RESEARCH



Caregiving burden, receipt of palliative care, and the use of bereavement support: secondary analysis of population-based data



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Abstract

Background The levels of support needs among people bereaved due to cancer are high; however, bereavement support services are underutilised. Reasons are unknown. We aimed to examine the relationship of caregiving burden and involvement of palliative care with the utilisation of formal bereavement support by family carers of people who died of cancer.

Methods Secondary analysis of population-based mortality follow-back study (QUALYCARE) with bereaved relatives of adults who registered the death of an adult due to cancer and involved in caregiving. We ran a multivariate logistic regression to determine whether caregiving burden and palliative care involvement explain the utilisation of bereavement support.

Results Out of 523 family members involved in caregiving (66% women, M_{age} =59 (SD = 14), 43% spouses/partners, 41% adult children), 149 (28.8%) utilised formal bereavement support (73.8% women, M_{age} =60 (SD = 14), 55% spouse/partner, 36% adult children). We found higher grief intensity (measured by the Texas Revised Inventory of Grief) than the reported population norms. Bivariate analysis confirmed the hypothesised associations. However, these were not retained in the multivariate model. Utilisation of bereavement support was associated with presence at the moment of death (OR 1.769, 95%CI=1.044–2.994) and grief intensity (1.036, 95%CI=1.015–1.058).

Conclusions Subjective experiences such as grief intensity and being present at the moment of death are associated with the need for formal bereavement support, raising the issue of continuity of care for family carers into bereavement. Further research is warranted to better understand the complex relationships between caregiving, bereavement, and the role of palliative care in facilitating access to bereavement support.

Keywords Bereavement, Grief, Palliative care, Neoplasms, Family, Caregivers, Secondary data analysis

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Introduction

Cancer is the most significant driver of disease burden worldwide [1] with projections of palliative care needs showing the increase in the next decades will be driven by cancer deaths [2, 3]. It is considered that each death leaves behind 5 people [4] and for some family members and friends, grief may cause considerable hardship [5]. When this is the case, formal approaches to support are recommended [6]. Evidence also shows the use of bereavement support services does not match the needs reported by bereaved people [7–9]. Rigorous research is crucial to understand the reasons for the discrepancy between the percentage of people in need and of those who receive formal bereavement support.

Poorer bereavement outcomes, such as the increased morbidity associated to higher levels of grief or persistent intense grief that extends for more than six to 12 months [10], are indicative of greater need for and use of bereavement support [11, 12]. Among the factors that explain access to and/or utilisation of bereavement support are those that commonly take place in the context of palliative care. Discussing concerns and prognosis with health professionals are positively associated with bereavement support use [8, 9, 13]. Factors that reflect caregiving burden also seem to explain the use of bereavement support. Providing hands-on care [8, 9, 14, 15], less available social support [11, 16], employment situations [15], and poor end-of-life experiences [17–19] have been shown as contributors to the use of bereavement support.

Theories explaining the relationship between caregiving burden and bereavement support are conflicting [20] and empirical studies show the direction of the association is inconsistent [17, 21]. A recent systematic review of 120 studies on 61.580 bereaved people concluded few studies have thoroughly examined the nature of the relationship between caregiving and burden [21]. One possible explanation for this inconsistency and dearth of evidence is the complex interplay of variables such as preparedness for caregiving and death, caregiving burden, grief, and social support [21, 22]. Further research is needed to explore how this relationship influences the need for and access to bereavement support.

We aimed to examine the relationship of caregiving burden and receipt of palliative care with the utilisation of formal bereavement support by family carers of persons who died of cancer.

Methods

Study design and population

This was a secondary analysis of data from the QUALY-CARE study, a population-based mortality follow-back postal survey of the variation in the quality of care, preferences and outcomes associated with place of death in cancer [23, 24]. The study was conducted in four health

districts in London, UK. All adults deceased from cancer in the four health districts, identified through death certificates, were considered in the sampling frame. The choice of the districts aimed to capture variations within the sample and were chosen based on ecological analysis of variables relevant for the aims of the primary study, namely home death rates and deprivation levels [25].

Choice and validity of data

To accurately estimate caregiver burden and the use of support in relation to palliative and bereavement care we need population-based data with sampling method that ensures representativeness and reach out to those who miss out on services (as opposed to service-based studies). To our best knowledge, there is no populationbased study other than the QUALYCARE study [23] that explored the combination of variables of our interest. Population-based studies like Grande's et al. [26] looked at caregiving burden and input of palliative care, however they used different metrics that are not comparable with QUALYCARE data. The QUALYCARE study [23] generated data on cancer bereavement that led to the identification of potentially modifying risk factors, conducting a comprehensive assessment of grief intensity in comparison to one-item questions, assessing contact with palliative care services and objective caregiving burden.

Although the primary study was conducted over 10 years ago, to our knowledge, there is a lack of populationbased studies that collected data on the variables we analysed. Working with this data set, collected and analysed with methods that are comprehensive and rigorous, permitted to explore a research question which remained unanswered and explore new potential associations without unnecessarily disturbing families at a sensitive time.

Circumstances in the UK have changed in the past years, resulting in different prevalence and distribution of the variables addressed in this study (palliative care, bereavement support and caregiving burden). Although organisation and provision of palliative care has seen changes towards better integration [27] and may be more accessible, the percentage of patients that had input from palliative care in our sample was already high (88.1%). Bereavement support has been in the spotlight since COVID resulting in increase in existing support and its'use [28] although one study shows 42% of those who wanted to access the support, did not receive it [29]. Reliance of carers and objective caregiving burden (hours of care per week) have also been increasing [26, 30]. In addition, the COVID pandemic created circumstances that are associated with higher intensity of grief [31–33], potentially resulting in more people expressing their needs and looking for support. We believe that results based on newer data may result in different strengths of association, whereas the direction and its relevance is

likely to remain stable and relevant along the time. In the absence of a newer data set, we conclude that QUALY-CARE data are still relevant and provide valuable insight into associations between variables and can generate new hypotheses that can be tested on a more contemporary population.

Sample

Participants were persons who registered the death of an adult due to cancer between March 2009 and March 2010. Out of 1516 eligible participants, 596 (39.3%) completed the survey, sometime between four to ten months after the loss. This time frame was defined based on the bereaved family carers' feedback [34]. For this analysis, we included "family carers", defined in the survey as family members, friends or neighbours who were involved in care. Of the 596 persons who responded to the survey, 523 met these criteria and were included.

Measurements

The QUALYCARE survey used an adapted short form of a questionnaire developed to measure patients' experiences of the last year of life from the perspective of their bereaved relatives [23]. The survey used validated outcome measures to assess health and social care service use (via the Client Service Receipt Inventory (CSRI)) [35], patient's palliative care concerns (using the Palliative care Outcome Scale (POS)) [36] and grief intensity via the Texas Revised Inventory of Grief (TRIG) [37].

The TRIG was chosen as it has been successfully used in previous studies with people with cancer [38, 39] and was deemed acceptable by participants in the QUALY-CARE pilot study. The scale was developed in the United States by Faschingbauer [37] and colleagues [40] as a response to grief in the late seventies. By then, grief was still not fully operationalised or established as a validated concept and TRIG arose as the first tool to permit a rapid evaluation of an individual's reactions to bereavement. The TRIG consists of 21 items divided into two subscales. The first TRIG subscale (8 items) measures feelings and actions at the time of the person's death (TRIG I - past behaviour), the second subscale (13 items) measures feelings at the time of survey completion (TRIG II - present feelings). Both subscales include Likert-type five-point items (1 - completely false to 5 - completely true), where higher scores indicate higher grief intensity. The total TRIG I score ranges 8 to 40 and TRIG II 13 to 65. Both subscales demonstrate good internal consistency, with Cronbacha0.87 and 0.93 for TRIG I and TRIG II, respectively [37].

Further questions in the survey explore preferred and actual place of death, presence of the participant at time of death, relevant local issues, socio-demographic and clinical data [23, 24].

Variables

The use of formal bereavement support was measured by the question "Since the patient died, have you talked to anyone from health and social care services or from a bereavement service about your feelings regarding the patient's illness and death?" Receipt of palliative care, measured as part of the CSRI, was considered as any contact with palliative care independently of the frequency, duration or setting in which the contact occurred (home, hospital, hospice, nursing home or residential home). This meant one or more of the following contacts: staying at a hospice, having contact with a Marie Curie nurse (specialised nurse providing care and support, usually overnight, to people living with any terminal illness and their families towards the end of their life, spending several hours at a time in their home) [41], Macmillan (specialised nurse for people with cancer providing advice on managing pain, controlling symptoms, including emotional support, working in hospitals, hospices and in the community) [42] or other specialist nurse, palliative care or "hospice at home" team in any of the above-mentioned settings.

Caregiving burden is comprised of multiple dimensions [43–45], broadly divided into role strain or objective strain (activities and tasks related to caring) and personal or subjective strain (emotional well-being aspect) [44]. We focused on the objective strain, measured in the CSRI by the following variables related to the last three months of the patient's life: availability of other friends/family members to help with taking care of the patient (yes/ no and number), involvement and time the respondent spent on caregiving tasks (personal care, help with medical procedures, going to appointments or treatments, household tasks, time spent "on call", time spent with the patient, i.e. doing things together), and changes in work situation (working hours or being off work).

Ethics

The primary study and conduct of any secondary study, subject to supervision by the primary research team, was approved by the King's College Hospital Research Ethics Committee (ref no.: 09/H0808/85). For this secondary study, we used a de-identified dataset.

Analysis

After describing the sample, bivariate analysis compared persons who used/did not use bereavement support. We used independent t-tests for continuous variables with a normal distribution, Mann-Whitney tests for ordinal variables or continuous variables without a normal distribution, and Chi-square tests for categorical variables. We ran a multivariate logistic regression (backwards likelihood-ratio model) to determine to what extent the caregiving burden and the receipt of palliative care explained

Table 1 Family carers' characteristics

Characteristic	n (%)
Sex ¹	
Female	344 (66.3)
Male	175 (33.7)
Age ²	59(14); (21–92)
M(SD); (min-max)	
Age groups ²	
20-49	120 (23.3)
50–59	143 (27.8)
60–69	118 (22.9)
70–79	92 (17.9)
80–89	41 (8.0)
90+	1 (0.2)
Relationship to the deceased	
Husband/wife or partner	226 (43.2)
Son or daughter	216 (41.3)
Other	81 (15.5)
Religion	
No religion	90 (17.5)
Christian	391 (76.1)
Other	42 (6.6)
Ethnic group ³	
White	472 (92.0)
Other	41 (8.0)

Note. ¹4 missing. ²8 missing. ³10 missing. *M*=mean, SD=standard deviation

the use of bereavement support, adjusting for potential confounders. In addition, we added the variables identified in the bivariate analysis as relevant to control for: the family carers' sex and relationship with the patient, whether the family carer was present at the moment of death, place of death and the intensity of grief at the moment of death and at survey completion. Based on literature, we added the patient's age.² We used IBM SPSS Version 25.

We conducted a sensitivity analysis, running the forward selection model. To ensure stability and improve the interpretability of the model, we analysed variance inflation factor (VIF) values to examine multicollinearity, applying the rule of thumb that if VIF > 10, multicollinearity is high.²⁰ We reported missing data, unadjusted (OR) and adjusted odds ratios (AOR). To ensure the validity of conclusions taking into account the missing data in the multivariate analysis, we compared the cases included and excluded from the model. All tests were conducted at a 5% significance level, with calculation of *p*-values and 95% confidence intervals.

Results

Sample characteristics

We included 523 family members, friends and neighbours who were involved in caring for a person with cancer in their last three months of life. Among these, three-quarters were female (n = 344, 66.3%). Most (Table 1) were

Table 2 Patients' characteristics

Characteristic	n (%)		
Sex			
Female	252 (48.2)		
Male	271 (51.8)		
Age			
M (SD); (minmax.)	74(13); (23–98)		
Length of illness			
Less than 6 months	162 (32.0)		
6 months to less than a year	89 (17.6)		
One year to less than 3 years	157 (31.0)		
3 years or more	99 (19.5)		
POS ²			
Me (IQR; minmax.)	24.0 (19–29; 10–44)		
POS-S			
Me (IQR; minmax.)	23.0 (19–26; 8–39)		
Place of death			
Home	168 (32.1)		
Hospice	180 (34.4)		
Nursing home	25 (4.8)		
Hospital	150 (28.7)		

Note. POS=Palliative care Outcome Scale. POS-S=Palliative care Outcome Scale – Symptoms

spouses or partners (n = 226, 43.2%) and adult children (n = 216, 41.3%) of the patients. Within Others (n = 81, 15.5%), 67 were other relatives (sibling, parent or other relative) and 14 were friends and neighbours. Those identifying as White and of Christian religion were overrepresented, accounting for 92.0% (n = 472) and 76.1% (n = 391) of the sample, respectively.

Patient characteristics are given in Table 2. The mean time from the patient's death to survey completion was 7 months (SD = 2; range 4–10 months). There was no association between time since death at survey completion and grief intensity. The family carer was present at death in 67.6% of cases (n = 350).

 $^{1}16$ missing. 2 122 missing. 3 125 missing. Me = median, IQR = interquartile range.

Health care and death-related circumstances

In their last three months of life, patients received care in one or more of the following places: at their home (n=461, 88.1%), in hospital (n=391, 74.7%), hospice (n=192, 36.7%) or in nursing/residential home (n=40, 7.6%). In general, independently of the place of care, most family carers thought the care was good, very good or excellent (77.2% for the care received at home, 73.1% hospital care, 97.4% for hospice care and 77.5% for care in a nursing/residential home). Most of those who received care at home (66.7%) felt they got as much professional help as needed. For the care received in hospital this was true for 57.0%, 92.7% for hospice-based care and 69.2% for care in a nursing/residential home. Others felt they did not receive as much help as needed or felt a lack of help. Just over a third of the participants (n = 191, 37.6%) were unhappy with at least one aspect of care.

Participants were asked if they or any other family member had a conversation with any health professional about the fact the patient was likely to die because of the illness. This happened in most cases (n = 403, 81.1%) and was corroborated by the fact that 87.7% (n = 447) had realised that the patient was going to die because of the disease. About half of them (n = 275, 55.3%) realised this during the six months before the patient died. One in ten of the family carers was never aware that the patient was going to die (n = 55, 11.1%). The family carer was present at death in 67.6% of cases (n = 350).

Dependent and independent variables

Formal bereavement support was utilised by 149 family carers (28.8%), of which 130 (87.8%) considered it helpful. For 15 family carers (11 females and 4 males) the bereavement support they got was unhelpful (described in Appendix 1). The TRIG scores of the sample were higher and more dispersed than the norms reported in TRIG's manual: M = 20.52 (SD = 8.04) vs. M = 15.70 (SD = 0.9) for grief at time of death and M = 45.00 (SD = 12.16) vs. M = 34.2 (SD = 1.5) for present feelings. The total and the subsample who received bereavement support showed a similar pattern in grief intensity considering the two moments of bereavement as per TRIG manual [37] (Table 1, Appendix 2).

Most patients had contact with palliative care services (n = 461, 88.1%) and had family members and friends to help with caregiving tasks, besides the family carer who responded to the survey (n = 358, 69.8%). Approximately one-third of the included family carers took time off work in the last three months before death as well as in the three months after death (n = 185, 36.3% and n = 197, 37.7%, respectively); only one in ten continued working as usual before and after the loss (n = 58, 11.4% and n = 4.8, 9.4%, respectively). Other aspects of the objective burden are presented in Table 3.

Those respondents who were present at the moment of death were more likely to use bereavement support (p < 0.001). Bereaved people who utilised bereavement support support experienced more intense grief than those who did not (p < 0.001 for both the time of the death and at survey completion). Full results of the bivariate analysis are shown in Appendix 3. Being present at death (OR 2.248; 95%CI 1.435–3.522) and intensity of grief (OR 1.047; 95%CI 1.020–1.074 for intensity of grief at the time of death, and OR 1.035; 95%CI 1.017– 1.054 for intensity at the time of survey completion) were among the variables directly associated with the use of bereavement support. Full results of individual regression models are in Appendix 4.

Table 3 Role burden of caregiving

Variable	n (%)
Other family and friends helping with caregiving ¹	
Yes	358 (69.8)
No	155 (30.2)
How many family/friends helped	
0	153 (30.3)
1	89 (17.6)
2	110 (21.8)
3	68 (13.5)
4 5 or more	55 (0.9)
Necessity of changing work situation due to	50 (5.5)
caregiving ² (before death)	
Time off work	185 (36.3)
Work as usual	58 (11.4)
Not working	266 (52.3)
Necessity of changing work situation due to caregiving ³ (after death)	
Time off work	193 (37.7)
Work as usual	48 (9.4)
Not working	271 (52.9)
Intensity of care in hours per week	
Personal care ⁴	
0 h	134 (27.0)
1–9 h	159 (32.0)
10–49 h	113 (22.7)
50 or more hours	91 (18.3)
Help with medical procedures ⁵	
0 h	132 (26.8)
1–9 h	234 (47.5)
10–49 h	59 (12.0)
50 or more hours	68 (13.8)
Going to appointments/treatment ^o	
0 h	83 (17.2)
1–9 h	319 (66.0)
10–49 h	66 (13.7)
50 or more hours	15 (3.1)
Help around/in the home (household tasks)'	
0 h	60 (12.6)
1–9 h	180 (37.8)
10–49 h	156 (32.8)
50 or more hours	80 (16.8)
Being on call ^o	
0 h	46 (9.2)
1–9 h	64 (12.8)
10–49 h	73 (14.6)
50– all the time	317 (63.4)
Time spent with the patient (doing things together) ⁹	
0 h	12 (2.4)
1–9 h	79 (15.7)
10–49 h	128 (25.4)
50- all the time	285 (56 5)

Note. ¹10 missing. ² 18 missing. ³ 11 missing. ⁴26 missing. ⁵30 missing ⁶40 missing. ⁷47 missing. ⁸23 missing. ⁹ 19 missing

Table 4 Multivariate model of factors associated with the use of formal bereavement suppo	Table 4	Multivariate model o	f factors associated	with the use of fe	ormal bereavement suppo	rt
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Bivariate		Multivariate	
OR	95% CI	AOR	95% CI
2.248	1.435-3.522	1.768	1.044–2.994
1.035	1.017-1.054	1.036	1.015-1.058
	Bivariate OR 2.248 1.035	Bivariate OR 95% CI 2.248 1.435-3.522 1.035 1.017-1.054	Bivariate Multivariate OR 95% Cl AOR 2.248 1.435–3.522 1.768 1.035 1.017–1.054 1.036

Factors were retained if p-value < 0.05. Model statistics: 389 cases included (71.5%). Nagelkerke R^2 = 0.074, Hosmer–Lemeshow χ^2 (8) = 7.230, p < 0.512. Correctly classified 71.5%. Multicollinearity diagnostics showed the model can be considered stable, with VIF among the independent variables ranging from 1.027 to 2.931.

Multivariate analysis

The final multivariate logistic model using backwards elimination of variables showed the most influential factors were being with the patient at the time of the death and the intensity of grief at survey completion (Table 4). The odds of utilising formal bereavement support were increased by 77% (AOR 1.768) for those who were present at death. For every point on the TRIG II subscale (indicating higher grief intensity at survey completion), the odds of utilising formal bereavement support increased by 3.6% (AOR 1.036). In other words, a family carers who scored 45 points on the TRIG II subscale (the mean value in our study) had a 36% more chance of using/accessing formal bereavement support in comparison with someone who scored 10 points less (the normative mean [46]).

Sensitivity analysis and missing data

A logistic regression with forward likelihood-ratio model confirmed the results of the backwards model. In addition, to assess potential selection bias due to the level of missing data in the final model (28.5%), we compared cases included in the model (with complete data for all dependent and independent variables) to those excluded from the model due to missing data in any of these variables. Although there were no differences in the use of formal bereavement support, more people whose data were included in the model had contact with palliative care (p = 0.027) and support from other family and friends (p = 0.002). They also had more additional people helping them (p=0.001). The carers included in the model had more often taken time off work due to caregiving or were working as usual before and after the death (p < 0.001). In relative terms, in the group included in the model there were fewer females (p = 0.011) and they were on average 6 years younger (58 vs. 64 years, p < 0.001), there were more adult children (p = 0.005) and fewer spouses. The two groups (included and excluded from the model) did not differ in the intensity of caregiving in hours, patient demographics, expectation or awareness of death, presence at death, place of death, and grief intensity.

Discussion

Main findings

We examined the relationship of caregiving burden and receipt of palliative care with the utilisation of formal bereavement support and the bivariate analysis confirmed the association: palliative care being involved doubled the chances of receiving/accessing formal bereavement support. One aspect of caregiving burden (helping with medical procedures) tripled the chances of having had formal bereavement support. However, in multivariate analysis, these two variables lost significance once adjusted for others. The two factors that remained significant were being present at the time of death and the intensity of grief.

What this study adds?

Caregiving burden and contact with palliative care are not associated with utilisation of formal bereavement support

In our study, we assessed objective carer burden in a group of family carer that appear to be satisfied with the care and the levels of support received. The stress theory states it is the interpretation and appraisal of the stressors that shape the individual's reaction [47]. For example, in an Italian longitudinal study of family cancer caregiving at home, emotional burden predicted poor bereavement adjustment [48]. A systematic review [44] on the impact of carer burden on mental health in bereaved carers of cancer patients showed a distinct effect of objective and perceived burden. Subjectively perceived strain predicted higher complicated grief scores, whereas results for objective strain were more ambiguous. Consideration of perceived burden may help to differ between those who access or not bereavement support.

The role of palliative care in receiving/accessing bereavement support has been rarely explored. As this is a variable that operates on a system level, its role may be complex. It may be that factoring in the frequency of the contact, timeliness, and intensity of the palliative care would result in a different association. Within palliative care, bereavement support is not consistently available [49], but given QUALYCARE's wide approach for considering bereavement support (*"talking about feelings"*) it is a surprising finding that a relatively basic grief-related conversation did not occur routinely.

If grief intensity is a proxy of need for support, then bereavement support is getting to those who need it

Need-related factors (such as grief intensity) are believed to be the most immediate predictor of health services use [50, 51]. About a third of our sample had used formal bereavement support, which is in line with the upper percentage of bereavement service use rates [8, 16, 51–53], This, encouragingly, suggests that in our sample bereavement support is getting to those who need it.

A question remains, whether all who needed it also received it. According to a three-tiered public health approach to bereavement support [6], 40% of the bereaved present moderate to high level of need for support outside of the immediate family and friends. Considering our sample and assuming that grief complications can be identified 6 months post-death [54] (on average, family carers in our sample filled in the survey 7 months post bereavement), about 10% of carers who would potentially require support, did not receive even basic bereavement support. We do not know how many of the carers looked for support later during bereavement. Additionally, our data does not allow for inferences on how wanted, adequate and helpful bereavement support was; crucial aspects for planning and setting up a bereavement-centric support services.

Being present at the moment of death – an indicator for need of bereavement support?

Being present at the moment of death is associated with increased odds of using bereavement support. To our knowledge, this is the first study to find this. The association found may be a sign of a close link with health care services, which later, in bereavement, facilitates supportseeking contacts. Presence at the moment of death has been identified as a consequence of preference-based care facilitated by palliative care services [55, 56]. This mediating effect seems to have occurred in our study as 70.4% (n=321) of those who had contact with palliative care were present at death. In comparison, less than half (46.8%, n = 29) of those without palliative care were with their family member at their moment of death $(Chi^2 = 13,896, p < 0.001)$. Another mediator worth considering is the closeness of the relationship. Presence at death may be a proxy for closeness of involvement in each other's lives, which is a recognised factor associated with grief severity [17].

Saying goodbye holds a significant importance for the families, as it may foster closure and facilitate coping [57]. Conversely, not being able to say goodbye may lead to increased feelings of anxiety, depression and other psychological morbidity [58, 59]. However, saying goodbye is only one aspect of being present at death. The process of dying is a relational event shaped by the physical asects and signs of dying, the heightened emotional impact, the dynamics of formal and informal care, and cultural and spiritual expectations. These factors may influence how family members experience the moment of death, its consequences and the subsequent supportseeking behaviour. Witnessing the moment of death of a loved one, especially when it occurs with less well managed symptoms or without adequate preparation of the carers, may be emotionally impactful at the least, and distressful or even traumatic at worst. In both scenarios, it may lead to a need to talk about the experience as a way of coping with it.

In a longitudinal national survey, Selman et al. [60] found that feeling less supported by healthcare professionals around the time of death is related with poorer outcomes in bereavement. Looking at the situation from a patient's perspective, not dying alone is considered an indicator of good death [61]. While we encourage the family to be present in striving to offer a quality end of life, and many may wish this to happen, do we make sure the family can cope with the impact of witnessing the moment of death? During the progression of the disease and especially at the end of life we often discuss the importance of continuity of care for the patient [62]. Continuity of care for the bereaved must also become standard practice [49].

Strengths and weaknesses

Overall, while our findings may not be directly applicable to all sociodemographic groups, they contribute to our understanding of the factors influencing access to formal bereavement support among family carers bereaved due to cancer.

Since the QUALYCARE study the prevalence and the distribution of the variables may have changed. The provision of palliative care, caregiving burden and the use of bereavement support are all likely to have increased (see Choice and validity of data). However, and most importantly, the association between them is likely to remain stable over the time. Notably, the use of this dataset allowed us to unveil an important association - between presence at death and the use of bereavement support. This is an original and clinically relevant finding, that was obtained without needing to survey more family carers at a sensitive time.

Surveying the bereaved involves unique challenges and considerations compared to other populations due to research being potentially intrusive in its timing or due to the nature of loss as an intimate personal experience, posing risks of distress, discomfort or impact on the wellbeing of the participant or researcher. A growing body of palliative care research suggests participation is more likely to have beneficial effects than to cause distress to family caregivers [63–65] and may even be perceived as a form of continuity of care by the bereaved [64]. Not-withstanding, bereaved caregivers report that the participation is stressful and emotionally burdensome at least in the short-term and, without the carefully planned approach, can even be seen as coercive, impersonal, confusing, and lacking compassion [66, 67]. Bereavement is, beyond doubt, a sensitive topic.

Participation in palliative and bereavement care research is often driven by altruism [66, 67]. By utilizing existing data, we maximize the timeless and valuable contributions of bereaved individuals toward improving support and services. This approach not only enhances the benefits of their participation but also allows for the generation of new hypotheses. This happened in our study regarding the impact of witnessing the moment of death, where we were able to lay foundational work for future studies to test this hypothesis. The uniqueness of the QUALYCARE data offered us a practical, ethical, and time- and cost-efficient opportunity for addressing a highly relevant and timely research question that was not explored in the primary study and in any other population-based study so far. Nevertheless, it is essential to critically evaluate the quality, relevance, and limitations of the data to ensure alignment with the research objectives. A thorough assessment of the data's appropriateness is detailed in Appendix 5 of the Supplement.

The advantages and disadvantages of a follow-back bereavement survey methodology in general and QUAL-YCARE in particular are described in previous publications, and include the retrospective study design, 40% response rate, and use of variables prone to recall and observer bias [23, 24, 68]. Secondary analyses and the historical context of the data also have strengths and weaknesses [69], outlined in Appendix 5.

TRIG was developed 40 years ago, and grief is not a static concept. Rather, conceptions of grief are susceptible to time and influenced by personal, cultural and societal factors [70]. Nowadays, TRIG is considered a measure of a "normal" grief reaction [71], as it includes manifestations of grief considered as normal response to loss. We acknowledge that other measures, such as the PG-13 [72], its revised version [73] and the ICG [71], have since emerged as gold standards. Nevertheless, higher scores on TRIG sub-scales remain associated with psychological and physical morbidity [22, 74], serving as a proxy for increased support needs. In recent studies [74, 75], TRIG has been found to be appropriate in terms of psychometric characteristics to use in bereavement after palliative care. It does not have the power of a diagnostic tool for prolonged grief disorder [76], but is still a useful tool for screening and conversation starter to explore needs for bereavement support [22, 77].

The multivariate model was performed on an effective sample of 323 individuals with backward selection from an initial pool of 13 independent variables, resulting in a ratio of 24 cases per independent variable, therefore, allowing for the sustainability of the model [78].The examination of multicollinearity and the sensitivity analysis demonstrated the stability, interpretability and validity of the final explanatory model of the use of bereavement support. The final model explained a relatively small percentage of variability and retained fewer variables than we would expect based on previous studies and it discarded sociodemographic and burden-related variables which are known predictors identified in prior research [7, 8, 15]. There are several possible reasons for this. The validity of the survey question used to measure the use of formal bereavement support needs to be considered cautiously. Responding with "yes" indicates that a conversation has taken place, however, the specific need that led to the contact, the type of support, its depth/duration, content, format and who delivered the support were not

captured and may vary. A person may have had a brief chat with a family doctor about their feelings. Considering the public health model of bereavement support [6], this is not considered formal support, hence access to formal bereavement support services to be lower than found. Furthermore, we have no information on how the question was understood by participants; for example, we do not know whether the item captures private psychotherapy or peer-to-peer bereavement support. Still, recognising whether or not such conversation and support took place is a first step which opens scope for further research to deepen knowledge of these issues.

Data on relationship with the deceased were not collected in a way that captures "chosen family" relevant for LGBTQ families and minoritised ethnic communities. This may result in underestimation of the bereavement support need among family carers, overestimation of the contact with formal bereavement support and possibly a different model of predictors. Having in mind recent evidence in relation to inequalities in bereavement support, the results of this study may be less transferable to minoritized ethnic communities [79].

Finally, the results might be confounded by unmeasured factors - intrapersonal, interpersonal, situational, or systemic. Several of them may have been at work in our sample. The nature and intensity of the grief process depend largely on the attachment style between the bereaved and the deceased [17]. The carer's need to share their experience with someone and/or to look for support, which our study showed is reflective of the intensity of grief, may also be related to the nature of the relationship between the two of them. The QUALY-CARE study aimed primarily to investigate the quality of care and health service experience rather than relational aspects [23]. Therefore, variables like the quality or perceived closeness of the relationship between the patient and the family carer were not measured. The inclusion of relational variables would add to the interpretability and explanatory power of the model.

Conclusion

In conclusion, our results align with previous studies, confirming that subjective experience such as grief intensity plays a role in determining the need for formal bereavement support. A novel finding is that being present at the moment of death may play a role in the need for formal bereavement support. This underscores the importance of considering the emotional impact of such experiences on carers. Our study indicates the need for further research into the complex relationships between caregiving, bereavement, and access to support services. Future studies should explore additional factors such as the quality of the carer-patient relationship and the role of palliative care in facilitating access to bereavement support. Our study provides a foundation for future research and interventions aimed at supporting family carers, most notably the question of the continuity of care for the bereaved.

Supplementary Information

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Supplementary Material 1

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Author contributions

All authors contributed substantially to the outline of this manuscript. MFB wrote the first draft of the manuscript. MFB and BG critically revised the manuscript after receiving comments from all authors. All authors approved the final manuscript for publications. All authors have sufficiently participated in this work to take public responsibility for appropriate portions of the content. MFB was responsible for the final submission.

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Data availability

The data that support the findings of this study are available from the QUALYCARE Study team upon reasonable request but restrictions apply under the QUALYCARE Study Confidentiality Agreement.

Declarations

Ethics approval and consent to participate

The primary study and conduct of any secondary study, subject to supervision by the primary research team, was approved by the King's College Hospital Research Ethics Committee (ref no.: 09/H0808/85). This study was conducted on a de-identified dataset. No further new data was gathered from participants for the purposes of the current study. The storage, handling, and supervised secondary analysis of QUALYCARE, in addition to primary approval, complied with the QUALYCARE Study Confidentiality Agreement, and the ethical approval of the original study.

In the primary study, together with the invitation letter and questionnaire, potential participants were mailed the study information sheet, a reply slip to decline participation, and a bereavement information leaflet. Return of a completed questionnaire was taken as informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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