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Research paper

Prolonged grief reactions and help-seeking in bereaved adults during the COVID-19 pandemic

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ABSTRACT

Background: The COVID-19 pandemic disrupted many care systems limiting bereaved peoples' ability to access social, community, and professional support. This study investigated help-seeking of people living with probable prolonged grief disorder (PGD) to identify challenges and facilitators of care, with the aim of informing bereavement practice and policy recommendations.

Methods: Participants ($N = 786$; 96.3 % female, $Mage = 54.51$. $SD = 11.64$) who were 12 or more months post-bereavement completed an online survey indexing pandemic bereavement experiences, mental health and functional outcomes, and help-seeking experiences. Probable PGD was defined as a score ≥ 30 on the Prolonged Grief Scale 13-Revised (PG-13-R). Results were analyzed using univariate statistics for closed questions and content analysis for free-text responses.

Results: Participants living with probable PGD (39.4 %) were more likely than others to: have sought help from professional or other structured grief supports ($\chi^2(1) = 41.18$, $p < .001$); have unmet bereavement needs ($\chi^2(1) = 91.87$, $p < .001$); and be living with significant functional impairment ($t = -26.55$, $p < .001$) and suicidal ideation ($\chi^2(3) = 117.38$, $p < .001$). Lack of provider availability and lack of relevant skills in working with grief and trauma were identified as challenges to care.

Limitations: The study used a convenience sample recruited online and so care is required before generalizing to less represented populations.

Conclusions: We identified both pandemic-specific and more general gaps within bereavement support systems. Our findings highlight a need to recognize care needs and elevate bereavement care within pandemic planning and health care systems more generally.

1. Introduction

Prolonged grief disorder (PGD) is a condition characterized by chronic, intense, and debilitating responses involving yearning for the person who has died, disbelief, emotional distress, a disrupted sense of self, emotional numbness, avoidance of reminders of the loss, meaninglessness, loneliness, and difficulties re-engaging with life (American Psychiatric Association, 2022; Boelen and Prigerson, 2007; Shear et al., 2016; see also World Health Organization, 2022). Exceeding cultural expectations and persisting for >12 months after the death, clinical interest in PGD stems from the range of negative outcomes associated with the condition including substantial functional impairment, reduced physical health, poorer quality of life, increased suicidal ideation, increased mental health morbidity, and greater health service utilization (Holland et al., 2016; Maciejewski et al., 2016; Molina et al., 2019; Sekowski and Prigerson, 2022). Pre-pandemic studies indicated that around 7 % of bereaved individuals were likely to be living with PGD (Lundorff et al., 2017; Maciejewski et al., 2016; Nielsen et al., 2017). In the context of mass deaths and wide-ranging disruptions to end-of-life care and death rituals associated with the COVID-19 pandemic, rates of PGD were expected to rise and calls were made for policy makers to prepare for a “shadow wave” of grief including preparing support

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services to meet the anticipated need (Eisma et al., 2020; Petry et al., 2021; Tucci and Doka, 2021).

Emerging models of bereavement support recognize that individuals have different bereavement care needs, and these occur at different times (e.g., Aoun et al., 2015; Lichtenthal et al., 2024; National Institute for Clinical Excellence, 2004; Stroebe et al., 2006; Irish Hospice Foundation, 2020). Typically illustrated as a pyramid, bereavement care models propose that at least three levels of care are needed. Informal social support provided by family and friends sits at the base of the care pyramid. It is considered relevant for all bereaved individuals and is thought to be sufficient for many. However, a smaller proportion of bereaved people are expected to have support needs outside of their usual networks, for example, those who are isolated or would like to talk about their experiences with others who have had similar losses (e.g., death of child) and may benefit from additional peer-to-peer support and/or support from community organizations. These supports form the middle level of the pyramid. At the top of the pyramid sit the supports thought to be required by an even smaller proportion of bereaved people, who are experiencing chronic and intense grief reactions. Services at this level may include specialized mental health interventions for PGD or other mental health conditions, or provision of counseling to assist with factors exacerbating grief reactions. People may access support at more than one level at any point in time; however, under normal circumstances, fewer people are thought to require such specialist grief support. Disappointingly, however, pre-pandemic literature found that those most likely to benefit from this specialist support did not receive it (Aoun et al., 2015; Lenferink et al., 2021; Lichtenthal, 2018; Lichtenthal et al., 2011; Thompson et al., 2017), generating expectations that this situation would worsen during the COVID-19 pandemic.

Potential barriers to accessing appropriate bereavement support have been identified at multiple levels, including health systems, communities, and the individual (Breen et al., 2019; Dennis et al., 2022; Dietl et al., 2018; Sealey et al., 2015; Thompson et al., 2017). In Australia, in anticipation of the economic, social, and health impacts stemming from the pandemic and the public health measures introduced to slow the spread of the virus and protect frontline workers, federal and state governments introduced a range of financial support packages (e.g., "JobKeeper"). These included extensions to public health care rebates to cover tele-health appointments and an increase to the number of rebated psychology sessions per calendar year (Australian Government, 2020; Australian Psychological Society, 2020; Shergold et al., 2022). However, in the context of cascading losses and ongoing uncertainty engendered by the pandemic, demands for mental health support skyrocketed and quickly exceeded supply (Australian Psychological Society, 2020). Concurrently, many support services closed or went online (Australian Psychological Society, 2022). Such disruptions to end-of-life-care and bereavement practices associated with physical distancing, visiting restrictions, mandatory isolation, curfews, and limits on gatherings all impacted people's ability to give and receive care and were further expected to exacerbate distress for the bereaved. In this context, the National Bereavement Study was established in Australia to document the mental health and support needs of Australians bereaved from any cause during the pandemic. Consistent with international pandemic bereavement studies (e.g., Downar et al., 2022; Harrop et al., 2021; Harrop et al., 2023; Kustanti et al., 2023; Tang and Xiang, 2021; Torrens-Burton et al., 2022; Yuan et al., 2024), baseline results revealed high levels of mental health distress (Maccallum et al., 2024) and multiple difficulties accessing emotional and practical bereavement support from family and friends, community organizations, health and other professional services, and governmental bodies (Ivynian et al., 2024).

In this study, we focused on participants from the National Bereavement Study who were living with probable PGD and their experiences seeking structured forms of grief support, compared to others. The aims were threefold. As probable PGD is likely to require specialist grief interventions (e.g., Irish Hospice Foundation, 2020; Shear et al., 2005; Shear et al., 2016), we first wished to map the professional help-seeking experiences of this group. We drew on responses to closed questions and free-text responses to examine the types of professional supports participants had approached, the care pathways to accessing these supports, the frequency and duration of care, and perceptions of helpfulness and unhelpfulness, to identify potential barriers and facilitators of care. Second, recognizing that access to professional bereavement support (e.g., primary care physicians, psychologists, grief counselors, social workers, psychiatrists) was impacted during the time of the pandemic, we were also interested in the extent to which these individuals sought out other forms of structured grief or mental health support (e.g. self-help resources, volunteer help lines, or support groups) and their experiences with these services. Third, given that PGD is chronic and associated with a range of negative long-term outcomes, we sought to identify the unmet and ongoing support needs of people living with this condition into their second and third year of bereavement to inform ongoing policy and practice. Based on previous work by Aoun et al. (2015; see also Thompson et al., 2017) we expected that, compared to those lower levels of grief, those living with probable PGD would be more likely to have sought professional or other forms of structured grief support, but would also be more likely to have unmet and ongoing support needs.

2. Methods

2.1. Participants and procedures

Survey participants ($N = 786$) were aged 18 years or over, living in Australia, had a family member or friend die from any cause between January 2020 and February 2022, and were bereaved 12 months or more when they completed the survey. Data collection was administered via the Research Electronic Data Capture (REDCap) platform, hosted by The Univeristy of Technology, Sydney. The survey was advertised on social media and newsletters of national and community bereavement support services and was open from April 2021 to April 2022. Participants clicked on a hyperlink to provide informed consent and to access the survey. The 20-minute survey comprised five sections completed in the following order: decedent and death characteristics, end-of-life experiences, formal and informal bereavement support use, mental health and well-being outcomes, and participant socio-demographics (see also withheld-for-blind-review). The study protocol was approved by the University of Technology, Sydney Human Research & Ethics Commitee (See Fig. 1 for participant flow).

2.2. Measures

Prolonged Grief Scale 13-Revised (PG-13-R; (Prigerson et al., 2021a). This self-report measure indexed the ten diagnostic criteria comprising PGD. Participants responded on 5-point Likert scales ($1 =$ not at all and $5 =$ overwhelmingly). Scores were summed to provide a total grief severity score. Following recommendations from Prigerson et al. (2021a), a score of 30 was used to identify probable PGD status. Participants who scored <30 formed the non-PGD group. Cronbach's alpha in this sample was 0.93.

Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001) is a widely used 9-item self-report measure of depressive symptoms experienced during the previous two weeks. Participants responded on 4-point scales ($0 =$ not at all; $3 =$ nearly every day). Scores of 10 or above are suggestive of at least moderate levels of major depression (Kroenke et al., 2001). Cronbach's alpha in this sample was 0.92.

Generalized Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006) is a widely used 7-item self-report scale of general anxiety symptom severity experienced during the previous two weeks. Participants respond on a 4-point scale ($0 =$ not at all; $3 =$ nearly every day). Scores of 10 or above are suggestive of at least moderate levels of anxiety. Cronbach's alpha in this sample was 0.93.

The Work and Social Adjustment Scale (WSAS; Mundt et al., 2002)

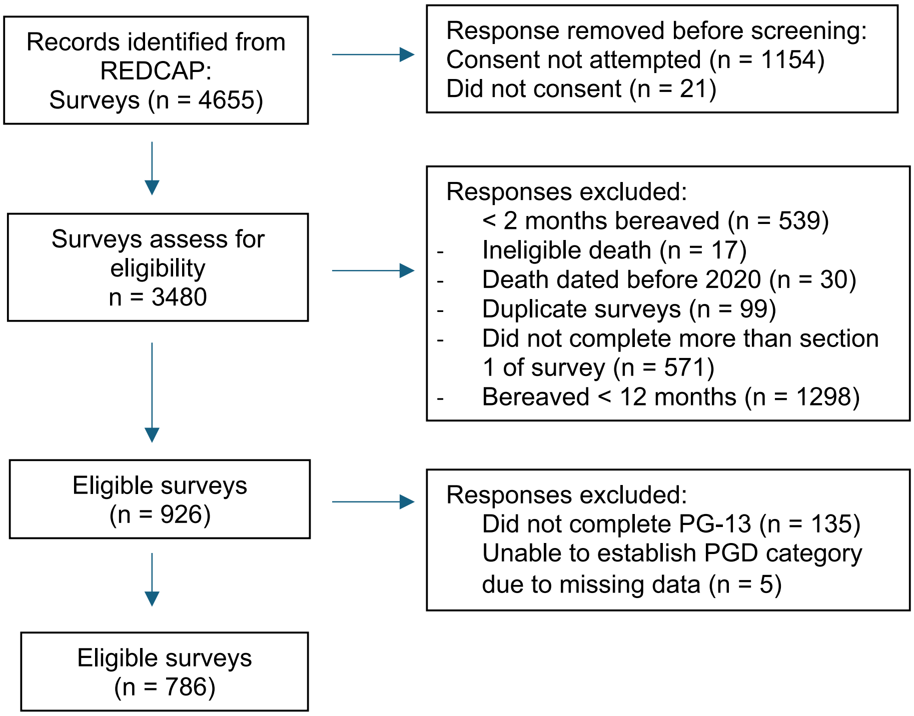

Fig. 1. Flowchart of participant eligibility and reasons for exclusion.

indexed grief-related impairment across five domains (work, household management, social leisure, private leisure, and relationships). Participants responded on nine-point scales (0 = not at all impaired 8 = very severely impaired). Scores were summed to indicate overall impairment (see also Shear et al., 2016). Cronbach's alpha in this sample was 0.93.

EQ visual analogue scale (EQ-VAS; (Herdman et al., 2011; The EuroQol Group, 1990) is a brief self-report tool that indexed current health-related quality of life (0 = worst imaginable health state, 100 = best imaginable health state).

Bereavement support use. Participants were shown a list of 13 common supports including informal (e.g. family and friends), structured (e.g. self-help, online community groups) and professional supports (e.g., grief counsellor, psychologist, social worker, psychiatrist, primary health care physician - known as a General Practitioner or “GP” in Australia), and “other”, and asked which they had sought for bereavement support. They were then asked which they found most helpful and provided with a free-text response box to outline their reasons for nominating their ‘most helpful’ support. They were also given the opportunity to provide a free-text response to nominate any support (s) they found unhelpful and explain their reasons.

Where participants indicated they had sought out a professional support, they were asked an additional set of questions for each form used. These included how they found out about the support, frequency of attendance, length of appointments, and perceived helpfulness. Participants were also asked to list “Which medication have you used, or currently use to manage your grief”.

Unmet needs. Participants indicated whether they felt their support needs had been fully met, partially met, unmet, or whether they had no support needs, and were given the opportunity to select from a list to indicate what types of supports they thought might have helped them if they had been able to access it (information, community-based support, professional support, don't know, no, other). Finally, there was the opportunity to provide a free-text response describing any additional unmet needs.

Subjective outcome trajectories. Participants were asked to rate their perceptions of their mental health and finances since the death, respectively, by choosing ‘improved’, ‘stayed the same’, ‘got a bit worse’, or ‘got a lot worse’ (Aoun et al., 2015). They were also asked whether they had taken took time off work for their grief and, if so, how many days.

2.3. Data screening and analysis plan

Data were analyzed using SPSS v27. Prior to analysis, data were screened for completeness (see Fig. 1). Univariate relationships between PGD status and outcome variables were examined using chi-square and independent sample *t*-tests as appropriate. A Bonferroni adjustment to correct for multiple comparisons indicated an adjusted alpha of $p < .001$. Inductive content analysis (Elo and Kyngäs, 2008) was conducted on the free-text items about helpfulness, unhelpfulness, and additional unmet needs for the probably PGD group to extract meaning from this data and descriptively comment on participants perceptions related to these three broad areas. To ensure rigorous analysis, data coding was completed independently by two researchers [FM and EAL] who then discussed codes and achieved consensus to ensure the validity of the findings (Bengtsson, 2016; Tong et al., 2007).

3. Results

Participant characteristics are presented in Table 1. Overall, most participants were female (95.6 %), partnered (59.8 %), living in a major city (66.7 %), born in Australia (79.2 %), and currently employed (61.2 %). The mean age was 55.08 years (SD = 11.89) and mean time since the death was 16.22 months (SD = 3.15). The most common death was of a parent (44.7 %) and the most common cause was cancer (34.7 %). The largest proportion of deaths occurred at home (28.8 %) or in a residential aged care facility (20.2 %). Nearly 40 % of participants ($n = 310$; 39.4 %) scored 30 or above on the PG-13-R, placing them in the probable PGD group. Participants in this group differed from those who scored <30 on the PG-13-R (non-PGD; $n = 476$, 60.6 %) in terms of their relationship with the deceased (χ^2 (5) = 137.83, $p < .001$), cause of death (χ^2 (6) = 24.30, $p < .001$) and location of death (χ^2 (6) = 34.85, $p < .001$). As can be seen in Table 1, the probable PGD group appeared more likely to have experienced the death of their partner or child, a

Table 1
Participant demographics, loss characteristics, and mean symptom and impairment levels.

	Probable PGD	Non-PGD	Full sample	p
	%, M (SD)	%, M (SD)	%, M (SD)	
	39.4 %; n = 310	60.6 %; n = 476	n = 786	
Female	96.3	95.1	95.6	
Age	54.51 (11.64) [21–82]	55.38 (11.97) [22–90]	55.08 (11.89) [21–90]	
Relationship status				
Single	17.7	13.0	14.8	
Partnered/married/defacto	45.6	69.0	59.8	
Separated/divorced	7.8	8.3	8.1	
Widowed	28.6	9.7	16.8	
Prefer not to say	0.3	0.9	0.6	
Employment				<.001
Employed	58.2	63.1	61.2	
Looking for work	6.7	1.8	3.8	
Retired	17.2	24.0	21.2	
Out of workforce (other reasons)	17.8	11.1	13.7	
Residential location				
Major city	62.5	69.2	66.7	
Inner regional	27.3	24.6	25.6	
Outer regional	8.9	5.8	7.7	
Remote/very remote	1.4	0.4	0.8	
Born in Australia	82.8	77.2	79.2	
Speak English at home	95.6	95.3	95.4	
Single person household	32.9	21.3	25.9	<.001
Tertiary education	47.6	64.1	56.4	<.001
Death characteristics				
Relationship of deceased				<.001
Parent	35.5	50.6	44.7	
Partner	31	8.8	17.6	
Child	16.1	2.7	8.0	
Sibling	7.4	11.1	9.7	
Other family	4.8	19.7	13.9	
Friend/nonfamily member	5.2	6.9	6.2	
Deceased's age	60.94 (23.98) [0–98]	74.43 (18.26) [0–102]	68.87 (22.07) [0–102]	<.001
Time since death	16.12 (3.14)	16.14 (3.03)	16.22 (3.15)	
Cause				<.001
Cancer	37.2	33.1	34.7	
Chronic health conditions	17.2	25.3	22.1	
Sudden/Short duration	19.1	20.3	19.7	
COVID-19	3.2	5.5	4.6	
Accident/injury	7.1	4.4	6.5	
Suicide	9.1	3.4	5.6	
Other	7.1	8.0	6.8	
Setting				<.001
Home	33.9	25.5	28.8	
Aged care facility	12.6	25.1	20.6	
General hospital ward	15.5	18.1	17.2	
Specialist palliative care unit	14.5	15.8	15.3	
Emergency/ICU	13.9	12.2	12.9	
Other hospital	1.9	1.3	1.5	
Other	7.4	1.9	4.1	
Mental health and functioning				
Grief (PG13-R)	37.62 (5.57)	19.78 (5.33)	28.80 (10.26)	<.001
Depression (PHQ-9)				
Mean	14.16 (6.51)	6.13 (5.32)	9.32 (7.01)	<.001
% ≥10	72.5	31.9		
Suicide ideation				
Not at all	55.5	89.5	76.0	
Several days	25.4	7.5	14.6	
More than half	8.4	2.0	4.5	
Nearly every day	10.7	1.1	4.9	
General anxiety (GAD-)7				
Mean	10.46 (6.08)	4.77 (4.79)	7.05 (6.01)	<.001
% ≥10	51.4	13.9		
Impairment (WSAS)				<.001
Total score	21.69 (10.20)	5.54 (6.43)	11.88 (11.30)	
Work[a]	56.5 %, 4.05 (2.54)	10.3 %, 1.05 (1.48)		
Home management	60.3 %, 4.28 (2.52)	10.6 %, 1.23 (1.58)		
Social leisure	74.2 %, 5.19 (2.30)	14.6 %, 1.39 (1.77)		
Private leisure	62.3 %, 4.28 (2.52)	8.4 %, 1.03 (1.51)		
Relationships	52.4 %, 3.97 (2.59)	4.8 %, 0.81 (1.38)		
Mental health trajectory				<.001
Improved	4.9	11.3	8.8	
Stayed same	10.8	33.8	24.8	
A bit worse	33.7	45	40.5	
A lot worse	50.7	9.9	25.8	
Financial trajectory				<.001
Improved	13.7	17.1	15.7	
Stayed same	45.0	70.9	60.7	
A bit worse	22.8	9.3	14.6	
A lot worse	18.6	2.7	18.6	
Time off work				
Yes	56.9	47.4	51.1	<.001
No	9.8	20.3	16.2	
Not relevant to me	33.3	32.3	32.7	
Days off	Median = 30 Mode = 14	Median = 10 Mode = 5		

Note: PG13R = Prolonged Grief-13 revised; PHQ9 = Public Questionnaire 9, GAD-7 = General Anxiety Disorder 7; WSAS = work and social adjustment scale. Residential location classified using the using the Australian Statistical Geography Standard Remoteness Structure (Australian Bureau of Statistics, *Remoteness Structure*. Canberra: ABS); "Other family members" includes all other family relationships not listed; "Other" cause of death includes nominated causes with small n's including "elderly", "natural causes" and "unknown": Gender: 4 participants preferred not to answer., "Other" employment status = out of workforce for health reasons, carer role, "taking a break", home duties.

[a] Percentages represent the % of participants in the group who reported definiate impairment in that domain.

death from suicide, and a death at home or "other" location (e.g., in a car or natural environment) than the non-PGD group. Conversely, they appeared less likely to have experienced the death of a parent or "other" family member, or a death due to a chronic health condition or in a residential aged care facility. The groups did not differ in their mean age or time since the death. The mean age of the deceased was younger in the probable PGD group (t (553.09) = 8.42, $p < .001$).

Table 1 also presents data related to grief impairment, and mental health and functional outcomes. The probable PGD group reported significantly more grief related-impairment (WSAS; $t(441.92) = -24.17$, $p < .001$): definite impairment (a score of 4 or more) was endorsed by >50 % of this group on each WSAS domain. They also reported significantly more depression $t(546.79) = -17.75$, $p < .001$) and anxiety $t(530.54) = -13.62, p < .001$), and were more likely to endorse recent thoughts that “they would be better off dead or of hurting themselves in some way” on the PHQ-9 (45.5 % compared to 10.5 %; ($\chi^2(3) = 117.38, p < .001$). Further, their current subjective health was significantly lower ($t(671) = -7.81, p < .001$), they were more likely to rate their mental health and financial trajectories since the death as “a lot worse” and “a bit”/“a lot worse”, respectively, and for those who were working, to have taken more time off work associated with their bereavement than the non-PGD group (modal number = 14 in the probable PGD group, 5 for the non-PGD group).

3.1. Bereavement support

As shown in Table 2, the probable PGD group were more likely to have accessed professional bereavement support and more likely to have seen a GP ($\chi^2(1) = 30.37, p < .001$), psychologist ($\chi^2$ (1) = 12.77, $p < .001$), grief counsellor (χ^2 (1) = 28.93, $p < .001$), or psychiatrist (χ^2 (1) = 18.10, $p < .001$), and to have been prescribed medication to manage their grief (χ^2 (1) = 47.42, $p < .001$). They were not more likely to have seen a social worker ($p = .304$) or palliative care service ($p = .404$). They were more likely to have accessed formal advice/telephone support lines (e.g., Lifeline, $\chi^2(1) = 8.44, p = .004$), self-help grief resources (χ^2 (1) = 31.39, $p < .001$), grief support groups (χ^2 (1) = 18.86, $p < .001$), social groups for bereaved people (χ^2 (1) = 14.04, $p < .001$), online community support groups (e.g. Facebook groups) (χ^2 (1) = 48.29, $p < .001$), and financial and legal services for grief support (χ^2 (1) = 36.49, $p < .001$.

Table 2
Frequency of use of professional, self-help, and community bereavement support.

	Probable PGD	Non-PGD	
	%, M (SD)	%, M (SD)	
	39.4 %; n = 310	60.6 %; n = 476	
Professional supports			
At least 1	60.6	38.0	<.001
Median	1.00	0	
Self-help/community support			
At least 1	52.6	28.2	
Median	1.00	0	<.001
Either	73.2	49.4	
Median	2.00	0	<.001
Attended			
GP	33.9	16.8	<.001
Psychologist[a]	29.7	18.7	<.001
Grief counsellor	20.3	7.4	<.001
Psychiatrist	7.4	1.5	<.001
Social worker	3.5	2.3	–
Palliative care	3.5	2.5	–
Support lines	5.2	0.4	.004
Self-help Online	39.7	21.2	<.001
Online community supports (.e.g. Facebook bereavement groups)	31.9	11.8	<.001
Grief support group	6.8	2.5	<.001
Grief social groups (e.g. walking groups)	6.5	1.5	–
Religious supports	5.5	8.6	<.001
Family and friends	81.9	86.8	–
No support used[b]	9.0	9.5	–
Medication	21.0	5.0	<.001
SSRI/SNRIs	18.1	4.0	
Benzodiazepines	9.7	1.9	
Other[c]	4.5	0.4	
Legal or Financial professionals	26.8	10.3	<.001

[a] Psychologist and grief counsellor were listed separately as the referral pathways, professional scope of work, training and minimum qualifications for these roles differ. However, it is possible that comments made about grief counseling are relevant to psychologists and vis-a-versa as, for example, psychologists can work in the role of grief counsellors.

[b] Includes no use of family and friends.

[c] Other = mood stabilisers, sleep medication, antipsychotic medication, beta blockers, other.

Participants from both groups who saw a GP for grief support were most likely to have had a pre-existing care relationship with this practitioner ($p = .667$; see Table 3). There were several pathways to seeing a psychologist including a pre-existing care relationship, referral by their GP, or other means (e.g., recommendations, own search). Almost twice the proportion in the probable PGD group than the non-PGD group found the psychologist by “other” means (χ^2 (5) = 14.63, $p < .012$). For grief counselors, both groups were most likely to have found the service through “other” means but were also referred by the service involved with the care of the deceased or their GP ($p < .957$). Fewer people overall accessed a psychiatrist ($n = 30$). In the probable PGD group ($n = 23$), they were twice as likely to have had a pre-existing relationship with the psychiatrist than to have been referred by their GP after the bereavement. In the non-PGD group they were likely to have been referred by their GP after bereavement.

Participants in the probable PGD group attended more GP (χ^2 (5) = 14.63, $p < .001$) and psychology appointments (χ^2 (5) = 14.63, $p < .001$; grief counseling, $p = .124$). The modal duration for psychology and grief counseling appointments was longer duration (45–60 min) than GP sessions (15 min). Face-to-face appointments were attended by a larger percentage of participants than telephone or video telehealth appointments; a minority reported attending both face-to-face and telehealth (GP 38.1 %; psychologist 30.4 %; grief counsellor 26.9 %; psychiatrist 30.4 %). Except for psychologists, telehealth appointments were most likely to be via telephone. Most GP, psychologist, and psychiatrist appointments were funded by Medicare (Australian Government funded health care system) or a combination of Medicare and out-of-pocket costs by the participant. Around 30 % of participants with probable PGD who attended a GP appointment and over half of those who attended psychological appointments incurred out-of-pocket expenses.

Most participants reported that the services they had accessed were at least “quite helpful.” However, the probable PGD group were more likely than the non-PGD group to rate the support they received as being only “a little” or “not at all helpful” (GPs 41 %, χ^2 (1) = 5.15, $p = .023$; psychologists 31.8 %, χ^2 (1) = 6.02, $p = .014$); grief counseling, 27. 4 % $p = .676$). Concurrently, participants in this group were more likely to report unmet bereavement support needs (χ^2 (4) = 115.64, $p < .001$; see Table 4). When asked what might have helped had they been able to access it, almost half the probable PGD group selected greater access to community-based (43.5 %; χ^2 (1) = 58.02, $p < .001$) and professional supports (40.3 %; χ^2 (1) = 27.99, $p < .001$). This compared with 18.5 % and 22.7 %, respectively, in the non-PGD group. The probable PGD group were also more likely to have endorsed an unmet need for information (17.1 % compared to 8.2; χ^2 (1) = 14.4, $p < .001$), although this “unmet need” was lower overall.

To gain a deeper understanding of the pandemic help-seeking experiences of those with probable PGD, we examined their free-text responses about reasons professional and structured supports were helpful ($n = 247$; 79.7 %) or unhelpful ($n = 128$; 41.3 %), and additional unmet needs ($n = 219$; 70.6 %). Reasons for perceiving professional support as helpful were mostly not specific to the pandemic and involved experiencing the provider as impartial, non-judgmental, listening to and validating experiences, and being knowledgeable about grief. Psychologists and psychiatrists were also seen as helpful where they possessed specialist skill sets for working with grief and trauma. In contrast, support was experienced as unhelpful where professionals were perceived as judgmental, not listening, impersonal, rushed, distracted, and without expertise in grief. Structural and systemic issues directly related to the COVID-19 context also contributed to perceptions of unhelpfulness. These included waitlists and delays in the ability to access desired forms of support, or receiving no options for further support. Experiences with telehealth services varied. Some described telehealth as providing them access to support that would have otherwise been unavailable. Others described challenges including lack of privacy at

Table 3
Frequency of professional health care access pathways, delivery methods, payment, frequency, duration and helpfulness.

	GP[*]		Psychologist		Grief counsellor		Psychiatrist	
	Probable PGD %[*] ($n = 105$)	NonPGD % ($n = 80$)	Probable PGD % ($n = 92$)	NonPGD % ($n = 23$)	Probable PGD % ($n = 63$)	NonPGD % ($n = 35$)	Probable PGD % ($n = 23$)	NonPGD % (n = 7)
Referral pathways								
Existing relationship	92.4	96.3	31.5	60.9	8.1	8.6	60.9	28.6
GP referral	–	–	27.2	30.4	24.2	25.7	30.4	57.1
Service involved with	0	0	6.5	0	27.4	20.0	0	0
End-of-life care	6.7	3.8	33.7	8.6	37.1	40.0	8.6	14.3
Other[a]								
Format								
Face to face	89.5	85.0	75.0	73.9	57.1	54.3	73.9	54.3
Telehealth phone/video	44.8/4.8	43.8/2.5	28.3/34.8	47.8/17.4	46.0/27.0	45.7/31.4	47.8/17.4	45.7/31.4
Funding								
Medicare[b]	84.8	90	67.4	69.6	31.7	22.9	69.6	85.7
Out of pocket[c]	28.6	31.3	53.5	39.1	31.7	31.4	39.1	57.1
Number sessions								
1–6	56.3	78.8	40.3	69.5	45.1	62.8	69.5	71.4
7–10	17.1	11.3	14.1	8.7	21.0	22.9	8.7	14.3
10+	23.8	5.0	43.5	21.7	32.3	14.3	21.7	14.3
Length (minutes)								
<15	58.1	68.8	1.1	13.0	3.2	2.9	13.0	14.3
15–45	33.3	27.5	17.6	34.8	11.3	25.7	34.8	28.6
45–60	6.7	3.8	74.7	52.2	74.2	68.6	52.2	57.1
Helpfulness								
Not or a little	41.0	25.1	38.1	30.4	27.4	31.5	30.4	14.3
Yes, helpful	59.0	74.9	61.9	69.6	72.6	68.2	69.6	85.7

[*] Note: n's refer to the number in each group who endorsed using this form of support. This number was used as the base to calculate % for the respective column. Palliative care is not included in the table as it was relevant for only a minority of participants (n = 23). Social work was not included due to the small numbers who used this service ($n = 22$). In Australia social workers often provide bereavement support in palliative care units and hospital settings. During the COVID-19 pandemic health jurisdictions initially classified social workers as “non-essential” which meant they were not physically present in hospitals. Several participants described being unable to access a social worker. This may explain the low frequency of use.

[a] “Other” = recommendation by friend/found by self/don't remember.

[b] Medicare is Australia's universal health care insurance scheme funded by Australian Taxpayers (https://www.healthdirect.gov.au/what-is-medicare).

[c] Indicated an out-of-pocket expense (not health insurance).

Table 4
Frequency of unmet needs for information, community and professional supports.

	Probable PGD % (n = 310)	NonPGD % (n = 476)	*p*
I did not feel I needed support	1.3	11.1	<.001
I got as much support as I needed	14.3	38.9	
I got some support but not as much as I needed	47.4	37.0	
I did not get the support I needed	34.4	12.6	
Other[c]	2.6	0.4	
Looking back, what might have helped you…			
Information/brochures	17.1	8.2	<.001
Community based support groups[a]	43.5	18.5	<.001
Professional support[b]	40.3	22.7	<.001
Don't know	20.6	31.5	<.001
Nothing	11.9	29.4	<.001
Other	10.0	6.5	–

[a] e.g., grief support group, community support groups, peer support.

[b] e.g., counsellor/psychologist.

[c] Statements about needs or distress without indication of whether they considered their needs met or not.

home, and its “impersonal” nature resulting in difficulty feeling connected. Some described delaying help-seeking because it was telehealth (see Table 5 for examples of pandemic-related concerns). Non pandemic factors such as lack of fit (e.g., “we didn't click”) or discomfort (e.g., “counseling is not for me”) were also reasons professional supports were perceived as unhelpful. Self-help and peer-supports were seen as helpful where they provided knowledge that participants “weren't alone”, and validated their experiences, reducing their sense of isolation. They were perceived as unhelpful when facilitators did not have sufficient knowledge or skills and/or discussions became focused on loss, generating feelings of hopelessness.

Free-text responses describing unmet needs also included factors specific to the pandemic and factors related to seeking bereavement care generally. Pandemic-specific factors included unmet needs for social connection and togetherness, and the need for government compassion and support at the time of the death when negotiating limits on visiting, travel restrictions, and quarantine mandates. Responses also reflected a desire for more professional help. With relevance for the chronicity of PGD, several participants commented on the timing of help-seeking, noting that they continued to struggle with the loss, and/or thought they may have benefited from either accessing professional support earlier or would benefit now. Participants also described the need for practical support to help with post-death administrative requirements (e.g., legal, financial) and caring for family members including children, which they felt were exacerbated by pandemic related closures. Several commented on the inability to pursue help-seeking due to other responsibilities (e.g., work and caring for family).

4. Discussion

This study compared help-seeking experiences of Australians bereaved during the COVID-19 pandemic who were living with probable PGD with those with lower grief to explore specific barriers and

Table 5
Pandemic-related themes identified in free-text response content analysis about support helpfulness and unhelpfulness, and unmet needs.

Reasons supports were "the most helpful"
"Counseling helped when my grief was it's most raw. It was initially via telehealth and, while it was not ideal, it provided me a reasonable avenue for communication."
"I was feeling very depressed and anxious mainly at nighttime or hours where my GP was not available, calling the helplines and knowing I can count on them at any time was very important."
"Because l was stuck at home, scared for my own humanity and my elderly parents. So l needed to lean on medication to keep me from falling into the rock bottom l started to feel escalate during this very difficult time". Medication 2421
Reasons supports were viewed as unhelpful
"I was offered no support. Restrictions meant we could travel to the funeral but had to fly immediately home into hotel quarantine. 4 walls only. No wake, no family to grieve with. …. We were declined compassionate exemptions to drive home together and home quarantine. [Organization name] knew of our circumstances, and not once were we offered any grief support while in hotel Quarantine: they were more concerned about covid symptoms."
"External supports were all helpful to some degree. The negatives I experienced were internalised ones, I felt very guilty that I was able to be with [deceased] in the final days and [] family were only able to visit once."
"Unhelpful because due to Covid it was via online Zoom. It was alienating and confronting, and I only attended for two weeks because it was unhelpful and distressing."
"Too busy and not able to target my support, lack of expertise or find me the support that did not have a waiting list a mile long. It takes 6 months to get in to see a psychiatrist and I'm still waiting." General practitioner - 520
Additional unmet needs
"I needed to also deal with the resentment I had towards the aged care home and their lack of communication and limited access to [the deceased] in the final weeks. I needed extra support to help me with my [surviving parent] whose [health condition] deteriorated rapidly after [deceased's] passing. I felt guilty that I couldn't do more."
"I felt it was too difficult to reach out during COVID restrictions and my grief almost seemed overshadowed by the pandemic."
"Telehealth appointments made me less likely to reach out to my GP, it felt impersonal and I avoided phone conversations."
"I really just felt that I had to just suck it up. That this was an extraordinarily difficult time in the world with Covid, that there were people experiencing similar or worse situations and that there was no point complaining. Suffered in silence."
"The isolation, loneliness and numbness were unbearable." 3819

facilitators to care. Although it was anticipated that many individuals bereaved during the pandemic would experience difficulties accessing their desired supports, people living with probable PGD were considered at greater risk due to their anticipated need for specialist health and community supports, the delivery of which were greatly impacted during the pandemic. Overall, our findings add to a growing body of literature documenting high levels of bereavement-related distress and unmet bereavement support needs among those bereaved during the COVID-19 pandemic (Downar et al., 2022; Harrop et al., 2021; Tang et al., 2021; Torrens-Burton et al., 2022; Yuan et al., 2024). Concerningly, almost half of participants in our probable PGD group reported recent thoughts of self-harm or suicidal ideation. Consistent with pre-pandemic findings (Aoun et al., 2015) those living with probable PGD were more likely to have sought professional support. Not surprisingly, however, a key challenge reported by participants was accessing these types of support. Many participants noted that in the context of the pandemic, many GPs and psychologists either had long waiting lists or had closed their books to new patients. This led to participants not pursuing these support options and/or relying on medications and self-help options.

Encouragingly, many of those who could access professional support found it helpful, however, experiences overall were mixed. For those with probable PGD, a third reported receiving no or little benefit from the supports. Interestingly, the reported reasons for finding professional supports helpful appeared less relevant to the pandemic context and more relevant to the individual professional's skill and knowledge base. In contrast, the reasons that support was experienced as unhelpful appeared related to both pandemic and non-pandemic factors. Telehealth offered some additional avenues for receiving support, however, the varied experiences and attitudes towards telehealth highlight the need to maintain a range of service delivery options, and, when restrictions are required, to minimize the duration of closures of face-to-face services [see also Ivynian et al., 2024]. Out-of-pocket expenses also presented challenges for participants. The degree to which these cost concerns were exacerbated by economic impacts of the pandemic is uncertain. We note, however, that almost half the probable PGD group reported a worsening of their finances since the death, highlighting an economic vulnerability among this group.

The pandemic related increase in available Medicare-rebated sessions helped some, but where gap payments were required or services not available due to overwhelming demand, many were not able to benefit from this initiative. In this context, it is not surprising that many participants accessed self-help websites and online community groups, with rates of access higher among the probable PGD group. As with professional supports, however, experiences varied. The desire for greater access to skilled community and peer support was evident in the reported unmet needs. Those who found these supports helpful reported experiencing a sense “they were not alone”. Given the documented associations between loneliness and mental health and bereavement outcomes (Maccallum et al., 2024; Vedder et al., 2022), this underscores the importance of these forms of support (Breen et al., 2022). The wider availability of evidence-based online support options may also improve outcomes during future pandemics (Reitsma et al., 2023).

Notwithstanding the need for greater community support, available evidence suggests that those with PGD will require more specialist forms of health care irrespective of pandemic conditions (Irish Hospice Foundation, 2020). We found that many participants who accessed a GPs or psychologist, reported a pre-existing relationship with this provider. This was generally seen as helpful as it reduced the need to “re-tell their story”. It is notable, however, that Australian psychologists and GPs typically receive little to no foundational training in grief and bereavement, and so the extent to which practitioners have the expertise to recognize and refer or support and treat those with different levels of need will likely reflect that professional's own additional independent training. Consistent with this general lack of training, some participants described consulting multiple professionals before finding one they felt had the skills to help them; while others, it appeared, gave up.

Acknowledging that grief has no set timeline, it is also worth noting that while experiencing some professionals as helpful, and attending numerous appointments, those living with probable PGD continued to endorse high levels of ongoing distress, including grief-related impairment at a levels consistent with treatment-seeking samples (Shear et al., 2005; Shear et al., 2016), frequent thoughts of self-harm or suicidal ideation, and a range of unmet support needs. This may reflect that those in the probable PGD group were more likely have experienced deaths associated with more severe reactions (e.g., death of child/spouse, suicide,) or have had more complex or uncertain circumstances surrounding the death, as evidence by being more likely to have consulted legal and financial professionals. Nonetheless, our findings underscore an imperative for greater investment in bereavement care, pandemic or not, including upskilling providers and systems to meet individuals' bereavement support needs and to enable access to evidence-based treatments for those with PGD (Lichtenthal et al., 2024). This should include basic training in providing general grief support and information and specific training in recognizing and intervening with PGD relevant to the role (identification, treatment options) for health and counseling professionals. Our findings suggest GPs offer a pivotal opportunity to facilitate initial and ongoing bereavement care (O'Connor and Breen, 2014). Non-judgmental inquiry about grief and support needs months and years after a bereavement is also encouraged, including for those bereaved during the pandemic, to optimize outcomes. For example, while some found medications helpful in the pandemic circumstances (“a life saver”), or to manage individual reactions (e.g, sleep or anxiety), evidence suggests that drug treatments such as SSRIs are not an optimal treatment for PGD (Shear et al., 2016).

Regarding PGD, we used recommendations from Prigerson et al. (2021a) to identify those likely at risk for the disorder. We chose our method and terminology as previous work suggests that grief at this level is associated with a range of poorer outcomes (Prigerson et al., 2021a). Indeed, we note the significant difference in mean levels of impairment reported by our two groups. However, our use of the term “probable PGD” is not meant to imply these individuals' meet criteria for a clinical diagnosis of PGD. A clinical assessment is required prior to determining a person's diagnosis status; hence our use of “probable”. It is also important to recognize that the diagnostic criteria for PGD have undergone several changes since the condition was first proposed and ongoing investigation is required to validate these recommendations (Eisma, 2023; Prigerson et al., 2021b). Further, several simulation studies have drawn attention to the potential stigma associated with the PGD diagnosis. For example, simulation studies show that participants judged bereaved people with PGD more negatively, had more negative emotions, and had a stronger desire to distance themselves from them, compared to people without PGD (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Zammit et al., 2023). Consistent with concerns that such stigma may become internalized (Dennis et al., 2022; Lenferink et al., 2021), our free-text data shed light on people's experiences of being surprised by the persistence and intensity of their grief, their uncertainty about seeking help, and shame and hopeless about their situation. In parallel, however, Lichtenthal et al. (2018) provides a compelling demonstration that providing clinicians with information about PGD and a straightforward et of diagnostic criteria can increase diagnostic accuracy, resulting in better treatment recommendations (i.e., for psychotherapies targeting mechanisms with direct relevance to PGD) without pathologizing normative grief.

We recognize a number of limitations to the conclusions that can be drawn from this descriptive study. Our convenience sample was predominately female, educated, and English-speaking. Although evidence suggests there are few gender differences in the experience of PGD (Lundorff et al., 2020; Maccallum et al., 2023), gender differences may exist in attitudes towards help-seeking and grief counseling (Breen et al., 2019; Schut et al., 1997). Additionally, almost all participants were recruited online. Australia has a high rate of active smartphone and internet use (>90 %), and social media use (ABS, 2016–17; Datareportal, 2023), so this method aided the timely collection of data from a large sample. However, people with limited digital literacy or limited access to the internet may be underrepresented. Therefore, more work is needed to understand the experiences of help seeking for other genders, culturally and linguistically diverse populations and those less familiar with using the internet. It is also important to recognize that people were reporting on their experiences retrospectively, and thus, perceptions of helpfulness/unhelpfulness may have been impacted by current symptom levels. Further, we provided free-text responses made by the probable PGD group for illustrative purposes only (see [removed for blind review] for a full qualitative data).

5. Conclusions

The COVID-19 pandemic caused widespread disruptions to the activities of daily living, dying, and grieving. This study explored the help seeking experiences of those at heightened risk for long-term adverse outcomes. We found that while those individuals living with probable PGD were more likely to seek professional and structured forms of grief support, a majority reported unmet needs for professional and community support associated with pandemic related barriers, such as restrictions on gatherings, closure of face-to-face services and a huge general increase in the demand for mental health services. Significantly however, our findings also revealed broader gaps in Australia's bereavement support systems and thus have ongoing relevance for practice and policy. We must learn from the experiences of the COVID-19 pandemic and improve bereavement support systems if we are to reduce long-term harms for bereaved people. This not only includes elevating bereavement care within future pandemic planning processes to minimize unmet needs, but also investing more broadly in upskilling professionals and expanding the availability of evidence-based bereavement services, including increasing accessibility of interventions for PGD and quality community-based bereavement support.

CRediT authorship contribution statement

Fiona Maccallum: Writing – review & editing, Writing – original draft, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Lauren J. Breen:** Writing – review & editing, Methodology, Conceptualization. **Serra Ivynian:** Writing – review & editing, Project administration. **Michelle DiGiacomo:** Writing – review & editing, Conceptualization. **Tim Luckett:** Writing – review & editing, Conceptualization. **Elizabeth A. Lobb:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization.

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Declaration of competing interest

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