Title

Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care.

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Abstract

Objective: To identify the proportion of female carers who experience death thoughts and the factors associated with these thoughts, using data from the Australian Longitudinal Study on Women's Health (ALSWH).

Methods: A cross-sectional analysis of the fifth ALSWH survey was conducted. 10,528 middle-aged women provided data on caring and death thoughts, 3,077 were carers and 2,005 of those were included in the multivariate analysis.

Results: 7.1% of female carers had felt life was not worth living in the previous week and were classified as having experienced death thoughts, compared with 5.7% of non-carers ($p = .01$). Carers with death thoughts had poorer physical and mental health, higher levels of anxiety, lower levels of optimism, and reported less social support ($p < .01$). In a multivariate model social support, mental health, carer satisfaction, and depressive symptoms significantly predicted death thoughts. Carers with clinically significant depressive symptoms were four times more likely to experience death thoughts than those without. Carers who were satisfied with their role were 50% less likely to have experienced death thoughts than those who were dissatisfied.

Conclusions: A small but significant proportion of female carers experience death thoughts and may be at risk for suicide. These findings add to the growing body of evidence on suicide-related thoughts and behaviours in carers and have implications for health professionals and service providers.

Keywords

Suicidal ideation, caregivers, mental health, depression, death thoughts

1. Introduction

In Australia there are 2.6 million people providing informal (unpaid) assistance to those needing care as a result of a disability or old age [1]. These carers are typically family members, and of those who are primary carers (i.e. the main person providing care), more than two-thirds are women [1]. These women are predominantly middle-aged, with more than one-quarter of all women aged 45 to 54 regularly providing care for an older person or a person with a disability (compared with just 16% of men in the same age bracket; [1]). Similar statistics have been reported in the UK and the USA [29,30]. This type of care provision is known to lead to high rates of depression, anxiety, hopelessness and poor physical health, and these effects have been reported in a range of caregiving contexts, including cancer, mental illness, and neurodegenerative disorders [2 - 6].

Anxiety, hopelessness, depression and poor physical health are all risk factors for suicide in the general population [7], but there have been only two quantitative studies exploring suicidality (a collective term for suicide-related thoughts and behaviours) in informal carers. In one study, of men caring for male partners with AIDS, as many as 50% had contemplated suicide during the caregiving journey and this was irrespective of their own HIV status [8]. Thoughts of suicide in that group were associated with a perceived lack of social support, lack of social integration and caregiver burden. In another study, 1 in 4 family carers of people with dementia had contemplated suicide more than once in the previous 12 months, and one-third of those said they were likely to attempt suicide in the future [9]. Suicidal carers in that study had higher levels of burden, hopelessness, depression, and anxiety than non-suicidal carers. They also used more dysfunctional coping strategies, were less optimistic, had lower levels of self-efficacy for service use, and were less satisfied with the social support they were receiving. In a multivariate model, however, depression was the

Abbreviations: ALSWH – Australian Longitudinal Study on Women’s Health; SF-36 – Short Form 36 Quality of Life questionnaire.

only significant predictor of suicidal thoughts. These studies suggest that suicide-related thoughts and behaviours might be a significant phenomenon among informal carers, but they are limited by their focus on specific illnesses. Furthermore, despite the fact that the majority of informal carers are women, neither study focused specifically on female carers.

The present study sought to explore one aspect of suicidality, namely ‘death thoughts’, in a convenience sample of female informal carers. Death thoughts, the term used to describe the feeling that life is not worth living, are considered an important phenomenon in the spectrum of suicide-related thoughts and behaviours and are also considered by some to represent the first stage in a continuum of thoughts and behaviours which might ultimately lead to death by suicide [10 -16]. Using data from the Australian Longitudinal Study on Women’s Health (ALSWH), the aim of the study was to identify the proportion of female carers who feel that life is not worth living and the factors associated with this feeling.

2. Methods

2.1 Sample

ALSWH was established in 1996 to investigate multiple factors affecting the health and wellbeing of women over a 20-year period. Women in three age groups (‘young’ – 18 to 23 at first survey; ‘mid age’ – 45 to 50; and ‘older’ – 70 to 75) were randomly selected from the national Medicare database (which includes all permanent residents of Australia). The complete methods for ALSWH have been published in detail elsewhere [17]. The Human Research Ethics Committees of the University of Newcastle and the University of Queensland approved the research protocol for ALSWH and all women gave informed consent.

2.2 Participants

The mid-age ALSWH cohort (born between 1946 and 1951) has been surveyed six times since 1996. The analyses in this study draw on data from Survey 5 (collected in 2007) at which questions on feeling that life was not worth living and caring were included in the survey. At Survey 5, 10,528 women, aged between 56 and 61 years, answered both questions.

2.3 Measures

The ALSWH surveys comprise a range of scales and questions on health and wellbeing (see www.alswh.org.au for complete surveys). For the purpose of this analysis, the following questions and scales were of interest: *In the past week, have you been feeling that life isn't worth living?* This question had a yes/no response option. Women who answered 'yes' were classified as having experienced death thoughts. *In the past six months, have you ever deliberately hurt yourself or done anything that you knew might have harmed or even killed you?* This question had a yes/no response option. Women who answered 'yes' were classified as having self-harmed or attempted suicide. *Do you regularly provide care or assistance to any other person because of their long-term illness, disability or frailty?* This question was used as a measure of care provision. Sub-statements of 'for someone who lives with you' and 'for someone who lives elsewhere' had a yes/no response option. Women who answered 'yes' to either sub-statement were classified as carers. Woman who answered 'no' to both questions were classified as non-carers. *Are you happy with your share of the following tasks and activities?* [Sub-question - *Caring for another adult who is elderly/disabled/sick*]. This question was used as a measure of satisfaction with the caring role. The response options were 'happy the way it is', 'would like other household members to do more', 'would prefer another arrangement' and 'not applicable (don't do this)'. Women who selected 'happy the way it is' were classified as satisfied carers. Those who selected 'would like other household members to do more' and 'would prefer another

arrangement’ were classified as dissatisfied carers. Those who selected ‘*not applicable*’ were classified as non-carers.

2.3.1 Physical and mental health.

The Short-Form 36 Quality of Life questionnaire (SF-36) was used to measure health status and quality of life [18]. The physical function summary score and the mental health summary score were used for this analysis.

2.3.2 Depression.

The short version of the Center for Epidemiologic Studies Depression Scale [19] was used to measure depressive symptoms. Total scores ranged from 0 to 30 and a score of 10 was used to distinguish women with clinically significant depressive symptoms [19].

2.3.3 Anxiety.

The anxiety subscale of the Goldberg Anxiety and Depression Inventory [20, 21] was used to measure anxiety symptoms. Total scores ranged from 0 to 9, with higher scores indicating greater anxiety.

2.3.4 Optimism.

The Revised Life Orientation Test [22] was used to measure optimism. Total scores ranged from 0 to 24, with higher scores indicating greater optimism.

2.3.5 Social Support.

The Medical Outcomes Study Social Support Index [23] was used to measure perceptions of social support and social interactions. Total scores ranged from 19 to 95, with higher scores indicating more social support.

2.4 Analyses

The data were analysed using SPSS Statistics Version 18. Women with missing values on the caring and death thoughts variables were excluded from the analysis. Women with missing values on the other variables were excluded on case-wise basis (as a result there

are some differences in the sample size of each analysis). Chi-square tests were conducted to identify the proportion of carers and non-carers who had experienced death thoughts and who reported suicide attempts/self-harm. Independent t-tests were conducted to identify the differences between carers who had experienced death thoughts and carers who had not on the psychosocial variables. Where there were significant differences, the psychosocial variables were entered as predictors in a logistic regression with death thoughts as the dichotomous outcome.

3. Results

3,077 women (29%) were classified as carers at Survey 5, with the remaining 7,451 classified as non-carers. The average age of the women in the sample was 58.5 years ($SD = 1.45$) and approximately three-quarters were married. There were no significant differences in age or marital status between carers and non-carers, although more carers than non-carers were unemployed (35.6% vs. 31.3%, $\chi^2(2) = 27.79, p < .00$).

Just over seven percent of carers (7.1%) had felt that life was not worth living in the previous week and so were classified as having experienced death thoughts; significantly more than non-carers (5.7%; $\chi^2(1) = 6.62, p = .01$). There were no significant differences between carers and non-carers in the proportion reporting self-harm/suicide attempts (less than 1% in both groups).

There were significant univariate differences between carers who had experienced death thoughts and carers who had not on all the psychosocial variables (see Tables 1 and 2). Carers who had experienced death thoughts reported less social support, more symptoms of anxiety, less optimism, and poorer physical and mental health (all significant at $p < .01$). A greater proportion of these carers also met the cut-off for clinically significant depressive symptoms (80%, compared with 22% of carers who had not experienced death thoughts, $p <$

.01) and were dissatisfied with the caring role (54%, compared with 27% of carers who had not experienced death thoughts, $p < .01$).

Table 1. Differences between carers with and without death thoughts, on continuous measures of wellbeing.

Variable	Carers without	Carers with	t (df)	p
	death thoughts	death thoughts		
	M (SD)	M (SD)		
Anxiety	3.90 (2.64)	6.74 (2.30)	-17.25 (256) ^a	.00
Optimism	16.36 (3.92)	11.79 (4.70)	13.93 (238) ^a	.00
Social Support	3.98 (0.89)	3.16 (1.07)	10.88 (230) [†]	.00
SF-36 Physical Health	80.41 (19.76)	66.03 (27.19)	7.60 (231) [†]	.00
SF-36 Mental Health	76.16 (16.03)	48.46 (21.37)	18.66 (233) [†]	.00

^aAdjusted for unequal variances. Note: The sample sizes for these analyses were 3,062 (SF-36 Physical Health), 3,065 (SF-36 Mental Health), 3,047 (Anxiety), 3,047 (Optimism), and 3,024 (Social Support).

Table 2. Differences between carers with and without death thoughts, on dichotomous measures of wellbeing.

	Carers without	Carers with death		
Variable	death thoughts	thoughts	$\chi^2(df)$	p
	$N(\%)$	$N(\%)$		
Satisfaction				
Dissatisfied	521 (27)	76 (54)	46.25 (1)	.00
Satisfied	1423 (73)	66 (46)		
Depressive Symptoms				
Not Significant	2240 (78)	43 (20)	361.701 (1)	.00
Clinically	618 (22)	174 (80)		
Significant				

Note: The sample sizes for these analyses were 2,086 (Satisfaction) and 3,075 (Depressive Symptoms).

When the seven psychosocial variables were entered as predictors in a direct logistic regression, with death thoughts (yes/no) as the dichotomous outcome, the model was significant ($\chi^2 (7) = 312.58, p = .00$). Social support, mental health, carer satisfaction and depression each made significant unique contributions (see Table 3). Carers who met or exceeded the cut-off for clinically significant depressive symptoms were nearly four times more likely to have experienced death thoughts than those who did not meet the cut-off ($Exp (B) = 3.95, p < .01$). Carers who were satisfied with their role were nearly 50% less likely to have experienced death thoughts than those who were dissatisfied ($Exp (B) = .56, p < .01$).

Table 3. Significant predictors in a logistic regression with death thoughts as the dichotomous outcome^a.

Significant Predictors	<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>p</i>	<i>Exp (B)</i>
Anxiety	.10	.06	2.98	1	.08	1.10
Optimism	-.03	.03	1.10	1	.30	.97
Social support	-.30	.11	7.95	1	.005	.74
SF-36 Physical Health	-.01	.01	1.07	1	.30	1.00
SF-36 Mental Health	-.04	.01	27.43	1	.000	.97
Carer Satisfaction	-.58	.21	7.74	1	.005	.56
Depression	1.37	.31	20.32	1	.000	3.95

^aModel: $\chi^2(7) = 312.58$, $p = .00$; Cox & Snell $R^2 = .14$; Nagelkerke $R^2 = .37$. Note: The sample size for this analysis was 2,005.

4. Discussion

To our knowledge this is the first study to explore an aspect of suicidality in women providing informal care to a person with a long-term illness, disability or frailty. The findings suggest that these women experience death thoughts at a significantly higher rate than their non-caring counterparts. Given that the data come from a large, representative study of middle-aged Australian women, the findings are of concern and, when taken together with the work of Rosengard and Folkman [8] and O'Dwyer and colleagues [9], they suggest that suicidality in carers might be an overlooked issue in health and social care.

Just over seven percent of female carers had felt that life was not worth living in the previous week and so were classified as having experienced death thoughts; significantly more than the 5.7% of non-carers. Death thoughts may be a precursor to more serious suicide-related thoughts and behaviours, and so knowing that significantly more carers than non-carers report these feelings is an important contribution to the caregiving literature.

Scocco and De Leo [13], for example, in a study of elderly Italians, found that of those who had seriously considered taking their own lives, the majority had also felt that life was not worth living. Also, Skoog et al. [15] reported that, in a study of elderly Swedes, the 3-year mortality rate was significantly higher (in fact, more than double) in women who felt that life was not worth living, compared with those who did not, and that this association was independent of any physical or mental disorders. Of those women who died, none died by suicide and the cause of death was cardiovascular for 73% [15]. This suggests that even in the absence of a suicidal act, the experience of death thoughts may have significant health implications. While death thoughts are clearly a significant phenomenon, they are just one aspect of suicidality. Future research should explore the prevalence of other suicide-related thoughts and behaviours in female carers, including specific suicidal ideation, suicide plans, and suicide attempts.

Carers who had experienced death thoughts scored significantly worse than carers who had not on a range of psychosocial measures, but only mental health, satisfaction with the caring role, perceptions of social support, and depressive symptoms significantly predicted death thoughts in the multivariate model. Limited social support, poor mental health, and depression are all considered important risk factors for suicide in the general population [7] and have been associated with death thoughts in other large studies [11, 12, 16]. Dissatisfaction with the caring role, however, may represent a unique risk factor among carers. Although the large body of literature on ‘caregiver burden’ is often interpreted to mean that all carers are dissatisfied, the current findings suggest that this is not necessarily the case. Nearly three-quarters of carers who had not experienced death thoughts said they were satisfied with their role. Carer dissatisfaction could, therefore, be a potentially modifiable risk factor for suicide-related thoughts and behaviours in this group, although

more research would be required to identify the factors that contribute to a sense of dissatisfaction.

While it was not within the scope of this study to explore longitudinal changes in the experience of death thoughts over the course of the caring journey, research suggests that caregiver burden does not necessarily abate after the institutionalisation or death of the care recipient [24,25]. Consistent with this, Rosengard and Folkman [8] found a significant association between bereavement and suicidal ideation in their sample of HIV carers, with all but one of the carers who were bereaved during the course of the study reporting more suicidal ideation after the death of their partner than before. Rates of suicide-related thoughts and behaviours at different stages of caring, therefore, should be a focus of future research.

Future research should also explore suicidal phenomena in male carers, particularly in light of evidence which indicates that the ratio of attempted to completed suicides is markedly lower in men than in women [16, 26] and that a substantial proportion of domestic homicide-suicides are committed by male, spousal carers [27, 28].

Finally, the cross-sectional nature of this study is a limitation. It is possible that the caring role may not be the cause of, but rather the catalyst for, death thoughts. In a qualitative study of family carers of people with dementia, O'Dwyer, Moyle and Van Wyk [31] found that the majority of carers who had contemplated suicide had experienced mental health problems prior to becoming a carer, the symptoms of which were then exacerbated by the caring role. Regardless, however, of whether the caring role is cause or catalyst, the fact that female carers are experiencing death thoughts at a higher rate than their non-caring counterparts is a cause for concern.

5. Conclusions

This study suggests that a small, but significant proportion of female carers feel that life is not worth living and may be at risk of suicide. Health professionals and community

workers must work to identify and support these carers. Female carers who are showing symptoms of depression, are dissatisfied with their role, or who feel unsupported, would be the logical target of this work.

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