson, Schoenrade, and Ventis 1993) based on two types of religion, namely intrinsic and extrinsic, is still the most influential in the field (Williams 1994; Dein 1997; Kaldestad 1995). Allport’s ROS, according to Williams (1994), “represent[s] the most widely used measure in the empirical study of religion” (p. 139). Allport’s distinction between intrinsic and extrinsic religious orientation is grounded in the Weberian approach to religion.

According to Weber (1964), what makes religion consequential for human behavior is the meaning provided by religious ideas. In this regard, he distinguished conceptions of the supernatural based on taboo from those based on religious ethics. While the former focus on the perception and proscription of behavior, the latter involve a more general orientation to all aspects of life and social relationships. In line with the Weberian approach, Allport distinguished between intrinsic religion, which “is an internalized, all pervasive, organizing principle” (Williams 1994, 139), and extrinsic religion, which “is external and instrumental, a tool that is used to provide needs such as status and security” (Williams 1994, 139). Simply, by persons with intrinsic religiosity, Allport means persons who “find their master motive in religion” and for whom “other needs, strong as they may be, are regarded as of less ultimate significance” such that “they are brought into harmony with their religious beliefs” (Allport and Ross 1967, 434). By persons with extrinsic religiosity, Allport means persons who “use religion for their own needs” and whose values are “instrumental and utilitarian” (Allport and Ross 1967, 434).

The relation between intrinsic religion and health is still a hypothesis that has not yet been examined in a population-based study. Despite this fact and despite some critiques that the ROS has received (Stark and Glock 1968; Kirkpatrick and Hood 1990), it has been proven that the ROS is empirically useful and theoretically enlightening in sociological studies of religion and health in societies such as the United States or some European countries where people practice their religion in organizational as well as nonorganizational ways (see, e.g., Donahue 1985). Yet, with regard to the cultural specificity of Swedish society, there is a need for the development of methodological approaches that focus on people who practice their “religion” in a spiritual and subjective way rather than an organizational way and/or have a mystical view of nature as well as a divine other.

Spiritual Assessment Inventory (SAI). A new, theoretically based measure of spiritual maturity is the SAI. The SAI is “based on a model of spiritual maturity that integrates relational maturity from an object relations
perspective and experiential God-awareness” (Hall and Edwards 1996, 233). Two hypothetical dimensions of spirituality, that is, awareness of God and quality of relationship with God, are measured by developing a pool of items that are used in two factor analytic studies. The awareness dimension of spiritual maturity involves “developing an awareness of God conjointly communicating to us and through us, as well as communicating to us through our own thoughts and feelings and through others” (Hall and Edwards 1996, 237). The quality dimension of the SAI was designed to assess different developmental levels of relationship with a divine other.

Although the SAI seems more useable as a measure of spirituality even among individuals who are not involved in organized religion (such as many Swedes), it was specially designed and validated for clinical use of pastoral counselors and clinicians working with religiously oriented clients (Hall and Edwards 1996, 234).

Another problem is that, like other measures of religiousness and spirituality that were explained before, studies on the basis of which the SAI was developed are conducted among Americans who are in many cultural and ideological aspects different from Swedes. Because of these two major problems, research in a Swedish context cannot directly use the SAI’s model of spirituality. Accordingly, inquiring into religious and spiritually oriented coping strategies, both the ROS and the SAI should be taken into consideration when developing an alternative scale and model for measuring spirituality based on the cultural specificity of Swedish society.

Summing up, in societies such as Sweden where secularism and individualism are deeply internalized in the ways of thinking of the people and where people practice their “religion” in a spiritual, subjective, and/or nonorganizational way rather than an organizational way, it is necessary to develop a new alternative scale to measure spirituality and new models of the meaning and importance of religious and spiritual coping with serious illness from perspectives that consider the cultural context of such societies. In this respect, the ROS and the SAI seem to be appropriate methods on which the new models can be based.

Let us, before finishing this article, say some words about the implications of research on religious and spiritually oriented coping strategies in a Swedish context.

The empirical findings and theoretical approaches in the research on religious and spiritually oriented coping strategies in a Swedish context suggest several implications for health research and practice.

Emotion-regulating or palliative coping behaviors, among other religious and spiritually oriented coping, are strategies employed to maintain mental and physical health during stressful life events and time periods. For many individuals, old age is a time when the strength and
durability of coping strategies undergo their true test, and it is in this set-
ing and at these behaviors that research efforts should be directed. The
research on coping strategies with different mental and physical dis-
eases in Sweden suffers seriously from a lack of theoretical clarity in
defining distinct religious and spiritual dimensions and specifying
appropriate analytical relationships and methodological approaches
regarding religious and spiritually oriented coping strategies among
Swedes. Research on these issues can be a step to fill this gap.

There are several alternative ways that religious involvement and
spiritual-based feelings and efforts on one hand and mental and physi-
cal health on the other hand are potentially related. The majority of these
alternative ways are developed on the basis of studies conducted in soci-
eties where people practice their “religion” in an organizational way.
Accordingly, the complexity and meanings of these constructs and their
relations will bring about serious error when adapting to empirical stud-
ies of Swedes who practice their “religion” in a spiritual, subjective,
and/or nonorganizational way rather than an organizational way. The
findings of the research based on a study conducted in an extremely sec-
ular society such as Sweden with its specific cultural and social charac-
teristic can contribute to the development of new theoretical and meth-
odological approaches in gerontology and health research regarding
coping mechanisms.

However, to obtain better knowledge of specific behaviors that older
people perceive as effective when dealing with a serious illness is helpful
not only for theoretical purposes but also from a clinical standpoint.

Inability to cope with high life stress may strongly influence physical
and mental health (Ruberman et al. 1984; Cohen and Lazarus 1979;
Gotham, Brown, and Marsden 1986). A vital task of health care providers
is, therefore, to assist older persons to choose appropriate coping strate-
gies when dealing with stressful life changes resulting from physical ill-
ness and other causes. Older persons often use coping strategies that
have worked effectively for them in the past. In this regard, clinicians
may guide their patients by first inquiring about strategies being used
and then helping them to deal with disadvantages resulting from illness.
Research on religious and spiritually oriented coping strategies can
make it clear to what extent religion and spirituality can represent a
resource of coping. Then professionals, being aware of this resource, will
feel freer to draw on it in their efforts to help. On the other hand, profes-
sionals need to be aware that some forms of religious and spiritually ori-
ented coping may be problematic or in fact harmful to the coping
process.

Knowledge about the prevalence and effectiveness of religious cop-
ing behaviors among older persons may help health care providers to
project a broader and more rational plan for supporting and affirming
healthy behaviors while discouraging self-destructive ones. On the other hand, such knowledge may aid them in figuring out the extent to which they can benefit from readily available mental health resources in society. This is with regard to the fact that when physician time and mental health resources are becoming increasingly scarce, alternative strategies must be sought to help meet the needs of elderly population.

NOTES

1. It is perhaps worthy of mentioning that Christianity did not become the official religion of Sweden until the 11th century. The institution of the Church went, however, through great changes after the Uppsala Meeting in 1593. A monolithic Church was replaced with a monolithic state that had “ett av de mest fullgängna legislativa system för skapandet av andlig konformitet inom ett kulturfolk” [one of the most developed legislative systems for the creation of spiritual conformity among civilized people] (Stjernberg 1926, 61). This had major consequences for the destiny of Christianity in Sweden. One of them was the ordinance of konventikelplakatet. The high degree of privatization of religion and of secularization of the social and private lives of Swedes is likely to be due, among other things, to this ordinance. Besides, the labor movement’s criticism of the Church and Christianity in the beginning of the twentieth century can be regarded as one of the most important factors explaining the low degree of interest among Swedes in church attendance and religious actions (see Kallenberg, Bråkenhielm, and Larsson 1996).

2. Percentages in the table were added by the author of this article to the original statistics.

3. For the conceptualization of these terms, see the section devoted to a methodological approach.

4. Maybe the following information (Jeffner 1988, 37) tells us quite enough about this fact. When asked how often they attend church, responses included every week (4 percent), every month (5 percent), very occasionally (53 percent), and never (38 percent) (N = 394). In another study conducted in 1996 among 2,810 Swedes, respondents were asked whether during the past 30 days they had had a religious attendance. Eighty-five percent of respondents answered “no” to this question (Belaga, cited in Lewin et al. 1996, 1:8).

REFERENCES


Fereshteh Ahmadi Lewin completed her Ph.D. in sociology at Uppsala University in 1995. She is now working as a researcher, presently specializing in issues related to gerontology, spirituality, and health. In addition, she does research on gerontology and international migration. Her books and articles focus mainly on the sociology of religion.
The Process of Acculturation in Israel among Elderly Immigrants from the Former Soviet Union

Pnina Ron
University of Haifa

Between 1989 and 1995, more than a half million immigrants arrived in Israel from the former Soviet Union (FSU). Data show that elderly persons (65 and older) composed 14 percent of this immigration wave. The process of immigration from the FSU is a process of change extending to all areas of life, including environmental changes (climatic conditions, household arrangements); problems of language, culture, mentality, and social norms; and the personal and emotional changes accompanying such a process. Each of these transitions requires a process of personal adjustment to new situations of life that may negatively affect the immigrants’ personal well-being, as individuals and as a group. Elderly immigrants are at risk as far as their capacity to adjust to changes. This study is an attempt to examine the main difficulties facing elderly immigrants from the FSU and the effect these problems have on their well-being during their acculturation in Israel.

CHARACTERISTICS OF ELDERLY IMMIGRANTS AND THEIR DIFFICULTIES DURING THEIR PROCESS OF ACCULTURATION

The process of immigration is often accompanied by a sense of dispossession caused by the loss of motherland, extended family, friends, culture and language, and sometimes even status. Among an elderly population, there are, in addition to the aforementioned feelings of loss, the additional losses associated with the individuals’ age, so that acculturation becomes even more arduous (Horowitz 1996). In spite of the existence of a diverse literature concerning immigration and acculturation in general, little attention has been given to old immigrants and their acculturation process, especially when such differences reign and

Address correspondence to pitzyron@research.haifa.ac.il
Illness, Crisis & Loss, Vol. 9, No. 4, October 2001 357-368
© 2001 Sage Publications
mentality between the motherland and the new land are so significant. Moreover, in Israel most of the exclusive literature concerning former Soviet Union (FSU) new immigrants is about young adults, with no attention given to the elderly. For example, the social activities of the elderly FSU new immigrants are characterized by unique patterns, from cultural and normative aspects. It seems that new immigrants do not tend to assimilate among veteran Israelis, even if the latter were themselves new immigrants from the FSU twenty years ago. The majority of social relations are with other new immigrants (54 percent have never visited a veteran Israeli household). When they need help, they tend to turn to other immigrants, new or veteran, even though there has been an increase in the number of immigrants reporting that they have no one to whom to turn for assistance (Sagi and Leklansky 1993).

Another sociocultural difficulty is the stress put on the balance between the private life and public life of the individual. Whereas immigrants from the FSU maintain a separation between their public lives and private lives, in Israel, the border between these areas is blurred or more open. Personal friendships are far less intimate and public life far more open, informal, and tumultuous. Studies done on immigrants from the FSU found that these immigrants tend to have limited intimate relationships and do not develop wide social ties (Horowitz 1992). This pattern slows the social integration and acculturation process of immigrants into the new society.

Learning the language is a central activity of each immigrant group in the first half of their acculturation process in a new country (Polani 1991). The Hebrew-language immigrant classroom (Ulpan) is perceived as an agent for social change, while Hebrew is viewed as the key to entrance into Israeli society, culture, and mentality. In examining the social adjustment of immigrants from the FSU, it was found that a knowledge of the language meets a condition for satisfaction and a feeling of psychological well-being (Matlin 1994).

**THE PROCESS OF ACCULTURATION AND THE DEGREE OF PERSONAL, SOCIAL, MENTAL, AND PHYSICAL WELL-BEING AMONG ELDERLY IMMIGRANTS**

The process of acculturation in a new society has several stages: the first one is the stage of enthusiasm (known also as feeling drunk with freedom or the honeymoon period). The immigrant experiences the first weeks of residence in the new country as a dreamer or as a tourist on vacation. A multitude of stimuli, the end of the struggle to emigrate, and so forth produce a sense of release and freedom accompanied by a feeling of great curiosity. The curiosity actually constitutes the beginning of the second acculturation stage: heading for reality. The immigrant starts
taking an interest in his or her new world and acquires the appropriate
skills for this reality, such as language, culture, and mentality. Acquiring
these skills gives the immigrant a sense of control, ability, and personal
well-being. In spite of these feelings, in the third stage, an awareness of
the loss of the known environment of the motherland grows. This sense
of awareness may reduce the level of functioning in the acculturation
process, and at this phase there is a tendency by immigrants to ally with
anything that reminds them of the old country: people who speak Rus-
sian, people who have similar cultural activity patterns, other immi-
grants, and so forth. At this stage, the screen that has been blocking out
the frustrations of reality and the recognition of their losses fades. The
immigrants start to experience the pain of the failures and limitations
they encounter in their daily reality and the lack of a recognizable envi-
ronment. Among elderly populations, these obstructions become more
significant due to problems such as lack of mobility, the inability to make
new friends, losses extending over longer periods of time, and memories
of more life events associated with their homeland. At this point, immi-
grants see the needs their dependence engenders. They feel sadness,
longing, loneliness, and a lower degree of personal well-being in all
areas of life (Mirsky and Koashinsky 1989; Lerer 1993).

Scott and Scott’s (1989) model elucidates the variables included in the
concept of adjustment with a differentiation being made between objec-
tive and subjective adjustment. Objective adjustment is the evaluation
by others of the individual’s functioning, whereas subjective adjustment
is the degree of personal well-being arising from the individual’s satis-
faction in a particular area. The researchers’ hypothesis was that we can
hope for a synergy between the two types of adjustment and that
together they will reflect the degree of general well-being felt by an indi-
vidual. The objective adjustment of the elderly immigrants is problem-
atic since they are primarily a consumer group and not a producing
group. This fact is not a particularly well-liked feature in Western soci-
ety, including Israel. The absence of an evaluation by the absorbing soci-
ety also influences the subjective adjustment of this immigrant group
that is not satisfied with its adjustment. The synergy between the objec-
tive and subjective adjustments in this case is found in a negatively
based synergy: the more the objective adjustment level falls, the more
the subjective adjustment level that affects the personal well-being of the
elderly immigrants as a group and as individuals falls.

Another area that may also affect the personal well-being of the immi-
grant is the characteristics of the absorbing population: its attitudes, its
prejudices, and the degree of willingness that it demonstrates to absorb
the immigrant. Being unwilling to make friends and sometimes even
feeling rebuffed socially are seen as risk factors for the mental health of
the immigrant in a new society (Mirsky 1995). The ability of a veteran
population to develop spontaneously informal, transitional support systems for the immigrants during their initial absorption is limited mainly to the older, more educated, and higher income sector. However, the financial distress of these immigrants forces them to be concentrated in lower income neighborhoods and outlying towns alongside veteran populations with sociodemographic characteristics associated with negative attitudes toward immigrants and immigration (Leshem 1993). Cohen (1994) added that during immigration, several support systems are unhinged simultaneously: the physical one (food, clothing, housing), the social and emotional one (sense of security, sense of belonging, sense of acceptance), and others. In his opinion, immigrants can survive without the presence of these systems, yet these are the ones that determine the personal well-being of the individual and are thus necessary for the long term. Hence, right from the start of the acculturation process, the immigrant must develop for himself new support systems. However, since support systems in Israel appear in a different cultural wrapping, the immigrant does not always have the ability and skills to develop support networks and may find himself or herself in a situation in which different needs affect his or her personal well-being and physical health. It can be said that in the first five years of the elderly immigrant’s absorption into Israel, the social intake occurs primarily in dormitory frameworks (Horowitz 1996), with a trend for small and intimate groups (Fein 1993) with social segregation and the danger of marginalization for the elderly immigrants. All these have a direct influence on the degree of this population group’s subjective personal and social well-being and health.

From all the aforesaid, it would seem that the problems of elderly immigrants, among whom are included immigrants from the FSU, require study and special attention in both the mental-cultural area and the expressive and interpersonal area. This study is an attempt to shed light on some of the elderly immigrant population’s unique problems and to answer the following question: What are the effects of the problems experienced as part of the acculturation process in Israel on the degree of well-being of the elderly immigrants from the FSU?

METHOD

SAMPLE

The study population (see Table 1) was chosen at random from thirteen senior citizen centers in northern Israel in which about 4,000 new immigrants who came to Israel between 1990 and 1996 participated. From this sum, 357 men and women were interviewed. Of these, 23 were
disqualified for the following reasons: age was below sixty (7 participants were between the ages of fifty-three and fifty-nine), eight questionnaires were not completed, and 8 participants decided during the interview that they did not want to continue.

The population included 334 subjects (128 men and 206 women). The majority of participants (75.5 percent) were married or living with a partner, and most had a high school education (practical and professional) and came from different states in the FSU.

INSTRUMENTS

The questionnaire was drafted in Hebrew and translated into Russian and then retranslated into Hebrew and tested in a pilot study with twenty interviewees.

Students of the School of Social Work at the University of Haifa, Israel, interviewed the participants personally according to the questionnaire

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>22.8</td>
</tr>
<tr>
<td>60-65</td>
<td>22.8</td>
</tr>
<tr>
<td>66-70</td>
<td>41.3</td>
</tr>
<tr>
<td>71 and older</td>
<td>35.9</td>
</tr>
<tr>
<td>Gender</td>
<td>38.3</td>
</tr>
<tr>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>61.7</td>
</tr>
<tr>
<td>Family status</td>
<td>75.5</td>
</tr>
<tr>
<td>Married or living with a partner</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>17.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>6.8</td>
</tr>
<tr>
<td>Country of birth</td>
<td>41.3</td>
</tr>
<tr>
<td>Ukraine</td>
<td></td>
</tr>
<tr>
<td>White Russia</td>
<td>14.6</td>
</tr>
<tr>
<td>Baltic states</td>
<td>13.2</td>
</tr>
<tr>
<td>Caucus</td>
<td>11.7</td>
</tr>
<tr>
<td>Moldavia</td>
<td>10.6</td>
</tr>
<tr>
<td>Bukhara</td>
<td>8.6</td>
</tr>
<tr>
<td>Education</td>
<td>4.5</td>
</tr>
<tr>
<td>Elementary school</td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>37.1</td>
</tr>
<tr>
<td>Academic</td>
<td>58.4</td>
</tr>
</tbody>
</table>

NOTE: N = 334.
in Russian. The students spoke Hebrew and Russian, and most of the participants spoke only Russian. The questionnaire had several parts. The first part examined different demographic variables, which included how long participants were in Israel. The second part looked into the difficulties experienced by the elderly immigrants when they reached Israel. In this part of the questionnaire, the participants were presented with a list of possible difficulties divided into three levels: the interpersonal-expressive level covered problems such as feelings of loneliness as well as homesickness for the motherland, past friends, and so forth; the mental-cultural level included problems such as knowledge of Hebrew, cultural friendship patterns, and adjustment to Israeli mentality and others; and the third level presented a list of problems, which included housing and livelihood difficulties and so forth. For each difficulty, the interviewees were asked to rank the particular difficulty on a Likert-type scale of five grades running from 1 = do not find it particularly difficult to 5 = it’s very hard for me.

The third part of the questionnaire examined participants’ reports of their present sense of personal, mental, and social well-being. In this part, interviewees were asked three questions. The first question asked them to describe the degree of general personal well-being they had felt since their arrival in Israel. The second question was, “Describe the degree of your mental-cultural well-being since coming to Israel.” The third question asked them to describe their subjective health since arrival in Israel. These variables were also checked using the Likert-type scale of five grades running from 1 = terrible to 5 = very good.

FINDINGS

To check the research question dealing with the ability to foresee autonomous variables such as years of residence in Israel and different problem levels against the level of the elderly interviewees’ different feelings of well-being during their acculturation in Israel, a stepwise regression analysis was conducted. The degrees of general personal well-being, subjective health, and mental-cultural well-being were checked, as were the relative contribution of each of the independent variables to these variables. To do this, two stages of stepwise regression analyses were conducted for each of the dependent variables described above. The results are presented in Tables 2, 3, and 4.

The independent variables predict about 20 percent of the differences as explained in relation to the level of the research population’s subjective health ($F = 2.95, p < .05$).

The most influential independent variable is the expressive difficulties level (Beta = .536).
The cultural difficulties level and the instrumental difficulties level contributed little to explaining the overall differences (from 8.1 percent to 21 percent).

As indicated by Table 3, it appears that the degree of overall personal well-being is explained by a rate of more than 27 percent from the

| Table 2 | Stepwise Regression Analysis for Predicting Subjective Health by Years of Residence and Acculturation Difficulties in Israel |  |
|---|---|---|---|---|
| Step Introduced Variable | Beta | R | $R^2$ | $R^2$ |
| 1. Expressive difficulties | -.536** | .286 | .081 | .081 |
| 2. Cultural difficulties | -.462* | .317 | .100 | .091 |
| 3. Years of residence in Israel | -.243* | .425 | .180 | .041 |
| 4. Instrumental difficulties | -.119 | .458 | .209 | .029 |

NOTE: N = 334.
*p < .05. **p < .01.

| Table 3 | Stepwise Regression Analysis for Predicting Personal Well-Being by Years of Residence and Acculturation Difficulties in Israel |  |
|---|---|---|---|---|
| Step Introduced Variable | Beta | R | $R^2$ | $R^2$ |
| 1. Expressive difficulties | -.682** | .359 | .128 | .128 |
| 2. Years of residence in Israel | -.505** | .377 | .142 | .014 |
| 3. Cultural difficulties | -.361* | .432 | .186 | .044 |
| 4. Instrumental difficulties | -.214 | .522 | .272 | .031 |

NOTE: N = 334
*p < .05. **p < .01.

| Table 4 | Stepwise Regression Analysis for Predicting Mental-Cultural Well-Being by Years of Residence and Acculturation Difficulties in Israel |  |
|---|---|---|---|---|
| Step Introduced Variable | Beta | R | $R^2$ | $R^2$ |
| 1. Expressive difficulties | -.665** | .445 | .198 | .198 |
| 2. Years of residence in Israel | -.613** | .484 | .234 | .036 |
| 3. Cultural difficulties | -.508* | .532 | .283 | .049 |
| 4. Instrumental difficulties | -.285 | .604 | .364 | .008 |

NOTE: N = 334
*p < .05. **p < .01.
The expressive difficulties level is the strongest influencing independent variable for the explanation of the differences \((F = 3.96, p < .01)\). Additional significant variables contributing to the explanation of differences are cultural difficulties (about 4.5 percent) and instrumental difficulties (slightly more than 3 percent). Length of residence in Israel contributed little to the overall explanation of differences (from 8 percent to 27.2 percent).

As indicated in Table 4, the degree of mental-cultural well-being is explained at a rate of more than 36 percent of the differences using the primary independent variables \((F = 6.12, p < .01)\). For example, the level of mental-cultural difficulties, the central variable \((\text{Beta} = .66)\), explains close to 20 percent of the overall differences (ranging from 19.8 percent to 36.4 percent). Also contributing to the explanation of differences are the expressive difficulties level (4.9 percent) and length of residence in Israel (3.6 percent).

To summarize these findings, it can be said that most of the independent variables (excluding the instrumental difficulties level) gave clear results. Prominent among them was the expressive difficulties level.

**DISCUSSION**

My objective in this research was to try to highlight the primary difficulties that elderly new immigrants undergo during their initial years of acculturation in Israel.

The degree of mental well-being that the elderly immigrants from the FSU experience is related to the level of their experiences and the manner in which these affect their Israeli absorption and acculturation process. The other aim of this study was to determine the degree of influence these difficulties have on overall personal well-being, mental-cultural well-being, and level of subjective health during the elderly population’s process of acculturation.

Of the range of difficulties cited by those elderly who were interviewed for this study, a knowledge of the Hebrew language was one of the prominent difficulties reported by them (79 percent of the subjects did not know any Hebrew at all before coming to Israel), especially during the first year of acculturation. This problem affects one’s capacity to make friends and to integrate into the local culture, mentality, and so on. These data support other studies, which noted that knowledge of the language of the absorbing country is a key to acculturation (Grove and Torbiorn 1985; Scott and Scott 1989).

On the same level of mental-cultural difficulties can be found problems in patterns of cultural socializing and adjusting to the Israeli mentality. The research population reported a state of moderate and below moderate subjective health, which was found to be correlated to
different levels of difficulty in absorption. The professional literature supports these research findings and indicates the existence of expressions of a drop in status of mental health affecting physical health (Lerner, Mirsky, and Barasch 1992; Litwin 1995; Shuval 1993). On this level of difficulties, there is an additional aspect: cultural-social friendship patterns. It would seem that elderly immigrants, both men and women, find it difficult to make friends with veteran society, even if this society comprises veteran immigrants from the FSU. The reason for this was not examined in this research, yet the results of these difficulties cause the elderly immigrants to make friends with other immigrants and avoid association with relatively new groups.

On the level of expressive difficulties, the problems of loneliness and homesickness for the motherland were most manifest for the participants, particularly during their year of acculturation in Israel. These difficulties have a strong influence on the elderly immigrants’ overall personal well-being, on their mental-cultural well-being, and their subjective health. Various researchers have defined these two difficulties, particularly homesickness for the old country, as unique stresses accompanied by a sense of loss, requiring a process of adjustment similar to that during bereavement (Grinberg and Grinberg 1989). Shuval (1993) added that pressured situations such as these may cause regression as a result of the many changes, and the author notes the great importance of an individual’s defense mechanisms and the use of them in coping with the acculturation process. Their purpose is to raise/return as quickly as possible the individual’s sense of well-being.

It was found that the third level of difficulties, related to problems of work, salary, housing, and styles of residence, was less experienced as a difficulty by those interviewed. On this level, the difficulty of living in a shared household of two or more generations of immigrants was the most prominent problem. This difficulty is found in the general gerontological literature as affecting the degree of personal well-being of all members of the multigenerational household (Morgenstein and Cohen 1980; Stoller 1985; Weil et al. 1988), on top of which may be added other unique problems of the acculturation process.

The research findings dealing with the subject of veteran immigrants in Israel during the first four years of acculturation requires special attention. From these results, it seems that the longer the elderly immigrants remain in Israel, the lower the degree of the various senses of well-being felt by them and the level of their subjective health. These findings are correct for both men and women. These do not match other research findings conducted in Israel and abroad, which reported the opposite phenomenon: the longer the residence in the new country, the higher the sense of overall personal well-being (Driman and Shinar 1996; Feireico 1992; Winchie and Carment 1988). Since most of the studies
done up to now examined younger populations (adolescents, students), it may be that elderly groups tend to react in a different manner to the acculturation process, seen in a drop in the level of well-being and health as the period of residence in the new country increases. There is a place for further research of this phenomenon raised by this study.

In summary, it would seem that different levels of difficulties do indeed have a large influence on the degree of absorption of elderly immigrants from the FSU into Israel. These affect the degree of different senses of well-being felt by the immigrants and their level of health. Since this population group attains only partial solutions during their absorption process in Israel (elderly immigrants have lower priority in learning the language in Ulpans), it is important to find ways to reach each and every immigrant, to study their difficulties and distress, and to try to assist as much as possible. Furthermore, I would point out that the policy of direct absorption, in which the immigrants are asked to select for themselves their place of residence in Israel, to find on their own the same or at least similar jobs to those they had before, and to use their “absorption basket” as they see fit, is more suitable to a younger population with more personal strength and resources to cope with all of this. This is not the situation of the elderly population, and their process of absorption must be attended by different professionals with the objective of helping these immigrants during their acculturation process and preventing them from turning into a population dependent on different government offices or alternatively into a group of individuals in situations of unresolvable personal, cultural, and social distress.

In conclusion, it is important to note that this research used as its sample a group of elderly immigrants who participated in different activities in senior citizen centers spread out through the northern region of Israel and did not use a random sample of different immigrants who were active and not active in the senior citizen centers. However, these findings on the different difficulties of elderly immigrants from the FSU can be generalized, and different preparations can be made for their absorption.

REFERENCES


Pnina Ron, Ph.D., is a gerontologist and social work lecturer at the Center for Research and Study on Aging in the Faculty of Social Welfare and Health Studies at the University of Haifa, Israel. Her current research includes three investigations of depression, suicide ideation, and bereavement behavior among the elderly. These include (1) a comparison of elderly people living in the community and those who are institutionalized, (2) a comparison between the veteran elderly and new immigrant elderly from the countries of the former Soviet Union, and (3) a comparison between elderly and young populations.
Communicating with Parents Who Experience a Perinatal Loss

Karen Kavanaugh  
John B. Paton  
University of Illinois at Chicago

The importance of communicating with parents who experience a perinatal loss has been documented repeatedly in the research literature. Yet, parents do not consistently receive adequate information when they experience a loss. Effective communication with parents who have experienced a loss requires ongoing dialogue throughout all phases of care, starting well before the loss of an infant. To communicate effectively, clinicians need to know the type of information to give, how and when to give the information, and how to assess parents’ understanding of the information. Professionals who are skilled at communicating with and caring for parents who experience a loss should serve as mentors for their colleagues to ensure the ongoing availability of competent clinicians.

The importance of communicating with parents who experience a perinatal loss has been documented repeatedly in the research literature (Calhoun 1994; Covington and Theut 1993; Crowther 1995; Dunn et al. 1991; Forrest, Standish, and Baum 1982; Giles 1970; Harper and Wisian 1994; Kavanaugh 1997; Lasker and Toedter 1994; Lemmer 1991; Mahan et al. 1981; Malacrida 1997; Radestad et al. 1998; Rowe et al. 1978; Schreiner, Gresham, and Green 1979; Sexton and Stephen 1991; Stringham, Riley, and Ross 1982; Swanson-Kauffman 1986). Guidelines for talking to parents who have experienced a perinatal loss were described as early as 1970 (Giles 1970). Subsequent related discussions documented including parents in decision making for critically ill newborns (Able Boone, Drokecki, and Smith 1989; American Academy of Pediatrics [AAP] 1996; Harrison 1993; Jellinek et al. 1992), communicating medical bad news (Girgis and Sanson-Fisher 1995; Krahn, Hallum,

Effective communication with parents who have experienced a perinatal loss requires ongoing dialogue with parents throughout all phases of care, beginning with antenatal counseling for parents with a pregnancy that is considered at risk for poor infant outcome. Currently, standardized checklists for caring for families who experience a loss (Beckey et al. 1985; Ryan, Cote-Arsenault, and Sugarman 1991) are available, but these checklists are often focused on tasks, such as providing infant mementos and encouraging parents to see and hold their infant. This task-driven approach does not always allow for adequate assessment and individualized care (Leon 1992) or provide guidelines for the way these tasks should be carried out. Furthermore, because standardized care plans are typically focused on care after the infant has died, there is little direction for clinicians to provide anticipatory counseling before the loss. An approach that does not incorporate communication as a process can result in inadequate communication with the parents.

The purpose of this article is to discuss the problems that contribute to inadequate communication with parents who have experienced a perinatal loss and to offer suggestions for addressing these problems. Talking to parents under these circumstances will never be easy but can be done in a way that enables clinicians to believe that they have delivered sensitive, competent care that is consistent with a model of caring that ultimately enhances the well-being of parents (Swanson 1991, 1993).

**ANTICIPATORY COUNSELING**

Perinatal loss is a tragic and unexpected outcome of pregnancy and childbirth. Advances in technology and the medicalization of pregnancy have led to the mistaken notion that perinatal loss has been eliminated (Layne 1992). Little attention is given to pregnancy loss in the popular press, and information on pregnancy loss is not uniformly covered in childbirth education classes for fear that presenting this information will
cause unnecessary worry and stress. Furthermore, hospital incentives to attract the health care market of childbearing women are characterized by environments to support and names to reflect birth as a celebration of new life. The news media’s focus on births of higher order multiples reinforces the public impression that tinier, sicker infants survive. This view further reinforces providers’ and parents’ expectations that death is avoidable. Ironically, the prevalence of advanced technology, which can be used to inform clinicians and assist with communicating and caring for families, has instead sometimes interfered with communicating within a context of caring. For example, according to anecdotal information and published research (Malacrida 1997), confirmation of fetal death during a prenatal ultrasound procedure is often delayed until the woman’s primary provider receives the results and then contacts her. Parents might suffer for hours or even days while waiting for the confirmation. Clinicians in these circumstances should place the same priority on communicating with parents as they would on a placental abruption or other medical emergency.

Both health professionals and parents (AAP 1996; Harrison 1993) recommend that parents should be included in making decisions for treatment plans for their unborn infant, especially when the infant’s prognosis is poor or uncertain. However, the frequency of parental involvement in prenatal decisions is not clear, except in conjunction with interruption of pregnancy for genetic reasons (Lorenzen and Holzgreve 1995; McKinney, Downey, and Timor-Tritsch 1995; Zeanah et al. 1993). In several studies in which investigators have examined decision making in the neonatal intensive care unit, physicians have reported that many parents were involved in treatment decisions for their newborns (Cook and Watchko 1996; Doron et al. 1998; Duff and Campbell 1973; Wall and Partridge 1997). Yet, in all studies in which parents have been asked to describe their level of involvement in decision making for their hospitalized newborns, most parents perceived that they had little or no involvement (Kavanaugh 1997; King 1992; Pinch and Spielman 1990; Scholmann and Fister 1995). Recent discussions on a neonatal listserver have indicated discrepancies between parents’ and clinicians’ philosophies toward treatment decisions for newborns and amount of parental involvement in making these decisions—with parents wanting more input for fear of overtreatment of their infants. This discussion underscores the importance of dialogue with parents.

Clinicians need to be skilled at adequately assessing parents’ prior experience with the situation, understanding of the events, and definition of what it means to be a good parent, which will often be influenced by other family members. In addition, clinicians must use extreme care in choosing language for sharing information with parents. In one study of perinatal loss of infants whose birth was at the margin of viability
(Kavanaugh 1997), a mother who was experiencing symptoms of preterm labor remembered being advised to “hold on 2 more weeks.” This choice of language, given to a woman in a vulnerable state, distorted the mother’s perceptions of her ability to influence the outcome of her labor and contributed to her guilt when her labor was not halted and she delivered twin girls who lived only briefly.

HOW AND WHEN TO PROVIDE INFORMATION

Effective communication with parents is a process that requires clinicians to know what type of information to give, how and when to give the information, and how to assess parents’ understanding of the information. Clinicians who care for parents experiencing a loss need specific information on the behaviors and needs of these parents as a foundation for applying the guidelines on communicating medical bad news (Girgis and Sanson-Fisher 1995; Myers 1983; Ptacek and Eberhardt 1996; Sharp, Strauss, and Lorch 1992) and involving parents during decision making (Jellinek et al. 1992).

On hearing bad news, parents may respond with behaviors or questions that appear to reflect a lack of understanding of the severity of the infant’s condition or prognosis. For example, a parent may focus on what clinicians perceive as insignificant information, such as the infant’s pattern of weight gain. When this happens, communication can be hindered if the care provider does not know how to accurately assess parents’ understanding of the situation and know how to respond sensitively to the parents. Parents may ask questions about their infant’s weight because that is the only type of question they know to ask, especially if the prognostic information for their infant has been framed around infant weight. Also, parents may view being a “good parent” as being someone who maintains hope for their infant (Kavanaugh 1997; Rushton 1994) and thus may persevere with the hope that their infant will beat the odds and survive. As one mother explained, “If the mother doesn’t have hope, there isn’t going to be a lot of hope for the babies” (Kavanaugh 1997). Traditionally, these parental behaviors have been dismissed as interfering with communication, and parents have been described as in denial, an inappropriate adaptation of grief theory (Kubler-Ross 1969).

Clinicians must understand these behaviors and develop communication skills that will enable them to accurately assess parents’ understanding of the information. All behaviors are not manifestations of denial. Parents often hear the information but then make “sense” of it according to what the information means to them. Furthermore, parents may be emotionally overwhelmed and must hear simple explanations...
repeated several times. However, clinicians also must recognize situations in which accurate and timely information is essential—for example, when an infant’s condition is first becoming critical or unstable. In these situations, clinicians should not offer false information over the telephone to spare parents’ feelings.

Parents must make many decisions after their infant’s death and need to be guided during this process (Calhoun 1994; Kavanaugh 1997; Lemmer 1991; Malacrida 1997; Sexton and Stephen 1991). These decisions will have a lifelong effect; parents must be given adequate time to make the necessary decisions and be given an opportunity to change their minds within a time period that is appropriate to the decision. In many institutions, clinicians have implemented successful strategies for assisting parents with some decisions, such as the decision to have pictures of the infant. However, assisting parents with choices in such areas as autopsy and burial has received less attention from the care providers, even though parents have described the importance of autopsy and burial counseling (Calhoun 1994; Crowther 1995; Dunn et al. 1991; Harper and Wisian 1994; Kavanaugh 1997; Khong 1997; Lasker and Toedter 1994; Malacrida 1997; Primeau and Lamb 1995; Radestad et al. 1998; Sexton and Stephen 1991). Parents may not fully realize the importance of certain choices, such as consenting for an autopsy or arranging a private burial, until weeks or months after their loss. Clinicians should encourage parents to arrange for a private burial or memorial service and to give consent for an autopsy if medically indicated. Clinicians must acknowledge to parents that although these decisions are difficult to make, the consequences become more important as time passes.

Parents need accurate and complete information about the cause of their infant’s death. Requesting an autopsy is one of the rights of bereaved parents (Primeau and Lamb 1995). However, clinicians may overlook the importance of autopsy in their desire to spare parents any further pain, particularly when the parents have verbalized that their infant has suffered enough. Clinicians need a good understanding of autopsy counseling to identify the type of autopsy—partial or complete—that is necessary, and they also must examine their feelings and attitudes concerning autopsies because these might influence the way in which the consent is obtained (Chiswick 1995; Khong 1997). Furthermore, mothers should not be expected to make decisions alone and unsupported. Mothers should be given short explanations and concise written information on autopsy and options for burial that they can share with their partners and other family members. Clinicians must also convey a timeline for these decisions that is determined by legal or institutional policy rather than by the convenience of the clinician.

The importance of giving anticipatory guidance about grief has also been documented consistently in the research literature (Calhoun 1994;
Harper and Wisian 1994; Lasker and Toedter 1994; Lemmer 1991; Malacrida 1997; Sexton and Stephen 1991). Yet, parents do not consistently receive this information in a way that is helpful to them. One way to provide anticipatory guidance is to give booklets to the parents about newborn death. However, such booklets typically contain too much information and cover a long period—from decisions that are made in the hospital to feelings about a subsequent pregnancy. Although these topics are important, most parents will be too overwhelmed to locate the timely information needed right after their infant has died. A useful strategy is to link information to certain time periods and develop single sheets of information that can be accumulated in a folder for parents to keep. For parents who benefit from reading, clinicians can recommend one or two books to parents and can also recommend to other family members, who are often at a loss about how to help the parents, that they purchase the books as gifts.

Follow-up is a necessary (Harper and Wisian 1994; Malacrida 1997; Mahan et al. 1981; Rowe et al. 1978) but sometimes neglected aspect of care. Again, an individualized approach is critical. Strategies must be in place for communicating with all parents, especially those parents who have not consented to an autopsy. Phone calls made within one week of a loss and again in one to two weeks, or in conjunction with the mother’s postpartum appointment, are critical components of follow-up. Ideally, the person talking to the parent will be one of the members of the health care team who knows the family. However, it is even more important that the person who contacts the parent know how to communicate well. During this follow-up contact, the clinician should clarify information, validate parents’ feelings, and help parents to identify effective ways of coping and sources of support (Friedrichs, Daly, and Kavanaugh 2000). Therefore, clinicians who provide follow-up support must have mechanisms for getting information requested by parents and must also understand the full range and intensity of responses common for many months after a perinatal loss (Davis 1996; Jansen, Cuisinier, and Hoogduin 1996).

If the parents have consented to an autopsy, the clinician who has maintained contact with the family should be a part of the autopsy counseling session with the parents. One standard approach for follow-up care is to arrange a meeting for autopsy counseling after the autopsy results are complete, which could be as long as two to three months after the loss. However, follow-up should not be limited or delayed until the clinician receives the autopsy results. During autopsy counseling, information should continue to be given in such a way that parents can understand the results. The actual autopsy report should be translated into lay language so that the information is meaningful to the parents. Because not all parents will be able to return to the hospital for a counsel-
ing session, other options should be explored. Counseling sessions should be scheduled at times and locations that are accessible to parents rather than just convenient for clinicians. If parents do not return for autopsy counseling and a copy of the autopsy results is sent to them, it should be accompanied by a letter with a description of the autopsy results in lay language and should include the name and phone number of a person parents can call if they need further information.

Another common approach to meeting the postdischarge needs of parents is to provide the names of support groups for bereaved parents. Although many parents do not attend support groups, they often say that they appreciate receiving the information. Options for follow-up referrals should be individualized and comprehensive. An alternative for parents who use the Internet might be to provide them with Web site addresses on perinatal bereavement. Other parents might benefit from information from newsletters for bereaved parents, especially those developed for parents with special needs, such as loss in a multiple birth.

OVERCOMING INADEQUATE PREPARATION

Clinicians must learn how to communicate well with parents. This can be accomplished in their formal educational programs, mentoring, and ongoing educational activities. Yet, many clinicians do not receive information on caring for families who experience a perinatal loss, especially if perinatal loss is an area that is considered too specialized to include in a generic professional program. Therefore, clinicians may not receive information about nontraditional, emerging models of grief (Solari-Twadell, Bunkers, and Wang 1995) that allow for a more complete understanding of the individual nature of grief and the needs of the bereaved. Therefore, formal educational programs and mentoring of novice clinicians is critical.

Although formal orientation programs for nurses and residency training programs for pediatricians are widespread, anecdotal information suggests that information and techniques for communicating with parents are not addressed consistently or in depth. Often the focus of teaching is on mastery of technical skills, not communication skills. Mentors find that communication skills are challenging to teach and evaluate. Role play is an option, but role play often makes people uncomfortable, especially if those involved have not had the didactic information on communicating that is essential before attempting role play. Morgan and Winter (1996) have implemented a successful educational program for pediatric residents on communicating with families. The educational packet includes didactic material, an enactment of an interaction, and seminars with role play. In addition, investigators (Greenberg et al. 1999) have reported that pediatrics residents and
fellows improved their communication and counseling skills after participating in simulated sessions on delivering medical bad news.

Communication skills are a necessary component of care, but priority is typically not given to learning these skills. In clinical practice, novice clinicians, especially nurses, are often given assignments intended to provide opportunities for increasing technical expertise. Because of this approach, novice nurses often care for infants and parents around the time of a perinatal loss. Yet, as novices, they are typically not prepared to provide time-intensive care to the infant and equally intensive care to the family. This dilemma is a particular problem in tertiary care units in which there is a high concentration of perinatal losses and large number of novice clinicians. Those who assign clinicians to parents must consider the time needed for family support, even for expert nurses.

Novice clinicians should be mentored by clinicians who are experts at caring for families who have experienced a loss. On many units, one clinician, often a nurse, is identified as the person who is skilled in caring for parents who have experienced a loss. This person should be assigned to mentor others, including professionals in other disciplines, so that care is based on a model of caring (Swanson 1991), which has been supported in clinical (Leon 1992) and research (Kavanaugh 1997; Lemmer 1991) literature. Novices must be allowed time to learn how to use a model of caring, which requires experience and intuition. Experts can and should guide care and communication with parents, especially in situations wherein clinicians are providing autopsy and burial counseling by virtue of their position in the institution rather than because of their familiarity with the parents and communication skills.

Finally, ongoing educational programs centered on death and grief, including staff feelings about loss, are not often offered routinely. One strategy to incorporate ongoing learning is to review cases, similar to the way a critical incident, such as a cardiopulmonary resuscitation, would be reviewed. Case reviews would provide novices as well as experts the opportunity to learn. This approach would also underscore the importance of the family as care recipient and call attention to their needs, especially when the care delivery to the infant might have been perceived as futile.

**SUMMARY**

In summary, clinicians must recognize the importance of good communication throughout all phases of care for families who are at risk for experiencing perinatal loss. Clinicians who talk to parents who experience a perinatal loss should be well informed about the behaviors and needs of parents experiencing such a loss so that their communication is a component of a model of caring for the parents. Furthermore,
clinicians who are skilled at caring for parents who experience a loss should serve as mentors for their colleagues to ensure the ongoing availability of competent clinicians.

REFERENCES


Karen Kavanaugh, R.N., Ph.D., is an associate professor in the Department of Maternal-Child Nursing at the University of Illinois at Chicago. Dr. Kavanaugh has concentrated her professional career on caring for parents who have experienced a perinatal loss. She has authored many publications on perinatal loss, presented at national and international meetings, and is currently completing her second study on perinatal loss that has been funded by the National Institutes of Health.

John B. Paton, M.D., is currently a consultant in perinatal health at the Chicago Department of Public Health and a clinical associate professor of pediatrics at the University of Illinois School of Medicine. As a practicing neonatologist, Dr. Paton has more than twenty-five years' experience caring for families who have experienced a perinatal loss.
A Personal Journey through Grief

Mary Ann Pathy
The Canadian Centre for Bereavement Education and Grief Therapy

In this personal journey of grief, the author compares and contrasts her grief reactions and process of mourning at two stages of life. The first death, that of her father, occurred when she was thirteen and resulted in unresolved grief that later led to two suicide attempts and chronic depression. The second death, that of her best friend, occurred forty-eight years later. This time, she buried none of her feelings, and there was catharsis and healing. With this second death, she felt angry that her friend had died with so much turmoil in her life and without finding peace. These feelings catapulted her back to the time of her father’s death. The author concludes that while all losses are traumatic, the consequences of a childhood loss are more devastating than at any other stage of life. For a child, the death of a parent is the loss that is forever.

Grief is not an intellectual exercise. Grief breaks our hearts and hits us like ocean waves. It devastates us, diminishes us, changes us, and forces us to grow and become new people.

—Johnson (1999)

Grief refers to the thoughts and feelings that one experiences upon the death of a loved one. It is an internal experience, what we do within ourselves to redefine our relationship with the deceased. Any creature that bonds grieves when it experiences separation… the very young child no less than the old man. And, when those bonds are broken, a piece of us breaks or is traumatized by that loss.

Mourning, on the other hand, is the outward expression of our grief. One way to clarify the difference between grief and mourning, according to Wolfelt (1999), is to state that mourning is “grief gone public” (p. 5). It is the outward manifestation of internal feelings. One must express that grief and literally give in to that grief. As Dayton (1997) so aptly stated,
one must “sit in the wound” if one is to restore one’s life. Only when one is able to go deep down into the pain, to surrender to the grief and “move through the emotional turmoil of a grieving process” (Dayton 1997, 19) can one grow, be restored to life, and learn how to go on living without the deceased. This is what was denied me. And, it has resulted in lifelong turmoil and continual relapses to that particular time of my life.

In this article, I compare and contrast my own grief reactions and process of mourning at two different stages of my life. The first of these occurred when I was thirteen and my father died suddenly while in New York on what I thought was simply another business trip. The other death, also sudden, occurred forty-eight years later when I was in my early sixties. This time, it was a stroke that felled my best friend. Although I have experienced several other deaths over the years, these two have had the most profound effect on me. Both of these, while occurring at two entirely different stages of my life, were connected with each other, and each had a tremendous impact on me and on my life. The second death, that of my friend Evelyn, was a catalyst that reopened the wounds of my father’s death, and I reexperienced the grief, but this time I was able to mourn.

I would like to state at the outset that throughout this article I have used the terms child and adolescent interchangeably. While there is a great difference between a five-year-old and a fifteen-year-old, it is very difficult to differentiate between an eleven-year-old and a thirteen- or fourteen-year-old. Both are still children. There is a bridge between late childhood and early adolescence, and one moves back and forth along this continuum. This was certainly true for me. During adolescence, one flirts with adulthood, and then one snuggles back into childhood. Furthermore, I would say that fifty years ago (the time of the first sudden death of which I write), a thirteen-year-old was not as precocious as is a thirteen-year-old today. The point I am making is that chronological age and maturation age are not synonymous. And, just as there is no set time for grief resolution and no two people accomplish the tasks of grief and move through the phases of grief at the same rate, I feel that there is an overlap, a smudging of borders between late childhood and early adolescence. In the book Beyond the Innocence of Childhood (vol. 3), Ben Wolfe and Linda Senta (1995) discuss their work with nine to thirteen-year-olds in their bereavement support groups. They use the terms “child” and “youngster” when referring to their clients.

The Bible (Authorized King James Version) says, “When I was a child, I spake like a child, I understood as a child, I thought as a child: but when I became a man, I put away childish things” (1 Cor. 13:11). This suggests to me that one is a child until one becomes an adult, and even that transition is very idiosyncratic.
MY FATHER’S DEATH

As a child, I spent little time at home with my parents. When I was four years old, and for the next fourteen years, I was sent to camp for two months every summer, and at the age of nine, I was also sent to boarding school. I longed to live at home, and I formed my strongest attachment with my father. He was the most important person in my life . . . my father and my mentor. When I turned thirteen, he, realizing that I was growing up, allowed me to become a day girl at school, and he promised me that I would never have to return to boarding school. Five months later, however, he died suddenly, and the world as I knew it ended abruptly. “Sudden death shatters a child’s core belief that the world is a safe and predictable place. When terrible things happen without warning, a child is left feeling vulnerable and insecure” (Worden 1991, 10). When a parent disappears or dies, the child’s reaction is one of overwhelming anxiety, panic, confusion, and terrifying insecurity, and above all there is a profound emptiness. Like a tidal wave, the flood of emotions engulfs her. Nothing in the child’s life remains untouched; the catastrophe is all encompassing. The child experiences grief.

With the death of my father, I found myself in a hostile world. My mother, who believed that children do not have feelings, totally abandoned and rejected me. I recall that the day he died, I was standing in the doorway of the living room, alone, lonely, frightened, and confused. No one spoke to me, and no one came near me, including my mother. In short, I had to repress the grief that engulfed me for I was not allowed to cry. I was not allowed to talk about my father. I was not allowed to ask any questions about death, the meaning of life, or what would now happen to me and to my family. I was expected to continue my life as before, with one exception. For a year, I was not allowed to go to parties or socialize with my friends as that would have been disrespectful to my father. So, the abandonment I felt was complete. My father was dead, my mother ignored me, and I was not allowed to be with my all-important peers.

The visitation and funeral were especially traumatic for me. I had never been in a funeral home, never seen a dead person, and never been to a funeral. But no one gave me any preparation for these frightening experiences. And, I had no idea what was expected from me or what I could expect. When we walked into the visitation room and I saw the coffin from a distance, I remember how afraid I was. But, once again, I was left to fend for myself, and I had to approach the coffin alone. In the stillness of the moment, I mustered up my courage, and I touched my father. I was terrified that I would be seen because I felt sure that I was being “bad” to touch him. I was so overcome with the smell that I fled the room unnoticed and roamed the funeral parlor, visiting other rooms and
touching other corpses. (Years later I learned that the smell was the embalming fluid, a smell that still today transports me back to my father lying in his coffin.) I think I was trying desperately to figure out what death was all about.

One incident at the time illustrates the devastation I felt and points out how tentatively I stood between childhood and adulthood. The day of the funeral, I went into my mother’s room dressed and ready. She had scarcely noticed me all week, and now suddenly she looked at me and told me to go and change my shoes. I thought that she was joking. I was wearing black pumps with a tiny heel. My mother had bought me the shoes, and they were my first foray into the world of adulthood. I had nothing else that suggested that I was growing up. I remember telling my mother that I wanted to wear those grown-up shoes to the funeral so that I could show my father that I would be a big girl now that he was gone. I begged and pleaded with my mother to let me wear those shoes, and I tried to explain to her that this was the last thing I would ever be able to do for my father. But, she would not listen to me, and once again I was the child who would not be allowed to go to my father’s funeral if I did not change my shoes.

Thus, I never had the chance to show my father that I was grown-up. Snatched from me was the opportunity to do one last thing for him. I realized what the words never again meant, and I experienced untold pain and panic that I was helpless to change anything. I do not know what the shoes meant to my mother, but to me they would have permitted me to become what I thought my father wanted me to be. Attig (1995) noted that bereaved children “are troubled by lost opportunities to complete unfinished business. Most commonly, they long to share anticipated experiences, realize hopes and aspirations for accomplishing something together, utter unspoken words of love and affection, and say goodbyes” (p. 55). He might have been writing about me. I had no chance to say good-bye to my father when he was alive, and even in death this was denied me. I knew that he would never see me graduate from high school, never see me set foot in the world as an adult, and never know what kind of person I would become.

So often in the past forty-nine years, I have harbored regrets that I did not try harder to please my father when I had the chance. I was a child who did not take anything too seriously; my father was there and I thought he always would be. Death was the farthest thought from my mind, and I took my father for granted. There has been much unfinished business with him, and largely because of that, there has also been a mantle of guilt hanging around my neck. I wish so much that I had been a better child. I often think that if I could have made my father happy, he might not have died. Attig (1995) noted that “when bereaved children or adolescents perceive themselves as in any way responsible for the death,
guilt can be excruciating” (p. 55). I have and still do live with much of that guilt. I do not think that I caused my father’s death, rather that I could have, or should have, prevented it.

THE DEATH OF MY CLOSEST FRIEND

When my dearest friend, Evelyn, suffered a stroke a year and a half ago, it was a different story. I became a supporter for her family, and I in turn received their support. Unlike the occasion of my father’s death, this time I was involved in all the arrangements, and in fact I gave the eulogy and assisted in preparing a memory board that was on display at the funeral. Following the service, the family gave me her picture, which had also been on display in the chapel. I was constantly talking with family members and friends, sharing our shock, disbelief, and memories. There was something very healing and very healthy about this stream of reminiscences. In fact, Evelyn’s other best friend and I have developed a very close friendship of our own since Evelyn’s death. Her loss brought us together.

I felt love and protection when Evelyn died; I felt alone and in the way when my father died. Over and over again, when Evelyn died, I talked with family and friends about her. We reviewed her life and her death; we grieved together and we found solace with each other. Unlike during the aftermath of my father’s death, I buried none of my feelings. There was catharsis and there was healing by virtue of communication and sharing and doing together.

Initially, as with my father, I felt shock and disbelief. I wanted to know what had happened, and I needed to know. First, it was the doctors who were so open with me, and then, since I was the only one with a key to Evelyn’s house, I was the one asked to go and look for a will and other papers. In so doing, I had another shock. The friend whom I had always believed to be a happy, well-adjusted, organized, efficient human being turned out to have feet of clay after all. I found bottles of diet pills (speed) and other pills; her papers and affairs were in total disarray, and I saw that the man whom she had always loved abandoned her as she lay in a coma until the second stroke took her two days later.

VISITING AND REVISITING
MY FATHER’S DEATH

When my father died, I felt lost and bewildered. I did not understand anything, and there was no one I could question, no one who would talk to me. I was the fifth wheel. I was a nuisance; I was in the way. I was told only that my father had died of a heart attack in New York. There were no details, and I never even knew where his death took place or the
circumstances. The attitude was that since I was a child, it did not affect me at all. That he was the most important person in my life did not seem to matter to anyone. And, it was not until I was in my fifties, long after my mother too had died, that one of my uncles told me that my father had really died during shock treatment for depression. What hurt the most was that all my cousins and everyone in my family with the exception of my brother and me knew the truth.

At the time of my father’s death, I reacted in a manner fairly typical of a thirteen-year-old, particularly one without any support. “Although grief is personal,” Wolfe and Senta (1995) asserted that “most young people experience common feelings when coping with a death” (p. 204). Night after night, I ran away from home in a desperate attempt to search for him; I needed him so badly. The searching terminated only when I was once again packed off to boarding school, thus precluding any further searching. Nightmares and fantasies of him scratching to get out of his coffin were dealt with by sending me back to bed with the admonishment not to bother my mother any more. Initially, I could not believe that he was really dead. I did not know what dead meant. I did not know where he had gone. I could not make sense out of the chaos of my life. I was unable to concentrate at school, and my marks dropped. I became sad and withdrawn. I was confused, I acted out, I had huge panic attacks, I often became hysterical, and I had moments of uncontrollable rage. Every summer, my mother went to Europe for two months, and every year this engendered terrible panic attacks; I was so afraid that she too would not come back. These behaviors were met with a shot from the doctor or further abandonment, punishment, and rejection. As a result, I went “underground.” I buried my emotions, I buried my grief, I buried my pain, and I buried my father in the dark recesses of my heart. This underground flared up at various times in my life when I revisited my grief, leading to two suicide attempts and long periods of depression during which I was virtually bedridden and immobilized. Without any support or communication, I grew up not knowing what was wrong with me. As John Bowlby (1980) wrote, “sooner or later some of those who avoid all grieving break down…usually with some form of depression” (p. 158).

As I revisit my father’s death in writing this article, I find that I am once again confronted with the confusion and disorganization I experienced at the time of his death. I have written many articles, including a thesis (I have an M.A.), but I have rarely experienced the difficulty I am presently experiencing in trying to organize and write this article. I am back in the chaos of my thirteen-year-old world.

Furman (cited in Wolfe and Senta 1995, 206) identified four factors that interact to hinder or assist a child in the mourning process. Applied
to myself prior to the time of my father’s death, I perceive them as
follows:

First, Furman (cited in Wolfe and Senta 1995) noted the importance
of the individual characteristics of the child. It is my recollection that I was
a fairly typical thirteen-year-old: outgoing, becoming more independ-
ent, involved with my peers, rather carefree, and taking nothing too seri-
ously. Life at school was fun, and I had all the time in the world to take on
the responsibilities of adulthood.

Second, Furman (cited in Wolfe and Senta 1995) spoke of the impor-
tance of the relationship with the deceased. My father was the most
important person in the world to me. I did not see a great deal of him as I
was always away from home, and as he was a businessman, he too was
absent from home a great deal. Nonetheless, he was my anchor, and he
was my protection. My love for literature and learning is one of his lega-
cies to me.

Third, Furman (cited in Wolfe and Senta 1995) considered life stress-
ors prior to the death and following it. In my case, stressors preceding
my father’s death were those of any young adolescent. I was on a teeter-
totter with one foot in childhood and one tentatively on the threshold of
adulthood. I vacillated between the two. I was also in the process of
growing up with all its attendant physical and emotional changes. After
my father’s death, I could not cope with the stress. I was punished and
rejected when I tried to grieve in the only way I knew how. I regressed
when I was expected to be grown-up, and I tried to be grown-up when I
was considered to still be a child.

Fourth, Furman (cited in Wolfe and Senta 1995) considered the impor-
tance of the support provided by family and others. In my case, there
was no support. It was deemed unnecessary because I was only a child,
and children, my mother said, do not have feelings.

GRIEF AS A FOUNDATION FOR
GROWTH AND DEVELOPMENT

Adolescents, like adults, are affected by death and dying. In fact,
according to Wolfe and Senta (1995), “grief is often more traumatic and
severe for a child than an adult. The outcome of their grief is less predict-
able and may be more emotionally crippling because children are build-
ing a foundation for growth and development” (p. 206). In addition,
Wolfe (cited in Wolfe and Senta 1995) described the family unit

as a mobile, with the entire structure changing its shape while trying to
maintain an equilibrium. The “parts” are all interrelated and what affects
one part of the mobile will affect the others. Each “part” will grieve in his
or her own way. (P. 207)
But, I was apart from my family rather than a part of it. When my friend Evelyn died, I felt shock and disbelief, and I was angry that she died with so much unfinished business and without ever finding peace. My anger and sadness that she died with so much turmoil in her life catapulted me back to the time of my father’s death. It made me realize that I too had much unfinished business and much unresolved grief. She opened a door for me, and I walked across the threshold and entered intensive therapy in which I am revisiting my father’s death and mourning his loss. Her death made me aware of my own mortality, and I did not want to die with the unresolved pain with which she died. It made me take a close look at my own life and in particular see the results of my father’s ungrieved death.

McGoldrick and Walsh (1991) suggested that children who lose a parent “may later experience difficulty in forming intimate attachments and may carry catastrophic fears of separation and abandonment” (p. 39). How true this is in my case. I have been engaged three times but was never able to make that final, total commitment. I was too afraid. I was not prepared to love and lose again. I was never able to forge deep and committed relationships with men. The fear of abandonment and loss was too great. There has always been an emptiness, a huge void that I have never been able to fill. Because I was denied permission to mourn, and because my family did not mourn as a family, I became locked in time. As McGoldrick (1991) noted, such people “may become so concerned about potential future losses that they are unable to engage in the relationship they do have fearing that to love again will mean further loss” (p. 52).

I believe that each member of my family in time accepted the reality of my father’s death. Thus, we accomplished Worden’s (1991, 10) first task of mourning. However, each one of us did this independently, and I know that I for one, while accepting his death, never decathedected from him . . . never severed an emotional tie with him. Because we did not speak of my father and because I was given no memento by which to remember him, my memories of my father, like faded photographs, are fuzzy and fragmented. I cannot remember the color of his eyes or the sound of his voice. Only his hands remain fixed in my memory, and I still want those hands to hold me and touch me. I know that he will always remain in my memory, for memories cannot be taken away from me. I also know that I am a part of him, and he a part of me. But, I have yet to integrate him into myself, to let go of an emotional investment in him. Parkes and Weiss (1983) said it best when they wrote,

The amputee has to learn not to step on a foot that is not there, the nearly blind must learn that it is useless to look toward the source of the noise,
and, in like manner the bereaved must stop including the dead person in their plans, thoughts and conversations. (P. 70)

I never had a chance to say good-bye to my father, to complete unfinished business, or to know what his hopes and dreams were for me. I am struggling to decatch from him, but I am so afraid to let go, and it is now fifty years later. How powerful is the unconscious.

THE LOSS THAT IS FOREVER

Grief is not a disease. It is not something we get over without mourning our loss. Even then, it is something that stays with us for the rest of our lives. As Alan D. Wolfelt (1997) wrote, “remembering the past makes hoping for the future possible. Your future will become open to new experiences only to the extent that you embrace the past” (p. 36). I am realizing that surrendering to a process of mourning is allowing me to take in life again. It is ironic that Evelyn’s death reminded me of my own mortality and simultaneously started me on my journey to live my own life and to banish the demons with which I had lived since the death of my father. Once I clear out the unresolved pain from yesterday, I will feel freer and more in control, for I will no longer be governed by the unresolved grief buried in my unconscious. By mourning all my death losses, and working through my grief, I am learning to savor and find meaning in my life. With Evelyn’s death, I realized that “I had lived in the shadow of early loss my entire life” (Harris 1996, xvi).

With Evelyn’s death, I was finally able to grieve. But, what exactly does that mean? Attig (1996) proffered “the idea of grieving as a process of relearning the world” (p. 11). He suggested that while “learning one’s way in the world is familiar . . . it is a short leap to seeing how bereavement disrupts the process of learning our way in the world, demanding we learn new ways of going on without those who have died.” When Evelyn died, I lost my best friend, and I was disillusioned and heartsick that the face she had shown to the world was just a mask, a persona that belied the insecurities and pain that beset her. Her death marked a turning point in my life. In relearning the world, I realized that I had “miles to go before I sleep” (Frost 1947), but I was determined to put my demons to rest and finally to find peace. With a strength I did not know I possessed, I put my hand into my doctor’s hand, and he is leading me through the tunnel from the darkness of the past to the light of the future. It was the death of my father that kept me emotionally age thirteen, and it was Evelyn’s death that allowed me, in fact drove me, to grow emotionally and spiritually and to relearn the world.

If children are to cope with the death of a parent, they must have support and assistance and permission to grieve. Simon and Drantell (1998)
expressed it best when they wrote that “for most bereft children there is a day in time when the world really was ending” (p. 63). It is a day of devastation, a day that divides one’s life into before and after. I remember so many details of that day. Although it happened almost half a century ago, it remains the most vivid day of my life and the day that my life was shattered. The grief of losing a parent always remains a part of the child, and “every new experience is filtered through the lens of loss” (Simon and Drantell 1998). Unfortunately, my mother did not understand or could not accept that I too had suffered a tremendous loss. That I might also be grieving was an untenable thought to her. Regrettably, she was supported in her beliefs by our family physician. When I acted out or ran away, when I became angry or withdrawn, he told her that I was just being bad and should be punished.

Rando (1984) noted that “a child of any age will often exhibit shock, denial, anxiety, distress and anger when confronted with the sudden death of a parent” (p. 160). She pointed out that “anger is often inappropriately labeled as difficult behavior and the child loses support or receives punishment” (p. 161).

One incident that illustrates what little support and understanding I received stands out in my mind. It also underlines how my reactions to the loss of my father were labeled as bad behavior and I was punished. I said that I used to run away frequently in my desperate search for my father. Each time, I was picked up and brought home either by my older brother or by mother’s lawyer. I was punished on each of these occasions. But one time, when our lawyer found me wandering the streets, he picked me up and drove me to a secluded spot. In a loud, angry voice, he told me that I had a choice. I could go back to boarding school, or he would take me to court, charge me with being incorrigible, and I would be sent to reform school where they would beat the badness out of me. I did not even know what incorrigible meant, and I was far too frightened to ask. My father had promised me that I would never again be sent back to boarding school, and this threat just served to exacerbate my feelings of loss, confusion, and loneliness. In the face of this threat, I behaved inappropriately. I began to laugh. It was a terrifying, uncontrollable laughter that echoed the terror, pain, and isolation I felt. Never again did I roam the streets searching for my lost father. In a short time, I was packed off to boarding school, and my childhood as I had known it was over. It was here, at school, that I buried my feelings, buried my pain, and buried my father deep in my heart. And so, the die was cast, and the wound was allowed to fester all my life.

Rando (1984) suggested that “not to assist the bereaved child in actively confronting the death is to predispose him to significant pathology and life-long problems” (p. 155). That was certainly true in my case. Furman (1970) agreed with this and went on to point out that
when a person is unable to complete a mourning task in childhood, he
either has to surrender his emotions in order that they do not suddenly
overwhelm him, or else he may be haunted constantly throughout his life
with a sadness for which he can never find an appropriate explanation.
(P. 76)

For me, it was more than just a sadness. I could never again love another
human being for fear of once more losing the one whom I loved and
reexperiencing the trauma of my father’s death.

All losses are traumatic. Death, the great leveler, changes the mourner
forever; no one who has suffered the loss of a loved one is ever the same. I
believe, however, that the consequences of an adolescent loss are more
devastating than the consequences of a loss at any other stage of life. Cer-
tainly, this is true in my case.

Early loss sets a child on a particular path, and like all roads it has detours
and potholes and smooth patches. It is the road that will lead that child to
become a certain man or a particular woman. Would another road have
been better? Who knows. All we can say is that it would have been differ-
ent. (Harris 1996, xvii)

An adolescent is still developing. He or she is still soft clay that is
being molded and shaped in preparation for his or her life. When light-
ning strikes, as in the death of a parent, that clay undergoes a shock. It is
traumatized and becomes distorted. A child at this age does not have the
resilience to cope with pain and stress alone. Much support and help in
working through this grief is necessary if the child is to grow strong,
healthy, and straight. While the loss of a loved one at any age is traumatic
and devastating, I believe that a childhood loss is the loss that is forever.
A loss in adulthood, if it is worked through, enables one to grow spiritu-
ally and to gain a deeper understanding of the meaning of life. When
that loss happens to a child at age thirteen, the child is not mature
enough and does not have the resources to cope with the loss. Adoles-
cents do not typically think of death . . . in particular, they do not think of
it in terms of a parent’s dying. I know that I took my father for granted.
He was just there, and I never thought it would be otherwise.

I like to think of life as a river meandering out to the sea. In its course
are many currents, eddies, rocks, and other impediments to its journey.
When it encounters a huge boulder or other massive hindrance, its
course is altered, and it never flows as before. An interesting twist or a
curious division may replace what might otherwise have been a gentle
meandering path. It may continue to flourish; it may still provide a home
for fish and other water creatures, but it is not the same river it would
have been had it not encountered this huge obstruction. It may be more
interesting this way, but its shape and its journey have been altered forever.

When an adolescent experiences the death of a parent, her journey in life is altered forever. A death experienced at any age is an overwhelming loss, but when it occurs at the crossroads between childhood and adulthood, its impact is greater, and certainly in my experience it is a loss that is forever: a loss that has changed the course of my life.

CONCLUSION

A family is the most important unit in the world. Even animals have families, and it is through nurturing and trust that each one of us is able to grow up strong and independent. However, if the family fails one at a time of crisis, the reverberations may be felt for many years . . . often for a lifetime. Drop a pebble into a body of water, and it will resonate far beyond its innocuous entrance into the water. And so it is with the death of a member of the family.

Fortunately, I have found a very wise therapist who is guiding me through the tunnel from the darkest days of my father’s death to the light at the end of the tunnel and a future in which I will be free and I can find peace. I am working on clearing out the unresolved pain from yesterday and all the old baggage. I will not love my father less, only differently. I think and I believe that my father would approve of the journey I have undertaken. It is the most difficult and painful path I have ever walked, but like the phoenix, I will arise anew and I will be empowered to have a true and honest encounter with myself and, I hope, with others.

I regret that I could not accomplish the tasks of mourning at the time of my father’s death. I regret the estrangement that existed within my family. I regret that there was no support and communication among us. United, we would have found peace; divided, we each suffered more. As the Bible says,

To everything there is a season,
And a time for every purpose under Heaven:
A time to be born, and a time to die; . . .
A time to break down, and a time to build up;
A time to weep, and a time to laugh;
A time to mourn, and a time to dance. (Eccles. 3:1-4)

Because I never had the opportunity to mourn, I have lived with my unresolved grief for most of my life. Only now am I beginning to see a glimmer of light at the end of the tunnel. I will never forget my father, and he is in my prayers always. One day, I will walk through the valley of the shadow of death, and I hope and I pray that I will meet him again.
REFERENCES


Mary Ann Pathy earned her M.A. in education from the University of Toronto, having taught English and communications at the high school and college level. She has edited
an arts magazine and has been a career counselor. Her interest in grief therapy grew out of personal experience as well as volunteer work. With her therapy dog, she visits patients at a psychiatric hospital at which she found so much depression related to unresolved grief. Ms. Pathy currently is studying bereavement counseling and grief therapy at the Canadian Centre for Bereavement Education and Grief Therapy in Toronto, Ontario.
Reviews & Resources


Rando has brought together some familiar names and perspectives and some very new ones to offer us another outstanding book that will be in the “Rando Treasures Corner” of my library. That is not a light remark but a tribute to a woman of endless insight into, energy for, and devotion to the cause of bereavement care whose high standards equip the standards within ourselves.

This is not just a revisiting of the discussion of anticipatory grief that Rando brought to us in Loss and Anticipatory Grief (Lexington Books, 1986). We have learned a great deal. What has come through is a major rethinking of anticipatory grief, leading to anticipatory mourning. It is more than a change of words. It is also the issuance of something of an alarm, because a lack of understanding of this anticipatory process in past years has caused anguish and complication simply because individuals, and often those (who should know better) providing care, assumed that anticipatory meant getting things in order and eliminating pain and sorrow later. How wrong we often were.

So it is stated early on, “Far too many major changes had taken place in the medical, technological, psychosocial, legal, sociocultural and sociopolitical contexts for anticipatory mourning—and clinical conceptions related to it had been transformed in consequence” (p. 2). Stated in a different way, anticipatory mourning, the right of the griever, can be a useful gift to meet the bereavement challenges of the moment. Whether from within or from others, it can be a coercive power for complication if considered a mandate, a program, or some fix-all for the deep need to mourn.

Rando has touched more deeply, and allowed others to touch more deeply, the significance of both spirituality and religion in how people grieve. It is acknowledged as not only a factor but also a risk factor. We will cite where we are beginning to own that not all spiritual expressions are healthy and that we must be diligent in helping people explore what they perceive as their inner strength. We must do this exploration as discussion/invitation, lest we become additional perpetrators by suggesting that their beliefs or practices are wrong. My regret in this area is that it was not fleshed out more, and there was no significant contribution by active clergy serving in parishes and pastoral care ministries. Doka did a very fine job of introducing it, but clergy continue to miss the mark because they have not claimed their space and they have not addressed their own grief.
issues. What is happening is that academic and clinical perspectives are taking over spiritual care!

While it is the responsibility of all of us, there is a significant measure of expertise (especially with pastoral counselors and chaplains) that can truly more holistically be offered by those who bring the priestly, ministerial, rabbinic, and prophetic viewpoints to the discussion and to the care provided. Clergy are getting passed over, in part due to their silence or indifference, or simply because they stay busy without telling others their story. In this day and time, especially with managed care and its impact on mental health particularly, this is no longer acceptable.

Rando opens with a very thorough treatise on the subject, her very special gift to the reader. She integrates her foundation definitions captured from other books with new twists and perspectives necessary for this book.

Several definitions emerge, though this skilled editor is careful not to impose one definition. The result is that each contributor develops his or her own definition, allowing us to see many viewpoints and many approaches.

The complexity is articulated by Rando:

As the proposed definition implies, anticipatory mourning is not a unitary concept that remains unaffected by person, place, time and experience. Rather, it is multidimensional, occurring across four perspectives (the life-threatened or dying individuals, intimates, concerned others, and caregivers) and three time foci (past, present and future). Its content and course are determined by three classes of influencing factors (psychological, social, and physical) and are subject to two major sources of adaptational demands (experiences of loss and experiences of trauma). The phenomenon involves seven generic operations (grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing, conflicting demands, and facilitating an appropriate death), which are played out on three contextual levels (intrapsychic, interpersonal and systematic). (P.5)

Rando then cites the two goals or outcomes that can result when anticipatory mourning is understood and encouraged: “It offers that person the opportunity to have the best possible experiences in his or her living with illness, dying, and death.” For the people surrounding the ill person, “those intimates are subsequently better able to relate to the ill person and enable him or her to realize whatever would personally constitute a better life with the illness and a more appropriate death” (Weisman 1972, 5).

These definitions are followed by a crucial warning. “Many writers have erroneously interpreted anticipatory mourning as being a process that fully reconciles the survivors with what they will have to contend with subsequent to the death” (p. 6).

The second section of the book is “Anticipatory Mourning from Different Perspectives,” and the concluding section is “Applied Cases,” which includes prenatal diagnosis, chronic illness, HIV/AIDS, Alzheimer’s, ALS or Lou Gehrig’s disease, irreversible coma, the role of advance directives, organ donations, and the human-animal bond.
There are so many noteworthy chapters that require you to read this book. I must make a comment on a few. William M. Lamers, Jr., M.D., a physician and advocate for hospice, has written one of the best chapters I have ever read on the real world of the care of the dying, about physicians who are untrained, hide from death, run from their own mortality, and still must find ways to assume the lead in the quality of care. It is a gripping chapter that we are using here as our workbook to develop better quality care for seriously ill and dying patients. It is a road back to the patient and through the murky waters often muddied by the people who should be the source of clarity and strength.

Doka helps us wrestle with spirituality and religion, giving good definitions that enable us to think, without giving us surefire (they do not exist) definitions or “rules” to surround ourselves with regarding these issues. He helps us build a better link between spirituality and meaning, which is essential, and does well at calling to our attention the issues surrounding spiritual abandonment. We do not talk enough about that. We are reminded that spirituality is a journey, as is our religious expression and experience, so we cannot just look at the moment without “tracing a client’s religious and spiritual beliefs from childhood” (p. 111). Rituals are explained, both for their meaning and their purpose. It should be noted that “the Catholic sacrament of anointing the sick” is catholic in that it is universal, but it is not limited to the Roman Catholic Church. A study of the majority of communions within the Judeo-Christian tradition, as well as many of the other of the world’s religions, will include some ritual of cleansing, anointing, and healing. He closes with the crucial reminder,

Being present at moments in the spiritual struggle is both an honor for caregivers and of value to clients, but it has the potential to take a toll on caregivers. Therefore, they may need to be sensitive to their own spiritual needs. Spiritual resilience becomes as essential as any other aspect of life-style management. (P. 112)

Bill Worden’s “Towards an Appropriate Death” fleshes out the significance of palliative care and helps us integrate it more effectively into the care of the dying and the care of caregivers. It is important to note here, however, that the cutting-edge trends in health care would suggest that palliative care must be what we are about for all of our patients, not just a select few, and we have much to learn about comfort care and pain management.

Pattison’s discussion of the dying process,

acute crisis phase
chronic living-dying phase
terminal phase (p. 27),

is very helpful. Charles Corr, himself a contributor to the book, is included in the introductory remarks for his task-based approach to understanding and interpreting dying. His four areas of task work are physical tasks, psychological tasks, social tasks, and spiritual tasks. Study this further (p. 31). Dale Larson has a crucial discussion of burnout in which he claims that it is not about exhaustion as much as it is about values and meaning (p. 386). He also helps us understand “helper anticipatory mourning” (p. 385).
The Ashtons make a fine contribution in their discussion of chronic/terminal illness or the disability of a child. In it, they give a good look at spiritual issues, especially (using a diagram by Ryan) considering the centrality of our inner strength/spirit. They remark, “Spirituality provides meaning and purpose to this world and one’s place in it. Many individuals successfully nourish their spirituality through formal religious practices and beliefs” (p. 426). From that definition, they courageously address abusive expressions of spirituality and how people become spiritually injured. We must address that if we are to learn how to recognize it but also keep our boundaries (and definitions) clear, lest we become the next abuser.

This book is a very thorough study. It is packed. It will require many readings plus the development of your own index to find the categories of resources that are in the book for when and how you need them. The book will serve you well.

—Richard Gilbert

The World Pastoral Care Center
dick.gilbert@shermanhospital.org

REFERENCE

Instructions for Authors

MISSION

Illness, Crisis & Loss (ICL), sponsored by the Center for Death Education and Bioethics, is a quarterly journal publishing peer-reviewed articles, book reviews, and essays on psychosocial and ethical issues associated with life-threatening illnesses, traumatic crises, and grief and loss. ICL features editorials, research notes, letters to the editor, commentaries, essays, clinical cases, news, and announcements. Occasional theme issues and guest editorials address current issues and policies of interest to readers who are critical thinkers and practitioners involved in psychosocial and ethical issues. ICL is a reflective forum for practitioners, researchers, leaders, and students from a variety of fields whose interdisciplinary insights and perspectives link theory, research, and practice.

MANUSCRIPTS

PROCEDURE AND FORMAT

Submissions, including articles, essays, and news notes, should be sent to the ICL editor. Requests to write a book review should be submitted to the ICL editor or book review editor prior to submitting a review. All submissions are reviewed by at least two referees. Every effort will be made to return reviewers’ comments within two months of submission. After publication, ten tear sheets of the article will be furnished free by the publisher. Additional reprints will be available for purchase.

ICL articles are limited to 5,000 words or twenty pages of manuscript (double-spaced, 12-point type with one-inch margins, including tables, figures, and references), essays to 2,500 words (ten pages of manuscript), and book reviews to 1,000 words (four pages of manuscript). All articles should include an abstract of not more than 150 words. Endnotes and references should follow the text, with tables and figures following on separate pages. To facilitate anonymous review, the name, affiliation, mailing address, phone, fax, and e-mail information of each author should

Illness, Crisis & Loss, Vol. 9, No. 4, October 2001 399-401
© 2001 Sage Publications
be listed on a separate page. Authors are invited to consult articles in current issues of ICL regarding any questions about format.

STYLE AND PERMISSIONS

Prepare manuscripts according to the Chicago Manual of Style, fourteenth edition (Chicago B). Double-space all material, including the abstract, endnotes, references, quotations, appendixes, and tables. Do not use bold or italic type; indicate italics by underlining. Tables and figures should each be on a separate page, grouped together after the reference section. Except for size, all figures will appear as submitted; they must be camera ready. Please do not submit glossies. Pages must be numbered (lower right corner preferred).

Written permission must be obtained from the copyright holder for all quotations over 500 words from any one academic source, for any tables and/or figures taken from a source in which one does not hold the copyright, and for all quotations of any length from newspapers, radio and television broadcasts, magazines, movies, songs, or poems.

CITATIONS AND REFERENCES

Citations in the text should list the author’s last name and year of publication without a comma in between. For example, “Olsen (1993) asserted that . . .” or “Most researchers assert that . . .” (Olsen 1993). If there are more than three authors, use only the first author’s name and et al. in the text. In the reference section, however, all authors’ names must appear, even if there are more than three. For the first author, list last name first, followed by a comma and initials; for other authors, put the initials before the last name. Numbers in the text that identify endnotes should be without parentheses and a half step above text line.

The five examples below are references for books, book chapters, journal articles, government documents, and information from the Internet, respectively:


**SUBMISSION AND QUESTIONS**

Submission to *ICL* implies that the manuscript has not been published elsewhere and is not under consideration by any other journal. Once an article is accepted for publication, authors will be asked to submit it on either a clearly labeled Macintosh or IBM-compatible computer disk. Please do not provide a disk with the initial submission. Please contact the *ICL* editor about *ICL* policy and procedures regarding submissions.

Mail four copies of your manuscript to:

Robert Bendiksen, Ph.D.
Editor, *Illness, Crisis & Loss*
Center for Death Education and Bioethics
Soc/Arc Dept.—435 NH
University of Wisconsin–La Crosse
La Crosse, WI 54601-3742

e-mail: CDEB@uwlax.edu
Fax: (608) 785-8486
Office: (608) 785-6781
INDEX

to

ILLNESS, CRISIS & LOSS

Volume 9

Number 1 (January 2001) pp. 1-160
Number 2 (April 2001) pp. 161-240
Number 3 (July 2001) pp. 241-320
Number 4 (October 2001) pp. 321-404

Authors:

BALK, DAVID E., see Wrenn, R. L.
BERTMAN, SANDRA, “Thinking Out Loud, or What’s a Humanist Like You Doing in a Place Like That?” 70.
BLAKE, DEBORAH D., “‘We Wanted to Include Him’: Personhood in One Hispanic Family’s Experience of the Genetic Illness and Loss of Their Son” [Issues & Commentary], 323.
COX, GERRY R., “Guiding Your Child through Grief, by Mary Ann Emswiler and James P. Emswiler” [Reviews & Resources], 312.
HOWELL, DORIS A., “One Woman’s Travels (Travails) through Thanatology,” 55.

Illness, Crisis & Loss, Vol. 9, No. 4, October 2001 402-404
© 2001 Sage Publications
INDEX 403

Articles:

“Barriers and Facilitators Experienced during My Career: From the Perspective of Being a Woman in the Field of Thanatology,” Martinson, 63.

“A Crossroads,” Foster and Wald, 42.


“It Makes a Difference,” Silverman, 111.


“One Woman’s Thanatological Journey,” Vachon, 129.

“One Woman’s Travels (Travails) through Thanatology,” Howell, 55.


“Thanatology and Human Rights,” Benoliel, 8.

“Thinking Out Loud, or What’s a Humanist Like You Doing in a Place Like That?” Bertman, 70.
“A Woman of Many Abilities,” Sanders, 50.

Issues & Commentary:
“Cancer Care across Two Contexts: A Comparative Approach with Personal Meanings,” Magnuson-Martinson, 163.
“We Wanted to Include Him: Personhood in One Hispanic Family’s Experience of the Genetic Illness and Loss of Their Son,” Blake, 323.

Principles & Practice:
“A Personal Journey through Grief,” Pathy, 381.

Reviews & Resources:
“Guiding Your Child through Grief, by Mary Ann Emswiler and James F. Emswiler,” Cox, 312.

Theory & Research:
“The Cycle of Loss, Grief, and Violence as Exhibited in the Lives of Inner-City Youth,” Kelly, 284.
“Hospice Care and the Bereavement Process in Two Countries: Experience from the United States and the Netherlands,” Wrenn et al., 173.
“Living and Dying in Different Worlds: Gender Differences in Violent Death and Grief,” Stillion and Noviello, 247.