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Challenges in Palliative Care Research on Family Caregivers: Who Volunteers For Interviews?

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Abstract

Background: Interviews are a common method of data collection in palliative care research because they facilitate the gathering of rich, experiential data that is important for theory and practice. What is less clear is the extent to which those interviewed are representative of the larger group.

Objective: The aim of this study was to determine if family caregivers who volunteer to be interviewed were similar or different to those who do not.

Design: This study used data from the Caregiving and Bereavement study, a prospective, longitudinal mixed-methods study of family caregivers' general health, quality of life, and grief.

Setting/Subjects: The 16 caregivers who volunteered to be interviewed were compared to the 20 who did not.

Measurements: Comparisons were made in terms of the caregivers' demographic characteristics as well as measures of their quality of life, general health, general grief, and caregiver prolonged grief (i.e., prior to death).

Results: Compared to caregivers who did not volunteer for an interview, those who volunteered were significantly older and reported less caregiver prolonged grief. Logistic regression showed that for each 1-unit increase in the caregiver prolonged grief score, individuals were 13% less likely to agree to an interview.

Conclusions: Research findings based upon family caregivers who volunteer for research interviews might not provide a full picture of their experiences and needs. Researchers are encouraged to consider strategies that sample broadly and promote the participation of the full range of family caregivers in research to address the neglected areas of pre- and post-death bereavement care.

Keywords palliative care, mixed-methods research, research design, interview, family caregivers, grief

Introduction

Palliative care researchers face numerous challenges in their attempts to conduct high-quality research, including ethical concerns about participant burden and distress, difficulties recruiting large samples, and limited time and resources [1-5]. A further challenge is conducting randomized controlled trials, which are the gold standard for evidence but are not always feasible in palliative care [6,7]. Common methodological issues by palliative care researchers attempting randomized controlled trials include attrition and missing data due to fatigue and considerable mortality [2,8]. Ethical concerns are also common, particularly regarding randomization to interventions that might not match participant preferences [8]. Thus, selecting an appropriate methodology can be especially challenging in palliative care research.

Studies based on interviews and focus groups are common in palliative care [9,10]. Additionally, syntheses of qualitative findings are becoming more common in guiding practice [11,12]. Mixed-method studies offer both hard numerical data and rich experiential accounts of the phenomena of interest and there is strong agreement on the utility of such approaches in palliative care [6]. A common mixed-method approach in palliative care is to gather quantitative data based upon validated measures from a sample and then invite volunteers from that sample to complete an interview [6]. What is typically not reported or known, however, is the extent to which the sample being interviewed is reflective of the larger study population. This knowledge is important for the generalizability (or in qualitative terms, transferability) of the results [7,13]. The aim of this study was to determine if family caregivers who volunteer for a research interview are similar or different to those who do not.

Method

Design

The data reported here were drawn from The Caregiving and Bereavement Study, a mixed-methods study comprising two components: (1) a prospective, longitudinal study of family caregivers of people receiving palliative care and (2) semi-structured interviews with a subset of those caregivers. The aims of the prospective study was to determine how caregivers' grief, general health, and quality of life changed following death compared to non-caregivers and whether pre-death grief predicted these outcomes. The aim of the interview component was to explore family caregivers' preparations for death. The findings from both studies are published elsewhere [14,15].

Participants and Recruitment

The study received ethical approval from the South Metropolitan Health Service (Ref number:12/284), Hollywood Private Hospital (Ref number:HPH378), and Curtin University (Ref number:HR131/2012). The family caregivers were recruited from three specialist palliative care services in Western Australia—an in-patient palliative care service in a private hospital in a metropolitan area, a consultative palliative care service in a public hospital in metropolitan area, and a community-based palliative care service in a public hospital in a regional area. A total of 38 family caregivers participated in the larger study and 16 of these volunteered for the interview. All participants provided written informed consent prior to participation.

Materials and Procedure

Data were collected at four time points: once before the death (Time 1), and three times post-death—3-4 months (Time 2), 6-7 months (Time 3), and 9-10 months (Time 4). Across the four time points, participants completed valid and reliable measures of general grief (Hogan Grief Reaction Checklist, HRGC, [16]), general

health (Short Form Health Survey, SF12v2, [17]), and quality of life (The Quality of Life Index, QOL, [18]). At Time 1, caregivers completed the caregiver prolonged grief measure (the Prolonged Grief-12 caregiver version, PG-12, [19]) and were invited to participate in a semi-structured, face-to-face interview with the first author. The PG-12 is used to measure caregivers' prolonged grief arising from the impending death of the care recipient. It was adapted from the PG-13 measure that is used at least six months after death to screen for Prolonged Grief Disorder [19].

Statistical Analysis

The primary analysis was a binary logistic regression to quantify how individual differences in predictors were related to the probability of having volunteered for an interview. However, given that both only a small sample size was available, and the higher sample size requirements for logistic regression [20], a single analysis with all variables would be markedly underpowered and unlikely to detect any effect. Instead, a two-step approach was used.

A series of univariate tests was conducted to identify which demographic variables or measures significantly differed between the caregivers who volunteered for an interview and those who did not. For categorical variables (e.g., gender, marital status, cultural background, usual and current employment), a Fisher's exact test was used. For continuous variables (e.g., age; HGRC, SF12v2, QOL, and PG-12 scores), a *t*-test was used. The *p*-values from these analyses were then adjusted using a Bonferroni-Holm correction to account for the multiple comparisons. Those variables that significantly differed were then entered into a logistic regression with interview volunteering (yes/no) as the outcome. Analyses were conducted using the 'stats' package in R 3.6.1. In order to maximize statistical power, two caregivers were removed from the analyses due to substantial missing data, resulting in a final sample size of 36 caregivers.

Results

Of the demographic variables and collected measures, only participant age and the PG-12 significantly differed between the groups (after correcting for multiple comparisons). Individuals who volunteered for an interview were significantly older and had lower PG-12 scores than those who did not (see Table 1). As such, age and PG-12 were entered into the logistic regression. The results indicate that for each additional year of age, individuals were 10% more likely to have volunteered for an interview. Further, for each 1-unit increase in the PG-12, individuals were 13% less likely to have volunteered (see Table 2).

Conclusions

Research on family caregiver wellbeing is a high priority for health professionals working in palliative care [1,21]. Bereavement care for family caregivers is a growing area of interest and sophistication in palliative care [22], and was identified as an important research priority in a recent Delphi study that resulted in a research agenda for adult palliative care [23]. However, the provision of best-practice bereavement care is challenging due to questions concerning a lack of evidence about who to support, for how long [24], and when [14].

Caregivers' motivation to participate in interviews include wanting to help others, wishing to express gratitude or concerns about care, needing to talk to someone, and desiring information or access to services [1,25]. Our analysis indicates that, at least for The Caregiving and Bereavement Study, those caregivers who are interviewed are likely to be older and have less distressing grief than those who are not. Relying on those who volunteer might mean we do not hear from the full range of caregivers, including those who might have more needs. As a result, our findings on caregivers' preparations for bereavement [15] might not reflect the wider

experiences and needs of the wider population of caregivers. It is also likely that findings drawn from interviews with caregivers might not provide a full picture of their experiences and needs. Many of those studies do not have the opportunity to compare those who do participate with those who do not.

There is increasing emphasis in facilitating access to palliative care for underserved and vulnerable groups [26]. In order to do this well, we also need strategies that facilitate research participation. Researchers are encouraged to consider strategies that sample broadly and promote the participation of the full range of family caregivers in research when they are eligible. These approaches might include sampling strategies that attempt to recruit across the diversity of caregivers, as opposed to relying on volunteers to come forward, and the development of approaches to target the full range of family caregivers (e.g., the provision of respite from caregiving to facilitate research participation) [27]. Additionally, promoting caregiver involvement in all aspects of the research process, including strategies for participant recruitment, can improve research relevance and quality [28]. We encourage researchers to report data about the representativeness (or otherwise) of samples to determine the extent of the problem in palliative care research and exploring caregivers' reasons for non-participation, as has been done for patients [29]. Such information is of utmost importance to policymakers in order to meet the needs of vulnerable caregivers.

Study Limitations

Our analysis determined the ways in which the interviewed participants differed from those who participated in the larger study but not the interviews. What we cannot determine, at least from our study, is if and how the interviewed caregivers differ from those who declined to participate in the larger study, or whether and how the caregivers who participated in the larger study might differ from those who did not. Additionally, although we recruited caregivers from three types of palliative care, our sample size prohibited further analyses comparing participants and non-participants between the types of palliative care from which we recruited caregivers. Issues concerning how well samples are representative of palliative care populations are therefore necessary to document across methodologies, data types, and service modalities [13,27].

Clinical Implications

The complexity of delivering and evaluating quality palliative and end-of-life care services, including bereavement care, requires the collection of knowledge from multiple sources in order to provide the solid and robust evidence required for best-practice. The study showed that family caregivers with elevated grief and lower age are less likely to volunteer for research interviews. These findings are relevant to palliative care policymakers when considering the supportive and bereavement needs of caregivers. Palliative care researchers may wish to consider their sampling and recruitment strategies so as to optimise the transferability of their findings. Improving the representation of family caregivers in our research will ultimately help to address the neglected area of bereavement care.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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Table 1

Differences in Characteristics of Study Participants According to Interview Participation

	No Interview N = 20	Interview N = 16	BH-Corrected p value
Age	55.10 (10.77)	64.44 (8.55)	.030
Female	14 (70%)	12 (75%)	.999
Marital Status			.128
Single/Never Married	1	1	
Widowed	3	0	
Divorced	4	0	
Married/De-facto	12	15	
Cultural Background			.626
Australian	10	10	
Other English Speaking	8	6	
Non-English Speaking	2	0	
Usual Employment			.263
Paid	5	10	
Pensioner	9	5	
Self-Funded Retiree	2	2	
Other	0	3	
Current Employment			.277
Paid	4	8	
Pensioner	9	5	
Self-Funded Retiree	2	2	
Other	1	5	
HGRC	136.44 (28.93)	116.23 (24.37)	.080
QoL	10.78 (4.39)	13.27 (3.73)	.164
SF12v2	36.82 (3.86)	37.95 (3.08)	.374
PG-12	29.83 (8.83)	22.38 (5.35)	.030

Table 2

Odds Ratios, Confidence Intervals, and P-Values for Binary Logistic Regression

Predictor	Odds Ratio	[95%CI]	p
Age	1.10	[1.02, 1.21]	.026
PG-12	0.87	[0.75, 0.97]	.021