

Original Article

Experiencing Missing Contact With Professionals and Long Term Bereavement Outcome

Emilie Stendahl Ramstad, MD, Laura Sabroe Thegen, MD, Mai-Britt Guldin, PhD, psychologist specialist, senior researcher, Mette Asbjørn Neergaard, MD, PhD, professor, consultant, and Mette Kjaergaard Nielsen, MD, PhD, postdoc, GP trainee

Research Unit for General Practice (E.S.R, L.S.T, M.G, M.K.N), Aarhus, Denmark; Department of Clinical Medicine (M.A.N), Aarhus University, Aarhus, Denmark; Aarhus University (E.S.R, L.S.T)

Abstract

Context. The Danish health care system provides palliative care for terminally ill patients and their family caregivers. However, initiatives to support family caregivers are not systematically organized.

Objectives. We aimed to examine the association between self-reported experience of missing contact to health care professionals involved in palliative care, and symptoms of grief and depression three years post-loss.

Methods. We conducted a prospective population-based survey of 3635 family caregivers to terminally ill patients. At six months follow-up, the caregivers reported whether they missed contact to the general practitioner, home care nurse, hospital staff, and/or palliative care team. Associations between missing contact and symptoms of prolonged grief (Prolonged-Grief-13) and depression (Beck Depression Inventory-II) three years after bereavement were analyzed with multivariable logistic regression analysis.

Results. We found that an experience of missing contact with health care professionals six months after bereavement was significantly associated with symptoms indicative of prolonged grief disorder and depression after three years. The strongest association was found for missing contact with the general practitioner with an adjusted OR = 4.0 (95%CI: 1.9;8.3) for prolonged grief and an adjusted OR = 5.2 (95% CI: 3.4;7.9) for depression.

Conclusion. Experiencing missing contact with health care professionals shortly after bereavement was associated with adverse psychological reactions. Family caregivers may benefit from bereavement support to prevent further complications. A proactive approach with assessment of support needs and risk of complications early during the patient's illness trajectory may target support at those who needs it. *J Pain Symptom Manage* 2022;000:1–9. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Key Words

Family caregiver, Complicated grief, Depression, Health care professionals, Bereavement

Key Message

The paper is based on a prospective population-based survey of 1,735 bereaved family caregivers. We found an association between missing contact to health care professionals shortly after bereavement and symptoms of prolonged grief and depression three years post-loss. Suggesting that caregivers may benefit from assessment of need for bereavement support.

What was previously known

Bereaved caregivers are at risk of developing prolonged grief and depression, and only about half of bereaved caregivers suffering from depression or PGD have sought some type of bereavement service. Caregivers with

Address correspondence to: Emilie Stendahl Ramstad, MD, Garnisonsbakken 12A, 9912 HESSENG, NORWAY. E-mail: emstendahl@gmail.com

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prolonged grief disorder and depression benefit from support from healthcare professionals.

What this study adds

We found the self-reported experience of missing contact with healthcare professionals shortly after bereavement was associated with adverse psychological reactions such as prolonged grief and depression.

How this study might affect research, practice or policy

The findings in this study point at a need for systematic risk assessment of family caregivers' support needs and risk of complications. A systematic risk assessment may enable health care professionals to direct support for those who need it, and thereby prevent adverse bereavement outcome by early interventions.

Introduction

A family caregiver can be defined as the patients' close relative who provides caregiving for the patient. Being a caregiver may be physically and emotionally distressing during the patient's illness trajectory¹⁻³ and after the patient's death.⁴ Hence, bereavement is associated with diverse psychological reactions.⁴ If the caregiver's psychological resources are exceeded it can lead to adverse bereavement outcomes such as prolonged grief disorder (PGD) and depression.^{2, 5}

PGD is a condition with intense yearning and pervasive longing for the deceased to an extent that impairs normal psychological, social, and daily functioning beyond six months or more after bereavement, depending on cultural and contextual factors.⁶⁻⁸ A meta-analysis by Lundorff et al. found a 9.8% prevalence estimate of PGD among bereaved adults in various populations.⁹ Studies in other populations found lower prevalence: In the current cohort, an 8% prevalence was found six months after bereavement using the Prolonged Grief-13 scale (PGD_{PG-13})⁵ and three years after bereavement, Zordan et al. found a prevalence of 5%.¹⁰ Depression is another adverse outcome following bereavement. A systematic review of family caregivers to patients in hospice care found a depression frequency of 26-57%,¹¹ and the prevalence of moderate-severe depressive symptoms in a study from the current cohort was 12% six months after bereavement.⁵

The development of adverse bereavement outcomes such as PGD and depression has shown to be related to a broad range of factors in a complex interplay.¹² Socioeconomic factors such as female gender, spousal relation, young age, and lower education have been found to be risk factors for PGD.¹³ In another study, the socioeconomic factors of female gender, young age and low education were also proved to be risk factors of post-loss depression in caregivers.⁵ Psychosocial factors

such as perceived caregiver burden, difficulty in accepting death, and low social support have also been identified as risk factors for PGD.¹³

Furthermore, occurrence of depressive and grief symptoms before death has been described as risk factors for both PGD¹³⁻¹⁵ and depression.⁵ Low psychosocial resources¹⁶ and high levels of distress at the time around the loss¹⁷ has been associated with depression after the patient's death.

During the patient's illness trajectory, health care professionals are in regular contact with the caregiver, but this contact primarily concerns the patient and often ends when the patient dies. The bereaved caregiver can be left with a sense of abandonment from the health care system.¹⁸ Earlier findings have shown that only 47% of family caregivers with PGD and 64% of family caregivers with depression, received professional bereavement care from a general practitioner (GP), psychologist, or chaplain.¹⁹

Today, systematic standard procedures for health care professionals to assess the caregiver's need for support during bereavement are lacking. Bereavement support in primary care has been described as inconsistent and GPs have reported a lack of training in the area.²⁰ Nevertheless, risk assessment has been found to be both feasible and helpful.²⁰ Hence, existing literature suggests that there is a gap in bereavement care in the health care systems that could possibly be resolved. In this study, we wanted to shed further light on bereavement care and the role of health professionals.

We aimed to investigate if there was an association between bereaved caregivers' self-reported experience of missing help from healthcare professionals during the first six months after the patients' death and symptoms of PGD and depressive symptoms three years after the loss.

Method

We conducted a prospective population-based cohort study with follow-up at six months and three years after the patient's death. Data included self-reporting questionnaires linked with register-based data.

Setting

The Danish health care system provides healthcare free of charge financed by taxes.²²

Terminally ill patients are entitled to drug reimbursement after application from a physician at the Danish Medicines Agency.²³ This means that the patient can receive prescribed medicine free of charge.

In Denmark, there is no formal task distribution between health professionals performing palliative care and bereavement care. The GP acts as the primary care provider and most citizens are affiliated with a GP. Other staff groups such as home care nurses employed by municipalities, hospital staff, and specialized palliative

care teams affiliated with major hospitals are involved in palliative care when needed.²⁴

Study Population

Data for this analysis were collected in a nationwide prospective population-based cohort study.^{3, 5} The study included caregivers of all Danish patients with terminal illness granted drug reimbursement in 2012. Patients were sent a baseline questionnaire and a request to hand it to their closest relative, which is referred to as the caregiver. Caregivers were asked to give informed consent, enter their ID number, and complete the questionnaire.

Data

Register-Based Data. All Danish citizens are registered with a personal ID number (CPR number) that was linked with national Danish health registers at Statistics Denmark.^{25, 26} Register-based information included educational level (< 10 years, 10-15 years, >15 years) according to the International Standard Classification of Education²⁷ and cohabitation status (married/cohabiting, living alone). The date of the patients' death was obtained from the Danish Civil Registry.²⁸

Questionnaire-Based Data. Information on the caregivers' relation to the patient was retrieved at baseline (partner, adult child, other). Level of PGD symptoms and depressive symptoms before death were also collected at baseline.

The exposure was the item "To which extent did you miss contact with below mentioned health care professionals after bereavement?". It was assessed six months after bereavement in the following groups of health care professionals: GP, home care nurse, hospital staff, and palliative care team on a 4-point Likert scale ("not at all" to "highly"). We dichotomized in categories "missing contact" ("highly" and "to some extent") and "not missing contact" ("to a lesser extent" and "not at all").

Outcomes were fulfillment of criteria of PGD on the PG-13 scale (PGD_{PG-13}) and symptoms of depression on the 21-item Beck Depression Inventory II (BDI-II) three years after bereavement. The PG-13 scale is a 13-item self-report scale to evaluate symptoms of grief. PG-13 contains five dichotomized (yes/no) criteria (A-E) that must be met to fulfill the criteria of PGD_{PG-13}.²⁹

BDI is a 21 item self-report scale that assess cognitive/affective and somatic symptoms of depression within the last two weeks.³⁰

Statistics

Data were presented as frequencies and proportions. Only complete cases on exposure and outcome were included in the analysis. We analyzed the associations

between exposure and outcome in a multivariable logistic regression model adjusted for socioeconomic factors (age, gender, personal relation with the patient, and educational level). The estimates were presented as Odds ratios (ORs) and adjusted ORs with 95% confidence intervals (CI). Statistical analyses were performed using Stata version 14 (StataCorp LLC, College Station, TX).

Results

Study Population

Of the 3,635 participants at baseline, caregivers who were bereaved within six months were contacted for follow-up at six months. Of the 2,215 participants at the first follow-up, 1,735 family caregivers completed a questionnaire three years after bereavement (Fig. 1).

Out of 1735 respondents at follow-up, we included 1505 bereaved caregivers with complete responses on both PG-13 and BDI-II.

The bereaved caregivers were characterized with a mean age of 61.4 years, predominantly female gender (69.8%), and spousal relation (63.9%). Regarding educational level, 23.9% had less than ten years of education and 27.4% had more than 15 years of education (Table 1).

At baseline, 214 caregivers (14.2%) had severe pre-death grief symptoms and 220 (14.6%) had moderate or severe pre-death depressive symptoms. At 3-year follow-up, 107 (7.1%) caregivers had moderate-severe depressive symptoms and 32 (2.1%) had PGD_{PG-13}.

Missing Contact to Health Care Professionals

The largest proportion of caregivers, who had missed contact with a group of health professionals was 237 (15.7%) who missed contact with their GP (Table 2), and 33 (2.2%) missed contact with all four groups of health care professionals.

An association between reporting missing contact to health care professionals at six months follow-up and symptoms of PGD_{PG-13} at three years follow-up was found and it was statistically significant for all groups of health care professionals. The association was strongest for caregivers reporting to miss contact with their GP (adjusted OR = 4.0 (95% CI: 1.9;8.3)) (Table 3).

Regarding depression, the association between reporting missing contact to health care professionals at six months follow-up and moderate-severe depressive symptoms at three years follow-up was also statistically significant in all groups of health care professionals, with the strongest association for missing contact with the GP (adjusted OR = 5.2 (95% CI; 3.4;7.9) (Table 4).

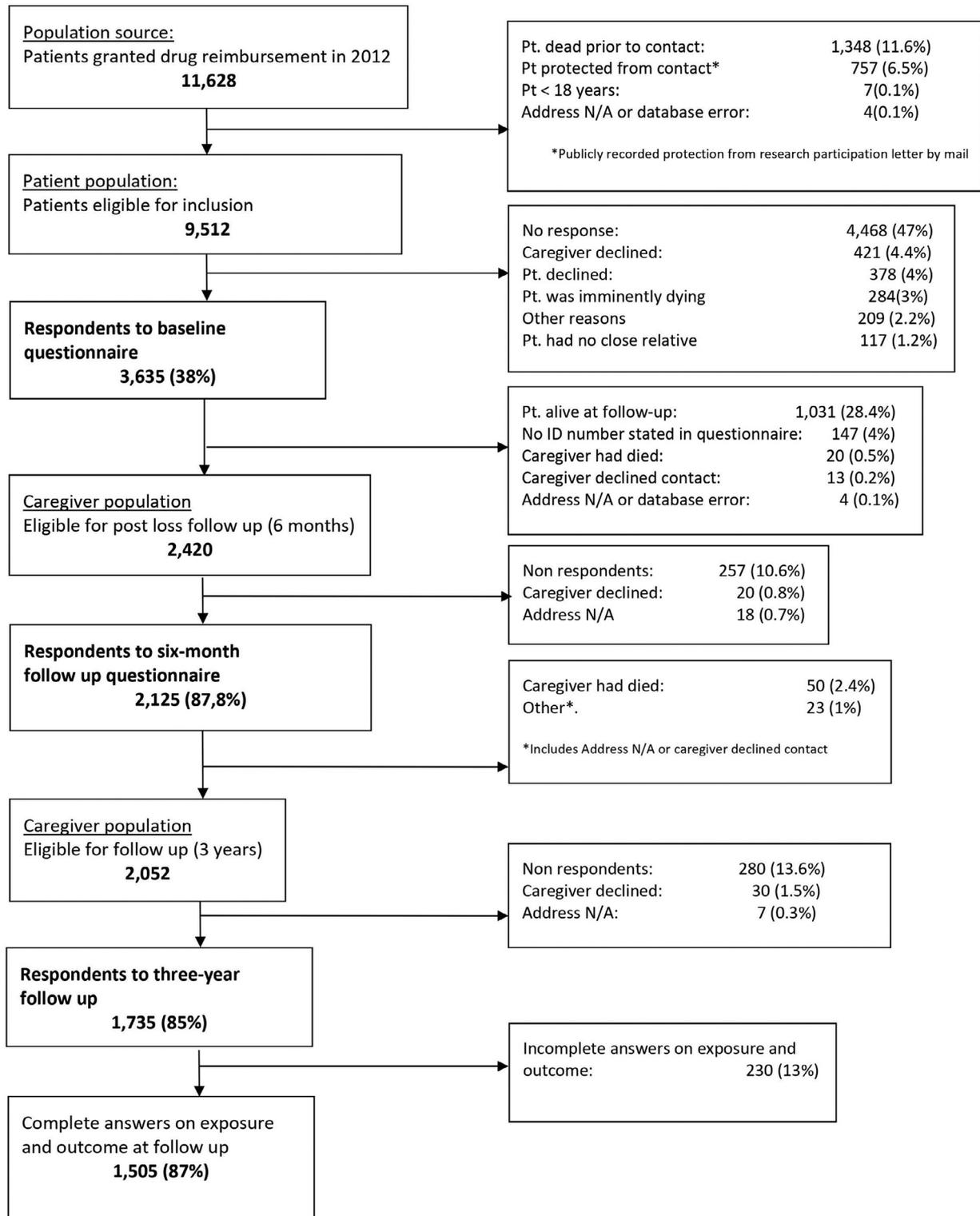


Fig. 1. Flow diagram of the study population.

Discussion

In this nationwide prospective cohort study, we found that reporting missing contact to health care professionals six months post-loss was associated with symptoms of PGD_{PG-13} and depression three years after bereavement.

The association between missing contact and symptoms of PGD_{PG-13} and depressive symptoms was significant for all types of health care professionals, including GPs, home care nurses, hospital staff, and palliative care team. The strongest association was found for missing contact to GPs for both PGD_{PG-13} and depression.

Table 1
Characteristics of the Caregiver Cohort

n(%)	1,505 (100.0)
Socioeconomic characteristics of the caregiver cohort	
Age, mean (95%CI)	61.4 (60.8; 62.0)
Gender, n (%)	
Male, n (%)	455 (30.2)
Female, n (%)	1,050 (69.8)
Relation	
Partner, n (%)	961 (63.9)
Other, n (%)	544 (36.1)
Education level	
Low (<10 years) n (%)	360 (23.9)
Intermediate (10-15 years) n (%)	732 (48.6)
High (> 15 years), n (%)	413 (27.4)
Pre-death PGD symptoms	
Few/mild grief symptoms, n (%)	1,257 (83.5)
Severe grief symptoms, n (%)	214 (14.2)
Missing, n (%)	34 (2.3)
Pre-death depressive symptoms	
None-mild depressive symptoms, n (%)	1,228 (81.6)
Moderate severe depressive symptoms, n (%)	220 (14.6)
Missing, n (%)	57 (3.8)
PGD 3 years post-loss	
Few/mild grief symptoms, n (%)	1473 (97.9)
Severe grief symptoms, n (%)	32 (2.1)
Depressive symptoms 3 years post-loss	
None-mild depressive symptoms, n (%)	1398 (92.9)
Moderate severe depressive symptoms, n (%)	107 (7.1)

Strengths and Limitations

The strengths of the study include the systematic sampling from a nationwide population-based cohort in a prospective setting and a large sample size. The response rates at follow-up were high (87% at six months and 85% at three years' post-loss) and the proportion of questionnaires with complete data were high (87%). The linkage between questionnaire data and register-based data with high completeness through the CPR number increased the intern validity of data.

The recruitment rate in this study was 38% of family caregivers to the terminally ill patients, who were invited at baseline. The patients of non-responding caregivers were more likely to have higher age and lower educational level than respondents. A lower socioeconomic position has been linked with increased psychological distress³ and has furthermore been related to non-participation in questionnaires.³¹ As these factors have been linked with psychological

distress this could have caused an underestimation of psychological distress in the present study.⁵

The exposure was the subjective assessment of the caregivers' experience of no contact to health professionals. Hence, we are not able to describe whether the subjective assessment was equal to the actual number of contacts, which is a limitation.

Earlier studies have found that pre-death grief symptoms and depression were risk factors of PGD and post-loss depression.^{5,14,15} The sample size in this study was too small to conduct stratified analysis according to pre-loss symptoms of the association between missing contact and PGD_{PG-13}. Hence, we cannot rule out that the association between missing contact and PGD_{PG-13} might be influenced by pre-death grief symptoms or other factors. We did only include four groups of health care professionals in the questionnaire. Hence, it cannot be ruled out that information of contact with other health care professionals such as psychologists or psychiatrists may contribute to residual confounding. We must also consider that the organization of health care systems and offer of professional bereavement support differ among countries which may affect the ability to generalize the results to health care settings in other countries.

The information regarding "missing contact" as exposure is collected retrospective at six months post-loss which entails a risk of recall bias. This could lead to an overestimation of the association, considering that bereaved caregivers who have developed adverse psychological outcomes, could be more likely to exaggerate when reporting missing contact to health care professionals than caregivers who do not experience problems at six-months post-loss.

Existing Literature

To our knowledge, our study is the first to show that experience of missing contact with health professionals during the first six months of bereavement were significantly associated with moderate to severe depressive symptoms and PGD three years after the bereavement in a longitudinal large-scale survey.

Yet, other studies have investigated associations between support needs after the loss and bereavement outcome in other study designs: In an American longitudinal study, the vast majority (64.8% at 5-years and 88.7% at 8 years) of caregivers to cancer patients reported unmet needs in managing the loss. The unmet needs were found to be associated with PGD and Posttraumatic Stress Disorder-like symptoms at five and eight years of follow up.³²

A cross-sectional study found that among 678 caregivers, the caregivers at high risk of developing PGD reported low perceived support post-loss more frequently than caregivers at low risk of developing PGD (64% compared to 20%).³³ Hence, our findings are in

Table 2
Proportion of Caregivers Reporting Missing Contact With Health Professionals (n=1505)

	Missing contact	Not missing contact
General practitioner ^a , n(%)	237 (15.7)	1,268 (84.3)
Home care nurse, n(%)	145 (9.6)	1,360 (90.4)
Hospital staff n(%)	165 (11.0)	1,340 (89.0)
Palliative team, n(%)	213 (14.2)	1,292 (85.8)
All four groups of health care professionals	33 (2.2)	1472 (97.8)

^aCaregiver's general practitioner

Table 3

Association Between Missing Contact to Health Professionals at Six Months Post-Loss and Symptoms of Prolonged Grief Three Years' Post-Loss

	PGD _{PG-13} ^a , n (%)	No PGD _{PG-13} ^a , n (%)	OR ^b (95%CI ^c)	Adjusted OR ^{b,d} (95% CI ^c)
General practitioner				
Not missing contact	18 (1.4)	1,250 (98.6)		
Missing contact	14 (5.9)	223 (94.1)	4.4 (2.1;8.9)	4.0 (1.9;8.3)
Home care nurse				
Not missing contact	25 (1.8)	1,335 (98.2)		
Missing contact	7 (4.8)	138 (95.2)	2.7 (1.2;6.4)	2.6 (1.1;6.2)
Hospital staff				
Not missing contact	23 (1.7)	1,317 (98.3)		
Missing contact	9 (5.5)	156 (94.5)	3.3 (1.5;7.3)	3.1 (1.4;7.0)
Palliative team				
Not missing contact	21 (1.6)	1,271 (98.4)		
Missing contact	11 (5.2)	202 (94.8)	3.3 (1.6;6.9)	3.2 (1.5;6.9)

^aPGD_{PG-13}=prolonged grief measured by PG-13 scale.

^bOR = odds ratio.

^cCI = confidence interval.

^dAdjusted for age, gender, personal relation to the patient and level of education.

line with earlier studies and extend the knowledge in a longitudinal study, implying that missing contact to health professionals is associated with PGD and depressive symptoms three years after bereavement.

In our study, 9-16% of the caregivers reported missing contact to at least one group of health care professionals. Prior studies have investigated whether those with symptoms or needs received support. In a prior study from our group, only about half of the bereaved caregivers suffering from moderate to severe depression or PGD had sought some type of bereavement service.¹⁹ A study on bereavement during intensive unit care (ICU) found that 68% of the family members reported a wish for bereavement support, and only 31% did receive help from health care professionals.³⁴ Lichtenhal et al. found that only 43% of bereaved caregivers with PGD had used mental health services in time after the loss.³⁵ This indicates that in the current state of practice there seems to be a disproportion in canalizing the resources to the most vulnerable caregivers who need interventions the most.

Our results showed that missing contact with the GP was most frequently reported. In the Danish health care system, the GP acts as a gatekeeper who handles referrals to other health care professionals.³⁶ The palliative team and the hospital staff are not involved in all illness trajectories and thus are not available for all patients and caregivers. This difference among health care professionals may explain that we found a stronger association between missing contact to the GP and outcome measures than for the other groups of health care professions. Hence, reporting missing contact with the GP could be interpreted as a general expression of missing contact with the health care system rather than a specific health care professional. A systematic review concluded that although GPs considered bereavement care as an important part of their job, they reported a lack of training in the area, and the authors found that there was great variation in what kind of support different GPs offer bereaved caregivers.²⁰ This points out that the GPs have an important task in offering bereavement support and our findings highlight that this task needs to be optimized.

Table 4

Association Between Missing Contact to Health Professionals at Six Months Post-Loss and Symptoms of Depression Three Years Post Loss

	Depression ^a , moderate-severe, n (%)	Depression ^a , none-mild, n (%)	OR ^b (95%CI ^c)	Adj OR ^d (95%CI ^c)
General practitioner				
Not missing contact	59 (4.7)	1,209 (95.3)		
Missing contact	48 (20.3)	189 (79.7)	5.2 (3.5;7.9)	5.2 (3.4;7.9)
Home care nurse				
Not missing contact	85 (6.3)	1,275 (93.8)		
Missing contact	22 (15.2)	123 (84.8)	2.7 (1.6;4.4)	2.6 (1.6;4.3)
Hospital staff				
Not missing contact	85 (6.3)	1,255 (93.7)		
Missing contact	22 (13.3)	143 (86.7)	2.3 (1.4;3.7)	2.1 (1.3;3.5)
Palliative team				
Not missing contact	79 (6.1)	1,213 (93.9)		
Missing contact	28 (13.1)	185 (86.9)	2.3 (1.5;3.7)	2.0 (1.3;3.2)

^aDepression measured by BDI-II.

^bOR = odds ratio.

^cCI = confidence interval.

^dAdjusted for age, gender, personal relation to the patient and level of education.

Clinical Implications

Experience of missing contact to health care professionals after the death of a close relative, were associated with adverse bereavement outcomes amongst bereaved caregivers. To address the subjective needs of bereaved caregiver is an important task for the health care professionals which have been described by Lichtenthal³⁷. Systematic risk assessment to identify caregivers who need support and/or are at risk of complications may enable health care professionals to direct support for those who need it. In an earlier study in our research group, health care professionals in a palliative care setting identified caregivers at risk of adverse bereavement outcomes and their support needs using an assessment tool.²¹ Such initiatives to map needs of support and risks of complications at an early time point in the patient's illness trajectory may reduce the experience of unmet needs and mitigate bereavement reactions. These circumstances indicate that GPs play an important role in identifying support needs of family caregivers and initiating psychological or practical support. After the patient's death, an earlier study found a significantly reduced risk of severe mental health outcomes among caregivers who received early talk therapy in a population-based register setting.³⁸ The GP most often has a prior relation to the patient and the setting in primary care ensures a broad contact to family caregivers. Hence, optimizing bereavement support in general practice may reach a wider public health aim.

Further Investigation

A study that investigates the association between the experience of missing contact with health care professionals and the actual extent of support offered by health care professionals would shed more light on the unmet needs of bereaved caregivers. This will help us understand the shortcomings and potential for improvement in today's bereavement support.

Based on the findings of the current studies, research to enhance the contact between caregivers and health professionals should be initiated including assessment of support needs to target the supportive intervention.

For health care professionals in primary care to meet caregiver's needs of contact and support at an early time point, a caregiver care model including systematic assessment of support needs are currently being adapted and tested for implementation in the health care system.

The beneficial effect the model and pro-active intervention for caregivers needs to be further investigated.

Conclusion

Our study shows that the experience of missing contact to health care professionals six months' post-loss is significantly associated with symptoms of PGD and depression three years after bereavement.

The results extend findings from prior studies and provide estimates from a large-scale longitudinal cohort. The findings have important implications for clinical practice and suggests a need for systematic risk assessment of family caregivers' support needs and risk of complications. Ultimately, adverse bereavement outcome may be prevented by early interventions.

For instance, systematic risk assessment of caregivers in the patient's illness trajectory has already been shown to be helpful and feasible in a specialized palliative care setting.²¹ Future studies of early assessment of caregiver's support needs and risks in primary care and basic palliative care settings at hospital are warranted.

Declarations

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Conflict of interest: The authors declare that there are no conflicts of interest.

Availability of data and material: Data sharing is not applicable to this article, due to protection of personal information.

Compliance with ethical standards: As data for this study is provided through a questionnaire survey, it does not require ethical clearance by the Danish Act on Research Ethics Review of Health Research Projects, according to the Committee on Health Research Ethics of the Central Denmark Region. The study was conducted according to the ICMJE guidelines, and approved by the Danish Data Protection Agency (File no. 2013-41-2603).

Consent to participate: Informed consent to participate in the study was obtained together with the baseline questionnaire.

Consent to publish: According to the Act on Processing of Personal Data, researchers may use personal data to carry out scientific studies, if the study is considered to be of significant public importance, provided that the results do not reveal the identity of the participants, or otherwise compromise the individuals.³⁹

Authors' contributions: Emilie Stendahl Ramstad and Laura Sabroe Thegen contributed equally to this work. Material preparation, and analysis were performed by Emilie Stendahl Ramstad, Laura Sabroe Thegen and Mette Kjærgaard Nielsen.

Data collection was performed by Mette Kjærgaard Nielsen, Mette Asbjørn Neergaard and Mai-Britt Guldin.

All authors participated in drafting the article, interpretation of results, and critical revision. All authors read and approved the final manuscript.

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