Bereavement Challenges and Their Relationship to Physical and Psychological Adjustment to Loss

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Abstract

Objective: The psychosocial challenges confronted by bereaved survivors may contribute to poor bereavement adjustment. Measures of the challenges of bereavement are limited. This study is a preliminary examination of the factor structure of a new measure of bereavement challenges and their relationships to quality of life and mental illness in bereaved cancer caregivers. This measure was designed to identify intervention targets to reduce the likelihood of prolonged grief.

Methods: Caregivers of advanced cancer patients were administered measures of bereavement challenges (Bereavement Challenges Scale, BCS), quality of life (Medical Outcomes Study Short Form-36), prolonged grief (PG-13), and mental disorders (Structured Clinical Interview for the DSM-IV). Principal component factor analyses identified the underlying factor structure of the BCS. We examined associations between the factors and caregiver quality of life, prolonged grief, and rates of mental disorders.

Results: A factor analysis identified five factors: “Challenges with Connecting with Others,” “Challenges with Change,” “Challenges Imagining a Hopeful Future,” “Challenges with Accepting the Loss,” and “Challenges with Guilt.” Greater endorsement of bereavement challenges was associated with worse quality of life, more severe symptoms of prolonged grief, and greater likelihood of meeting criteria for a mental disorder.

Conclusions: Assessing the challenges associated with bereavement is important to understanding barriers to bereaved individuals’ adjustment. The five factors of the BCS point to potential targets for clinical intervention. Additional research on the BCS is needed, including validation in larger more diverse samples, and confirmation that reduction of these challenges is associated with less psychiatric morbidity and, specifically, symptoms of prolonged grief.

Keywords: bereavement; cancer; mental health; oncology; prolonged grief; quality of life

Introduction

THE DEATH OF A LOVED ONE is among the most stressful of life events, associated with numerous poor physical and psychological outcomes.^{1–3} Bereaved individuals are at increased risk for serious physical illness^{4,5} (e.g., cancer,⁶ myocardial infarction⁷) relative to nonbereaved individuals. Bereaved individuals also report higher rates of healthcare utilization than nonbereaved individuals,⁴ including a greater number of visits to primary care^{8,9} and higher rates of hospitalization.^{9,10}

Bereaved individuals also report worse quality of life,^{11,12} experience decrements in mental health,¹³ and report greater distress than nonbereaved individuals.^{12,13} Up to 44% of bereaved individuals are at risk for a mental disorder.^{14–16} Bereaved individuals are also more likely to report suicidal ideation than nonbereaved individuals with up to 31% of bereaved cancer caregivers reporting suicidal thoughts in the previous year.¹¹ Bereaved individuals visit mental health providers^{8,9} and use psychotropic medication at higher rates compared with nonbereaved individuals.^{8,9}

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Approximately 10–15% of individuals bereaved from natural deaths in later life experience Prolonged Grief Disorder (PGD). PGD is characterized by intense yearning for the deceased and related impairment that persists more than six months after the loss.^{17,18} Prolonged grief has been associated with increased risk for anxiety,^{19,20} major depressive disorder (MDD),¹⁷ and suicidal ideation.^{17,21,22} Prolonged grief is also associated with worse physical health over time,⁵ including more frequent headaches and flu symptoms,²² greater pain,²³ and elevated systolic blood pressure.²²

Numerous psychosocial challenges impede adjustment in the wake of a significant interpersonal loss. These challenges may include interpersonal pressure from others to “move on” before the bereaved individual is ready²⁴ or learning to socialize as a single person within a social network of couples.²⁵ Functional challenges may include the assumption of new responsibilities that had been performed by the deceased (e.g., cooking).²⁵ Psychological challenges such as the loss of identity conferred by the relationship with the deceased (e.g., no longer a spouse/partner) can prove another barrier to bereavement adjustment.²⁴ Cognitive challenges such as negative beliefs about the self, others, and one’s own grief are associated with worse mental health in bereaved individuals.^{26,27}

Understanding how these challenges relate to bereaved individuals’ physical and mental health has significant clinical implications. The Bereavement Challenges Scale (BCS) represents an initial attempt to quantify the challenges experienced by bereaved individuals. The purpose of this study is to conduct a preliminary examination of the factor structure of the BCS and its relationships with quality of life and mental illness in a sample of bereaved cancer caregivers. We hypothesize that more severe challenges in bereavement will be associated with worse quality of life and greater risk for a mental disorder in recently bereaved individuals.

Methods

Participants and procedures

The present study examined the bereavement responses of caregiver participants in the Coping with Cancer (CwC) study. CwC is a National Cancer Institute (NCI)- and National Institute of Mental Health (NIMH)-funded prospective, longitudinal, multisite study of terminally ill cancer patients and their informal or unpaid caregivers. Patients and caregivers were recruited from September 2002 to February 2008 from the Yale Cancer Center (New Haven, CT), Veterans Affairs Connecticut Healthcare System (West Haven, CT), Simmons Comprehensive Cancer Center (Dallas, TX), Parkland Hospital Palliative Care Service (Dallas, TX), Dana-Farber Cancer Institute (Boston, MA), Massachusetts General Hospital (Boston, MA), and New Hampshire Oncology-Hematology (NHOH). Approval was obtained from the human subjects’ committees of all participating centers; all enrolled participants provided written consent and received \$25 for their participation.

Caregivers were identified by patients as the individual providing most of their unpaid care. Patients and caregivers completed a baseline face-to-face interview administered by trained research staff. Caregivers of patients who died during the study observation period were interviewed again in English or Spanish, a median of 6.34 months following the patient’s death. The present study utilizes demographic

characteristics assessed during the baseline interview and survey data from the second interview conducted with caregivers after the patient’s death. Data from 162 bereaved caregivers with complete data on study measures were analyzed in the present report.

Measures

Sample background characteristics. Patient characteristics included self-reported age, gender, race, education, religious affiliation, and insurance status. Caregiver characteristics included self-reported age, gender, race, education, religious affiliation, and the caregiver’s relationship to the patient.

Bereavement challenges. The BCS is a 35-item measure assessing challenges confronting bereaved individuals. Each item is rated on a five-point scale from “not at all” (1) to “a great deal” (5). BCS development involved (1) extensive review of the literature to develop content and (2) presentation of initial BCS items to a small sample of bereaved individuals to obtain feedback on content validity. One item focused on the development of new romantic relationships (“I worry about what others would think of me if I started to date again”) was dropped in the present analysis due to its lack of relevance to caregivers grieving relationships that were not romantic.

Health-related quality of life. The Medical Outcomes Study Short Form 36 (SF-36) was used to assess caregivers’ health-related quality of life (HRQOL). The SF-36 is a 36-item measure and consists of the Physical Component Summary Score (PCS; Cronbach’s $\alpha = 0.96$) and the Mental Component Summary Score (MCS; Cronbach’s $\alpha = 0.92$). All items were linearly transformed to a 0–100 scale with higher scores indicating better HRQOL.²⁸ The SF-36 has adequate reliability and validity,²⁸ including among caregivers of advanced cancer patients.^{29,30}

Prolonged grief. The PGD Scale (PG-13) assessed caregivers’ severity of prolonged grief symptoms at approximately six months postloss.^{17,31} Items were rated on a five-point scale and responses to the 11 Likert-scale items were summed to create a total PGD symptom severity score (Cronbach’s $\alpha = 0.88$) with higher scores indicating more severe levels of PGD symptomatology. Only a subset of the full sample ($n = 65$) was administered the PG-13. Analyses of the relationship between the BCS and grief are limited to this subset.

Mental disorders. The Structured Clinical Interview for the DSM-IV (SCID) Axis I modules³² was used to diagnose MDD, post-traumatic stress disorder, panic disorder, and generalized anxiety disorder in the past month. The SCID was administered by an interviewer trained to an acceptable standard ($\kappa > 0.85$). Participants were dichotomized into those who met criteria for at least one disorder and those who did not meet criteria for any disorder.

Statistical analyses

Thirty-four BCS items were included in an exploratory principal component factor analysis with varimax rotation.

BCS factors with eigenvalues greater than one and three or more items with factor loadings greater than 0.40 were included in further analyses. Decisions regarding items with factor loadings greater than 0.40 on multiple factors were made based on theory and consensus of team members. Subscale scores were created by averaging item responses.

Pearson correlation coefficients were used to examine relationships among BCS subscales and between the BCS subscales and caregiver and patient characteristics. Linear regression analyses were used to examine relationships between BCS subscales and quality-of-life dimensions (continuous outcomes). Logistic regression analyses were used to examine relationships between BCS subscales and mental disorders (dichotomous outcome). Base models regressed each outcome (i.e., physical quality of life, mental quality of life, grief, and mental disorders) on the BCS subscales separately. In models adjusting for confounders, caregiver and patient characteristics associated with the BCS subscale ($p < 0.05$) were added to the base models. All statistical inferences were based on two-sided tests with $p < 0.05$ considered statistically significant.

Results

Exploratory factor analysis

Five BCS factors consisting of 31 items had eigenvalues greater than one, and three or more items with factor loadings greater than 0.40, meeting the criteria for inclusion in further analyses (Table 1). The first factor, "Challenges with Connecting with Others," explained 37.03% of the total variance and included 10 items. The second factor, "Challenges with Change," explained 8.34% of the variance; factors loadings were highest for eight items. The third factor, "Challenges Imagining a Hopeful Future" included five items and explained 5.92% of the variance. The fourth factor, "Challenges with Accepting the Loss" explained 4.80% of the variance and included three items. The fifth factor, "Challenges with Guilt" explained 4.47% of the variance and included five items. A subscale score was calculated for each factor. Correlations among subscales ranged from $r(162) = 0.40$ to $r(162) = 0.67$.

Characteristics of bereaved individuals and their associations with BCS subscales

Bereaved individuals in the sample were primarily female ($n = 118$, 77.1%), white ($n = 105$, 69.5%), and Christian ($n = 117$, 77.0%) with an average age of 52.71 years ($SD = 13.12$) and 13.61 years ($SD = 3.79$) of education (Table 2). Caregivers had been bereaved an average of 6.64 months ($SD = 1.39$, range = 2.53–13.63).

"Challenges with Connecting with Others" ($M = 1.21$, $SD = 0.48$, Cronbach's $\alpha = 0.91$) and "Challenges with Change" ($M = 1.73$, $SD = 0.79$, Cronbach's $\alpha = 0.85$) were negatively associated with white race and education and positively associated with being the spouse of the patient. "Challenges Imagining a Hopeful Future" ($M = 1.61$, $SD = 0.75$, Cronbach's $\alpha = 0.84$) was positively associated with spousal relationship to the deceased and age and negatively associated with education. "Challenges with Accepting the Loss" ($M = 2.52$, $SD = 1.17$, Cronbach's $\alpha = 0.82$) was positively associated with spousal rela-

tionship and negatively associated with academic site for patient care. "Challenges with Guilt" ($M = 1.27$, $SD = 0.50$, Cronbach's $\alpha = 0.77$) was positively associated with spousal relationship with the deceased. The total BCS score ($M = 1.55$, $SD = 0.54$, Cronbach's $\alpha = 0.94$) was negatively associated with white race and education and positively associated with spousal relationship.

Characteristics of deceased patients and their associations with BCS subscales

Patients were primarily white ($n = 109$, 69.4%) and Christian ($n = 116$, 73.9%) with 50.3% ($n = 79$) male (Table 3). Two-thirds of the patients ($n = 101$, 66.0%) had health insurance. Patients' average age at the baseline survey was 59.97 years ($SD = 12.55$) with an average of 12.97 years of education ($SD = 4.08$).

"Challenges with Connecting with Others" was negatively associated with white race, being insured, and education. "Challenges with Change" was negatively associated with white race, being insured, and age. "Challenges Imagining a Hopeful Future" was negatively associated with female gender. "Challenges with Accepting the Loss" was negatively associated with age. "Challenges with Guilt" was negatively associated with female gender and age. The total BCS score was negatively associated with female gender, white race, being insured, and age.

BCS subscales as predictors of quality of life and mental disorder

In separate base linear regression models, higher scores on "Challenges with Connecting with Others" ($B = -0.31$, $p < 0.001$; Table 4), "Challenges with Change" ($B = -0.23$, $p < 0.01$), "Challenges Imagining a Hopeful Future" ($B = -0.47$, $p < 0.001$), and the BCS total score ($B = -0.33$, $p < 0.001$) were associated with worse physical HRQOL. These relationships remained significant after controlling for confounding caregiver and patient characteristics. The relationship between "Challenges with Guilt" and physical HRQOL was significant in controlled analyses ($B = -0.18$, $p < 0.05$; Table 4).

In separate base linear regression models predicting mental HRQOL, higher scores on "Challenges with Connecting with Others" ($B = -0.56$, $p < 0.001$; Table 4), "Challenges with Change" ($B = -0.60$, $p < 0.001$), "Challenges Imagining a Hopeful Future" ($B = -0.61$, $p < 0.001$), "Challenges with Accepting the Loss" ($B = -0.48$, $p < 0.001$), "Challenges with Guilt" ($B = -0.44$, $p < 0.001$), and the BCS total score ($B = -0.68$, $p < 0.001$) were associated with worse mental HRQOL. These results remained significant after controlling for caregiver and patient characteristics.

In separate base linear regression models predicting prolonged grief, higher scores on "Challenges with Connecting with Others" ($B = 0.54$, $p < 0.001$; Table 4), "Challenges with Change" ($B = 0.70$, $p < 0.001$), "Challenges Imagining a Hopeful Future" ($B = 0.59$, $p < 0.001$), "Challenges with Accepting the Loss" ($B = 0.74$, $p < 0.001$), "Challenges with Guilt" ($B = 0.59$, $p < 0.001$), and the BCS total score ($B = 0.84$, $p < 0.001$) were associated with higher levels of grief. These results remained significant after controlling for caregiver and patient characteristics.

TABLE 1. FACTOR ANALYSIS OF THE BEREAVEMENT CHALLENGES SCALE (N=162)

<i>BCS item</i>	<i>BCS factor eigenvalue (%variance explained)</i>			
	<i>Challenges with connecting with others 12.59 (37.03)</i>	<i>Challenges with change 2.84 (8.34)</i>	<i>Challenges imagining a hopeful future 2.01 (5.92)</i>	<i>Challenges with accepting the loss 1.63 (4.80)</i> <i>Challenges with guilt 1.52 (4.47)</i>
Rotated factor loadings				
I believe that my life will never be as meaningful again.	0.17	0.10	0.69	0.51
I believe that my life will never be as happy or enjoyable again.	0.04	0.24	0.70	0.48
This death hurt me and I don't want to be hurt like this again.	0.13	0.68	0.12	0.13
I worry about getting close to someone only to lose him/her again.	0.41	0.45	0.32	0.11
It is hard to trust people since the death.	0.53	0.25	0.20	0.18
I believe that it's too late for me to try new things or develop new relationships.	0.27	0.25	0.74	0.07
I am afraid of the unknown.	0.32	0.12	0.50	0.16
I don't like to have to change the way I do things.	0.26	0.45	0.34	0.16
I believe that I'm too old to start over or start a new life.	0.14	0.31	0.71	-0.04
I'm so emotional that people don't want to spend time with me.	0.70	0.09	0.32	-0.03
I depress people who spend time with me.	0.85	0.16	0.12	0.06
I'm so angry about the death that it is unpleasant for others to be around me.	0.88	0.10	0.12	0.07
I have trouble feeling close to people since the death.	0.67	0.27	0.21	0.37
None of the new people I meet is as good as the one who died.	0.17	0.66	0.15	0.16
Other people don't understand what I'm going through.	0.27	0.53	0.24	0.07
The pain of missing [the deceased] is all that I have left of the relationship and I'd rather be miserable than give that up.	0.59	0.40	0.33	-0.002
I'm not ready to let him/her go.	0.14	0.20	0.29	0.74
I still need him/her.	0.02	0.37	0.29	0.59
A part of me feels like s/he is not really gone.	0.09	0.15	0.05	0.74
I'll never have a relationship as meaningful again, so socializing with others is not worth the effort.	0.27	0.44	0.37	0.09
No one will ever love, value, or understand me as much as [the deceased].	0.06	0.75	0.25	0.20
I'm too busy caring for my family and running the household by myself to engage in new activities or focus on my own needs.	0.42	0.53	0.02	0.34
I worry that I will forget the person I lost, especially if I get too busy with other things.	0.08	0.30	-0.002	0.15
Engaging in new tasks or starting new relationships feels like a betrayal to [the deceased].	0.22	0.29	0.15	0.18
I worry about what others (e.g., friends and family of the person I lost) would think of me if I started to make new friends.	0.59	0.09	0.03	0.58^a
Pursuing new activities or relationships would be selfish.	0.09	0.14	-0.03	0.63

(continued)

TABLE 1. (CONTINUED)

<i>BCS item</i>	<i>BCS factor eigenvalue (%variance explained)</i>			
	<i>Challenges with connecting with others 12.59 (37.03)</i>	<i>Challenges with change 2.84 (8.34)</i>	<i>Challenges imagining a hopeful future 2.01 (5.92)</i>	<i>Challenges with accepting the loss 1.63 (4.80)</i> <i>Challenges with guilt 1.52 (4.47)</i>
Trying to force myself to move beyond grief would be a sign of weakness.	0.71	0.07	0.19	0.11
I feel guilty about things I did or didn't do related to the loss.	-0.01	0.05	0.11	0.02
I'm uncomfortable around others who try to console me or who pity me.	0.53	0.35	0.14	-0.13
I'm uncomfortable around others because they want to talk about the person I lost.	0.79	0.15	0.04	0.16
I'm uncomfortable around others because they don't want to talk about [the deceased].	0.21	0.02	-0.16	0.17
I think others look down on me because I'm grieving.	0.50^a	0.16	-0.06	0.50
Since my loved one died, I feel angry at God.	0.11	0.18	0.04	0.13
I feel guilty about moving on with my life.	0.37	0.04	0.25	0.11

The highest factor loading for each item is in bold. Items in bold were averaged to create subscale scores.

^aFactor loadings for this item were similar across multiple factors. The bold factor loading indicates the factor on which the item was placed based on consensus among experts on the study team. BCS, Bereavement Challenges Scale.

TABLE 2. CAREGIVER CHARACTERISTICS AND RELATIONSHIP WITH THE BEREAVEMENT CHALLENGES SCALE SUBSCALES

	<i>M (SD)</i> <i>Total sample</i>	<i>Pearson correlation coefficients</i>					
		<i>Connecting with others</i> 1.21 (0.48)	<i>Change</i> 1.73 (0.79)	<i>Imagining a hopeful future</i> 1.61 (0.75)	<i>Accepting the loss</i> 2.52 (1.17)	<i>Guilt</i> 1.27 (0.50)	<i>BCS total</i> 1.55 (0.54)
Gender (<i>n</i> ,%)		0.10	0.04	0.001	−0.02	−0.002	0.04
Female	118 (77.1)						
Male	35 (22.9)						
Race (<i>n</i> ,%)		−0.31***	−0.30***	−0.10	−0.06	−0.03	−0.24**
White	105 (69.5)						
Other	46 (30.5)						
Relationship to the patient (<i>n</i> ,%)		0.18*	0.37***	0.43***	0.34***	0.41***	0.42***
Spouse	71 (48.3)						
Other	76 (51.7)						
Religious affiliation (<i>n</i> ,%)		−0.01	−0.01	0.07	0.07	−0.008	0.03
Christian	117 (77.0)						
Other	35 (23.0)						
Academic medical site (<i>n</i> ,%)		−0.13	0.05	−0.08	−0.20*	0.07	−0.07
Yes	47 (29.7)						
No	111 (70.3)						
Age, years (M, SD)	52.71 (13.12)	−0.13	−0.04	0.22**	−0.07	−0.06	−0.03
Education, years (M, SD)	13.61 (3.79)	−0.34***	−0.24**	−0.16*	−0.11	−0.11	−0.26***
Months since patient's death (M,SD)	6.64 (1.39)	−0.01	0.01	−0.10	−0.13	0.001	−0.05

* $p < 0.05$.** $p < 0.01$.*** $p < 0.001$.

Gender (Male=0, Female=1); Race (Other=0, White=1); Relationship to patient (Other=0, Spouse=1); Religious affiliation (Other=0; Christian=1); Academic site (Parkland, VA, NHOH=0; Yale, DFCI, Massachusetts General Hospital, Simmons=1).

TABLE 3. PATIENT CHARACTERISTICS AND RELATIONSHIP WITH THE BEREAVEMENT CHALLENGES SCALE SUBSCALES

	<i>Total sample</i>	<i>Pearson correlation coefficients</i>					
		<i>Connecting with others</i>	<i>Change</i>	<i>Imagining a hopeful future</i>	<i>Accepting the loss</i>	<i>Guilt</i>	<i>BCS total</i>
Gender (<i>n</i> ,%)		−0.12	−0.12	−0.19*	−0.08	−0.20*	−0.17*
Female	78 (49.7)						
Male	79 (50.3)						
Race (<i>n</i> ,%)		−0.29***	−0.28***	−0.08	−0.07	−0.03	−0.22**
White	109 (69.4)						
Other	48 (30.6)						
Religious affiliation (<i>n</i> ,%)		0.05	−0.02	0.06	0.01	0.04	0.03
Christian	116 (73.9)						
Other	41 (26.1)						
Insurance status (<i>n</i> ,%)		−0.35***	−0.22**	−0.01	−0.04	−0.09	−0.21*
Yes	101 (66.0)						
No	52 (34.0)						
Age, years (M, SD)	59.97 (12.55)	−0.15	−0.28***	−0.13	−0.21**	−0.18*	−0.25**
Education, years (M, SD)	12.97 (4.08)	−0.22**	−0.08	−0.03	−0.04	0.02	−0.11

* $p < 0.05$.** $p < 0.01$.*** $p < 0.001$.

Gender (Male=0, Female=1); Race (Other=0, White=1); Religious affiliation (Other=0; Christian=1); Insurance status (No=0, Yes=1).

TABLE 4. RELATIONSHIP BETWEEN BEREAVEMENT CHALLENGES SUBSCALES AND QUALITY OF LIFE AND PSYCHIATRIC DIAGNOSES

Challenges with	Linear regression analyses ^a						Logistic regression analyses	
	Physical quality of life ^b		Mental quality of life ^b		Grief		Psychiatric diagnosis ^b	
	Beta	Adjusted beta	Beta	Adjusted beta	Beta	Adjusted beta	OR	Adjusted OR
Connecting with others ^c	−0.31***	−0.30**	−0.56***	−0.53***	0.54***	0.34*** ⁱ	26.39***	28.83**
Change ^d	−0.23**	−0.25**	−0.60***	−0.61**	0.70***	0.59*** ⁱ	4.26***	4.42**
Imagining a hopeful future ^e	−0.47***	−0.43***	−0.61***	−0.62***	0.59***	0.38**	3.35***	5.04***
Accepting the loss ^f	−0.15	−0.09	−0.48***	−0.41***	0.74***	0.61***	2.11**	2.10**
Guilt ^g	−0.15	−0.18*	−0.44***	−0.40***	0.59***	0.53***	3.87**	3.92*
BCS total ^h	−0.33***	−0.37***	−0.68***	−0.73***	0.84***	0.77*** ⁱ	12.53***	31.31**

* $p < 0.05$.** $p < 0.01$.*** $p < 0.001$.^aAll betas are standardized.^bPhysical quality of life: Physical Component Summary Score of the SF-36; Mental quality of life: Mental Component Summary Score of the SF-36; Grief: PG-13; Psychiatric diagnosis: Meeting criteria for at least one psychiatric disorder (major depressive disorder, post-traumatic stress disorder, panic disorder, and generalized anxiety disorder) in the past month on the Structured Clinical Interview for the DSM-IV.^cAdjusted regressions control for caregiver race, caregiver relationship to patient, caregiver education, patient race, patient insurance status, and patient education.^dAdjusted regressions control for caregiver race, caregiver relationship to patient, caregiver education, patient insurance status, and patient age.^eAdjusted regressions control for caregiver relationship to patient, caregiver age, caregiver education, and patient gender.^fAdjusted regressions control for caregiver relationship to patient, academic site, and patient age.^gAdjusted regressions control for caregiver relationship to patient, patient gender, and patient age.^hAdjusted regressions control for caregiver race, caregiver relationship to patient, caregiver education, patient gender, patient race, patient insurance status, and patient age.ⁱCaregiver race was excluded from the model due to collinearity.

In separate base logistic regression models, higher scores on “Challenges with Connecting with Others” (OR, 26.39 [95% CI, 5.19–134.12], $p < 0.001$; Table 4), “Challenges with Change” (OR, 4.26 [95% CI, 2.27–8.00], $p < 0.001$), “Challenges Imagining a Hopeful Future” (OR, 3.35 [95% CI, 1.85–6.07], $p < 0.001$), “Challenges with Accepting the Loss” (OR, 2.11 [95% CI, 1.36–3.28], $p < 0.01$), “Challenges with Guilt” (OR, 3.87 [95% CI, 1.69–8.89], $p < 0.01$), and the BCS total score (OR, 12.53 [95% CI, 4.03–38.96], $p < 0.001$) were associated with greater likelihood of meeting diagnostic criteria for a mental disorder. These relationships remained significant after controlling for confounding characteristics.

Discussion

This study examined bereavement-related challenges with the newly developed BCS. Evaluation of the BCS factor structure identified five factors: Challenges with Connecting with Others, Change, Imagining a Hopeful Future, Accepting the Loss, and Guilt. Greater endorsement of bereavement challenges was associated with worse HRQOL, more severe grief, and greater likelihood of meeting criteria for a mental disorder.

The close association between the BCS and grief severity is consistent with the original purpose of the BCS, namely, to identify challenges that lead to or exacerbate grief. The BCS and PG-13, therefore, serve distinct but complementary functions. The PG-13 is a validated diagnostic tool that identifies bereaved individuals who meet diagnostic criteria

for PGD.^{17,31} The BCS was designed to identify particular challenges confronted by bereaved individuals that may increase their risk for chronically severe levels of grief. It is important to note that the PG-13 was developed and validated while the DSM-IV was being used as the diagnostic manual for psychiatric disorders. Since the completion of the current study, the American Psychiatric Association published the DSM-5, which included criteria for Persistent Complex Bereavement Disorder (PCBD). A recent empirical analysis of the criteria for PGD as assessed by the PG-13 and PCBD indicated they are substantively the same diagnostic entity with only semantic differences in the naming of the symptoms.³³ Thus, the grief severity score used in the current study is consistent with PCBD as defined in DSM-5 and that, in turn, the BCS is relevant to the current DSM-5 operationalization of prolonged, impairing grief.

The five factors of the BCS highlight the range of challenges experienced by bereaved individuals. First, bereaved individuals may experience negative emotional reactions to their loss that interfere with relationships (“Challenges Connecting with Others”). This type of challenge was closely associated with poor quality of life and likelihood of meeting criteria for a mental disorder. These results are consistent with research demonstrating that higher levels of social support are associated with better mental^{34,35} and physical health among bereaved individuals.³⁵ Promoting the maintenance of current relationships or the development of new relationships may be a key intervention target.³⁶

Our findings that “Challenges with Accepting the Loss” and “Challenges with Change” were associated with worse mental health and quality of life are consistent with bereavement adjustment models that highlight the importance of accepting the loss.^{37,38} Furthermore, our results are consistent with research indicating that individuals who experience a resistance to change are more likely to struggle with their loss.^{39,40} Several items of the “Challenges with Change” and “Challenges with Accepting the Loss” factors reflect bereaved individuals’ strong continued attachment to the deceased. An important task in adjusting to loss is transforming the relationship with the deceased into an *adaptive* continuing bond, acknowledging that although a loving connection persists, the nature of the relationship needs to be altered.^{40,41}

The “Challenges Imaging a Hopeful Future” factor of the BCS assessed individuals’ views of the future. Bereaved individuals who endorsed a negative or hopeless view of the future were more likely to report poor quality of life and meet criteria for a mental disorder. Prior research indicates that negative views of the future are associated with more severe grief and depressive symptoms in bereaved individuals.^{27,42} A *post hoc* analysis of a grief intervention found that a reduction in negative thoughts about the future accounted for 31% of the treatment effect.⁴³ These findings highlight the potential value of assessing and treating pessimistic cognitions about the future in bereaved individuals.

Finally, research on guilt in bereavement suggests that approximately one-third (29.4%) of bereaved adults endorse feelings of guilt six months after the death.⁴⁴ “Challenges with Guilt” emerged as a BCS factor associated with worse mental HRQOL and increased risk for a mental disorder, consistent with prior research.^{45–47} Guilt may interfere with adjustment to bereavement over time⁴⁶ and response to psychological treatments.⁴⁸ Assessing guilt in bereavement and interventions targeting guilt may be beneficial for some individuals.

The BCS is not intended to identify psychiatric comorbidity or to diagnose a mental disorder. Rather, the five factors of the BCS may point to targets for intervention to reduce the severity of prolonged grief. The BCS could be used in tandem with the PGD-13 to identify specific behaviors or thought processes underlying grief that can be targeted clinically. Future research is needed to examine causal relationships between the BCS and caregiver mental and physical health and quality of life. However, the BCS may inform treatment planning for bereaved caregivers with prolonged grief.

Limitations

This study adds to our understanding of the experience of bereaved individuals but represents preliminary work and is limited by multiple factors. First, the study is restricted to individuals bereaved by cancer. While cancer accounts for approximately one-quarter of deaths in the United States,⁴⁹ the degree to which the BCS is relevant to individuals bereaved by other causes is unclear. Second, the associations examined in this analysis are cross sectional, precluding conclusions regarding the causal relationship between bereavement challenges and quality of life and mental health. Third, the BCS items were developed based on the expertise

of researchers and clinicians in the assessment and treatment of grief, consistent with Stage 1 of the Instrument Maturity Model of instrument development.⁵⁰ Studies that obtain feedback on the items from bereaved caregivers and assess the psychometric properties of the BCS in larger samples will inform further development of the BCS. Finally, the sample consisted primarily of white caregivers with advanced education. The type and severity of bereavement challenges may differ in caregivers from different backgrounds. In addition, caregiver ethnicity was not assessed; analyses in the current study are restricted to race. Future studies should examine bereavement challenges in more diverse samples to consider cultural and demographic differences across the diverse population of caregivers.

The current study is a preliminary examination of a new measure of types of challenges associated with the death of a loved one. These challenges predicted poor quality of life and an increased risk for a mental disorder, including prolonged grief. Our findings support further development of the BCS as a measure with the potential to guide the development of interventions tailored to the unique challenges a given individual faces.

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