



Journal of Loss and Trauma International Perspectives on Stress & Coping

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/upil20

Grief after Pandemic Loss: Factors Affecting Grief Experiences (the CO-LIVE Study)

Yvonne N. Becqué, Erica Witkamp, Anne Goossensen, Ida J. Korfage, Liza G. G. van Lent, H. Roeline Pasman, Bregje D. Onwuteaka-Philipsen, Masha Zee & Agnes van der Heide

To cite this article: Yvonne N. Becqué, Erica Witkamp, Anne Goossensen, Ida J. Korfage, Liza G. G. van Lent, H. Roeline Pasman, Bregje D. Onwuteaka-Philipsen, Masha Zee & Agnes van der Heide (2023): Grief after Pandemic Loss: Factors Affecting Grief Experiences (the CO-LIVE Study), Journal of Loss and Trauma, DOI: <u>10.1080/15325024.2023.2229137</u>

To link to this article: https://doi.org/10.1080/15325024.2023.2229137

9

© 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 03 Jul 2023.

Г	
L	19
L	2
_	_

Submit your article to this journal \square

Article views: 165



View related articles 🖸



View Crossmark data 🕑

Routledge Taylor & Francis Group

OPEN ACCESS Check for updates

Grief after Pandemic Loss: Factors Affecting Grief Experiences (the CO-LIVE Study)

Yvonne N. Becqué^{a,b} (**b**), Erica Witkamp^{a,b} (**b**), Anne Goossensen^c (**b**), Ida J. Korfage^b (**b**), Liza G. G. van Lent^d (**b**), H. Roeline Pasman^e (**b**), Bregje D. Onwuteaka-Philipsen^e (**b**), Masha Zee^e (**b**), and Agnes van der Heide^b (**b**)

^aResearch Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands; ^bDepartment of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands; ^cUniversity of Humanistic Studies, Utrecht, the Netherlands; ^dDepartment of Medical Oncology, Erasmus MC Cancer Institute, University Medical Center Rotterdam, Rotterdam, the Netherlands; ^eDepartment of Public and Occupational Health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, Amsterdam, the Netherlands

ABSTRACT

It has been suggested that grief after losing a significant other person during the COVID-19 pandemic is more severe than before the pandemic. However, little is known about the factors associated with COVID-19-related grief. This study aims to examine whether grief among relatives of people who died during the first COVID-19 wave was associated with factors such as (in)sufficient opportunity to be with the dying person, relatives' appreciation of how the person died, and "unfinished business" between the bereaved and the deceased. The study involved 200 Dutch relatives who had lost a person during the pandemic. Grief was measured with the Hogan Despair subscale. Data were analyzed using correlations and multivariable regression analysis. Our findings revealed that two-thirds of bereaved relatives reported that they had not had sufficient opportunity to be with the dying person in the final days. However, this experience was not significantly correlated with despair. A negative appreciation of the dying process and remaining unfulfilled wishes as part of "unfinished business" between the dying person and their relative were associated with higher levels of despair, particularly among partners. It is crucial to ensure that relatives can experience good end-of-life care for their dying loved one and be enabled to resolve family issues, to mitigate the impact of the pandemic.

ARTICLE HISTORY

Received 16 May 2023 Accepted 11 June 2023

KEYWORDS

COVID-19; end-of-life; grief; loss; relatives

CONTACT Yvonne N. Becqué 🔄 y.becque@erasmusmc.nl 💽 Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands.

This article has been corrected with minor changes. These changes do not impact the academic content of the article.

 $\ensuremath{\mathbb{C}}$ 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http:// creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Introduction

In 2020, the world was overwhelmed by the COVID-19 pandemic. Early 2023, the SARS-CoV-2 virus had caused more than 760 million confirmed infections and more than 6.8 million deaths worldwide (World Health Organization, 2023). To mitigate the spread of the virus during the first wave of the pandemic, many drastic measures were implemented, such as social distancing, lockdown regulations, and visitor restrictions in health care facilities. These measures posed challenges to relatives of ill persons, particularly those who were in the last stage of life, and may have affected relatives' perceptions and experiences of death and dying.

Many relatives did not have the possibility to visit their dying family member or friend in the last weeks or days of life (Onwuteaka-Philipsen et al., 2021). They were not allowed to say goodbye or had to say goodbye by phone, through a video screen or through a window. Sometimes relatives had to experience that their family member died alone (Becqué et al., 2022). As a result, relatives may have perceived the dying process as undignified (Becqué et al., 2022). In addition, the restrictive measures could prevent relatives from being with a dying loved one in the last phase of life, which could subsequently lead to unresolved relational issues (Menzies et al., 2020), e.g. because loved ones were unable to tell the dying person how much they were loved or had to cope with secrets that were not shared.

Concerns have been raised that the unique circumstances around loss in the context of the COVID-19 pandemic may have hampered the grieving process of bereaved families (Gesi et al., 2020; Goveas & Shear, 2020; Mortazavi et al., 2020; Wallace et al., 2020). Grief, including physiological and emotional symptoms, is a normal reaction to bereavement (Shear, 2015). During the early bereavement period a common emotional response is despair, which is manifested in feelings of hopelessness, sadness, and loneliness (Hogan et al., 2001; Selman et al., 2021). Most bereaved relatives develop a new sense of normalcy in their life after some time, but for some the grieving process results in grief-related complications, such as unusually severe and prolonged mourning and impairments in daily functioning (Shear, 2015). Complicated grief may involve significant depressive symptoms (Holtslander, 2011).

Previous research (conducted pre-COVID) has identified numerous risk factors for grief-related complications (Probst et al., 2016), which are particularly relevant for the COVID-19 pandemic. One of these factors is the appreciation of death and dying by bereaved relatives (Lobb et al., 2010; Mason et al., 2020). A study by Wright et al. (2008) showed that a better quality of life for patients nearing death was related to a better quality of life for relatives during the bereavement period: relatives felt better prepared for death and experienced less regret. Additionally, Wilson et al. (2018) discovered that a lower perceived quality of death was associated with higher grief levels. Furthermore, the location of death also influenced relatives' well-being during bereavement (Waldrop & McGinley, 2020). In a sample of 108 bereaved relatives of a hospice patient, those who reported incongruence between the preferred and actual location of death demonstrated more intense symptoms of bereavement.

Another factor that may affect bereavement is "unfinished business" between the bereaved and the deceased (Klingspon et al., 2015; Lobb et al., 2010). Unfinished business refers to incomplete, unexpected or unresolved relational issues, and is comprised of two related factors. The first factor, unfulfilled wishes, involves perceptions of missed opportunity with the deceased and/or the belief that some final words were left unspoken. The second factor, unresolved conflict, assessed the extent to which an argument, or secret was never fully resolved during the deceased's lifetime (Holland Klingspon et al., 2020). Several researchers reported that higher unfinished business scores were associated with more grief symptoms (Klingspon et al., 2015; Lobb et al., 2010). For example, a study by Holland Plant et al. (2020) found that relatives with unfinished business were more likely to experience complications in their grieving process. In addition, they found that the presence of unfinished business varied according to the cause of death, with frequencies being higher in cases of sudden and violent death. It is likely that the COVID-19 context, where death was also relatively often unexpected, social isolation had an impact on being able to complete and resolve issues between the relative and dying person.

Not being able to say goodbye is also a risk factor that may negatively affects the grieving process (Otani et al., 2017). Otani et al. (2017) found that families' presence at death was not associated with grief but rather the ability to say goodbye before death. Several studies emphasize the importance of saying goodbye (Rietjens et al., 2006; Witkamp et al., 2015). Not being able to say goodbye may lead to "unfinished business" (Holland Klingspon et al., 2020). The preventive measures during the COVID-19 pandemic limited the ability of relatives to see and visit their loved one, potentially making goodbyes more difficult.

Lastly, personal factors, such as the relationship with the deceased, influence grief. A review of Lobb (2010) showed that relationships with the deceased that were close, supportive, confiding, and dependent were associated with a higher risk of complicated grief.

Recent research suggests that grief of people who lost a significant other during the COVID-19 pandemic is more severe than before the pandemic. Eisma and Tamminga (2020) found that US adults who had recently (at most five months earlier) lost a loved one during the COVID-19 pandemic had higher levels of grief than those who had experienced a recent loss before the pandemic (Eisma & Tamminga, 2020). However, little is known about which 4 🕢 Y. N. BECQUÉ ET AL.

factors are associated with grief in the context of COVID-19. Therefore, we examined the impact of the relationship between the bereaved and the deceased, as well as factors that characterized the circumstances in which loss occurred during the COVID-19 pandemic, on the grief experienced by bereaved relatives. The study focused on six factors, which include:

- 1. The relationship between the bereaved and the deceased.
- 2. If the deceased person had a confirmed or suspected COVID-19 infection.
- 3. If there was sufficient opportunity to be with the dying person.
- 4. Relatives' appreciation of how the person died.
- 5. Unfulfilled wishes in the relationship with the deceased person.
- 6. Unresolved conflicts between the bereaved and the deceased.

Based on pre-COVID-19 research, we hypothesized that being a partner of the deceased, a COVID-19 infection of the dying person, insufficient opportunity to be with the dying person, a negative appreciation of how the person died, unfulfilled wishes and unresolved conflicts would be associated with higher levels of grief.

Materials and methods

Design and study population

This questionnaire study is part of the CO-LIVE study, which is a repeated observational online survey study in the Netherlands. The study aimed to examine the experiences of bereaved relatives who lost a person during the first wave of the COVID-19 pandemic. The baseline questionnaire could be completed by individuals (18 years) who had experienced the death of a family member or friend, either with or without the COVID-19 virus, between 1 March and 1 July 2020. Participants were recruited through various channels, including palliative care organizations and networks, volunteer organizations and personal contacts throughout the Netherlands. The baseline questionnaire focused on relatives' experiences with end-of-life care and the death of their loved one (Yildiz et al., 2022). To study the well-being of relatives after their loss, we analyzed the data of a follow-up questionnaire provided between 25 November 2020 and 25 January 2021.

A total of 322 respondents had filled in both the baseline and follow-up questionnaires. However, 80 respondents did not complete the follow-up questionnaire, and data of 42 questionnaires were excluded because it was clear from the answers that relatives had completed the questionnaire twice. The analyses were thus based on 200 respondents who completed both questionnaires.

The STrengthening the Reporting of Observational studies in Epidemiology (STROBE) guidance was used as the underlying structure for this article (Vandenbroucke et al., 2007).

Data collection

Information on sociodemographic characteristics of the respondents and the deceased persons (gender, age, relationship), whether the deceased person had a confirmed or suspected COVID-19 infection and the setting where the person died was retrieved from the baseline questionnaire. Baseline data collection is further described in a previously published article (Yildiz et al., 2022). The follow-up questionnaire contained questions about (1) how the respondents had experienced end-of-life care, the dying process, and the opportunity to be with their loved one during last days of life, and (2) relatives' grief. Parts of existing questionnaires were used for this follow-up questionnaire, as described below.

Measures

Hogan Grief Reaction Checklist (HGRC)- The HGRC measures symptoms of grief. We used the Despair subscale, which is one of the six subscales of the HGRC and consists of 13 items describing the emotional component of grief, i.e. thoughts and feelings about hopelessness, sadness and loneliness. Items for instance include "feeling heaviness in heart" and experiencing "shattered hopes" (see Table 2 for all items). Response options ranged from 1 "does not describe me at all" to 5 "describes me very well" (Hogan et al., 2001). The total despair score is calculated by summing the scores of all 13 items of the Hogan Despair subscale, with higher scores indicating more despair (ranging from 13 to 65). The Despair subscale previously demonstrated a Cronbach's alpha of 0.89 and there was evidence of construct validity (Hogan et al., 2001).

Sufficient opportunity to be with the dying person- A self-developed question elicited information on whether respondents had had sufficient opportunity to be with the dying person: "Was there sufficient opportunity to be with your loved one in the last days of his or her life?" Response options were "Yes, more than sufficient", "Yes, sufficient", and "No, not sufficient". The three response options for "sufficient opportunity to be with their loved one" were dichotomized into yes ("yes, more than sufficient") and no ("no, insufficient"). Respondents were invited to explain their answer in a free text box. Quotes from these comments are used to illustrate and support the quantitative data.

Appreciation how the person died—We asked respondents to select one or more terms which best described their loved one's dying process from a list that has also been used in previous research (Witkamp, 2015). The 12 items were: sad, quiet, painful, shocking, degrading, restless, peaceful, dignified, hectic, good, touching and intimate. Relatives' selection of terms to indicate how their loved one died was summarized into two categories: only "negative" terms and "positive" terms, either or not combined with "negative" terms. Sad, hectic, shocking, painful, degrading and restless were considered "negative" terms, whereas quiet, good, intimate, touching, dignified, peaceful were considered "positive" terms.

Brief Unfinished Business in Bereavement Scale (UBBS)- To measure unresolved relational issues between the bereaved and the deceased, we used an abbreviated version of the validated UBBS, consisting of ten items, with five items tapping into Unfulfilled Wishes and five items tapping into Unresolved Conflict (Holland Klingspon et al., 2020). This abbreviated scale was composed on the advice of the UBBS developer. The Unfulfilled Wishes subscale (5 items) refers to missed opportunities to address issues with the deceased person, for instance, "I wish I would have taken my chance to say goodbye". The Unresolved Conflicts subscale (5 items) concerns unaddressed disputes, for instance "There were secrets in our relationship that should have been discussed". The respondents were asked to indicate how distressed they had been about an issue as addressed by the 10 items over the last months using a five-point Likert scale ranging from 1 "not at all distressed "to 5 "extremely distressed" (Holland Klingspon et al., 2020). The total UBBS score was calculated as the average score of all 10 items (1-5). Additionally, the average scale scores for the 5 Unfulfilled Wishes items and 5 the Unresolved Conflicts items was calculated (Holland Klingspon et al., 2018). The ten items were translated into Dutch by our research team using a forward-backward method.

Analysis

First, descriptive analyses were performed to summarize the characteristics of the respondents and the deceased persons. To better understand despair, a total mean score and mean scores per item were calculated. Frequencies or averages of the other variables were calculated. Second, to perform factor identification for multivariate analysis, correlations (univariate analysis) were computed while adjusting for age and gender. Pearson correlations were used to examine the association between continuous measures, while Point Biseral correlations were employed when a variable was dichotomous (e.g. gender, sufficient/insufficient opportunity to be with the dying person). Only variables that were significantly correlated (p value of <.05) with the outcome variable despair were included in the regression model. Finally, to investigate the association between despair (dependent variable) and the independent variables, multivariate linear regression analysis was performed. Multicollinearity was checked by calculating the variance inflation factor. Results of the linear regression are presented with unstandardized and standardized regression coefficients (Beta), and their corresponding 95% confidence intervals (95% CI). Missing data were handled using mean imputation. All analyses were conducted using SPSS Statistics software (version 28). A two-sided significance level of p < .05 was applied.

Ethical considerations

Respondents were asked for consent to use their data in the study, before they completed the questionnaire. Respondents could stop completing the questionnaire at any time. They were advised to contact their general practitioner if they felt the need to share their experiences. The Erasmus MC Medical Ethical Research Committee assessed that the rules laid down in the Medical Research Involving Human Subjects Act did not apply to this study [ref. MEC-2020-0254].

Results

Characteristics of bereaved relatives and deceased persons

As shown in Table 1, the majority of relatives were female (85%), with a mean age of 57. Most relatives were children (68%), or partners (17%) of

Bereaved relatives	Ν	%
Sex		
Female	169	84.5
Male	31	15.5
Age, mean (SD, range)	57 (11; 26–88)	
Relation to deceased person		
Child	136	68.0
Partner	34	17.0
Other relative	30	15.0
Deceased persons	Ν	%
Sex		
Male	107	53.5
Female	91	45.5
Other	2	1.0
Age, mean (SD, range) ^a	80 (12; 0–99)	
COVID-19 ^a		
Confirmed/suspected COVID-19	103	57.9
No confirmed/suspected COVID-19	75	42.1
Setting where person died ^a		
Nursing home	84	47.2
Hospital	51	28.7
Home	23	12.9
Hospice	12	6.7
Other	8	4.5

Table 1. Characteristics of the bereaved relatives and the deceased persons (n = 200).

^aMissing observations: age 1, COVID-19 22, and setting where person died 22.

the deceased person. The mean age of the deceased persons was 80 years, and most of them died in a nursing home (47%), followed by hospital (29%), home (13%), and other care settings (12%). The time between the death of the deceased and completion of the follow-up questionnaire was on average 33 weeks (SD 3.7, range 21-40).

Despair, the emotional component of grief

Table 2 presents the mean despair scores. The total mean despair score was 24.2 (SD 9.6, range 13–63). The mean scores of bereaved relatives were highest for feelings such as heaviness in the heart, being agonized over death, crying frequently, having difficulty accepting death, and little control over sadness.

Hogan Despair subscale items (13)	Mean (SD)	Range
Total despair	24.2 (9.6)	13–63
Heaviness in heart	2.7 (1.4)	1–5
Agonize over death	2.5 (1.2)	1–5
Frequently cry	2.4 (1.2)	1–5
Difficulty accepting death	2.1 (1.3)	1–5
Little control sadness	2.1 (1.1)	1–5
Loneliness	1.8 (1.1)	1–5
Shattered hopes	1.8 (1.1)	1–5
Feel hopeless	1.7 (1.0)	1–5
Feel like I am in shock	1.6 (1.0)	1–5
Never happy again	1.6 (1.0)	1–5
Feel like walking in my sleep	1.5 (0.9)	1–5
I should have died	1.2 (0.5)	1–5
Wanting to die	1.2 (0.6)	1–5

Table 2. Mean Hogan despair items (n = 200).

Experiences of the last days of life

Sixty-two percent of the relatives reported not having had sufficient opportunity to be with their loved one in the last days of life. Table 3 presents some quotes from relatives about their experiences.

Terms most often selected by bereaved relatives to describe the death of their loved one were: sad (63%), quiet (42%), painful (29%), shocking (28%), and degrading (27%). Half of the respondents selected only "negative" terms and the other half selected "positive" terms either or not combined with "negative" terms.

The total mean score of the UBBS scale was 1.72 (SD 0.64, range 1–4). The total mean scores of the Unfulfilled Wishes subscale and the Unresolved Conflicts subscale were 2.16 (SD 0.97, range 1–5) and 1.28 (SD 0.55, range 1–3.4) respectively (Table 4).

Table 3. Experiences of bereaved relatives of having had (in)sufficient opportunity to be with the dying person.

"It was very hectic. By the time we were allowed to be with her, she was already in a coma." (Daughter-in-law, 58 years)

"I was only allowed to visit her once every 24 hours. We were not allowed to be present when she was in the final stage of her life and so she died alone." (Daughter, 57 years)

- "I spent one and a half day at my husband's bedside in full protective clothing (moon suit). My husband was no longer conscious because of the palliative treatment that had already been started before my arrival. I was not able to say goodbye to him. It was waiting for him to die." (Partner, 79 years)
- "On my enforced request, I was able to be with her the last 20 minutes before she died. Unfortunately, she was already unconscious. If the nurses had known better how fast the process could go, I could have been with my mother earlier. I could have calmed her down in the last desperate minutes of her life. It was degrading for her to suffer alone. Degrading that I had always cared for her but was not allowed to be with her at the most important moment of her life." (Daughter, 45 years)

"My husband was at home and I could stay away from work for as long as I needed." (Partner, 63 years) "Unfortunately, we (my partner and me) had to alternate in the hospital due to the covid measures. Because of the case [the death of a young child], we were allowed more space, which we appreciate enormously. It is very difficult for grandpa and grandma that they were not allowed to visit our son in the last month of his life." (Parent, 38 years)

"The total ban and NEVER being allowed to see him when he was in the hospital is almost unbearable for me at times. Never having been able to hold his hand and be close to him is sometimes an almost physical pain for me. I have the feeling that I let him down when it became very difficult. And that makes it very difficult for me to cope with his death." (Partner, 74 years)

	n	%
Sufficient opportunity to be with dying person ^a		
Yes, (more than) sufficient	76	38.2
No, insufficient	123	61.8
Appreciation how person died ^{a,b}		
"Negative" terms		
Sad	125	62.5
Painful	57	28.5
Shocking	55	27.5
Degrading	54	27.0
Restless	46	23.0
Hectic	32	16.0
"Positive" terms		
Quiet	83	41.5
Peaceful	39	19.0
Dignified	37	18.5
Good	30	15.0
Touching	29	14.5
Intimate	22	11.0
Only "negative" terms	99	49.5
"Positive" terms, either or not combined with "negative" terms	98	49.0
Unfinished business (min 1–max 5), mean (SD)		
Unfinished business total	1.72	(0.64)
Unfulfilled wishes subscale	2.16	(0.97)
Unresolved conflicts subscale	1.28	(0.55)

Table 4. Impact of COVID-19 associated measures (percentages), n = 200.

^aMissing observations: sufficient opportunity to be with loved one 1, appreciation how person died 3. ^bMore than one answer possible.

[&]quot;Despite the lockdown we were allowed to say goodbye during the last 5 days. I was with him when he died. I am very grateful for that." (Partner, 76 years)

10 😔 Y. N. BECQUÉ ET AL.

Correlations

To determine which variables should be included in the regression analyses, correlations were calculated (Table 5). Being a partner of the deceased was correlated with higher despair scores, as was a negative appreciation of how the person died. In addition, unfulfilled wishes and unresolved conflicts were also correlated with despair. Age and gender of the bereaved relative, whether or not a person died with COVID-19, and having had insufficient opportunity to be with the dying person were not significantly correlated with despair.

Associations with despair

In the multivariate model, respondents who were partners of a deceased person reported higher levels of despair than children (Table 6). Further, respondents who selected only "negative" terms to appreciate how the person died had higher despair levels compared to those who selected only "positive" terms or both "positive" and "negative" terms. We also found

	Table 5.	Pearson	and Point	Biseral	correlations.
--	----------	---------	-----------	---------	---------------

	n	Despair	p Value
Age bereaved relative	200	0.007	.916
Gender bereaved relative ^a	200	0.016	.818
Relation to deceased person ^b	200	0.410	<.001
Confirmed/suspected COVID-19 ^c	178	-0.048	.521
(In)sufficiently opportunity to be with dying person ^d	200	0.023	.748
Appreciation how person died ^e	200	0.236	<.001
Unfulfilled Wishes subscale	200	0.342	<.001
Unresolved Conflicts subscale	200	0.180	.011

^aMale vs female.

^bChild or other relative vs. partner.

Yes vs. no.

^dYes, (more than) sufficient vs. no, insufficient.

^ePositive or combined with negative terms vs. only negative terms.

Significant correlations are presented in bold.

	مسمام سمغم سا		م ام بر مام بر م	10		n Valu	· • \///	2
(n = 200).	· - j							_
Table 6. Multivariate linear	rearession	analvze t	o explain	bereaved	relatives'	level of	despai	r

	Unstandardized β	Standardized β	95% CI	p Value	VIF
Partner of the deceased (vs child or other)	10.345	0.405	7.321–13.370	<.001	1.0
Only "negative" terms to appreciate how person died (vs only "positive" terms or both) ^a	3.217	0.1.66	0.800–5.635	.009	1.1
Unfulfilled wishes	2.478	0.250	1.153-3.803	<.001	1.3
Unresolved conflicts	1.026	0.059	-1.176-3.227	.614	1.2
Explained variance final model	$R^2 = 0.301$			<.001	
F value (df)	21.038 (4)				

Significant correlations are presented in bold.

that higher "unfulfilled wishes" scores were associated with higher levels of despair, but "unresolved conflicts" scores were not significantly associated with levels of despair.

In the multivariate model, 30% percent of the variance of the variable despair could be explained by the tested independent variables (Table 6). The type of relationship between the bereaved relative and the deceased person was the strongest predictor of despair ($\beta = 0.405$; p < .001), followed by "unfulfilled wishes" ($\beta = 0.250$; p < .001), and a negative appreciation of how the person died ($\beta = 0.166$; p = .009). Variance Inflation Factor scores varied between 1.0 and 1.3; indicating the absence of multicollinearity.

Discussion

This study was aimed at assessing whether the grieving process of bereaved people was affected by factors surrounding the death of a loved one during the first COVID-19 wave, such as having had (in)sufficient opportunity to be with the dying person, relatives' appreciation of how the person died, and unfulfilled wishes and unresolved conflicts between the bereaved and the deceased.

Our findings indicate that relatives who lost a loved one during the pandemic may experience high levels of despair, particularly those who lost their partner. This vulnerability of partners is supported by several studies. For example, Lee and Neimeyer (2022) found that individuals who lost a partner from COVID-19 had the highest grief scores. Similarly, research by Tang and Xiang (2021) among 422 Chinese participants who lost a close person due to COVID-19 revealed that first-degree family members, such as partners, experienced most grief. Additionally, they discovered that the level of closeness with the deceased was positively correlated with severity of grief. The bond of attachment between partners persists even after the death of one of them and may lead to disbelief that the person has died and to unresolved grief (Tang & Xiang, 2021).

The majority of the relatives reported to have had insufficient opportunity to be with their loved one during the final days of life. However, we found no significant correlation between insufficient opportunity to be with the dying person and despair levels. It is possible that we should have asked a more specific question, such as directly asking whether relatives were able to say goodbye to their loved one, rather than indirectly asking about their opportunity to be with them during their last days of life.

Confirming our hypothesis, we found an association between relatives' appreciation of how the person died and despair levels. Specifically, relatives who selected only "negative" terms (such as degrading and shocking) to describe their appreciation of how the person died reported more

despair than those who selected only "positive" terms, or a combination of "positive" and "negative" terms. During the first wave of the COVID-19 pandemic, many relatives faced challenges related to death and dying, including the isolation of their loved ones and restricted farewells (Schloesser et al., 2021). According to Lee and Neimeyer (2022), the inability to access positive memories about the deceased is a symptom of dysfunctional grief during the COVID-19 pandemic. These findings align with those of the study conducted by Mancini et al. (2015) among 115 bereaved spouses, which revealed that difficulty experiencing comfort in relation to memories around the deceased is associated with prolonged grief. Furthermore, Mancini et al. (2015) suggested that excessive rumination about the deceased can prevent bereaved individuals from accessing comforting memories. It is also possible that the circumstances surrounding death and dying during the pandemic were so extreme and painful that bereaved families mostly have negative memories, which makes it challenging to access positive memories.

We also found an association between "unfulfilled wishes" and despair. This finding is consistent with other qualitative studies (Becqué et al., 2022; Hanna et al., 2021), which found that relatives of seriously ill loved ones felt powerless due to the restrictive measures that prohibited them from visiting. Furthermore, relatives expressed that the visitor ban had limited their ability and wish to say goodbye. Sometimes relatives had to say goodbye by phone or were too late to say goodbye because their loved one was already unconscious (Becqué et al., 2022; Hanna et al., 2021).

Our study did not reveal an association between "unresolved conflicts" and despair. Although we cannot identify the reasons for this, during the interviews with bereaved relatives in our earlier qualitative research did reveal any conflicts between the bereaved and the deceased (Becqué et al., 2022). Lee et al. (2022), also conducted research on "unfinished business" among individuals who lost someone due to COVID-19. They found that "unfinished business" was associated with grief, but in their study grief could be attributed to the "unresolved conflict" dimension of "unfinished business." However, their research did not identify an explanation for this finding (Lee et al., 2022). It is possible that the unique COVID-19 pandemic conditions in different counties, or cultural differences, play a role, but future research is needed to confirm this.

Practical implications of this study include that it is important to ask relatives about their wishes to ensure that relatives can experience good, humane end-of-life care for their loved ones. They should be given sufficient time to resolve family issues preventing the persistence of unfulfilled wishes. These practices can help to alleviate the despair experiences by relatives during a pandemic.

Strengths and limitations

A strength of this study is that we were able to collect information on experiences with end-of-life care of a large number of bereaved relatives rather shortly after their loved one had died. It is remarkable that respondents often shared intimate experiences, which gave the quantitative data more meaning. However, our open and voluntary sampling procedure has led to an overrepresentation of women (85%) (Cheung et al., 2017), which is common in bereavement research (Eisma & Tamminga, 2020). Due to the survey's online format, there may also have been a selection bias toward relatives who were capable of getting access to and completing an online survey and who were relatively young.

Furthermore, we only used the Despair subscale to measure grief (Hogan et al., 2001). We did not assess other dimensions of grief, such as guilt and fear, or panic.

Our study concerns relatives who lost a loved one during the first phase of the COVID-19 pandemic, a time that involved a lot of hectic and uncertainty and may not be representative of other phases of the COVID-19 pandemic.

Bereaved relatives completed the questionnaire on average 33 weeks after the death of their loved one. Complicated grief may arise later, after 12 months when bereaved relatives have not developed a new sense of normalcy in their lives (Shear, 2015). Future research is needed to investigate the long-term impact of the COVID-19 pandemic on the grieving process of bereaved families.

Conclusion

Different factors related to death and dying during the first COVID-19 wave have impacted the grieving process of bereaved relatives, as measured by their level of despair. A negative appreciation of the dying process and remaining unfulfilled wishes in the relationship with the deceased increased the likelihood of high levels of despair. The vulnerability of partners in this respect must be acknowledged. Efforts should be made to ensure that relatives can have good experiences around death and dying, and always have the opportunity to resolve family issues.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This study was supported by ZonMw, The Hague, the Netherlands (project number: 844001803).

Notes on contributors

Yvonne N. Becqué, RN, MSc, PhD Candidate at the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, the Netherlands and Research Center Innovations in Care, Rotterdam University of Applied Sciences, the Netherlands.

Erica Witkamp, PhD, Professor of Family Caregiving at Research Center Innovations in Care, Rotterdam University of Applied Sciences, the Netherlands. Senior researcher at the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, the Netherlands.

Anne Goossensen, PhD, Professor of Informal Care & Care Ethics at University of Humanistic Studies, Utrecht, the Netherlands.

Ida J. Korfage, PhD, Associate Professor at the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, the Netherlands.

Liza G.G. van Lent, MSc, PhD Candidate at the Department of Medical Oncology, Erasmus MC Cancer Institute, University Medical Center Rotterdam, the Netherlands.

H. Roeline Pasman, PhD, Associate Professor of End-of-Life Studies at Department of Public and Occupational Health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, the Netherlands.

Bregje D. Onwuteaka-Philipsen, PhD, Full Professor of End-of-Life Research at Department of Public and Occupational Health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, the Netherlands.

Masha Zee, MSc, PhD Candidate at Department of Public and Occupational Health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, the Netherlands.

Agnes van der Heide[•] MD, PhD, Full Professor of decision making and palliative care at department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands

ORCID

 Yvonne N. Becqué ()
 http://orcid.org/0000-0002-9188-9911

 Erica Witkamp ()
 http://orcid.org/0000-0001-7475-0363

 Anne Goossensen ()
 http://orcid.org/0000-0001-5447-2167

 Ida J. Korfage ()
 http://orcid.org/0000-0001-6538-9115

 Liza G. G. van Lent ()
 http://orcid.org/0000-0002-4979-3051

 H. Roeline Pasman ()
 http://orcid.org/0000-0001-6856-2964

 Bregje D. Onwuteaka-Philipsen ()
 http://orcid.org/0000-0002-9440-1248

 Masha Zee ()
 http://orcid.org/0000-0002-7937-5854

 Agnes van der Heide ()
 http://orcid.org/0000-0001-5584-4305

Data availability statement

The data that support the findings of this study are available from the corresponding author, (YB), upon reasonable request.

References

- Becqué, Y. N., van der Geugten, W., van der Heide, A., Korfage, I. J., Pasman, H. R. W., Onwuteaka-Philipsen, B. D., Zee, M., Witkamp, E., & Goossensen, A. (2022). Dignity reflections based on experiences of end-of-life care during the first wave of the COVID-19 pandemic: A qualitative inquiry among bereaved relatives in the Netherlands (the CO-LIVE study). Scandinavian Journal of Caring Sciences, 36(3), 769–781. https://doi. org/10.1111/scs.13038
- Cheung, K. L., Peter, M., Smit, C., de Vries, H., & Pieterse, M. E. (2017). The impact of non-response bias due to sampling in public health studies: A comparison of voluntary versus mandatory recruitment in a Dutch national survey on adolescent health. *BMC Public Health*, 17(1), 1–10. https://doi.org/10.1186/s12889-017-4189-8
- Eisma, M. C., & Tamminga, A. (2020). Grief before and during the COVID-19 pandemic: Multiple group comparisons. *Journal of Pain and Symptom Management*, 60(6), e1–e4. https://doi.org/10.1016/j.jpainsymman.2020.10.004
- Gesi, C., Carmassi, C., Cerveri, G., Carpita, B., Cremone, I. M., & Dell'Osso, L. (2020). Complicated grief: What to expect after the coronavirus pandemic. *Frontiers in Psychiatry*, 11, 489. https://doi.org/10.3389/fpsyt.2020.00489
- Goveas, J. S., & Shear, M. K. (2020). Grief and the COVID-19 pandemic in older adults. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 28(10), 1119–1125. https://doi.org/10.1016/j.jagp. 2020.06.021
- Hanna, J. R., Rapa, E., Dalton, L. J., Hughes, R., McGlinchey, T., Bennett, K. M., Donnellan, W. J., Mason, S. R., & Mayland, C. R. (2021). A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliative Medicine*, 35(5), 843–851. https://doi.org/10.1177/02692163211004210
- Hogan, N. S., Greenfield, D. B., & Schmidt, L. A. (2001). Development and validation of the Hogan grief reaction checklist. *Death Studies*, 25(1), 1–32. https://doi.org/10.1080/ 074811801750058609
- Holland, J. M., Klingspon, K. L., Lichtenthal, W. G., & Neimeyer, R. A. (2020). The Unfinished Business in Bereavement Scale (UBBS): Development and psychometric evaluation. *Death Studies*, 44(2), 65-77.
- Holland, J. M., Plant, C. P., Klingspon, K. L., & Neimeyer, R. A. (2020). Bereavementrelated regrets and unfinished business with the deceased. *Death Studies*, 44(1), 42-47. https://doi.org/10.1080/07481187.2018.1521106
- Holtslander, L. F. (2011). Depressive symptoms, grief, and complicated grief among family caregivers of patients with advanced cancer three months into bereavement. *Oncology Nursing Forum, 38(1), 60-65.*
- Klingspon, K. L., Holland, J. M., Neimeyer, R. A., & Lichtenthal, W. G. (2015). Unfinished business in bereavement. *Death Studies*, 39(7), 387–398. https://doi.org/10.1080/ 07481187.2015.1029143
- Lee, S. A., & Neimeyer, R. A. (2022). Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss. *Death Studies*, 46(1), 14–24. https://doi.org/10.1080/ 07481187.2020.1853885

16 🕒 Y. N. BECQUÉ ET AL.

- Lee, S. A., Neimeyer, R. A., Mancini, V. O., & Breen, L. J. (2022). Unfinished business and self-blaming emotions among those bereaved by a COVID-19 death. *Death Studies*, 46(6), 1297–1306.
- Lobb, E. A., Kristjanson, L. J., Aoun, S. M., Monterosso, L., Halkett, G. K., & Davies, A. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies*, 34(8), 673–698. https://doi.org/10.1080/07481187.2010.496686
- Mancini, A. D., Sinan, B., & Bonanno, G. A. (2015). Predictors of prolonged grief, resilience, and recovery among bereaved spouses. *Journal of Clinical Psychology*, 71(12), 1245–1258. https://doi.org/10.1002/jclp.22224
- Mason, T. M., Tofthagen, C. S., & Buck, H. G. (2020). Complicated grief: Risk factors, protective factors, and interventions. *Journal of Social Work in End-of-Life & Palliative Care*, 16(2), 151–174. https://doi.org/10.1080/15524256.2020.1745726
- Menzies, R. E., Neimeyer, R. A., & Menzies, R. G. (2020). Death anxiety, loss, and grief in the time of COVID-19. *Behaviour Change*, 37(3), 111–115. https://doi.org/10.1017/bec. 2020.10
- Mortazavi, S. S., Assari, S., Alimohamadi, A., Rafiee, M., & Shati, M. (2020). Fear, loss, social isolation, and incomplete grief due to COVID-19: A recipe for a psychiatric pandemic. *Basic and Clinical Neuroscience*, 11(2), 225–232. https://doi.org/10.32598/bcn.11. covid19.2549.1
- Onwuteaka-Philipsen, B. D., Pasman, H. R. W., Korfage, I. J., Witkamp, E., Zee, M., van Lent, L. G., Goossensen, A., & van der Heide, A. (2021). Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study). *Palliative Medicine*, 35(5), 830–842. https://doi.org/10.1177/02692163211003778
- Otani, H., Yoshida, S., Morita, T., Aoyama, M., Kizawa, Y., Shima, Y., Tsuneto, S., & Miyashita, M. (2017). Meaningful communication before death, but not present at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients. *Journal of Pain and Symptom Management*, 54(3), 273–279. https://doi.org/10.1016/j.jpainsymman.2017.07.010
- Probst, D. R., Gustin, J. L., Goodman, L. F., Lorenz, A., & Wells-Di Gregorio, S. M. (2016). ICU versus non-ICU hospital death: Family member complicated grief, posttraumatic stress, and depressive symptoms. *Journal of Palliative Medicine*, 19(4), 387–393. https:// doi.org/10.1089/jpm.2015.0120
- Rietjens, J. A., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2006). Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliative Medicine*, 20(7), 685–692. https://doi.org/10.1177/0269216306070241
- Schloesser, K., Simon, S. T., Pauli, B., Voltz, R., Jung, N., Leisse, C., van der Heide, A., Korfage, I. J., Pralong, A., & Bausewein, C. (2021). "Saying goodbye all alone with no close support was difficult"-Dying during the COVID-19 pandemic: An online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. BMC Health Services Research, 21, 1–11.
- Selman, L. E., Chamberlain, C., Sowden, R., Chao, D., Selman, D., Taubert, M., & Braude, P. (2021). Sadness, despair and anger when a patient dies alone from COVID-19: A thematic content analysis of Twitter data from bereaved family members and friends. *Palliative Medicine*, 35(7), 1267–1276. https://doi.org/10.1177/02692163211017026
- Shear, M. K. (2015). Complicated grief. The New England Journal of Medicine, 372(2), 153– 160. https://doi.org/10.1056/NEJMcp1315618

- Tang, S., & Xiang, Z. (2021). Who suffered most after deaths due to COVID-19? Prevalence and correlates of prolonged grief disorder in COVID-19 related bereaved adults. *Globalization and Health*, 17(1), 19. https://doi.org/10.1186/s12992-021-00669-5
- Vandenbroucke, J. P., Von Elm, E., Altman, D. G., Gøtzsche, P. C., Mulrow, C. D., Pocock, S. J., Poole, C., Schlesselman, J. J., Egger, M., & Initiative, S. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): Explanation and elaboration. *PLoS Medicine*, 4(10), e297. https://doi.org/10.1371/journal.pmed.0040297
- Waldrop, D. P., & McGinley, J. M. (2020). "I want to go home": How location at death influences caregiver well-being in bereavement. *Palliative & Supportive Care*, 18(6), 691– 698. https://doi.org/10.1017/S1478951520000176
- Wallace, C. L., Wladkowski, S. P., Gibson, A., & White, P. (2020). Grief during the COVID-19 pandemic: Considerations for palliative care providers. *Journal of Pain and Symptom Management*, 60(1), e70–e76. https://doi.org/10.1016/j.jpainsymman.2020.04.012
- Wilson, D. M., Cohen, J., MacLeod, R., & Houttekier, D. (2018). Bereavement grief: A population-based foundational evidence study. *Death Studies*, 42(7), 463–469. https://doi. org/10.1080/07481187.2017.1382609
- Witkamp, F. E. (2015). [What happens and what matters]. [PhD thesis]. Erasmus University Rotterdam. http://hdl.handle.net/1765/77904
- Witkamp, F. E., van Zuylen, L., Borsboom, G., van der Rijt, C. C., & van der Heide, A. (2015). Dying in the hospital: What happens and what matters, according to bereaved relatives. *Journal of Pain and Symptom Management*, 49(2), 203–213. https://doi.org/10. 1016/j.jpainsymman.2014.06.013
- World Health Organization. (2023). WHO coronavirus (COVID-19) dashboard. World Health Organization. https://covid19.who.int/
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson, V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association*, 300(14), 1665–1673. https://doi.org/10.1001/jama.300.14.1665
- Yildiz, B., Korfage, I. J., Witkamp, E. F., Goossensen, A., van Lent, L. G., Pasman, H. R., Onwuteaka-Philipsen, B. D., Zee, M., & van der Heide, A. (2022). Dying in times of COVID-19: Experiences in different care settings – An online questionnaire study among bereaved relatives (the CO-LIVE study). *Palliative Medicine*, 36(4), 751–761. https://doi. org/10.1177/02692163221079698