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ORIGINAL ARTICLE

Loss of lifestyle: health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer

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Abstract

Purpose Little is known about how caring for someone affects the caregiver's health behaviours. We explore behaviour changes and their determinants in caregivers of women with ovarian cancer.

Methods Caregivers of 101 women with ovarian cancer completed a questionnaire 1.5–6 years after their family member's cancer diagnosis, providing information about their current health behaviours, height, weight and changes in these compared with pre-diagnosis. Information about the impact of ovarian cancer, other stressful events and distress was also collected for patients and caregivers. Logistic regression was used to determine characteristics associated with negative changes.

Results Half (54%) of caregivers did not meet Australian physical activity guidelines, 71% were overweight/obese, 40% ate <2 serves of fruit and 80% <5 serves of vegetables/day, 37% consumed >2 alcoholic drinks/occasion and 10% were smokers. Overall, 56% reported ≥1 negative change since their family member's diagnosis, with many decreasing their physical activity (42%) and/or gaining weight (35%). Caregivers were more likely to report negative changes if they had only school-level education (OR 3.0, 95%CI 1.1–8.4), they were unable to carry out usual daily activities due to caregiving (OR 2.0, 95%CI 0.7–5.4), they were clinically distressed (OR 3.4, 95%CI 1.1–10.1) or caring for a woman whose disease impacted on her usual daily activities (OR 4.3, 95%CI 1.4–13.2).

Conclusions Many caregivers of women with ovarian cancer do not meet Australian health guidelines and more than half describe negative changes after becoming a caregiver. More attention should be given to cancer caregivers with high physical and emotional demands.

Keywords Caregivers · Ovarian cancer · Health behaviours · Body mass · Risk factors

Introduction

Behavioural factors such as insufficient physical activity, poor diet, obesity, excessive alcohol consumption and smoking increase an individual's risk of diabetes, cancer and heart disease [1]. The prevalence of these health risk factors in family caregivers of cancer patients is unknown, however it is hypothesised that cancer caregivers may neglect their own health when they take on this often daunting and burdensome support role. Moreover a caregiver may be grappling with their own intense emotions

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[2] at the same time as providing support with acute illness episodes, administering treatments, navigating the health care system and in some circumstances providing hands on care with activities of daily living [3]. This role may extend for years and involve a considerable number of hours per week [3]. In the context of cancer, no studies have considered the potential effects of caring for someone else on a caregiver's own lifestyle behaviour.

Existing research indicates that caring for a family member with chronic disease is associated with significant levels of distress, with some caregivers reporting higher levels of distress than the patients themselves [4–6]. Family caregivers have also been found to have impaired immune function [7], greater incidence of coronary heart disease [8] and, when overburdened, increased cardiovascular reactivity [9] and mortality [10], compared to non-caregiving controls. For these reasons, caregivers have been described as 'second order patients' [11] and targeted attention to their health needs is becoming a priority for cancer service providers. With an aging population, increasing incidence of cancer, and therefore increasing numbers of family caregivers, the indirect impact on caregivers health while providing care for patients, needs to be considered.

Existing health behaviour research has focused on elderly caregivers in general [12] or caregivers of a family member with functional [13] or cognitive impairment [14]. Results show that compared to matched non-caregivers, these caregiving subgroups are less likely to engage in regular physical activity [13, 14] but no more likely to have worse nutrition [14] smoke, drink excessively or be overweight [12]. However, it is important to recognise that the level of caregiving and opportunity for self-care behaviours is likely to differ depending on the diagnosis, treatment, symptoms and prognosis of the person being cared for, and that it is important to consider the caregiver's health behaviours in relation to specific caregiving roles.

Caregivers of women with ovarian cancer may have a particularly difficult and prolonged support role to play. Most women with ovarian cancer are diagnosed with late stage disease and are typically treated initially with surgery and adjuvant chemotherapy. Approximately 80% of ovarian cancer patients experience disease recurrence [15] and receive multiple lines of chemotherapy over several years, before succumbing to their disease. Given the dearth of information about cancer caregivers health behaviours and the importance of maintaining caregivers' health, we used data from a national ovarian cancer study to document absolute levels of, and changes in, health behaviours (including physical activity, fruit, vegetable and alcohol intake, smoking) and body mass after becoming a caregiver of a family member with ovarian cancer. We also looked at the determinants of negative changes.

Methods

Participants and recruitment

Women with invasive ovarian cancer who participated in a case-control known as the Australian Ovarian Cancer Study (AOCS) [16–18] were invited to participate in a quality of life sub-study (AOCS-QoL) and asked to invite their caregiver into the study. The definition of caregiver was deliberately left for the patient to interpret however, when clarity was sought, a caregiver was described as someone who provided the patient with physical or emotional support. Paid caregivers were excluded. Caregivers were contacted separately and mailed the caregiver version of study documents. Participating patients and caregivers completed QoL questionnaires at 3–6 monthly intervals for a period of 2 years, beginning 3–55 months after diagnosis (median 19 months). The staggered recruitment time after diagnosis enabled comprehensive longitudinal assessment of health-related outcomes covering a large range of the disease trajectory within a shorter research study time frame. A self-report lifestyle questionnaire was mailed along with the caregiver QoL questionnaire in late 2007 and the data presented here pertain to this single time-point. The components of these studies were approved by the Human Research Ethics Committees of The University of Sydney, the Queensland Institute of Medical Research and all participating hospital sites.

Predictor variables measured

Socio-demographics: Age, *education*, and *marital status* were accessed via AOCS for patients and via QoL questionnaires for caregivers. *Relationship to patient* was collected via the QoL questionnaire.

Patient disease treatment and symptom burden: Date of diagnosis and *surgical stage* (FIGO, International Federation of Gynecology and Obstetrics) *at diagnosis* were accessed through AOCS. *Current treatment* was collected via the patient QoL questionnaire. *Symptom burden* was assessed by the 12-item additional concerns subscale of the Functional Assessment of Cancer Therapy—Ovarian (FACT-O) [19].

Caregiver and patient psychological distress impact of cancer, other stress: Both caregiver and patient QoL questionnaires assessed these outcomes. A*nxiety* and *depression* were assessed using the Hospital Anxiety and Depression Scale (HADS) [20]. Two sub-scales distinguish between 'normal' (0–7), 'sub-clinical' (8–10), and 'clinical' (11–21) anxiety and depression. *Impact of ovarian cancer* was estimated by a single item asking 'With respect to ovarian cancer, how many days during the last month were you unable to carry out your usual daily activities fully?'. *Other stressful life events* was assessed by asking 'Do you have any other problems, e.g. medical conditions or other stressful life events, which you feel have affected your answers?'

Primary outcomes measured

Caregiver health behaviour and body mass variables were collected via the lifestyle questionnaire.

Physical activity: The Active Australia Survey [21] was used to classify caregivers as sufficiently active (150 min per week using the sum of walking, moderate activity and vigorous activity (weighted by two)), insufficiently active (1–149 min per week), and sedentary (no physical activity), as per the National Physical Activity Guidelines for Australians [22].

Body Mass Index (BMI, kg/m2): This was derived from self-reported weight and height, and grouped according to guidelines into underweight (BMI<18.5), normal weight (18.5–24.9), overweight (25.0–29.9), and obese (≥30) [23]. Participants were also provided with a tape measure and asked to measure their waist circumference. As per the guidelines, a waist circumference above 80 cm in women or 94 cm in men was classified as overweight and a waist circumference above 88 cm in women or 102 cm in men was classified as obese [23].

Diet: Respondents were asked to report how many servings of fruits or vegetables they usually ate each day [24] and categorised as to whether they met the Australian recommendations of two servings of fruit or five servings of vegetables per day [25].

Smoking: Caregivers were asked if they were currently smoking, had given up smoking and, if so, when, or had smoked less than 100 cigarettes in their life.

Alcohol intake: Alcohol items were first prefaced with a definition of a standard drink of beer, wine, port/sherry and spirits, as per the Australian Guidelines [26]. Caregivers were then asked a) if they drank alcohol in the past 12 months and b) how many standard drinks they usually had on a day when they drank. They were then categorised into whether they met the guideline for reducing the risk of alcohol-related harm over a lifetime (i.e. usually had ≤2 standard drinks per occasion) [26].

Behaviour changes: Caregivers were also asked if their current level of each behaviour/weight was more than, less than, or the same as just before their family member's ovarian cancer diagnosis.

Statistical methods

Caregivers were classified as having at least one negative change over the pre- to post-cancer period if they reported decreasing physical activity or fruit or vegetable intake, increasing their smoking or drinking to above recommended limits, or gaining/losing weight to remain or become outside the healthy BMI range. We used stepwise logistic regression models to determine the characteristics associated with having at least one negative change in behaviour. We grouped predictor variables into three blocks reflecting the biopsychosocial conceptual model: Block 1 caregiver's core demographic characteristics; Block 2 caregiver's personal characteristics at the time of the lifestyle questionnaire and; Block 3 patient's characteristics. Using forward selection, we entered the blocks one by one and, with the exception of age and years of caregiving, excluded non-significant variables from subsequent block entries to limit over-specification of the model. Multicollinearity checks of suspected highly correlated independent variables were performed before modeling. As gender and relationship to patient were multicollinear we ran two separate block 1 models, one with each of these variables.

While conventional p values are reported, due to our small sample size we focused on meaningful group differences, (odds ratios above 1.8 or below 0.56) for evaluating the significance of independent variables worthy of future study. Where final adjusted point estimates did not differ appreciable from unadjusted point estimates we report unadjusted point estimates and their 95% confidence intervals.

Results

Participants

Seven-hundred and 98 (66%) eligible AOCS patients and 373 caregivers (88% of those nominated) participated in the QoL study. One-hundred and 24 caregivers were still participating in the QoL study by the time the lifestyle questionnaire was sent and, of these, 101 completed the lifestyle questionnaire.

Caregivers who completed the lifestyle questionnaire had a mean age of 58 years (range 22–84) and 75% were male, 72% were spouses and approximately half (56%) were college or university educated (Table 1). The patients they were caring for had a mean age of 59 years (range 26–78), were diagnosed on average 3.2 years earlier (range 1.5–6.0) with advanced stage disease (72%) and 21% were

Table 1 Demographic and personal characteristics of caregivers (n=101)

	%
Age, mean (range)	58 (22–84)
Gender	
Male	75
Female	25
Relationship to patient	
Partner	71
Child	21
Sibling	3
Other	5
Marital status	
Never married	5
Defacto/married	92
Separated/divorced	2
Widowed	1
Education level	
High school or less	24
Trade certificate	20
TAFE/college	22
University educated	35
Caring for women aged, mean (range)	59 (26–78)
Years of caregiving, mean (range)	3.2 (1.5–6)
Caring for a woman diagnosed with disease stage (FIGO)	
Early (I-II)	26
Late (III-IV)	67
Unknown	7
Days in the past month caregiving impacted on usual daily activities	
0	78
1–2	7
3–7	7
8–30	5
Any other stressful life events	
Yes	34
No	66
Distress[a]	
Clinical levels of anxiety	20
Clinical levels of depression	6
Clinical levels of anxiety or depression	22
Normal or subclinical levels	78

[a] Distress was measured using the Hospital Anxiety and Depression Scale (HADS) [20]

currently undergoing chemotherapy treatment. At the time of the lifestyle questionnaire, over one-fifth of caregivers (22%) reported being unable to fully carry out their usual daily activities on one or more days over the past month due to their caregiving role and 22% had clinical levels of anxiety and/or depression.

Prevalence of health behaviours, and body mass index

Compared to Australian guidelines, we found that 54% of ovarian cancer caregivers reported not meeting the physical activity recommendation for adults, 40% reported consuming less than adequate servings of fruit, 80% reported consuming less than adequate servings of vegetables and 37% reported usually drinking alcohol above the recommended level (≤2 standard drinks/day) for reduced lifetime risk of alcohol-related harm (Table 2). Furthermore, 71% of caregivers were overweight or obese under the BMI (kg/m^2) classification, 66% had an increased waist circumference and 10% were current smokers. Older caregivers were less likely to participate in sufficient physical activity and more likely to meet vegetable recommendations than younger caregivers (data not shown).

Table 2 Health behaviours and body mass index of 101 caregivers of women diagnosed with ovarian cancer 1.5–6 years earlier

	%
Physical activity	
Sufficiently active [a]	44
Insufficiently active	27
Sedentary	27
Body mass index (kg/m^2)	
Underweight (<18.5)	1
Healthy weight (18.5–24.9)	28
Overweight (25.0–29.9)	49
Obese (≥30)	22
Waist circumference (cm, men/women)	
Healthy (<94 cm/<80 cm)	34
Overweight (94–101 cm/80–87 cm)	43
Obese (≥102 cm/≥88 cm)	23
Fruit intake	
Adequate (≥2 serves/day)	60
Inadequate	40
Vegetable intake	
Adequate (≥5 serves/day)	20
Inadequate	80
Smoking	
Never smoked more than 100 cigarettes	49
Ex-smoker prior to family member's diagnosis	37
Quit smoking after family member's diagnosis	3
Current smoker	10
Alcohol consumption	
Non-drinker	16
1–2 standard drinks usually per occasion	46
>2 standard drinks usually per occasion	37

[a] Exercised for at least 150 min per week (using the sum of walking, moderate activity, and vigorous activity (weighted by two))

Changes in health behaviours, and weight

Forty-two percent of caregivers reported having decreased their physical activity since their family member was diagnosed with cancer and 35% reported gaining weight (Fig. 1), although only 27% of caregivers gained weight to a level that was above the healthy BMI range. Most caregivers (>80%) reported no change in their fruit and vegetable consumption (Fig. 1). Twelve percent reported increasing their alcohol intake (Fig. 1), although only 8% of caregivers increased to above the guidelines of two standard drinks on any day. As 87% of caregivers were non-smokers at the time of their family member's diagnosis, few changes were reported in smoking behaviour. Out of the 13 smokers at diagnosis, one reported increasing their daily cigarette intake.

Overall, 56% of ovarian cancer caregivers reported at least one out of the six negative changes in their heath behaviours or weight. The majority of these had one (32%) or two (16%) negative changes and 8% had greater than two.

Some positive changes were also reported by caregivers (Fig. 1): 14% reported increasing their physical activity, 20% reported losing weight without being underweight, 7% reported increasing their fruit and 13% reported increasing their vegetable consumption, 13% reported decreasing their alcohol intake without ceasing altogether and three out of the 13 smokers reported quitting smoking since their family member was diagnosed with cancer.

Correlates of negative health behaviour or body mass changes

The odds of caregivers reporting at least one negative change after their family member's diagnosis were higher for those caregivers whose education was limited to school compared to further education (OR 3.0, 95%CI 1.1–8.4), those caregivers experiencing clinical levels of anxiety or depression (OR 3.4, 95%CI 1.1–10.1) or those caregivers who were unable to fully carry out their usual daily activities due to caregiving responsibilities (OR 2.0, 95% CI 0.7–5.4) (Table 3). Higher odds of reporting at least one negative change were also observed for caregivers who were caring for a woman whose disease was currently impacting on her ability to fully carry out her usual daily activities (OR 4.3, 95%CI 1.4–13.2). Caregiver's gender and relationship to patient had clinically meaningful adjusted odds ratios with wide confidence intervals crossing 1.0 (Table 3). No other potential predictor variables described in the methods were associated with reporting at least one negative change.

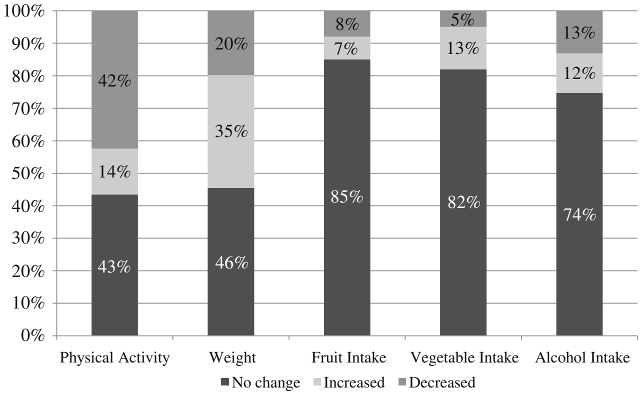

Fig. 1 Ovarian cancer caregivers self-reported changes in health behaviours and weight after their family member was diagnosed with cancer 1.5–6 years earlier

Discussion

Ours is the first study to explore cancer caregivers' health behaviours and changes after a family member's cancer diagnosis. We found that while a proportion of caregivers maintained or improved their health behaviours and/or weight, more than half of caregivers described negative changes after becoming a caregiver. For caregivers whose behaviour improved, there may have been a teachable moment [27] where, along with cancer patients, they were persuaded to adopt healthy lifestyle changes. However, the inability of many ovarian cancer caregivers to sustain healthy habits is likely due to the emotional and physical demands placed on them during inevitable disease recurrences and disruptions to their routine. Our risk-factor analysis supports this theory as it indicated that when caregiving was reported to interfere with usual daily activities it was associated with negative lifestyle and weight changes.

In addition we identified that caregivers from low educational backgrounds, who experienced distress or who cared for a woman whose disease impacted on her usual daily activities, were high-risk groups for deteriorating self-care habits and/or excessive weight gain. Cancer caregivers who fit this profile may benefit from preventative strategies or interventions. A targeted approach directed at these subgroups would facilitate the delivery of limited health care resources [28] as well as avoid the need for publicly funded formal care for cancer patients by maintaining caregivers health [29]. Furthermore, as approximately one-quarter of ovarian cancer caregivers reported adopting more than one negative behaviour change and almost all the caregivers did not meet all Australian health guidelines, individually tailored interventions that have the capacity to target a range of health behaviours, where applicable, may be valuable in this caregiving group.

Table 3 Correlates of caregivers reporting ≥1 negative health behaviour or weight change[a] 1.5–6 years after their family members diagnosis

	n	Unadjusted OR (95% CI)	*p* value	Adjusted OR (95% CI)	*p* value
Block 1 Caregiver's core demographic characteristics					
Age at diagnosis (years)					
<50	29	Referent	0.59	Referent	0.45
50–64	34	0.8 (0.3–2.2)		0.8 (0.2–3.0)	
≥65	36	1.3 (0.5–3.6)		1.7 (0.4–7.0)	
Gender[b]					
Male	74	1.5 (0.6–3.8)	0.35	2.2 (0.6–8.3)	0.26
Female	25	Referent		Referent	
Relationship to patient[b]					
Partner	70	1.6 (0.7–3.7)	0.32	1.8 (0.5–6.2)	0.33
All other	29	Referent		Referent	
Education level					
High school or less	24	3.0 (1.1–8.4)	0.04	2.7 (0.8–8.8)	0.11
Further education	75	Referent		Referent	
Block 2 Caregiver's personal characteristics at the time of the lifestyle questionnaire					
Years of caregiving					
1.5–2.5	28	1.4 (0.5–3.8)	0.49	1.4 (0.4–4.6)	0.39
>2.5–3.5	35	0.7 (0.3–1.8)		0.6 (0.2–1.8)	
>3.5–6.0	36	Referent		Referent	
Distress[c]					
Clinical levels of anxiety or depression	22	3.4 (1.1–10.1)	0.03	3.3 (0.9–12.2)	0.07
Normal or subclinical levels only	77	Referent		Referent	
Caregiving impact on usual daily activities					
Impacted ≥1 day over the past month	22	2.0 (0.7–5.4)	0.18	1.8 (0.5–6.9)	0.38
Not impacted	77	Referent		Referent	
Block 3 Patient's characteristics					
Ovarian cancer impact on usual daily activities at the time of the lifestyle questionnaire					
Impacted ≥1 day over the past month	24	4.3 (1.4–13.2)	0.01	4.9 (1.2–19.6)	0.02
Not impacted	51	Referent		Referent	
Unknown	24	–		–	

Adjusted for all variables presented in this table. Stepwise regression showed no correlation of negative change with caregiver's geographical location, work status or other stressful life events or with patient's disease stage, distress, ovarian cancer symptoms (as measured by the FACT-O ovarian cancer-specific subscale), other stressful life events or current chemotherapy status, when these independent variables were entered within their corresponding block.

[a] Reported decrease in physical activity, fruit or vegetable intake or increase in smoking or increasing drinking when usually drink more than 2 drinks per occasion or gain in weight when above healthy BMI or lose in weight when below healthy BMI

[b] Separate models were fitted for gender and caregiver's relationship to patient as these variables were highly correlated

[c] Distress was measured using the HADS [20]

n participant numbers, *OR* odds ratio, *CI* confidence interval

This was an opportunistic sub-study conducted to explore health behaviours among cancer caregivers. As such there are a number of limitations to acknowledge when considering our results. Our study design restricted recruitment to caregivers who remained in our overarching studies after several years. This meant we had a relatively small sample size and confidence intervals in our regression models are wide. As such emphasis is placed on clinically significant correlates rather than statistical significance. Also, Participants in the lifestyle sub-study tended to be longer-term caregivers and thus our results may not be generalisable to caregiving in the earlier time-phase after diagnosis.

There is also likely to be some recall bias related to asking patients to remember their health behaviours from several years ago and whether these have increased, decreased or stayed the same. While misclassification within these three broad categories is possible, it is unlikely that caregivers would selectively over-report negative changes, which are the main focus of our analyses. Caregivers may have felt pressure to report a healthier lifestyle so might have over-estimated positive behaviours. If this were the case the results reported here would only underestimate the magnitude of the problem.

Furthermore, from these data we were unable to tell if negative changes were directly related to caregiving or just reflective of ageing or other factors that occur within the general population. At face value, the proportion of ovarian cancer caregivers meeting Australian health guidelines for health behaviours and weight appears similar to the general population. The Australian Bureau of Statistics 2007–2008 National Health Survey indicated that 35% of Australian males aged 55–66 years were sedentary, 75% were overweight or obese, 47% ate inadequate serves of fruit, 93% ate inadequate serves of vegetables and 16% smoked [30]. However, the Australian Bureau of Statistics only records cross-sectional prevalences and there is no comparable published data on longitudinal changes in the general population over a similar timeframe. The fact that caregivers' changes occurred to a greater extent in subgroups with elevated emotional and physical demands suggests that it is less likely to be a simple consequence of aging. Our age-stratified analyses confirmed cross-sectional general population study findings [30] that older generations are less likely to participate in physical activity yet our multivariable modelling indicated that caregivers age was not associated with negative lifestyle changes over time. While it is probable that irrespective of the caregiving role some negative changes would have occurred, further research is needed to determine the proportion of behaviour change attributable directly to caring for a women with ovarian cancer.

Despite these limitations, findings from this current study suggest that more attention should be given to the health of cancer caregivers and that they may benefit from health promotion programs aimed at adopting and maintaining healthy lifestyles. Future studies are needed to document prospective levels and reasons for changes in cancer caregivers health behaviours after their family member's diagnosis. If a program is required it may be economical to targeted high-risk groups and tailor the intervention to address each individual's range of unhealthy behaviours.

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Conflict of interest statement The authors declare that there are no conflicts of interest.

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