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

Siobhan T. O'Dwyer[a,b,c,*], Wendy Moyle[a,b], Nancy A. Pachana[d], Billy Sung[a], Susan Barrett[a,b]

[a] *Centre for Health Practice Innovation, Griffith University, 170 Kessels Road, Nathan, QLD 4111, Australia*
[b] *Griffith Health Institute, Griffith University, 170 Kessels Road, Nathan, QLD 4111, Australia*
[c] *Australian Institute for Suicide Research and Prevention, Griffith University, Messines Ridge Road, Mt. Gravatt, QLD 4122, Australia*
[d] *School of Psychology, University of Queensland, St Lucia, QLD 4072, Australia*

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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, 3077 were carers and 2005 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.

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 45–54 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 [2,3]. 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 [4–8].

Anxiety, hopelessness, depression and poor physical health are all risk factors for suicide in the general population [9], 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 [10]. 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 [11]. Suicidal carers in that study had higher levels of burden, hopelessness, depression, and anxiety

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

* Corresponding author at: Centre for Health Practice Innovation, Griffith University, 170 Kessels Road, Nathan, QLD 4111, Australia. Tel.: +61 7 3735 6619; fax: +61 7 3735 3560.

E-mail address: s.odwyer@griffith.edu.au (S.T. O'Dwyer).

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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 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 [12–18]. 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 [19]. 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 [20]. 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 [21] 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 [21].

2.3.3. Anxiety

The anxiety subscale of the Goldberg Anxiety and Depression Inventory [22,23] 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 [24] 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 [25] 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

3077 women (29%) were classified as carers at Survey 5, with the remaining 7451 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%, $\chi^2(2) = 27.79$, $p < .00$).