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Utilization of Hospice Bereavement Support by At-Risk Family Members

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Abstract

Approximately 10% of the bereaved are at risk of bereavement-related mental health disorders. Hospices' bereavement services could potentially address needs of many at risk, but little is known about their service use. We analyzed data from 6160 bereaved family members of hospice patients. Risk of mental health problems was identified by hospice providers postloss. Of those characterized as "at-risk," 52% used services compared to 18% of the "low risk." Factors associated with service use among at-risk were female gender and younger age of death. Those who lost a child used services less than other bereaved. Although hospices appear to be skilled at identifying and providing bereavement services to the at-risk, services do not reach almost half. Results suggest the need to improve care access, especially among men and those losing a child.

Keywords

hospice; mental health; risk factors; bereavement; service utilization; family caregivers

Introduction

Bereavement, typically defined as the death of a close loved one, is common, with one study finding that 71% of US community-dwelling adults aged 65 years and older experienced bereavement within a 30-month observation period.¹

For most people, bereavement-related psychological distress naturally resolves over time, and enjoyment of life, purpose, and functioning are restored.² However, a minority (approximately 10%) of the bereaved develop clinically significant mental health problems, most notably depression and prolonged grief disorder (PGD).³⁻⁶ Both depression and PGD have been associated with negative health and mental outcomes, including weight loss,

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increased risk of hypertension,⁷ smoking,⁸ sleep impairment,⁴ and increased risk of suicidal ideation.^{9,10}

Despite the development of effective treatments for both depression and PGD,¹¹⁻¹⁶ less than half of older adults with bereavement-related mental health disorders receive treatment.^{7,17} Underdetection and limited availability of specialty providers have been identified as important reasons for the gap between need for treatment and its use.¹⁸

The purpose of this article is to examine the potential of hospices to lessen this gap. Hospice care involves pain management and symptom control, rather than treatment to cure disease, with the goal of allowing death with dignity and minimal suffering. In 2011, almost 45% of all US deaths were in hospice.¹⁹ Typically, a family member serves as the primary caregiver and helps make decisions for the terminally ill individual. Hospices are required by Medicare to provide bereavement services for 1 year to family members of died hospice patients.²⁰ Nationally, about 71% of hospice provide individual counseling and 51% provide support groups.²¹ Yet, although studies have described bereavement services offered by hospice,^{21,22} and found that about 11% of family members of hospice patients experience PGD and about 13% experience depression within a year after bereavement,^{23,24} little is known about services used by family members at highest risk of negative mental health outcomes.^{25,26}

The current analyses use clinical data collected at a large hospice over a 10-year period from bereaved family members. The analyses examine:

1. How frequently hospices identify those bereaved family members at risk of negative bereavement-related mental health outcomes.
2. Whether bereaved family members who are at risk of negative bereavement-related mental health outcomes receive available hospice bereavement services.
3. Whether any loss-related or sociodemographic factors are associated with hospice bereavement service use among at-risk family members.

Methods

Study Design and Sample

We analyzed deidentified clinical and self-report data on 6160 hospice family members collected from 2003 to 2012 by the Colorado Bereavement Care Project and Colorado's TRU Community Care Hospice (formerly HospiceCare of Boulder and Broomfield Counties). Although the hospice maintained records on a number of hospice patient loved ones (an average of 3 per patient), clinical risk assessments were only administered to those persons considered by hospice staff to be the primary caregiver. Persons identified as primary caregivers differed from other loved ones ($N = 20\,825$) by being more likely to have lost a partner (38.7% vs 13.8%), live in Colorado (91.1% vs 60.6%), be older ($M = 61.79$, standard deviation [SD] 16.14 vs 46.30 vs 21.16) and by the older age of the died loved one (mean age of person who died = 76.44 [SD = 15.02] vs 73.15 [SD 18.25]; all $P < .001$).

The clinical records were augmented with data on service use collected by surveys mailed to bereaved clients at 12- to 13-month point following the loss of their loved one. A total of 1261 individuals answered questions on use of individual or group treatment. Data on how many people were mailed surveys are unavailable, preventing us from identifying the response rate. Hospice staff were able to initially match clinical records to mailed surveys, as both records and surveys originally contained identifying information (eg, name, address). However, after matching records and surveys, hospice staff assigned random identification numbers to both records and surveys. All identifying information was removed before the researchers were given access to the data. This approach also enabled us to ensure that there were no duplicated clients in either surveys or clinical records. Our proposed analyses of deidentified data were reviewed, and found exempt from further review, by the Weill Cornell Medical College institutional review board.

Measures

Sociodemographic and loss-related variables—The clinical records and mailed surveys included data on client's age, client's gender, whether the client lived in Colorado, whom the client lost, and the age of the person who died. Due to small sample size in some categories, an "Other relative lost" was created for those who lost a grandparent, great-grandparent, grandchild, aunt, uncle, niece, nephew, cousin, in-law, or ex-partner.

Bereavement service use—Data on service use came from both clinical records and self-report. Clinical records included variables on whether each client had attended counseling, registered, and attended a hospice support group. The 12- to 13-month mailed survey contained 1 item related to use of groups services: "During this past year, I attended one or more support groups at hospice." (Yes/No).

Based on responses to these items, we created several service use-related dichotomous variables, "Attended individual counseling," "Attended support group," "Attended both individual counseling and group," and "Attended individual counseling or group."

Risk level—The Colorado Bereavement Services Project outlined guidelines for assessing risk which were utilized at TRU Community Care Hospice. Risk assessments were completed by the hospice bereavement counselor or trained volunteer, typically over the telephone within 4 to 6 weeks following the death.

A standardized risk assessment included a list of several factors that are generally considered indicative of high risk for negative bereavement-related mental health outcomes: possible alcohol substance use, history of mental health concerns, suicidal ideation/intent, extreme dependency, extreme anger, guilt or fear, an ambivalent or conflicted relationship with the person who died, a history of family violence, a sense of hopelessness, being estranged or isolated from one's support system, inadequate coping skills, multiples losses, difficulty coping with past losses, traumatic death circumstances, and inadequate financial resources. Determination of risk was based on a combination of a review of the standardized assessment combined with clinical judgment. We grouped "moderate-" and "high"-risk groups into a single "at-risk" category because the small size of the high-risk group limited 3-group comparisons.

Data Analysis

We described the sample characteristics and provision of bereavement services using standard descriptive statistics. We used chi-square and independent samples t tests to assess the risk level, sociodemographic and loss-related variables, and use of bereavement services.

Logistic regression analyses examined the associations between risk level and any service use (group and/or individual support), controlling for relevant sociodemographic and loss-related variables. The final set of logistic regression models examined whether, within the at-risk group only, sociodemographic or loss-related variables were associated with use of any services. Client age was omitted from regressions because >50% of clients were missing these data. State of residence was also omitted from regressions because almost all (96%) of those using services lived in Colorado.

Results

As shown in Table 1, the sample of 6160 bereaved family members was 67.8% female with an average age of 62. The majority had lost a parent (47%) or partner (40%). Almost all (93%) lived in Colorado. Bereavement staff categorized about 20% of family members as “at risk,” with 17% ($n = 1062$) at “medium” and 3% ($n = 154$) at “high” risk.

In total, 25% of the sample ($n = 1515$) used either group or individual hospice bereavement services and 5% used both (Table 2). In unadjusted analyses (Table 3), family members at high or medium risk of negative bereavement-related mental health outcomes were significantly younger and more likely to be female than low-risk family members. At-risk family members were also more likely to have lost a child and have lost a younger relative (all $P < .001$).

In unadjusted analyses (Table 3), at-risk family members were more likely than low risk to use both individual and group counseling. Of the at-risk family members, 52% used services compared to only 18% of those with low risk ($P < .001$).

In adjusted analyses, risk level remained associated with service use ($P < .001$), even when controlling for age of the person who died, type of loss, and gender of the family member. The at-risk were almost 5 times more likely to utilize services than the low risk (Table 4).

Finally, in adjusted analyses (Table 5) conducted only among at-risk family members, factors associated with higher service use (all $P < .05$) included female gender and younger age of the person who died. Those who lost a child were least likely to use services.

Discussion

A significant minority of bereaved adults develop clinically significant mental health problems. Despite the development of evidence-based treatments for bereavement-related mental health problems, few individuals receive these services. Our data suggest that hospices are well positioned, and already have the basic infrastructure needed, to increase access to evidence-based care for postbereavement depression and PGD. They also suggest that hospices are distributing services appropriately, as those family members characterized

as “at risk” for negative bereavement-related mental health outcomes were significantly more likely to utilize group or individual support, even when controlling for other factors that might influence service use, such as gender and type of loss.

Yet, despite evidence that hospices have the infrastructure to deliver bereavement-related mental health services, the services are not utilized by almost half of those identified as at risk. The few identified studies of help seeking in family members of died hospice patients found that reasons for avoiding formal bereavement support included not seeing the use in participating, not thinking that help was needed beyond family and friends, feeling that available services didn't fit needs or interests, and being uncomfortable talking to others about their problems.^{25,26} Future efforts might address some of these barriers, with efforts to enhance perceived need and increasing comfort level in discussing problems especially important.

The association found between gender, caregiver's age, died person's age, and service use is also consistent with previous literature.^{26,27} Our finding that child loss was associated with less use is novel. However, literature on child bereavement has identified several unique components of this type of loss, including increased levels of guilt and additional poor health outcomes, all of which could impact help-seeking behaviors. Moreover, child loss is a risk factor for poorer bereavement outcomes, including posttraumatic stress disorder and PGD.^{3,28} Avoidance is a key component of both conditions,²⁹ and this might include avoidance of treatment in the year after the death.

The greatest limitation of this study is reliance on clinical administrative data, which do not allow for the same level of detail as data collected in a research survey. Data on number of sessions attended are available for some of the bereaved family members but was missing for the majority and was therefore not analyzed here. Data on how risk was determined were not available; although hospice staff used a risk assessment checklist to help determine high risk, we did not have access to the checklist. As these determinations were somewhat subjective, risk ratings may have varied substantially by hospice provider. Neither the survey nor the clinical reports included items assessing PGD or depression in particular, and the at-risk group may have included other problematic bereavement reactions. Future studies could attempt to gather data on all of these details.

Nonetheless, this study appears to be the largest to date to examine hospice bereavement service use by family member risk level and the only identified study to gather data on hospice bereavement service over a lengthy (10-year) period. Although the data were collected for clinical purposes and not research, several factors suggest their utility. First, the prevalence “at-risk” categorization of bereaved family members (about 20%) is similar to the rates of depression and PGD found in other hospice samples using evidence-based screens (13%-20%). Also, factors associated with risk are consistent with previous literature, which found that female gender, younger family member age, and type of relationship with the person who died may have an impact on bereavement outcomes.^{3,28,30} Third, the utilization of group or individual bereavement support (about 25%) is similar to that found in smaller samples in other regions of the country.^{25,26}

There are also many additional factors that have been found to be associated with service use for bereavement which we did not have access to in this clinical data. These include lower religiosity,³¹ lower family and friend support,^{32,33} African American race,²⁷ witnessing highly distressing events pertaining to the patient's death, having assisted the patient with more instrumental activities of daily living prior to the patient's death, and physician communication with the caregiver about the patient's prognosis before the patient's death.²⁶ Other variables associated with lower levels of support seeking in general population samples, and which may also apply to bereavement support seeking, include poorer health,³⁴ lower socioeconomic status,³⁴ lower educational attainment,³⁵ attachment style,³⁶ mobility constraints, lack of matching of services to preferences and needs, and stigma.^{34,37-43} The role of these factors in hospice service support seeking could be examined in future large-scale studies.

Implications

Data from a large hospice in Colorado indicate that they are experienced in screening and providing bereavement services to family members at risk of negative bereavement-related mental health disorders. However, at-risk family members are still underutilizing services. Results suggest both the potential and need for collaboration with hospices to improve access, delivery, and engagement of evidence-based bereavement care for at-risk bereaved. Results also help identify subpopulations of at-risk family members who might have an especially large gap in services. Engagement efforts could be targeted to at-risk family members who are male, lost a child, and lost an older relative.

Previous studies of bereaved family members of hospice patients indicate that engagement efforts could focus on enhancing perceived need and decreasing stigma around bereavement service use.^{25,26} Several interventions have been developed to address these factors in older adults with depression (eg,⁴⁴⁻⁴⁶) and could be adapted for bereaved hospice family members.

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Table 1Sociodemographic and Loss-Related Characteristics of Family Member Sample.^a

	Mean (SD)	Range
Family member age (3492 missing)	61.88 (16.12)	3-97
Died person's age (47 missing)	61.13 (14.89)	0-107

	n	%
Gender		
Female	4176	67.8
Male	1828	29.7
Missing gender	156	2.5
Where family member lives		
In Colorado	5615	93.1
Out of Colorado	533	8.7
Missing residency data	12	0.2
Loss type		
Parent	2906	47.2
Partner	2441	39.6
Child	183	3.0
Sibling	257	4.2
Other relative	373	6.0
Risk level		
High	154	2.5
Medium	1062	17.2
Low	4944	80.3

Abbreviation: SD, standard deviation.

^aN = 6160.

Table 2Hospice Bereavement Service Use in Family Member Sample.^a

	n	%
No services used	4637	75.3
Individual counseling alone	645	10.5
Attended group alone	550	8.9
Attended both individual counseling <i>and</i> group	328	5.3
Attended individual counseling or group	1523	24.7

^aN = 6160.

Table 3

Sociodemographic, Loss-Related Characteristics, and Hospice Bereavement Service Use of Family Member Sample, by Risk Level for Negative Bereavement-Related Mental Health Outcomes.^a

	Low risk for negative mental health outcomes (n = 4944)		At risk for negative mental health outcomes (n = 1216)		Test-value (<i>t</i> test or chi-square), <i>P</i> value
	M	SD	M	SD	
Family member age (missing)	63.40	15.75	56.84	16.33	9.00, <i>P</i> < .001
Died person's age (missing)	77.85	13.99	71.03	17.07	12.80, <i>P</i> < .001
	Low risk for negative mental health outcomes (n = 4944)		At risk for negative mental health outcomes (n = 1216)		Test-value (<i>t</i> test or chi-square), <i>P</i> value
	n	%	n	%	
Female	3287	67.9	889	76.2	30.58, <i>P</i> < .001
Lives in CO	4492	91.0	1123	92.6	2.98, <i>P</i> = .084
Loss type					31.91, <i>P</i> < .001
Parent	2356	47.7	550	45.2	2.30, <i>P</i> = .129
Partner	1961	39.7	480	39.5	0.015, <i>P</i> = .903
Child	121	2.4	62	5.1	12.80, <i>P</i> < .001
Sibling	206	4.2	51	4.2	0.002, <i>P</i> = .966
Other relative	300	6.1	73	6.0	0.01, <i>P</i> = .932
Service use					726.95, <i>P</i> < .001
No services used	4058	82.1	579	47.6	
Individual counseling alone	322	6.5	323	26.6	
Attended group alone	396	8.0	154	12.7	
Attended both individual counseling and group	168	3.4	160	13.2	
Attended individual counseling or group	886	17.9	637	52.4	622.86, <i>P</i> < .001

The boldface values indicate statistically significant *p* values.

Abbreviations: M, mean; SD, standard deviation.

^aN = 6160.

Table 4

Association Between Risk Level for Negative Bereavement-Related Mental Health Outcomes and Hospice Bereavement Service Use in Logistic Regression, Controlling for Sociodemographic, and Loss-Related Factors.^a

	B	SE	AOR	95% CI	P value
At risk	1.503	0.073	4.495	3.894-5.190	.000
Control variables					
Died person's age	-0.038	0.003	0.963	0.958-0.968	.000
Female	0.426	0.075	1.532	1.322-1.775	.000
Loss type ^b					
Child	-1.490	0.220	0.225	0.146-0.347	.000
Parent	-0.272	0.073	0.762	0.660-0.879	.000
Sibling	-0.522	0.165	0.593	0.429-0.820	.002
Other relative	-0.055	0.151	0.947	0.705-1.272	.715
Constant	1.225	0.195	3.403		.000

Abbreviations: B, bereavement; SE, standard error; AOR, adjusted odds ratio; CI, confidence interval.

^aN = 6160.

^bReference group is loss of a partner.

Table 5

Variables Associated With Hospice Bereavement Service Use in Family Members At Risk for Negative Bereavement-Related Mental Health Outcomes in Logistic Regression.^a

	B	SE	AOR	95% CI	P value
Died person's age	−0.023	0.005	0.978	0.969-0.987	.000
Female	0.402	0.145	1.495	1.126-1.985	.005
Loss type ^b					
Child	−0.866	0.330	0.421	0.220-0.804	.009
Parent	−0.211	0.137	0.810	0.619-1.060	.125
Sibling	0.128	0.330	1.137	0.595-2.171	.697
Other relative	0.087	0.286	1.091	0.623-1.912	.761
Constant	1.538	0.335	4.656		.000

Abbreviations: B, bereavement; SE, standard error; AOR, adjusted odds ratio; CI, confidence interval.

^aN = 1216.

^bReference group is loss of a partner.