Published in final edited form as:

Psychiatr Serv. 2004 April ; 55(4): 421–426.

Bereavement in the Context of Serious Mental Illness

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Abstract

Objective—This study examined whether the situational factors that contribute to severe grief in the general population predicted the severity of grief in a sample of persons who had diagnoses of serious mental illness.

Method—Research participants who had a diagnosis of a serious mental illness and who reported the death of a close friend or family member during a five-year service evaluation project were asked to detail the circumstances that surrounded the death and to rate how the death affected their lives. Key research measures included the self-rated measurement of the impact of the death, the self-rated measurement of the duration of the reported grief, and scores on a psychiatric symptom assessment in the six months after the death. A regression analysis tested the cumulative count of four situational factors—residing with the close friend or family member at the time of the death, the suddenness of the death, having low social support, and having concurrent stressors—as a predictor of severe and prolonged grief.

Results—In the sample of 148 individuals with serious mental illness, 33 (22 percent) reported the death of a close friend or family member as a significant life event that resulted in relatively acute and brief grief (15 individuals, or 10 percent) or severe and prolonged grief (18 individuals, or 12 percent). The regression analysis confirmed that the more situational factors that occurred at the time of the death, the more severe the grief reaction was, irrespective of psychiatric symptomatology.

Conclusions—Mental health services for persons with serious mental illness should begin to incorporate preparation for parental death and bereavement counseling as essential services, and such interventions should approach bereavement as a normal rather than a pathological response to interpersonal loss.

Severe grief in response to the death of a close friend or family member is associated with a variety of physical and mental disorders (1–3) as well as with persistent depressive symptoms (4,5). Although the estimated incidence of prolonged, intense grief in the general population is only 11 to 15 percent (6–8), a study found that nearly a third of the psychiatric outpatients who were surveyed were currently experiencing intense grief that had already lasted an average of ten years (9).

A bereaved individual with a preexisting psychiatric disorder is especially vulnerable to depression and depression-related physical illnesses (10,11). However, the etiology of chronic, severe grief appears to be more circumstantial than psychiatric in nature. Maladaptive cognitions—for example, denial, self-blame, and ambivalence—do not appear to lengthen the

grieving process (12–15), but situational factors do. Circumstances that predict prolonged grief include a strong dependence on the close friend or family member before the death, the suddenness of the death, a lack of social support, and co-occurring other stressors (16–27). Co-occurring factors that can intensify grief or lengthen the time of grief include the concomitant loss of health or financial security, forced relocation, the sacrifice of a job to care for the dying person, or the burden of dealing with legal and practical problems related to the death (28–30). The loss of a close friend or relative may set in motion a cascade of negative events that culminate in serious physical illness (31) or even homelessness (32). As a whole, situational factors outweigh psychological factors in predicting prolonged, intensified grief.

Our study explored the prevalence of prolonged, severe grief among adults with serious mental illness who were recruited from a midsized city in New England. We hypothesized that the same situational factors that contribute to chronic, severe grief among the general population would contribute to chronic, severe grief among persons with serious mental illness, more so than the mental illness itself. Because we believe that interpersonal loss is best understood from a personal perspective (33,34), we studied retrospective accounts of 33 bereaved individuals, measuring the impact of death events in the context of other life events and engagement in mental health services.

Methods

Study sample

The research sample was taken from a project that was approved by the institutional review board of Fountain House in New York City, in which participants had been randomly assigned to either an assertive community treatment program (35) or a certified clubhouse program (36). The project was conducted from 1995 to 2000. The subsample used for this retrospective analysis included every participant who had interview data through the 24-month point of service (148 of 177 participants). This subsample was comparable to the total sample on all background characteristics and was similar to most population descriptions of persons with serious mental illness: 90 percent (N=133) were taking psychiatric medication, 80 percent (N=118) were unmarried, 36 percent (N=53) had less than a high school education, and 74 percent (N=110) were unemployed for a year or longer. A total of 51 percent of our participants (N=76) were male, 22 percent (N=32) belonged to an ethnic minority group, 53 percent (N=79) had a diagnosis of schizophrenia. The mean±SD age at enrollment was 38±9.7 years.

Research measures

Self-reported feelings of grief—A variety of criteria distinguish severe grief from other psychiatric diagnoses, including whether the grief was traumatic, prolonged, chronic, or complicated by other losses (3,37–40). Because our study relied on spontaneous subjective reports from research participants rather than on assessments from clinicians, we used only the most unambiguous criteria for severe grief: severity and duration, which Enright and Marwit (41) proposed as the most defining features of severe grief.

At the end of the five-year research study, each participant was asked to review and augment a chart of life events that he or she had spontaneously reported in earlier research interviews. Participants were asked to rate how they were doing at the time of each life event relative to a baseline self-rating by using a Likert scale that ranged from 3, “much better,” to –3, “much worse.” Participants could score each life event listed on the temporal chart, or they could draw a timeline that depicted their ups and downs over the course of the five-year project in relation to the various life events. Event impact was coded as the rating (3 to –3) on the left axis that intersected by the hand-drawn line at the point that the event occurred. Grief severity was measured as the change in the global self-rating from the death event to the immediately

preceding significant life event on each participant's retrospective time-line. If the death occurred before the participant entered the project (N=9), grief severity was measured by using the self-rating that was associated with the first timeline event described by the participant as being directly related to the death—for example, the loss of housing because of the recent death of a parent or spouse. A total of 33 participants reported the death of a close friend or family member; 28 of the 33 participants (85 percent) completed retrospective time-lines that provided measures of the severity of their grief. These timelines were completed three to five years after the participants' baseline interviews (1,398±337 days; median of 1,456 days).

The operational measure of prolonged grief was the repetition in the participants' spontaneous reports of grief that lasted a year or longer—that is, self-reports of grief at two or more six-month interviews or self-ratings that remained 3 or more points lower than the participants' baseline score for a year or longer after the death event. A total of 26 of the 33 participants who had experienced the death of a close friend or family member (79 percent) had follow-up periods of a year or longer between the death and the final interview, which allowed a classification of their grief episode as either brief or prolonged.

When participants were dichotomized on the basis of self-rated severity of grief (a median change in score that was higher or lower than -3) and on the basis of the duration of the reported grief (a period of grief that was less than one year or a year or more) a perfect match was seen between the categories that show the duration of grief and the severity of grief for the 21 participants who had both types of data. All the participants who reported that their grief lasted a year or longer had a self-rating for the death event that was 3 or more points lower than the rating of their immediately preceding event. To retain all 33 participants for statistical analysis, a composite variable was created on the basis of the self-rated severity or the self-reported duration of grief. This coding classified 15 participants (45 percent) as having experienced acute and brief grief and 18 participants (55 percent) as having severe and prolonged grief.

To allow for the severity ratings of the death event that were recorded in the retrospective timelines to be used as a continuous variable, the five participants who did not have severity ratings—because of their refusal to be surveyed, their inability to be contacted, or their own death—were assigned a score on the basis of the duration of grief that was documented in earlier interviews. Participants who fell into the prolonged grief group (N=4) were assigned the median rating for the severe impact group (-3), whereas the one participant who reported grief on only a single occasion was assigned the median rating for the acute grief group (-1).

Psychiatric symptoms

The primary psychiatric diagnosis was derived from medical records that were dated before the death event. Psychiatric symptoms were measured by using the Positive and Negative Syndrome Scale (PANSS) (42) during each biannual interview. Interviewers were trained by Lewis Opler, M.D., an author of the PANSS, and had high rates of interrater reliability for the three subscales: positive ($r=.95$), negative ($r=.89$), and general ($r=.94$).

Our rating of psychiatric symptoms for this study was the PANSS total score for the interview that immediately followed the death event. On average, this PANSS measurement was given three to four months after each death event (139±117 days; median of 100 days). Baseline PANSS scores were used for participants for whom the death event occurred before enrollment in the project.

Grief severity ratings appeared to be distinct from psychiatric symptoms. For the 24 participants who reported deaths that occurred during the project, no correlation was found between grief severity ratings and proximally measured PANSS psychiatric symptoms. In addition, the two groups that had different reactions to grief—acute and brief grief and severe and prolonged

grief—did not differ significantly on their PANSS total scores after the death event (a score of 64.53 ± 10.19 for participants who experienced acute and brief grief compared with 70.55 ± 15.75 for participants who experienced severe and prolonged grief) on any of the three PANSS subscales.

Factors expected to influence grief duration

The four situational factors hypothesized to complicate grief were coded as dichotomous variables and were summed to obtain a total score that ranged from 0 to 4. The four variables included sharing a residence, that is, living in the home of the deceased at the time of the death; the suddenness of death, that is, the death event was unexpected or was attributed by the participant to suicide, drug overdose, accident, acute illness, or homicide; the lack of social support, that is, data collected before the death event indicated that the participant did not have anyone to rely on for emotional or instrumental support except for the close friend or family member; and the co-occurrence of other stressors, that is, a significant negative life event reported by the participant that occurred within a year preceding or following the death event.

Results

Prevalence of bereavement

Nearly a quarter of the 148 study participants (33 participants, or 22 percent) spontaneously reported the death of a close relative or friend during a research interview. The majority of these deaths (24 participants, or 73 percent) occurred in the six months preceding enrollment (N=3) or after enrollment (N=21). Death events that occurred during the project were evenly distributed across the five years that the project lasted (2.59 ± 1 years; range of .5 to 4.5 years). This 16 percent death incidence rate—24 of 148 participants reported that a death event had occurred during the project period—over an average of four years of study participation is comparable to the 19 percent death incidence rate reported for a large nonpsychiatric sample of middle-aged adults in a study that covered a two-year retrospective span (43). The 33 individuals who reported a significant death event did not differ from the remaining 115 individuals in any background characteristics or in the total number of days in which there was any service contact with the assigned program.

Relationship to deceased

In keeping with the fact that the participants were largely middle aged or older, the deceased was most often a parent—that is, a mother (N=11) or father (N=10)—followed by a spouse or partner (N=5), sibling (N=5), or an adult child (N=2). Every participant who reported a death event recounted feelings of sorrow. Change in retrospective self-ratings from the significant life event that preceded the death to the death event ranged from -1 to -6 (-2.61 ± 1.60 ; median of -3), with 55 percent (N=18) of the 33 participants reporting a decline of -3 points or less.

Factors unique to prolonged and severe grief

As Table 1 shows, the only variable in which the group with acute and brief grief and the group with severe and prolonged grief differed significantly was age. Participants with more severe grief tended to be older, although participants in both groups were primarily middle aged. The two groups were also comparable in terms of the time they had spent in the research project, the total number of days in which there was any service contact with the assigned program, and satisfaction with the psychiatric services they had received (44). Also, equivalent numbers of participants who experienced severe grief had been randomly assigned to an assertive community treatment program (N=9) and clubhouse services (N=9).

As can be seen in Table 2, each of the four situational factors had a strong association with the intensity and duration of grief. Individuals for whom any one of the four situational factors accompanied the timing of the death of a close friend or family member were significantly more likely to experience prolonged and severe grief rather than brief and acute grief ($\chi^2=13.750$, $df=1$, $p<.001$).

Although only two participants had to deal with all four extenuating factors, 90 percent of the participants ($N=16$) with severe and prolonged grief reported at least two complicating factors. Three of these factors—lack of social support, residing with the close friend or family member at the time of the death event, and co-occurring stressors—were closely intertwined, with pairings between any two of the three factors occurring equally often. Among participants with severe and prolonged grief, about half of those who reported any one of these three factors had also dealt with a sudden loss.

A cumulative count of 0 to 4 for the four situational factors that are known to escalate grief was used as a measure of the “pile up” of situational distress in each individual’s life (33). This number of situational factors was entered as a predictor variable in a regression analysis that included as control covariates basic demographic variables and a dichotomous measure of socioeconomic status, with high socioeconomic status defined as having worked a white-collar or managerial job for more than five years or having a postsecondary education. Scores on the PANSS (42) administered during the research interview that followed each death event were also included to control for the role that psychiatric illness might play in aggravating or prolonging grief. Other covariates included whether the participant was assigned to an assertive community treatment program or to a clubhouse, the total number of days in which there was any service contact with the assigned program, and the length of time spent in the research project.

Table 3 shows that the full regression model containing all nine covariates was statistically significant and that the number of complicating situational factors and the total number of days in which there was any service contact with the assigned program were both statistically significant predictors of more severe grief, even when the analysis controlled for personal characteristics, psychiatric symptoms, and type of mental health services received. To explore the possibility that time between the death event and the retrospective task of reviewing the chart of life events could have influenced the participants’ recollection of grief, we repeated the analysis, this time including the number of days between the death and the retrospective interview as a covariate for participants for whom we had this data (24 participants, or 73 percent). The timing of the retrospective task was not a significant predictor of how the death event affected the participant, and the level of service use was not statistically significant. However, the number of situational factors remained statistically significant ($\chi^2=7.743$, $p<.01$), as did the model as a whole ($F=3.03$, $df=10, 22$, $p=.036$; adjusted $R^2=.480$).

Discussion

Limitations of the study include the small sample and reliance on participants’ self-reports. Nevertheless, the sample’s normative rate of reported bereavement and the close correspondence between self-reported measures of grief intensity and self-reported measures of the duration of grief provide confidence in the meaningfulness of the study findings. The results of the regression analysis suggest that the same situational factors that are predictive of more prolonged, severe grief in a general population further complicate and burden the lives of people with serious mental illness over and above the burden of psychiatric symptoms. It appears that even if grief is worse for someone who must also cope with psychiatric symptoms, the extent of any individual’s personal grief depends primarily on accompanying situational stressors. Stressors that are usually considered psychological in nature, such as emotional

dependence, may have situational determinants that are often ignored, such as social isolation or residing with the close friend or family member at the time of the death event. Persons with serious mental illness could benefit from knowing that grief is a normal reaction to the loss of a loved one and to cumulative life stress and not necessarily a reflection of their emotional fragility.

The correlation that we found between grief severity and more frequent service contact suggests that individuals with serious mental illness already turn to their service providers when facing bereavement. Because the majority of individuals with serious mental illness are middle aged and have aging parents, it seems imperative that service programs begin to offer practical planning for bereavement as an essential service; this planning can include counseling, help with funeral arrangements, financial planning, or arranging for a move to supported housing (45–48). A closer look at the participants who experienced the death of a parent while they were in the project showed the same strong relationship between accompanying situational stressors and severity of grief that was observed for the sample as a whole, even though the parents' deaths were less sudden overall than other types of bereavement (49). It is hoped that with continued research attention to the development of effective bereavement interventions, persons with mental illness can be empowered to control the situational factors that so powerfully shape their lives.

Acknowledgments

This work was supported by grant R01 MH-060828 from the National Institute of Mental Health, by collaborative agreement SM-51831 from the Substance Abuse and Mental Health Services Administration, and by endowments from the van Ameringen Foundation, the Rhodebeck Charitable Trust, and Llewellyn & Nicholas Nicholas.

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Table 1

Characteristics of and service use among 33 persons with severe mental illness who reported the death of a close friend or family member, grouped by severity of the grief reaction^a

Variables	Acute and brief grief (N=15)		Severe and prolonged grief (N=18)	
	N	%	N	%
Age (mean±SD years)	36.87±6.80		44.56±9.53	
Male	6	40	12	67
Member of an ethnic minority	3	20	4	22
Diagnosis of schizophrenia	7	47	7	39
Diagnosis of personality disorder	4	26	3	16
Baseline total score for the Positive and Negative Syndrome Scale (mean±SD) ^b	67.87±12.00		71.94±15.20	
Education (mean±SD years)	12.00±3.16		11.83±1.72	
High socioeconomic status	7	47	5	28
History of substance abuse	7	47	12	67
Baseline interest in paid work	12	80	16	89
Worked in the five years before the project	8	53	9	50
Total number of days in the project (mean±SD)	1,336±205		1,348±226	
Total number of days in which there was any service contact with the assigned program (mean±SD)	129±109		183±205	
Assigned to the clubhouse model	9	60	9	50
Satisfaction with assigned service at six months ^c	23.86±6.07		25.25±1.72	

^a Age ($t=2.62$, $p=.014$), gender ($\chi^2=2.35$, $p=.13$), all other group differences $p>.20$

^b Possible scores range from 30 to 210, with higher scores indicating more severe symptoms.

^c Satisfaction with the service assignment was measured by using the service satisfaction scale. Possible scores range from 8 to 32, with higher scores indicating greater service satisfaction. Data were missing for one participant in the acute and brief grief group and two participants in the severe and prolonged grief group.

Table 2

Situational factors related to grief intensity and duration among 33 persons with severe mental illness who reported the death of a loved one^a

Situational factor	Grief reaction			
	Acute and brief		Severe and prolonged	
	N	%	N	%
Sudden death of a close friend or family member	2	13	10	56
Was residing with the deceased at the time of death	3	20	12	67
Co-occurring stressors	4	27	14	78
Low social support	1	7	8	44
Any of the four factors	5	33	17	94

^a All group differences statistically significant at $p < .05$

Table 3

Regression analysis of predictors of the severity of grief among 33 persons with severe mental illness who reported the death of a loved one^a

Variable	Standardized beta	SE
Male	-.007	.415
Age	-.113	.026
Member of an ethnic minority	-.269	.585
High socioeconomic status	.214	.442
Score on the Positive and Negative Syndrome Scale after the death event ^b	.255	.019
Assignment to an assertive community treatment program (versus clubhouse)	.02	.497
Number of days in the project	-.062	.001
Total number of days in which there was any service contact with the assigned program ^c	-.398	.001
Number of situational factors ^d	-.675	.183

^aFull Model: $F=4.88$, $df=9, 32$, $p=.001$; adjusted $R^2=.521$

^bPossible scores range from 30 to 210, with higher scores indicating more severe symptoms.

^c $t=-2.554$, $df=9, 32$, $p<.001$

^d $t=-4.568$, $df=9, 32$, $p<.001$