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PARENTAL DEATH IN THE LIVES OF PEOPLE WITH SERIOUS MENTAL ILLNESS

Danson Jones,

McLean Hospital, Harvard Medical School, Boston, Massachusetts, USA

John Harvey,

Department of Psychology, University of Iowa, Iowa City, Iowa, USA

Debra Giza,

McLean Hospital, Harvard Medical School, Boston, Massachusetts, USA

Charles Rodican,

McLean Hospital, Harvard Medical School, Boston, Massachusetts, USA

Paul J. Barreira, and

McLean Hospital, Harvard Medical School, Boston, Massachusetts, USA

Cathaleene Macias

McLean Hospital, Harvard Medical School, Boston, Massachusetts, USA

Abstract

Nearly a fourth (22%) of the participants within a research sample of 148 individuals with serious mental illness reported the death of a loved one as a significant loss, and two thirds of these deaths involved the loss of one or both parents. The key determinant of the severity and duration of grief in response to the death of a parent was whether or not there were extenuating circumstances that complicated the death event, such as co-residence with the deceased at the time of death or a lack of regular social contact with anyone other than the deceased. In all instances of severe or prolonged grief, there was no preparation for the parental death, either through preparatory counseling or practical plans for funeral arrangements, financial repercussions, life-style changes, or residential relocation. Mental health agencies serving people with serious mental illness should begin to incorporate financial and emotional preparation for parental deaths and bereavement counseling as essential services.

The population of people with serious disabilities is growing older. As within the general population, a large “baby-boomer” generation of disabled adults is now entering its fifth decade and facing the multiple life complications characteristic of middle age, inclusive of parental death, divorce, children’s growth into adolescence, anxiety about financial security, and age-related health problems. When combined with a severe disability, such normal midlife concerns can become traumatic, and at times tragic. Concurrent and multiple losses make it difficult to cope with everyday problems or to sustain employment and meaningful life activities, and they can contribute to prolonged grief following the death of a loved one (Rando, 1993).

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Address correspondence to Danson Jones, McLean Hospital, 115 Mill Street, Belmont, MA 02478. djones@mclean.harvard.edu.

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The most universal and inevitable loss experience of middle age is the death of a parent. Death of any close other is associated with a variety of physical and mental disorders, including suicidal ideation and depression (Finley-Jones & Brown, 1981; Prigerson et al., 1997, 1999). Individuals who must deal with the death of a loved one in combination with pre-existing psychiatric disability are especially vulnerable to severe depression and depression-related physical illnesses (Mazure, Bruce, Maciejewski, & Jacobs, 2000; Surtees & Wainwright, 1999). Results of recent research studies underscore the vulnerability of people with serious mental illness to prolonged, severe grief. While a study of grief within a sample of physically disabled and nondisabled adults reported that only 11% had severe grief lasting 10 months or longer after the death of a loved one (Avison & Turner, 1988), a study of psychiatric outpatients reported that nearly a third experienced intense grief lasting an average of 10 years (Piper, Ogrodniczuk, Azim, & Weideman, 2001).

Over and above the emotional experience of severe grief, the loss of a parent or another relative on whom the mentally ill bereaved was financially or functionally dependent may set in motion a cascade of negative events that may not only worsen psychiatric symptoms, but may eventually culminate in serious physical illness (Lyons & Sullivan, 1998), homelessness (Morse, 2000), or even suicide (Peuskens et al., 1997). Factors predictive of prolonged grief in previous bereavement research include a variety of complicating circumstances, inclusive of the burden of dealing with burial and funeral arrangements, loss of income from the deceased, and forced relocation due to loss of residence (Demmer, 2000; Rando, 1993; Richardson & Balaswamy, 2001; Rosenblatt & Karis, 1993). It has been estimated that in New York State alone up to 1,200 individuals a year with serious mental illness are forced to relocate out of their parents' home when the parent dies, most without prior planning or preparation (Grosser & Conley, 1995).

The present study explores experience of parental loss within a representative sample of adults with serious mental illness recruited from a mid-sized city in New England. The purpose of the study was to determine the prevalence of loss due to death of a close other within this research sample, and to assess to what degree parental bereavement in particular affects the lives of people with serious mental illness. Believing that interpersonal loss can only be truly understood from a deeply personal perspective (Harvey, 2002; Harvey & Miller, 1998), we endeavored to place the death experiences of these bereaved individuals in the context of each person's ongoing life, looking both for ways in which he or she was able to endure and ways in which his or her life became nearly unbearable.

Method

Study Sample

The study sample was drawn from a larger research sample recruited for a randomized evaluation of mental health service effectiveness. (i.e., PACT, the Program of Assertive Community Treatment) (Test et al., 1997) versus the clubhouse model based on Fountain House in New York City (Anderson, 1998). The sample for the present study of grief was every participant who remained in the experimental project through at least the 24-month point of service ($N = 148$ of 177 total participants), and the 33 individuals within this 24-month sample who reported the death of a close other as an important life event.

Admission criteria for the research project were (a) age 18 or older; (b) a *Diagnostic and Statistical Manual of Mental Disorder* (4th ed.) diagnosis of serious mental illness, and (c) absence of severe mental retardation ($IQ > 60$). Recruitment was designed by the project's Advisory Council, which worked to ensure that the sample would be representative of persons with serious mental illness in the local community. The residential status of participants at the time of enrollment in the research project reflects the diversity in recruitment, with 54% living

independently, 17% living as a dependent with their family, 10% in the hospital, 13% in supported or assisted-living housing, 3% in jail, and 3% homeless at intake. The study sample was also diverse in age, varying from 18 to 75 years at the time of enrollment, and falling nearly equally above (42%) and below (58%) the age of 40, with an average age of 38. The largest ethnic minority groupings were Hispanic (10%) and African American (10%), and these percentages are comparable to the racial composition of the local population.

Illness Severity and Disability

The study sample was similar to most population descriptions of people with serious mental illness: 55% male, 35% without a high school education, and 80% unmarried at the time of enrollment. One half (52%) of the study participants were diagnosed as having a schizophrenia spectrum disorder, 30% as having major depression, and 18% as having bipolar disorder. The general prevalence of anxiety and depression found in all serious mental illness diagnoses (Hwang & Bermanzohn, 2001) was also evident within our study sample: About half ($n = 72$) of the total sample had formal diagnoses of an affective disorder with psychotic features, while a majority ($n = 76$) of the 90 clients who had formal diagnoses of a schizophrenia spectrum disorder had either a secondary diagnosis of major depression or a baseline assessment of “moderately severe,” to “extremely severe” depressive symptoms. Age of psychiatric illness onset varied greatly, with a fourth of the sample being hospitalized before age 20, a third being hospitalized for the first time in their 20s, another fourth being hospitalized first in their 30s or 40s, and only 4% becoming ill after age 50. Only four participants reported never being hospitalized for psychiatric reasons.

Overall, the sample was very disabled: 90% were on psychiatric medication, and two thirds (70%) were receiving Social Security benefits at the time they enrolled in the project. Approximately 75% of participants in each intervention had not worked in the previous year, and 40% had not worked for pay in at least five years. Disability was attributable to both psychiatric illness and physical health deterioration, with most participants having two or more serious physical problems in addition to a serious psychiatric diagnosis. The most common physical health problems were immobility due to injury or amputation (20%), respiratory disease (19%), cardiovascular problems (18%), and arthritis (14%). About one fourth of the sample reported less debilitating health problems, such as obesity, eating disorders, and gynecological problems, but only 14% of the sample reported being in generally good physical health. A majority of the sample (60%) also had a documented history of serious substance abuse.

In spite of the chronicity of their illnesses, 40% of the study participants were parents, and 28% had minor children living with them. However, social networks of “important others” averaged only 6–7 people, mostly family members, a restriction in social support that is characteristic of people with serious mental illness. Loneliness and social isolation were common complaints during research interviews, and a general lack of friendships and extended family resources made these individuals especially vulnerable to grief following the loss of a loved one.

Collection of Life Story Data

Retrospective interviews were conducted at the end of the mental health services research project to obtain each participant’s interpretation of the relative impact of specific life events in the context of a timeline of all significant life events occurring since enrollment in the project. These interviews were conducted in 1999–2001, 3 to 5 years after each participant’s enrollment ($M = 1,398$ days, $Mdn = 1,456$), depending on date of enrollment.

Prior to each retrospective interview, the researchers provided the interviewer with a list of key life events compiled from the participant’s previous biannual research interviews and

service records collected from 1995–2000. During the interview, the participant was asked to review and augment his or her personal timeline of key life events, adding missing dates and any previously unreported events that were now considered to be significant. Self-ratings of event impact (e.g., global change in emotions or functioning) were recorded on the timeline itself using a Likert scale ranging from 3 (*much better*) to –3 (*much worse*) that ran along the left axis. The interviewer explained that the rating should be relative to how the participant felt his or her life had been going at the time he or she enrolled in the project, and each participant's baseline global self-rating of functioning, expressed as a semantic label (*excellent, good, fair, or poor*), was recorded at the 0 point on the left axis to remind the participant of how he or she had been feeling at the time he or she entered the project. The participant could either mark a rating for each event or choose to simply draw a lifeline reflecting his or her ups and downs over the course of the project in reaction to the various life events so that the intersection of this hand-drawn line with the left axis ratings at the time of the death event would determine the impact rating for the death event. A few participants used both techniques, specifically rating some key events, but then drawing a timeline that visually reflected how their lives had progressed between key events. Of the 33 participants reporting a significant death event, 5 did not have retrospective timelines due to their own death, a move out of state, a refusal to be interviewed, or an inability to complete the timeline task because of substance abuse or cognitive impairment.

A content analysis of the recent life stories depicted by the retrospective timelines was conducted by the first author in collaboration with the interviewer. Those research participants who reported losing a parent during the course of the project were selected for particular attention, both because parental loss is the most common death event reported within the study sample and because parental death provides a context in which to study the dynamics of complicated grief. The life stories of the participants were examined for evidence of situational stressors contributing to complicated grief, and for ways in which the individual was able to mitigate against complicated or prolonged grief.

Results

Prevalence of Death Events

Nearly a fourth (22%) of the 148 study participants spontaneously reported the death of a close relative or friend at some point during the course of the project. The subsample of 33 individuals reporting a death event did not differ from the remaining sample of 115 in regard to any background characteristics, including gender, marital status, diagnosis, ethnicity, education, work history, income, socioeconomic status, or extent of participation in local mental health programs. Like the full sample, the subsample of those reporting deaths as significant life events was primarily middle aged ($M = 41$ years), with about half being over age 40 at the time of the reported death (range: 24–64).

The majority of these deaths (24 of 33) occurred either in the six months preceding enrollment ($n = 3$) or during the research project itself ($n = 21$). Deaths occurring during or immediately preceding the project ($n = 24$) were temporally evenly distributed, with about half occurring before the participant's 24-month anniversary in the project and half occurring between 2 and 4.5 years following enrollment ($M = 2.24$, $Mdn = 2.34$, range = –.5 to 4.5 years). Death dates were available for only 4 of the 9 deaths occurring prior to project enrollment, and these 4 deaths had occurred from 1 to 16 years earlier.

Relationship to the Deceased

In keeping with the fact that the participants were largely middle aged, the relationship of the deceased to the person with mental illness was most often parental. The deceased included

mothers ($n = 11$), fathers ($n = 10$), spouse/partners ($n = 5$), siblings ($n = 5$), and adult children ($n = 2$).

A comparison of research participants reporting parental deaths ($n = 21$) to participants reporting deaths of close others ($n = 12$) showed near equivalence in regard to all background variables, including gender, ethnicity, age, psychiatric diagnosis, history of substance abuse, education, employment history, and socioeconomic status, measured as having either a postsecondary education or having held a white-collar job for more than five years. Participants in the two groups were also equally divided between the two experimental service interventions (PACT and clubhouse), and were equivalent in regard to referral source for the project.

Complicating Situational Factors

Severe or prolonged grief is strongly related to a number of situational factors that make loss more difficult to bear, such as suddenness, co-residence with the deceased at time of death, lack of social support from someone besides the deceased, or other worries about health, housing, or finances (Cox, Bendiksen, & Stevenson, 2002; Rando, 1993). A look at the frequency with which such complicating factors were reported by the research participants (Table 1) reveals that parental deaths overall were less likely to be accompanied by complicating factors than were deaths of relatives or close others.

The parental death group differed significantly from the group reporting deaths of partners, friends, and other family members in regard to one particular situational factor: As would be expected, the deaths of parents were less sudden and more expected, and hence less likely to be accompanied by other life upheavals. Unexpected losses are usually more emotionally intense, and it is the immediate emotional impact of loss that is most predictive of grief duration, both in people with severe depression and normal adults (Amiel-Lebigre & Chevalier, 2002; Ginzburg, Geron, & Solomon, 2002). Suddenness also undermines effective preparation for loss (Barry, Kasl, & Prigerson, 2002; Bauer & Bonanno, 2001), at least when the deceased is not elderly (Carr, House, Wortman, Neese, & Kessler, 2001). For this reason, parental deaths in adulthood are potentially less stressful than the death of a spouse, partner, child, or another close other.

However, about half of the parental deaths (52%) were associated with potentially complicating factors. This nearly even split between parental deaths that were complicated ($n = 11$) versus not complicated ($n = 10$) made it feasible to compare the impact of complicating situational factors on severity of grief as measured by the event ratings in the retrospective interviews. A *t*-test comparison of participants' retrospective ratings of the impact of the death event on their overall life functioning relative to how they had been doing prior to the loss revealed that parental deaths that were accompanied by complicating situational factors resulted in more severe grief than deaths without complicating factors ($t = 2.38, p < .05$), with the average decline in functioning for the complicated grief group being a full point lower than that for the noncomplicated grief group ($M = -2.64$ and -1.40 , respectively). Complicating situational factors also resulted in more prolonged grief. When the participants were defined as having acute versus prolonged grief on the basis of whether or not their self-reports of grief were repeated over the course of a year or longer, 88% ($n = 7$) of the prolonged grief group had complicating situational factors, while only 31% ($n = 4$) of the acute grief group had such complicating factors ($\chi^2 = 6.39, p = .01$).

Clearly, the severity of grief and the bereaved individual's ability to cope with parental loss is dependent not simply on the characteristics of the person her- or himself, but on the absence or presence of complicating situational factors that surround the death event. Parental deaths, which should be more expected, natural, and less stressful than the loss of another close relationship in adulthood, are nevertheless traumatic when complicating factors are present.

This finding offers reassurance that the lives of people with even severe mental illness can be improved if they are better prepared for the deaths of their parents and provided with practical and compassionate help. However, most of the participants who had prolonged or severe grief reactions had not received any type of preparation for their parental loss, and the few who had been contacted by their service agencies rejected the help that was offered. A closer look at the role that situational factors play in a survivor's life suggests that foresight and the augmentation of existing parent support by regular, consistent help from alternative sources could greatly minimize the trauma and grief resulting from parental loss.

Illustrations

The following personal stories depict circumstances typical in the lives of people with serious mental illness. To protect the anonymity of study participants, we have changed their names and identifying characteristics, but each of their stories and the timelines created by the participants themselves remain authentic.

The Role of Caretaker

When the bereaved has been very close to the deceased and in daily contact, loss is often traumatic and long-lasting (Ross, 1997). For this reason, one key situational determinant of the effectiveness of coping with parental death is whether or not the survivor had co-residence with the parent at the time of death. Those individuals who lived separately from their parents, or who had established day-to-day independence, did not grieve as heavily or as long as those who lived with their parents and depended on them. However, in most cases of co-residence between a psychiatrically disabled adult and an elderly parent, there is more interdependence than dependence. Although often enabling and life-affirming, the reversal of caretaker roles when a disabled adult becomes the caretaker of an elderly or dying parent can intensify the interpersonal connection and socially isolate the new caretaker.

Henry is a 42-year-old man diagnosed with schizophrenia who has lived at home with his parents his whole life. Henry had hopes for a professional career before the onset of his illness in his early 20s. He has never married, and still lives in the same house he grew up in. Henry's mother was diagnosed with a terminal illness about one year into the study, shortly after he had taken a job that greatly improved his self-confidence and gave him hope that he could still build a career. Henry had to quit this job to take care of his invalid mother, who died about three years into the study (see Figure 1). He is now taking care of his father, who is dying of emphysema. Henry reports that the devastating loss of his mother and the approaching death of his father have led to financial difficulties, and the house may now have to be sold. Henry reflected that his earlier ability to cope well with his illness and success in finding a job had been built around the stability of home life and the close bond he had with both his mother and father. With this security gone, he is unable to work and is experiencing frequent episodes of acute anxiety and psychotic symptoms. Henry has no close friends, and other family members are not supportive, since they are eager to sell the house. Most of Henry's time is spent alone at home with his father watching television, and he has recently begun drinking heavily.

Loneliness and Isolation

Unavailability of social support generally weakens the ability to cope with any interpersonal loss (Pennebaker, 1990; Spooren, Henderich, & Jannes, 2001), especially when the survivor has few other close relationships (Large, 1989). People with diagnoses of severe mental illness typically have only a few people within their social networks on whom they can call for help in times of crisis, and most of these are family members (Green, Hayes, Dickinson, Whittaker, & Gilheany, 2002; Macdonald, Hayes, & Baglioni, 2000). Unfortunately, adult siblings, while usually compassionate and caring toward their mentally ill brother or sister, are typically unable

to assume the level of care or care oversight typically provided by a parent (Horwitz, 1993). When a dying or elderly parent is the only close relative on whom a disabled individual can depend, complicating situational factors may be more likely to co-occur, and grief may be more severe.

Maria is a 45-year-old woman with schizophrenia who has lived her entire adult life with her parents and has always relied on family support in place of professional help. Her father's death early in the project was a devastating event for her and her mother (see Figure 2). Maria's symptoms grew increasingly worse after the death, and she reports that she stopped taking her medications because she's too sad to cope with life. Her service program has tried to help them, but Maria's resistance to accepting their services has produced conflicts with program staff and resulted in her further isolation. She continues to live alone with her mother, who is in her late 80s and receiving services from a senior center. They are dependent on one another and not doing well. To make matters worse, Maria's cat was recently killed by a car, and she grieves for it as well. Maria has reported feeling depressed and suicidal recently.

Surviving and Moving On

The strongest positive factor in recovery from grief following the death of a loved one is compassionate support from friends and other family members (Harvey, 2002). For this reason, it may be more important to stockpile social and practical resources to ensure survival after a significant interpersonal loss (Hobfoll, 1989) than to try to deal with the grief through introspection or therapy afterward. Finding meaning in the midst of loss (Frankl, 1959) by building new relationships or strengthening old ones may also be the most effective way to recover from the death of someone close, especially if the new relationships encourage compassionate reflection.

Susan, a 42-year-old mother of three minor children with a diagnosis of severe and recurrent depression, was divorced shortly before entering the research project. To survive emotionally and financially, she and her children moved into the home of her parents. A few months later, she was blamed by her husband and his family for the accidental injury of her youngest child, and a custody battle ensued. In the midst of this turmoil, both of Susan's parents died suddenly in an automobile accident. The trauma of this loss, and its close proximity to her divorce, sent Susan into a severe depression. Within a few months, she had lost legal custody of her children to her husband and, soon after, she lost her job (see Figure 3).

Fortunately, Susan had become active in her assigned mental health program, and an outreach call from a staff worker connected her with the practical and emotional help needed to sustain her through these difficult times. With legal aid and help with finding a new job, she began the slow fight in the courts to regain her children. Nearly three years later, Susan won the court battle and had custody of her children again. At the last research interview, four years after her parents' deaths, Susan was still living in her parents' home with her children and making a successful new life as a single-parent family.

Discussion

One may ask, given the severity of the losses described in these stories, how individuals fortunate enough not to be struggling with a severe mental illness might have fared in similar situations. The findings of the present study underscore both the vulnerability of persons with serious mental illness to experiencing complicated grief and the normalcy of severe, prolonged grief in the face of such traumatic life circumstances.

Considering that the majority of individuals with serious mental illness are now middle aged, it is imperative that all mental health service systems begin to incorporate planning for parental

death and bereavement counseling. Bereavement treatments created for normal populations (Finley-Jones & Brown, 1981; Reynolds et al., 1999; Shear et al., 2001; Zimpfer, 1991) should be explored for their appropriateness for use with people who have mental illness, and new interventions need to be created that are tailored to specific types of people and specific illnesses. Likewise, planning for parental death should become an essential service. Similar to the planning services that already exist for families of people with mental retardation (Bigby, Ozanne, & Gordon, 2002; Botsford, 2000; Seltzer & Krauss, 2001), advocacy organizations for people with mental illness, such as the National Alliance for the Mentally Ill (NAMI), are beginning to establish resource networks to provide help in planning for parental death (Hyman, 2001; Lefley & Hatfield, 1999; Smith, Hatfield, & Miller, 2000). These advocacy services are intended to help families avoid the trauma that occurs when disabled adult children are left without essential resources to live without their parents, but such services can also assist with funeral arrangements, transition to supported housing, and practical money management. The middle-aged losses that would otherwise be considered normal consequences of growing older will not become crises in the lives of people with mental illness as long as service systems are willing to adapt to meet the population's changing needs (Hyman, 2001).

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Biographies

Danson Jones is a senior researcher within the Community Intervention Research division of McLean Hospital, Harvard Medical School. Previously, Dr. Jones was assistant superintendent and director of education and training at Richmond State School, Texas Department of Mental Health and Mental Retardation, and assistant dean in the School of Allied Health Sciences at the University of Texas Southwestern Medical Center.

John Harvey is a professor of psychology at the University of Iowa. He is a teacher and an author in the loss and trauma field, as well as the field of close relationships. He is the founding editor of the *Journal of Loss and Trauma*.

Debra Giza is a research interviewer within the Community Services Research division of McLean Hospital, Harvard Medical School, and is also affiliated with the University of Massachusetts Medical School in Worcester.

Charles Rodican is an NIMH grant project director within the Community Intervention Research division of McLean Hospital, Harvard Medical School. Previously, he was a program director and the research administrator of Fountain House in New York City.

Paul J. Barreira is chief of community clinical services and clinical director of the Bipolar and Psychotic Disorders Program at McLean Hospital, Harvard Medical School. Previously, Dr. Barreira was deputy commissioner of clinical and professional services, Massachusetts Department of Mental Health.

Cathaleene Macias is director of community intervention research at McLean Hospital, Harvard Medical School. Dr. Macias is principal investigator of the interdisciplinary “social psychology and services research” NIMH grant that funded the present study.

FIGURE 1.
Event timeline: Henry.

FIGURE 2.
Event timeline: Maria.

FIGURE 3.
Event timeline: Susan.

TABLE 1

Situational Factors Related to Parental Death

Relation to deceased	Co-occurring stressors	Co-residence	Low social support	Sudden death ^a	Any of the 4 factors ^a
Parental (n = 21)	48% (10)	33% (7)	24% (5)	14% (3)	52% (11)
Close other (n = 12)	67% (8)	67% (8)	33% (4)	75% (9)	92% (11)

^aGroup differences statistically significant at $p < .05$.