




Prolonged Grief and Bereavement Supports Within a Caregiver Population Who Transition Through a Palliative Care Program in British Columbia, Canada

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Abstract

Objective: To determine the prevalence of prolonged grief disorder (PGD), and self-reported resilience among bereaved caregivers within a palliative care program that serves a large region of the Lower Mainland in British Columbia, Canada. Additionally, to discern effective bereavement supports utilized by caregivers following the loss of a loved one. **Methods:** A descriptive study using both quantitative and qualitative methods. Sociodemographic information (n = 427) was collected from bereaved caregivers 3 months after their loss. PGD and resilience were prospectively assessed 12 months post-loss using the prolonged grief scale (PG-13, n = 212) and brief resilience scale (BRS, n = 215), respectively. A qualitative thematic analysis was conducted on responses to the open-ended question on what bereavement services or activities caregivers found helpful in coping with the loss of a loved one. **Results:** Of the 212 individuals that completed the PG-13, 4.7% met diagnostic criteria for PGD, 27.4% were moderate risk, and 67.9% were low risk for PGD. Of the 215 caregivers that completed the BRS, 48.4% had low resilience, 51.6% had normal resilience, and 0% had high resilience. The major themes of formal supports, informal supports, and self-care activities emerged from caregiver comments regarding effective bereavement supports. **Conclusion:** The incidence of PGD in caregivers is low within the Fraser Health Palliative Care program. Bereaved caregivers mainly utilize existing social networks and activities to cope with their loss. Focusing on a community-based approach to supports may improve bereavement experiences and lower rates of prolonged grief.

Keywords

palliative care, caregivers, prolonged grief disorder, resilience, bereavement care, support services

Introduction

The death of a loved one can be preceded by a long period of informal caregiving, including physical, emotional, and financial support.¹ Caring for an individual confronting a terminal condition may leave caregivers with a greater sense of connection. However, family caregivers of terminally ill cancer patients have increased rates of psychological morbidity, with 66.1% reporting high levels of distress, 68.8% high risk of depression, 72.3% high risk of anxiety, and 25.9% high risk of complicated anticipatory grief.² Bereavement is the phase following a person's death when the caregiver adjusts to a new reality without the person who died.³ Prolonged or complicated grief is distinct from the expected period of mourning and emotional lability following the loss of a loved one.⁴ There is lack of consensus on the formal name and diagnostic criteria

for prolonged grief.⁵ The Prolonged Grief Scale (PG-13) was developed to propose diagnostic criteria for prolonged grief

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disorder (PGD) for inclusion in the DSM-5 and ICD-11.^{6,7} The DSM-5 and ICD-11 are the main manuals used by health care professionals worldwide for assessing and diagnosing mental disorders.^{4,8} In the DSM-5, Persistent complex bereavement disorder (PCBD) was listed in Section III (Conditions for Further Study).⁴ However, in November 2020 the American Psychiatric Association (APA) approved the inclusion of PGD in the DSM-5-TR Section II (recognized mental disorders) thereby replacing the criteria for PCBD.⁹ Prolonged grief disorder is the name already utilized to describe prolonged grief in the ICD-11 and by Prigerson et al in the PG-13 scale.^{6,8,10} The diagnostic criteria for PGD in the DSM-5-TR, ICD-11, and PG-13 do not completely overlap but are similar in that they include intense yearning or preoccupation; cognitive, emotional, and behavioral symptoms; and impairment criteria.^{6,8,9} In the DSM-5-TR, PGD duration criteria is at least 12 months after death for bereaved adults.⁹ This differs from ICD-11 and PG-13 in which symptoms must have been present for at least 6 months after loss.^{6,8} A recent meta-analysis found a pooled prevalence of PGD of 9.8% in a general adult population who experienced non-violent bereavement (6.0 to 142.8 months post-loss).¹¹ Individuals with prolonged grief are at an increased risk of physical and mental health issues.¹² Developing a better understanding of prolonged grief will assist with the provision of care for patients and their family caregivers, decrease its incidence, offer better support to individuals suffering from PGD, and reduce the toll on the healthcare system.¹³

Pre-loss risk factors associated with prolonged grief disorder include female gender,¹⁴⁻¹⁶ spousal relationship to the deceased,^{14,16,17} pre-existing mood or anxiety disorders,^{16,18-20} previous psychological trauma, prior loss, insecure attachment with the deceased, and being unprepared for the death.¹⁶ Factors at the time or after death that affect the risk of developing prolonged grief include lack of information about the death, inability to follow cultural practices related to death and mourning, alcohol and substance use,¹⁶ and lower income.¹⁴ Resilience is the ability to recover from stressors and has been shown to help individuals cope with a negative life event.^{21,22} Higher resiliency is associated with decreased intensity of grief symptoms in spouses of partners who died of Acquired immunodeficiency syndrome.²²

The lack of availability of bereavement supports following death has been associated with a higher risk of prolonged grief.^{16,23} Palliative care services offer a range of bereavement supports, most commonly a telephone call, memorial service, letter, anniversary card, group sessions, information packages, and informal gatherings.²⁴ In one study, bereaved caregivers found this approach to be generic and impersonal.²⁴ Identifying bereavement supports that individuals find the most valuable would help guide the improvement of bereavement services, especially to individuals at high risk of prolonged grief.

This study aimed to identify the incidence of prolonged grief, self-reported resilience, and bereavement supports that caregivers found beneficial following the death of a loved

one within a single Palliative Care program that serves a large region of the Lower Mainland in British Columbia, Canada.

Methods

Setting

In British Columbia, Canada, Palliative Care is provided in both acute and community settings.²⁵ Palliative Care physicians provide consultation and support on medical units in all Fraser Health hospitals.²⁵ In Fraser Health, there are 3 palliative care units (PCUs). PCUs are specialized hospital units for palliative patients with complex physical and/or psychosocial needs.²⁵ In British Columbia, Palliative Care is provided in the community in patient's homes, residential care, and in hospices.²⁵ Hospices provide 24-hour care in a home-like setting where the focus is on comfort.²⁵

Study Design

This is a multicenter descriptive study using both quantitative and qualitative methods. Caregivers were enrolled between November 2017 and November 2019. A caregiver was defined as any person who provides physical or psychosocial support to an individual at the end of life.^{20,26} To be included in this study, participants had to identify as a caregiver of a deceased patient who previously received Palliative Care at the Fraser Health Authority (British Columbia, Canada), be ≥ 19 years of age, and able to read English. Caregivers were identified through provincial medical records. Information about the study was mailed to potential participants 3 months following the death of their loved one and instructions for how to access the online survey was provided. Caregivers who chose to participate completed an initial electronic survey (Checkbox Survey) at 3 months post-loss. This survey was not validated and was designed by study authors to collect information on sociodemographics, life stressors, and physical and mental difficulties. Caregivers who completed the 3-month survey were contacted at 12 months to complete the follow-up electronic survey to assess for prolonged grief and resilience using validated screening tools. Furthermore, participants were asked open-ended questions to describe what bereavement services or activities helped them cope at both time points. This study was reviewed and approved by the Fraser Health Research Ethics Board (Document dated 25 Aug 2017).

Measurements

Prolonged grief disorder was measured using the Prolonged Grief Scale (PG-13).^{6,7} PG-13 was chosen because it was established while developing the diagnostic criteria for PGD before its inclusion in the DSM-V and ICD-11.^{6,9} This tool has demonstrated internal consistency and test-retest reliability.^{6,7} Participants were assessed for PGD, 12 months post-loss. Twelve months was chosen to avoid potentially diagnosing a grief-related disorder too early after death, thereby pathologizing the normal grieving process.⁹ When utilizing the PG-13 tool, participants are able to score

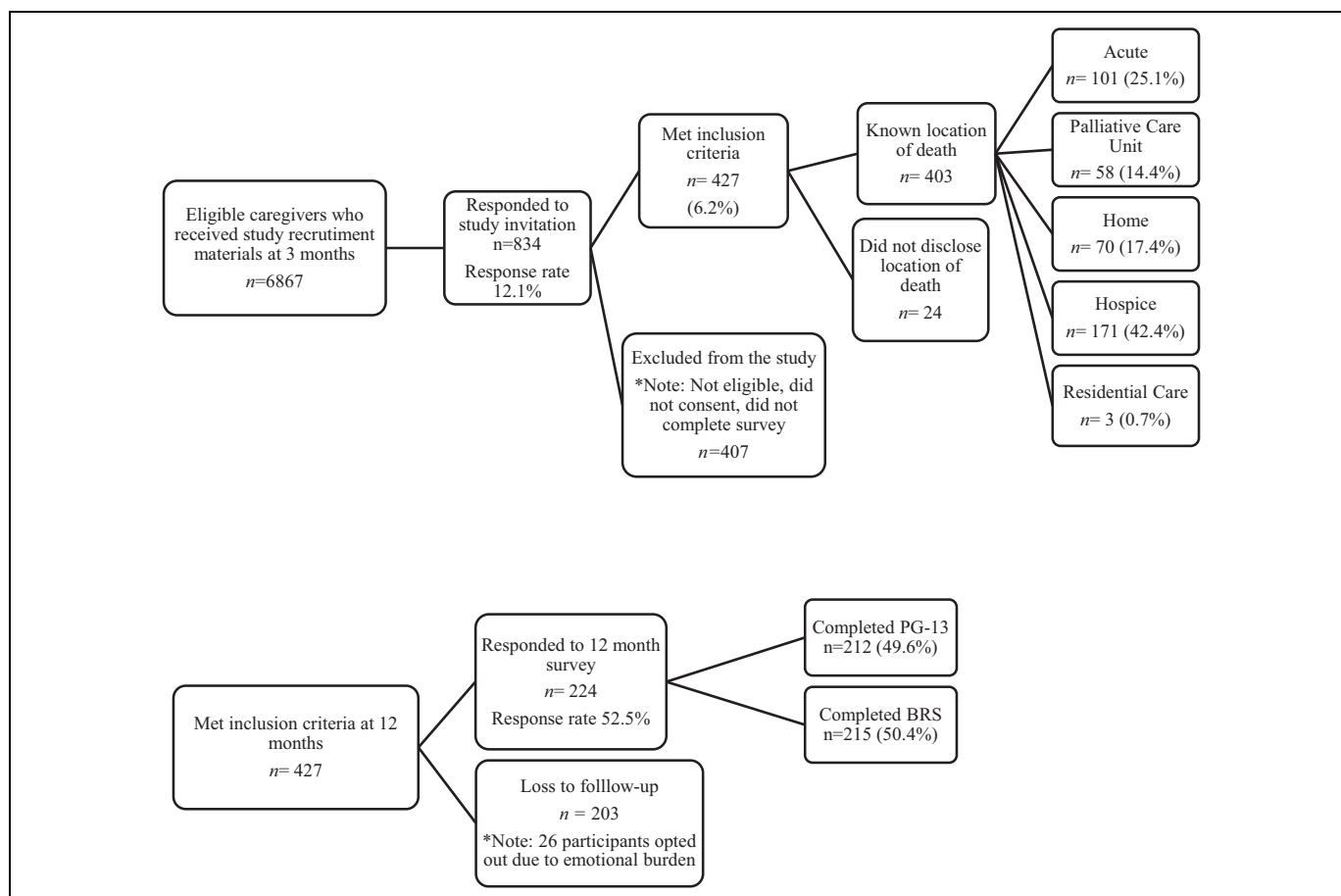


Figure 1. Flow diagram demonstrating study enrollment, along with reported location of death.

between 11-55.²⁷ Caregivers were then grouped into 3 risk categories (low, moderate, high) based on the number of diagnostic criteria met as previously described by Aoun et al.²⁷ To meet the criteria for PGD (high-risk category) individuals had to meet all diagnostic measures including 100% for both the duration and impairment criteria. The Brief Resilience Scale (BRS) was used to measure the caregiver's ability to bounce back from a life stressor in adults. This tool has been previously demonstrated to have good internal consistency and test-retest reliability.^{21,28} Of 15 resilience scales reviewed by Windle et al, the BRS received one of the highest psychometric ratings.²⁹ The BRS includes 6 questions with an equal number of positively and negatively worded statements for which respondents are asked to rate on a scale from 1 to 5 (strongly disagree to strongly agree).²¹ Participants were categorized into having low (score 1.00-2.99), normal (score 3.00-4.30), or high resilience (score 4.31-5.00).³⁰ An open-ended question at the end of the survey asked respondents to comment on what bereavement services or activities they found helpful in coping with the loss of a loved one.

Analysis

Descriptive statistics were used to describe the characteristics of the study population. Means, medians, and standard deviations

of PG-13 scores were calculated for each respondent, with results placed into the 3 risk groups. Fisher's exact test was used to compare the observed frequencies of each of the PG-13 criteria between the 3 risk groups. A one-way analysis of variance (ANOVA) was used to compare the mean PG-13 scores between the 3 risk groups. $P < 0.05$ was considered statistically significant. The frequencies of the 3 resiliency groups were calculated. A qualitative thematic analysis was conducted on responses to the open-ended questions. All team members read open-ended responses and categorized responses into themes using Excel to facilitate data extraction and analysis.

Results

The Fraser Health authority is the largest health authority in British Columbia and services over 1.8 million people.³¹ This study included caregivers of palliative care patients that died in multiple care settings. Six thousand eight hundred and sixty-seven caregivers received an invitation to participate in the study through the mail 3 months post-loss. Of these, 834 replied, resulting in a response rate of 12.1% at 3 months (Figure 1). Of the 834 caregivers that responded, 427 (6.2%) met the inclusion criteria and were enrolled in the study (Figure 1).

At 12 months post-loss, 224 out of the 427 eligible caregivers replied to the survey resulting in a response rate of 52.5% (Figure 1). Of these 224 participants, 212 (49.6%) and 215 (50.4%) completed the PG-13 and BRS, respectively.

Caregiver Demographics

Participant demographic data is presented in Table 1. The majority were between the ages of 55-74 (65.1%) and female (71.4%). Most participants identified as Caucasian (85.6%) with the primary language spoken at home being English (93.2%). The 3 most common relationships to the person who died were wife (33.6%), husband (22.6%), and daughter (18.7%). The majority of respondents were highly educated with 45.9% having completed post-secondary education and 9.7% graduate level studies.

Among bereaved caregivers, 63.2% had religious beliefs and 87.9% felt well supported by others. Eighty-two percent had experienced the previous loss of a loved one. Some caregivers reported having financial concerns (21.0%), substance use issues (4.4%), or a life-threatening illness (5.1%). Forty-two percent struggled with mental or emotional issues.

Location of Patient Death

Four-hundred and three participants provided information on the location of death of their loved one (Figure 1). In the acute care setting, 14.4% of patients died in a Palliative Care Units while 25.1% died in a different hospital ward. In the community setting, 17.4% died at home, 42.4% in hospice, and 0.7% in residential care.

Prolonged Grief Disorder at 12-Months Post-Loss

Two-hundred and twelve participants completed the Prolonged Grief Scale-13 (Table 2). They were grouped into 3 risk groups based on the number of diagnostic criteria met.²⁷ Ten bereaved caregivers (4.7%) were considered high risk, having met all 5 diagnostic criteria for PGD. High risk scores ranged from 40-52 (mean = 44.2, SD = 3.7). Fifty-eight participants (27.4%) were categorized as moderate PGD risk (3-4 criteria) with scores ranging from 16-47 (mean = 31.0, SD = 7.4). In the moderate risk group, 94.8% met the duration criterion, 93.1% experienced separation distress, and 48.3% had functional impairment. One-hundred and forty-four respondents (67.9%) were found to have low PGD risk (1-2 criteria) with scores ranging from 11-35 (mean = 18.6, SD = 5.9). In the low-risk group, no caregivers had cognitive, emotional, and behavioral symptoms. Additionally, only 6.3% had functional impairment and 8.3% met the duration criterion in the low-risk group. Large statistically significant differences were seen in the frequencies of all the PG-13 criteria between the 3 risk groups (Fisher's exact test). Statistical differences in the mean PG-13 scores were also found between 3 risk groups ($p < 0.00001$; One-Way Anova).

Table 1. Demographics of the Caregiver Population.*

Variables	Total (n = 427)	
Age range, years	n	(%)
35 to 44	14	(3.5%)
45 to 54	61	(15.2%)
55 to 64	134	(33.3%)
65 to 74	128	(31.8%)
75 or older	65	(16.2%)
Gender		
Female	287	(71.4%)
Male	115	(28.6%)
Education level		
High school	179	(44.4%)
Post secondary education	185	(45.9%)
Graduate studies	39	(9.7%)
Ethnicity		
Asian or Pacific Islander	34	(8.4%)
Multiple Ethnicity or other	24	(6.0%)
White or Caucasian	345	(85.6%)
Primary language spoken at home		
English	371	(93.2%)
Other	27	(6.8%)
Relationship status		
Married or common law	137	(34.0%)
Widowed	227	(56.3%)
Single, never married	21	(5.2%)
Other	18	(4.5%)
Living children		
No	114	(27.7%)
Yes, all over 18	256	(62.1%)
Yes, 1 or more under 18	42	(10.2%)
Relationship to person who passed away		
Husband	93	(22.6%)
Wife	138	(33.6%)
Father	23	(5.6%)
Mother	29	(7.1%)
Son	16	(3.9%)
Daughter	77	(18.7%)
Sibling	9	(2.2%)
Friend	7	(1.7%)
Other	19	(4.6%)
Financial concerns		
No	324	(79.0%)
Yes	86	(21.0%)
Religious or spiritual beliefs		
No	151	(36.8%)
Yes	259	(63.2%)
Mental/emotional issues		
No	237	(58.2%)
Yes	170	(41.8%)
Struggle with substance use		
No	390	(95.6%)
Yes	18	(4.4%)
Life threatening illness		
No	387	(94.9%)
Yes	21	(5.1%)
Feel well supported by others		
No	49	(12.1%)
Yes	356	(87.9%)

(continued)

Table 1. (continued)

Variables	Total (n = 427)	
Previous separation anxiety, nightmares, or other similar conditions		
No	245	(59.8%)
Yes	165	(40.2%)
Previous loss of a loved one		
No	72	(17.7%)
Yes	335	(82.3%)

* Participants had the option of leaving any of the demographic questions unanswered and therefore the totals for each question do not add up to the total number of participants at 3 months (n = 427).

Resilience

Of the 215 caregivers that completed the BRS 12 months post-loss, 48.4% had low resilience, 51.6% had normal resilience, and 0% had high resilience (Table 3).

Bereavement Supports

An open-ended question at the end of the survey asked respondents to comment on what bereavement services or activities they found helpful in coping with the loss of a loved one. Responses to the open-ended survey question were categorized into 3 thematic areas: formal supports, informal supports, and self care strategies (Table 4).

Formal supports. Several respondents commented that support both from healthcare providers and support groups were helpful in coping with the loss of a loved one. Caregivers described support from physicians, often emphasizing their family doctor, in addition to hospice staff, medical staff, social workers and counselors. Some respondents utilized private counseling and commented that counselling with someone who “gets grief” was important as this caregiver reflected:

Counseling gave me permission to be a mess and talk about my loss... I think doing that was the most beneficial thing to being able to process my grief... Being able to talk to a counsellor who GETS GRIEF [has helped me cope]. I felt I needed the help of an experienced Grief Counselor... I'm so grateful for [their] help and remember [their] words as I continue to struggle.

Along with support from healthcare providers, some bereaved caregivers found support groups helpful. While support groups offered by disease and situation-specific organizations (e.g. Alzheimer's group; suicide support group) were mentioned, it was the support groups facilitated by grief and loss counsellors that respondents highlighted, describing how being with others facing similar situations helped them to feel comfortable in expressing their grief:

The Hospice programs that I have attended, kindness that was shown, and the lack of judgment about showing your grief... The

hospice get togethers are very inclusive and make me feel like I belong to a group. It helps to be around people who understand we do our best and do not just get over it... Hospice bereavement counselling, they specialize in end of life and grief, especially for those of us who were caregivers to our loved ones. They understand that complexity of having to make certain decisions at end of life.

Informal support. Informal support consisted of support from friends and family. Bereaved caregivers found it helpful talking to others with similar experiences, spending more time with friends and family, talking about their loss, making new friends, joining social gatherings, and having a pet. Several caregivers shared how support from family and friends helped them cope with their loss:

Family checking in with me many times through out the day. Their sincere interest in how I am and that we all missed my wife and that we all loved her very much. Friends who allowed me to phone any time for a talk or a walk. These all have helped me tremendously... My friends invited me on a vacation. With all of my closest friends around me having fun together, I came out of my depression and am feeling good again... People in my life who give unconditional love, patience and empathy for what I'm feeling any particular day... Sharing feelings with a peer group suffering a similar loss. There is understanding and emotional support without judgment but with understanding and caring.

Self-care strategies. Self-care strategies were identified as one of the major themes of bereavement supports. Subthemes of self-care included spirituality, activities, and the mindset of moving forward. Having faith, praying, meditating, reading scriptures, going to church, meeting with their pastor or others of similar faith, and participating in faith-based activities were ways respondents coped with loss. For those that commented on spiritual ways of coping, many found hope in life after death and seeing their loved one again as these caregivers described:

My focus now is in the fact that although she is now absent from the body yet present with the Lord for all eternity. My number one goal is to pursue the things of the Lord so that I too will experience eternity with the Lord and be reunited in some way with my wife there also... Because of [a] past experience with my own death I do not believe in death being final. I am not religious [but] I had an out of body experience that has confirmed to me there is life after we pass... My Christian faith gives me confidence in knowing where my loved one is and where I will go when I die... Most helpful has been my personal faith in God and spiritual practices such as prayer.

Bereaved caregivers found various activities beneficial in dealing with their loss. Caregivers commented on activities such as volunteering, working, traveling, community activities, exercise, meditation, chores, and hobbies:

Table 2. PGD Criteria and PG-13 Scores for Low Risk, Moderate Risk, and High-Risk Groups.

PGD criteria met:	Low risk (1-2 criteria)		Moderate risk (3-4 criteria)		High risk (5 criteria)	
	n	%	n	%	n	%
Event criterion	144	100	58	100	10	100
Separation distress	21	14.6	54	93.1	10	100
Duration criterion	12	8.3	55	94.8	10	100
Cognitive, emotional and behavioral symptoms	0	0	8	13.8	10	100
Impairment criterion	9	6.3	32	48.3	10	100
PG-13 score:						
Median (Range)	17	(11-35)	32	(16-47)	43	(40-52)
Mean +/- SD	18.6	± 5.9	31.0	± 7.3	44.2	± 3.7

Table 3. Resilience at 12 Months Post-Loss as Determined by the Brief Resilience Scale.

	N	%
Low resilience	104	48.4
Normal resilience	111	51.6
High resilience	0	0

Table 4. Thematic Analysis of Supports Used by Bereaved Caregivers.

Formal supports	Informal supports	Self-care strategies
Healthcare professionals Support groups	Family Friends	Moving forward Spirituality Activities

Taking time alone and going for long walks along a favorite hiking trail where I can reflect, meditate, pray and let the tears flow has been helpful... Keeping up physical activity, regular exercise classes and workouts with friends has been really helpful... I decided to try & fill my days with volunteering, to do good and to keep busy... Travel has probably been the best for me. But it is transient relief.

Being able to move forward was identified as a subtheme within the main theme of self-care. Ways that respondents moved forward included reminiscing about the person, packing away their loved one's belongings, accepting their loved one's death, implementing change, and the passage of time. Individuals found doing things in their loved one's memory especially helpful:

On the 1-year anniversary I scattered Mom's ashes (as well my father's and Mom's dog's) in a beautiful, peaceful spot, one I can see from the house. The 3 of them were everything to me and to each other. It gave me a sense of release and peace. It also feels like it gave me the power to move forward.

Discussion

In this population of bereaved caregivers within the Fraser Health Authority, 4.7% (high-risk group) met the diagnostic

criteria for PGD 12-months after their loss. The rate of prolonged grief identified in this palliative care program is quite low. Studies that have similarly used the PG-13 to assess PGD, report rates between 1.8-15.1% at 12-13 months post-loss.^{17,32-34} Our findings fit within this range. Risk factors for PGD include being female, a spouse or parent of the deceased, having a life-threatening illness, lower income, lack of social support, cultural or language barriers, prior loss, pre-existing mood or anxiety disorders, substance abuse, previous psychological trauma, insecure attachment with the deceased, and the death being sudden or violent.^{3,14,16-20,23,35} One might have expected the rates of PGD to be higher in our study population given that the majority of caregivers were female, the spouse of the deceased, and had experienced the previous loss of a loved one. Furthermore, almost half had a mental or emotional issues or previous separation anxiety and nightmares, and 21% had financial concerns. However, the low rates of PGD in this population may be due protective factors observed such as having a high level of education, being Caucasian (implies minimal cultural/language barriers), having religious beliefs, feeling well supported by others, and not struggling with substance use.³ In addition, the ease of accessibility to counseling and bereavement support groups available through the hospice societies in the Fraser Health region may contribute to a lower incidence of PGD.

The location of death of their loved one identified by bereaved caregivers included acute care (25.1%), PCUs (14.4%), home (17.4%), hospice (42.4%), and residential care (0.7%). Sixty percent of the study participant's loved ones died outside of the hospital which may have contributed to the low rates of PGD in bereaved caregivers. In 2019, Statistics Canada reported that 58.9% of deaths in Canada occurred in hospital and 41.0% in non-hospital locations.³⁶ PCUs provide support for the most challenging palliative concerns and are thought to be similar in nature to that of the ICU. One study showed that the risk of post-traumatic stress disorder (PTSD) in caregivers is higher in ICU deaths and PGD risk is higher in hospital deaths compared to home hospice deaths.³⁷ Conversely, Probst et al did not find a difference in rates of PTSD or complicated grief in family members of patients who died in non-ICU versus ICU hospital settings.³⁸ For patients that died in hospital, it is possible that an acute medical issue occurred that resulted in

their admission. The in-hospital death may have been traumatic or unexpected which are risk factors for prolonged grief.³ Conversely, caregivers whose loved one died outside of hospital likely had more conversations about the impending death which may have better prepared them for their future loss.

Resilience, the ability to recover from stress, has been shown to be an independent and negative predictor of grief symptoms.²² In this population of bereaved caregivers, half had low resilience, half had normal resilience, and zero had high resilience. To our knowledge, this is one of the first studies assessing resilience using the Brief Resilience Scale in bereaved caregivers. In a previous study looking at patterns of grief among older bereaved spouses, those in the resilient cluster had lower levels of grief and depression.³⁹ Furthermore, this resilient cohort felt more prepared for death, perceived the death as peaceful, had higher self-esteem, and had someone to talk to about their problems.³⁹ Given the low levels of PGD in our respondents despite none having high resilience, it may imply that low or normal levels of resilience are sufficient to protect against PGD.

In a previous study looking at bereavement risk profiles, the bereaved caregivers in the high-risk group used more professional and community-based supports and were more likely to perceive lack of support.²⁷ In this study, participants that did not meet the diagnostic criteria for PGD were categorized into low (67.9%) or moderate (27.4%) risk. Individuals with low PGD risk have previously been shown to be satisfied with support through their own social networks.²⁷ In addition to the everyday supports, those in the moderate risk group were connected with bereavement follow-up programs.²⁷ In this study, a number of themes emerge, that demonstrate resources bereaved caregivers found to be effective in coping with their loss. The 3 main themes of formal supports, informal supports, and self-care strategies were identified. Formal supports from health-care professionals and support groups were beneficial to some respondents. In a prior study assessing the perceived benefit of bereavement supports, professional supports were used the least and had the highest levels of perceived unhelpfulness.⁴⁰ Caregivers in our population mainly found informal supports and self-care activities helpful in dealing with their grief. Informal supports were provided through family and friends and included talking about their loved one, spending time with others, and talking to others with similar experiences. Social supports and healthy family dynamics are associated with improved bereavement outcomes.⁴¹ Other studies have found that existing social networks are the principal support relied on by most bereaved individuals.^{27,40} The main self-care strategies utilized by participants in this study included moving forward, spirituality, and partaking in activities. Having religious beliefs and a high level of optimism increase resiliency and are protective against PGD.³ Furthermore, re-integrating into daily and social activities is thought to ease bereavement related distress in caregivers years after their loss.⁴²

Helping prepare caregivers prior to the death of their loved one may decrease the risk of prolonged grief post-loss and help identify those at higher risk who may require greater supports.

Individual, social, and geographical factors determine how receptive caregivers are to engaging with bereavement supports.⁴³ Themes observed in effective supports include attachment, reliable alliance, social integration and guidance.⁴⁰ Themes identified in ineffective supports include insensitivity, absence of anticipated support, poor advice, lack of empathy, and systemic hindrance.⁴⁰ Discussing bereavement services and matching supports to individual caregiver needs pre-loss may improve receptivity and usefulness of supports post-loss.⁴⁴

Strengths and Limitations

This is a large multicenter study that assessed bereaved caregivers whose loved ones received palliative care across different care settings. This is the first study assessing the rates of PGD, resilience, and effective supports in bereaved caregivers in this geographical region. There are several limitations in this study. Not all bereaved caregivers chose to participate in the study. Additionally, a large proportion of respondents did not consent to follow-up, or fully complete the initial survey and were excluded from the study. This may have led to selection bias which could have impacted our results. Information on non-respondents was not collected. Not all eligible caregivers completed the 12-month post-loss survey as they were lost to follow-up. Participants had the option of omitting any of the survey questions limiting the collection of complete data sets. A large proportion of participants were female, which is comparable to similar studies,¹¹ but may limit generalizability. The Fraser Health Authority is quite ethnically diverse and consists of 3 geographical regions: Fraser North, Fraser South, and Fraser East.⁴⁵ The percentage of individuals that identify themselves as visible minorities are 45.6%, 45.7%, and 20.3% in the North, South, and East regions, respectively.⁴⁵ Therefore, this study population may not be representative of the ethnic distribution within Fraser Health given that 85% of respondents were Caucasian. Participation was limited to individuals who could read English and were computer literate. Nevertheless, the percentage of individuals within Fraser Health whose first official language spoken is English is 89.0 to 95.9%.⁴⁵ This study did not investigate the cause of death of the loved ones of caregivers. A recent meta-analysis showed that the prevalence of prolonged grief disorder to be 49% following an unnatural death such as accidents, disasters, suicides, or homicides.^{11,46} Cancer as a cause of death has also been associated with a higher risk for complex grief.¹⁴

In future studies, it would be valuable to prospectively follow bereaved individuals to provide a longitudinal assessment of prolonged grief, and not just at a single point in time. For caregivers identified as having PGD, it would be helpful to determine how long it took them to return to normal functioning and whether they received evaluation from a mental health professional. Furthermore, it would be interesting to compare the support themes identified in the qualitative analysis between those with and without PGD.

Conclusion

The actual number of caregivers with prolonged grief disorder is low within the Fraser Health Palliative Care program. Many utilize general supports around them to cope with their grief. Focusing on a community-based approach to supports may improve bereavement experiences and lower rates of prolonged grief. Introducing bereavement supports to caregivers and assessing for PGD risk factors prior to loss may improve caregiver receptivity toward supports and may help identify those requiring higher levels of support post-loss.

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