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Mental well-being in bereaved carers: A Health Survey for England based population study

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Abstract

Objectives: The experience of caregiving may affect carers' well-being into bereavement. We explored associations between mental well-being and previous experience of bereavement of, and caring for, someone close at the end-of-life.

Methods: An end-of-life set of questions was included in population-based household survey administered to adults (age 16+). We used univariable regression to explore the cross-sectional relationship between our primary outcome (Warwick-Edinburgh Mental Wellbeing Scale [WEMWBS]) and possible explanatory variables: sociodemographic; death and bereavement including ability to continue with their life; disease and carer characteristics; service use; and caregiving experience.

Results: The analysis dataset included 7,606 of whom 5,849 (77%) were not bereaved, 1,174 (15%) were bereaved but provided no care and 583 (8%) were bereaved carers. WEMWBS was lower in the oldest age class (85+) in both bereaved groups compared with not bereaved (P<0.001). The worst WEMWBS scores were seen in the "bereaved but no care" group who had bad/very bad health self-assessed general health, (39.8 [10.1]), versus 41.6 [9.5]) in those not bereaved and 46.4 ([10.7]) in bereaved carers. Amongst the bereaved groups, those who would not be willing to care again had lower WEMWBS scores than those who would (48.3 (8.3) vs 51.4(8.4), p=0.024).

Conclusion: Mental wellbeing in bereavement was worse in people with self-reported poor/very poor general health and those with a worse caregiving experience. Although causality cannot be assumed, interventions to help people with worse mental and physical health to care, so that their experience is as positive as possible, should be explored prospectively.

Keywords: mental well-being, bereavement, WEMWBS, carers, caregiving

Introduction

Family members, friends or others who provide unpaid help and support for someone at the end of life (carers[1]) have a dual role. They are pivotal members of the patient's care team, and associated with supporting a patient's wishes to die at home if this is their preference,[2] but also need support for themselves as people affected personally by the patient's illness.

Many carers may find the experience of caring rewarding, with a consequent positive impact on wellbeing.[3] However, caring also may affect quality of life adversely, with deterioration in physical health, strain at work (or loss of employment), financial losses and social isolation.[4 5] Bereaved carers of people who died from cancer appear to have a higher prevalence of psychological morbidity (83%) than the general population (15%).[6] Psychological disorders amongst carers increases with advancing disease,[7] and there is increased mortality in older spousal carers.[8] Patient and carer burdens are positively correlated [7 9 10] and the carer's needs may exceed those of the patient.[2]

The experience of caregiving may have longer term effects on the carer's wellbeing into bereavement. Most people's symptoms of grief decline within one year after death, but 10-20% have continued distress,[11] and 20% have reduced function because of poor mental health.[12] Predictors of poor bereavement outcomes in carers of cancer decedents include carer well-being prior to the patient's death, closeness of relationship to the deceased, patients' disease characteristics, the caregiving experience and characteristics of terminal care, such as care setting and contact frequency between professionals and family carers.[13 14] For some, the caregiving experience is such that they would not take on the role again under the same circumstances.[15 16]

A population household survey showed that carers of decedents who had accessed specialist palliative care services, many of which provide bereavement support, were more likely to feel able to "move on" with their lives (86% vs 77%, $p = 0.0016$).[17] When the patient dies, the carers' dual role disperses. Both loss of burden and loss of reward (including contact with supportive services as both care providers and care recipients) during caring may affect bereavement. While data indicate an immediate effect of caregiving on bereavement, little is known about its long-term effect on a person's wellbeing.

The aim of this study is to explore the cross-sectional relationship between mental well-being and previous experience of bereavement of, and caring for, someone close at the end-of-life.

Methods

Data were collected in The Health Survey for England (HSE), a population based, observational study. HSE is an annual, face-to-face, cross-sectional survey conducted on behalf of the Department of Health. In addition to the general questions on health, health-related behaviour and sociodemographic variables, in 2013, we included a question set on caring for “someone close” at the end of life. Detailed survey methods and the development of the end of life question set are described elsewhere.[16 18]

A random probability sample of households (9,408 addresses in 588 postcode sectors) was included in the survey. The end-of-life set of questions was only administered to adults (age 16 or over), giving 8,870 for analysis. Fieldwork was completed in March, 2014.

Ethics approval and consent for the additional end-of-life care set of questions, was included in the HSE ethics approval processes for the 2013 survey, obtained by Oxford A Research Ethics Committee (reference 12/SC/0317).

Provision of Care

In line with the research question, the three groups of respondents are categorised as:

1. Indicated that someone close to them died from a life-limiting illness within the last five years and they provided personal care to this person (Bereaved and care).

2. Indicated that someone close to them died from a life-limiting illness within the last five years and they did not provide personal care to this person (Bereaved, no care).

3. No one died of a life limiting illness within the last five years (Not bereaved).

Dependent variable: measure of mental wellbeing

The primary outcome is the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS).[19] This is a 14 item subjective measure of mental wellbeing and psychological function. Each item represents a statement and is answered on a 1-5 Likert scale (1 = none of the time; 5 = all of the time). Single item values sum up to an overall score between 14 (poor mental wellbeing) and 70 (high mental wellbeing). Using validated scales of mental illness such as the CES-D measure of depression, a cut point of ≤44 indicates possible depression, and ≤40, probable depression.[19 20] Clinically, a change of 3 points in the overall score is considered to be important at a group level.[20 21]

Independent variables

The following respondent variables were explored.

- Sociodemographic: sex, age, ethnicity, relationship to deceased, highest educational qualification, and household income.
- Duration of bereavement and intensity of care: time elapsed since bereavement (year the person died), frequency of care (daily care), and duration of period of provided care.
- Disease and care characteristics: Cause of death (cancer or non-cancer), whether a palliative care service was used, and whether home was the place of death.
- Current status and views: current caring status (currently caring for someone with a long-term physical/mental ill-health, disability or problems relating to old age), physical or mental health conditions or illnesses lasting or expected to last 12 months or more, and self-assessed general health (very good, good, fair, bad, very bad) collapsed to three categories (very good/good, fair, bad/very bad), ability to continue with their life following the person's death, and whether they would be willing to care again (as a broad proxy measure for care experience).

Statistical Analysis

The data were weighted in line with HSE weights for individuals to help account for non-response bias.[18]

WEMWBS is summarised using mean and standard deviation (sd) as specified in the WEMWBS user guide [19]. ANOVA was used to compare WEMWBS between the three groups. To test the hypothesis that other factors moderate the relationship between group and WEMWBS, ANCOVA was used to control for covariates. To test the assumption of homogeneity of the regression slopes the interaction between the covariate and group was further included and if significant ($p<0.05$) the interaction term was retained in the model.

The mean and standard deviation (mean minus sd) was observed to examine groups more at risk of depression than others, using the cut of ≤40 to indicate probable depression.[20 21]

No adjustments were made for multiple significance testing.[22 23] Missing data were not imputed. A p-value of <0.05 was considered to indicate statistical significance. All analyses were undertaken on SPSS (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp).

Results

Data on WEMWBS and provision of care were available for 7,770 (88%) respondents. 164 stated that no one close to them died of a terminal illness within the last five years but yet gave the information that they cared for someone at the end of life (50 daily care, 115 care but not daily). These 164 cases were excluded from the analysis. Hence, 7,606 respondents for analysis: 5,849 (77%) indicated that no person close to them died of a terminal illness within the last five years (not bereaved), 1,174 (15%) were bereaved within the last five years but did not care for the deceased (bereaved but no care) and 583 respondents (8%) were bereaved and cared for the deceased (bereaved and care).

Table 1: Characteristics of groups

	Bereaved and care		Bereaved and no care		Not bereaved			
	Mean* (SD)	n (%)	Mean* (SD)	n (%)	Mean* (SD)	n (%)	p-value	p-value Interaction if <0.05
Whether personal care was provided by respondent to person at end of life	51.1 (8.6)	583 (100%)	51.3 (8.7).	1174 (100%)	51.6 (8.3)	5849 (100%)	0.212	
Sex							0.234	
Male	51.6 (8.6)	227 (39%)	51.4 (8.9)	581 (50%)	51.7 (8.3)	2855 (49%)		
Female	50.8 (8.6)	357 (61%)	51.2 (8.5)	592 (50%)	51.6 (8.3)	2994 (51%)		
Age							0.057	<0.001
16-24	53.9 (6.8)	59 (10%)	51.3 (8.1)	182 (16%)	51.6 (8.5)	852 (15%)		
25-34	51.4 (8.6)	87 (15%)	53.2 (7.0)	196 (17%)	51.8 (7.7)	997 (17%)		
35-44	49.3 (7.9)	75 (13%)	50.9 (9.4)	206 (18%)	51.8 (8.3)	1047 (18%)		
45-54	49.0 (9.5)	126 (22%)	49.5 (9.0)	221 (19%)	51.3 (8.5)	996 (17%)		
55-64	52.9 (8.0)	104 (18%)	52.0 (8.6)	158 (14%)	51.1 (8.8)	811 (14%)		
65-74	52.6 (8.3)	76 (13%)	52.9 (9.2)	127 (11%)	52.4 (8.2)	663 (11%)		
75-84	49.7 (8.6)	45 (8%)	49.8 (8.9)	70 (6%)	51.7 (8.4)	370 (6%)		
85+	47.5 (9.5)	11 (2%)	47.1 (8.7)	15 (1%)	50.5 (7.8)	112 (2%)		
Ethnic origin							0.398	0.045
White	51.1 (8.6)	549 (94%)	51.3 (8.6)	1054 (90%)	51.5 (8.3)	5087 (87.0)		
Asian	53.5 (7.1)	13 (2%)	52.8 (10.0)	61 (5%)	52.2 (8.6)	464 (8%)		
Black / African / Caribbean / Black British	47.3 (12.2)	13 (2%)	50.8 (9.8)	22 (2%)	54.0 (8.4)	152 (3%)		
Mixed / multiple ethnic groups	51.6 (3.7)	6 (1%)	48.2 (9.4)	20 (2%)	52.3 (7.3)	89 (2%)		
Any other ethnic group	48.1 (7.9)	4 (1%)	54.5 (8.7)	14 (1%)	50.2 (10.2)	55 (1%)		
Highest Educational Qualification							0.268	
NVQ4/NVQ5/Degree or equiv	52.4 (8.5)	164 (28%)	53.4 (6.5)	312 (27%)	53.6 (7.2)	1551 (27%)		
Below degree	51.0 (8.4)	299 (51%)	51.2 (8.7)	638 (54%)	51.4 (8.2)	3206 (55%)		
No qualification	49.7 (8.9)	119 (21%)	49.0 (10.3)	224 (19%)	49.4 (9.4)	1084 (19%)		
Household Income							0.095	
Lowest Quintile (<=£12,803)	47.9 (9.6)	87 (19%)	48.2 (11.0)	191 (19%)	49.3 (9.2)	860 (18%)		
Second lowest Quintile (>£12,803 <=£19,500)	50.5 (8.4)	96 (21%)	50.4 (9.2)	186 (19%)	50.2 (8.7)	813 (17%)		
Middle Quintile (>£19,500 <=£29,865)	51.2 (8.0)	95 (20%)	51.8 (7.4)	165 (17%)	52.2 (8.0)	903 (19%)		
Second highest Quintile (>£29,865 <=£49,016)	52.8 (7.5)	107 (23%)	52.3 (7.5)	220 (22%)	52.7 (7.4)	1051 (22%)		
Highest Quintile (>£49,016)	51.4 (6.8)	82 (18%)	53.1 (7.2)	224 (23%)	53.4 (7.3)	1061 (23%)		
Self-assessed general health							0.001	<0.001
Very good/good	52.3 (8.0	437 (75%)	53.3 (7.3)	893 (76%)	53.1 (7.4)	4565 (78%)		
Fair	47.9 (8.8)	112 (19%)	47.4 (8.7)	198 (17%)	48.1 (8.4)	939 (16%)		
Bad/very bad	46.4 (10.7)	34 (6%)	39.8 (10.1)	83 (7%)	41.6 (9.5)	343 (6%)		
Illnesses lasting 12 months or more							0.578	
Yes	49.4 (9.5)	266 (46%)	48.6 (10.0)	461 (39%)	49.5 (9.0)	2206 (38%)		
No	52.5 (7.4)	318 (55%)	53.1 (7.2)	713 (61%)	52.9 (7.6)	3639 (62%)		
Currently caring for someone because of health/old age							0.374	
Yes, currently caring	50.4 (8.7)	131 (22%)	49.7 (8.4)	237 (20%)	50.5 (8.2)	918 (16%)		
No, not currently caring	51.3 (8.6)	452 (78%)	51.8 (8.7)	936 (80%)	51.9 (8.3)	4930 (84%)		

** mean-value refers to the WEMWBS wellbeing score which ranges between 14 (poor mental wellbeing) and 70 (high mental wellbeing).*

Table 1 shows that there was no statistically significant difference in the WEMWBS score between the three groups (p=0.212). However, after adjusting for age (p=0.001) and for self-assessed general health (p<0.001) a significant differences in WEMWBS score was seen between the three groups.

In the highest age class (85+) WEMWBS was lower in the "bereaved carers" (47.5 [9.5]) and the "bereaved but no care" (47.1 [8.7]) group. In the group of "bereaved carers" middle-aged persons age 35-44 and 54-54 were associated with lower WEMWBS scores (49.3 [7.9] and 49.0 [9.5]) than respondents from the other groups and age classes. The youngest age class (16-24), however, had a higher WEMWBS score (53.9 [6.8]) in "bereaved carers" than persons of the same age in the other two groups.

The "bereaved but no care" group with bad/very bad health self-assessed general health had the worst WEMWBS scores, with levels indicative of probable depression (39.8 [10.1]), which compares to 46.4 ([10.7]) in "bereaved carers" and 41.6 [9.5]) in those "not bereaved"

Bereaved and care VS Bereaved and no care

Table 2 shows the WEMWBS scores between the two bereaved groups. There was no statistically significant differences when looking at the relationship to the person who died, year of death, type of illness, whether specialist palliative care was involved, if they died at home and feeling able to continue with life.

Bereaved and care

There was no significant difference in WEMWBS scores and the length of care provided or the intensity of care. However, those who would not be willing to care again had lower WEMWBS scores than those who would (48.3 (8.3) vs 51.4(8.4), p=0.024).

Groups at risk of depression

Groups in which a meaningful part (Mean sd)) would fall in the category of ≤ 40 points were: people of very old age (85+) in both bereaved groups and middle aged (45-54) in the bereaved carers group, people with Black, African, Caribbean, Black British ethnic origin in both bereaved groups, people with no educational qualification in the bereaved non-carer and the non-bereaved group, bereaved people with illnesses ≥12 months, and those with a household income of the lowest quintile in all groups. The scores indicate risk for depression in all three groups for fair and bad/very bad self-assessed general health.

Table 2: Characteristics of bereaved by caring

	Yes, bereaved and cared for		No care but bereaved		
	Mean* (SD)	n (%)	Mean* (SD)	n (%)	p-value
Relationship to person who died					0.700
Spouse/partner	50.0 (9.8)	91 (16%)	50.3 (59.8)	19 (2%)	
Parent	51.0 (8.5)	199 (34%)	50.7 (8.3)	142 (12%)	
Child	52.3 (6.9)	23 (4%)	48.3 (9.4)	30 (3%)	
Brother/sister (including half or step brother or sister)	50.4 (8.1)	39 (7%)	50.8 (9.4)	125 (11%)	
Other relative	51.6 (8.5)	175 (30%)	51.6 (8.6)	664 (57%)	
Friend	51.7 (8.4)	44 (8%)	51.9 (8.7)	170 (15%)	
Other	51.4 (7.9)	11 (2%)	49.9 (7.2)	23 (2%)	
Year of death					0.537
2008	50.7 (7.5)	68 (12%)	51.7 (7.5)	105 (9%)	
2009	51.9 (8.7)	95 (16%)	52.4 (8.8)	182 (16%)	
2010	52.6 (7.5)	120 (21%)	50.7 (7.7)	207 (18%)	
2011	50.5 (9.1)	116 (20%)	50.8 (9.3)	197 (17%)	
2012	50.1 (8.2)	115 (20%)	51.1 (8.9)	284 (24%)	
2013	50.7 (10.7)	69 (12%)	51.9 (9.0)	191 (16%)	
Type of illness					0.606
No, died from other disease than cancer	51.4 (9.3)	172 (29%)	51.0 (8.8)	330 (28%)	
Yes, died from cancer	51.0 (8.3)	412 (71%)	51.5 (8.7)	844 (72%)	
PC Service involved					0.650
Yes, PC involved	51.1 (8.9)	373 (65%)	51.6 (8.7)	598 (55%)	
No, no PC involved	51.3 (7.8)	203 (35%)	51.0 (8.5)	492 (45%)	
Died at home					0.627
Yes, died at home	50.7 (51/7.9)	192 (33%)	50.6 (8.6)	365 (31%)	
No, did not die at home	51.3 (52/8.9)	391 (67%)	51.7 (8.7)	801 (69%)	
Able to continue with life					0.343
I have been able to continue with my life	52.0 (8.0	486 (83%)	51.6 (8.5)	1119 (95%)	
I am starting to continue with my life	46.9 (9.2)	89 (15%)	46.6 (11.2)	36 (3%)	
I have not been able to continue with my life	40.9 (14.2)	8 (1%)	47.8 (11.4)	19 (7%)	
Length of provided care					0.677
Days	50.3 (7.9)	69 (12%)			
Weeks	52.1 (7.0)	122 (21%)			
Months	50.8 (10.0)	207 (35%)			
More than a year	51.0 (8.1)	185 (32%)			
Care intensity/daily care					0.781
Yes, care provided daily	51.0 (8.8)	291 (51%)			
No, care provided, but not daily	51.3 (8.4)	285 (50%)			
Willingness to care again					0.024
Would not take on the caregiving role again	48.3 (8.3)	49 (9%)			
Would take on the caregiving role again	51.4 (8.4)	523 (92%)			

** mean-value refers to the WEMWBS wellbeing score which ranges between 14 (poor mental wellbeing) and 70 (high mental wellbeing).*

Discussion

This exploratory study is the first to examine mental wellbeing in bereaved carers at the population level and including carers who are not identified through health and social care services. We found that mental wellbeing in bereavement was directly associated with (a) current self-reported general health and (b) with care experience. In general, the overall differences in mental wellbeing are consistent with other work [24-30] adding face validity to our findings; worse mental wellbeing in the oldest old, those with lower levels of education, who were less affluent, with poorer self-assessed health and with illnesses themselves.

The known relationship between physical and mental well-being is mirrored in our findings. People with bad/very bad self-reported health had lower WEMWBS scores in all three groups. The group of bereaved non-carers with bad/very bad health had the lowest WEMWBS score; below the level for probable depression. However, the mental wellbeing in bereaved carers was higher than the non-bereaved with similar health status. While we cannot draw conclusions about causality, as we only describing associations, this may indicate a positive effect on mental wellbeing in bereavement from having provided care for the person who died. Conversely, it may be they represent a subgroup with better mental wellbeing despite physical ill-health who were thus better equipped psychologically to provide care. Whichever the direction, it highlights the need to support the mental wellbeing of those with poor health themselves especially when they have the additional burden of someone close to them with a life-limiting illness. If caring does play a protective role regarding mental wellbeing in bereavement, then provision of support in this situation is clearly important.

People who would not be willing to care again under the same circumstances reported a lower WEMWBS score. Again, we cannot deduce causality from this observational dataset; mental wellbeing might have been low when the caretaking role was taken on which thereby influenced the care experience or, conversely, a poor care experience may have adversely affected the carers' mental wellbeing in bereavement. However, other studies indicate that quality of care experience does affect bereavement.[13] Previously reported data from this dataset showed that younger carers, and those where palliative care services had been involved were more likely to be willing to care again under similar circumstances [16] and that involvement of specialist palliative care ameliorated the adverse effect of socioeconomic deprivation on deaths at home.[31] The South Australian Health Omnibus Survey found bereaved carers were more likely to be able to "move on" with their lives if specialized palliative care service had been involved in care.[17] At five years, one in seven people were still indicating that they were unable to "move on".(17) These possibilities are consistent with Schulz' *et al* distinction of two types of predictors of complicated grief after care taking: those related to the experience of caregiving and the carer's mental health before the death of the patient.[12] Although not reaching statistical significance, these HSE data showed that those able to continue with their lives had higher mental wellbeing than those who were not; bereaved carers who could not continue with their lives had scores only just over the level of probable depression.

The data also point to other issues that may influence mental wellbeing in bereavement. In the two bereaved groups, those with the highest risk of depression and psychological distress seem to be in the oldest bereaved, non-carers where the decedent was a child, more recently bereaved carers (year of death in 2013), those starting to/not able to continue with their life, and carers who were unwilling to provide care again. Lower income and educational levels have been related to an increased risk of complicated grief and higher probability of post-bereavement depression.[12 13] Although our data support this, the findings were non-significant.

Implications for clinical practice and research

A meta-summary of qualitative research on bereaved carers showed that (i) many different aspects of the caregiving experience impact bereavement, (ii) every bereavement experience is unique, and (iii) a variety of supports must be developed and made available to caregivers to meet these unique needs (37). Care experience can be positively influenced by relatively small interventions or activities to support caregivers.[6] Given the observed relationships between poorer health and poorer mental wellbeing and bereavement experience, then support for people with poorer mental and/or physical health, especially the oldest old, who have someone close to them with a life-limiting illness seems a clear priority. Supporting them to care so that their care experience is, on balance, better than it otherwise would have been may have benefits with regard to longer term outcomes e.g. complex bereavement. However, data showing that we can predictably change the course of prolonged grief is in its infancy.[32] In order to have a better understanding of the relationship between mental wellbeing, physical health, carer experience, and bereavement experience, taking into account other characteristics, a longitudinal observation of mental wellbeing during care taking and on through bereavement is needed.

Limitations

The main limitation is the observational nature of the data, thus we cannot apportion causality. Secondly, although the HSE is a representative survey the numbers for the two bereaved subgroups are small in some item characteristics. Thirdly, we cannot account for other confounders that were not measured. Physical and emotional burden experienced by carers reduces survival in older spousal caregivers.[8] Some may have been so severely impaired by their loss and/or general wellbeing that they were too unwell to respond, or had died at the time the survey was conducted thus under-estimating prevalence for those most severely affected. This may also partly explain why we did not find an association between spousal relationship and mental wellbeing.

Another limitation relates to the question used to divide respondents into bereaved and not bereaved persons due to “a life-limiting illness within the last five years”. Dementia was not given as a specific option, and may not have been recognised by respondents as a life-limiting disease. Respondents responding “no” to the stem question “life-limiting illness”, but yet reported caregiving at the end of life were excluded, however there may also have been some respondents in the “not bereaved” group who were actually bereaved although they did not provide care.

Conclusion

In this population-based study, we found that mental wellbeing in bereavement was worse in people with self-reported poor/very poor general health and those with a worse caregiving experience. Although causality cannot be assumed, interventions to support people with worse mental and physical health to care, so that their experience is, on balance, as good as it can be, needs to be explored prospectively.

Author contributions: MJ, DC, FH conceived and designed the experiments. FH, VA analysed the data. All authors helped with data interpretation. FH drafted the paper. All authors provided intellectual content on drafts and approved the final manuscript.

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Data Sharing: The data used in this analysis are available at the UK Data Archive:

NatCen Social Research and University College London. Department of Epidemiology and Public Health, Health Survey for England, 2013 [computer file]. Colchester, Essex: UK Data Archive [distributor], January 2015. SN: 7649, http://dx.doi.org/10.5255/UKDA-SN-7649-1

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