



Caring for women with ovarian cancer in the last year of life: A longitudinal study of caregiver quality of life, distress and unmet needs [☆]



Phyllis N. Butow ^{a,b,*}, Melanie A. Price ^{a,b}, Melanie L. Bell ^b, Penelope M. Webb ^c, Anna deFazio ^d,
The Australian Ovarian Cancer Study Group ^{c,d,e},
The Australian Ovarian Cancer Study Quality of Life Study Investigators ^{a,b,c}, Michael Friedlander ^{f,g}

^a Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), School of Psychology, The University of Sydney, Sydney, Australia

^b Psycho-oncology Co-operative Research Group (PoCoG), The University of Sydney, Australia

^c QIMR Berghofer Institute of Medical Research, Gynaecological Cancers Group, Brisbane, Australia

^d Department of Gynaecological Oncology, Westmead Hospital and Westmead Institute for Cancer Research, The University of Sydney at Westmead Millennium Institute, Westmead, Australia

^e Peter MacCallum Cancer Centre, Melbourne, Australia

^f Australia New Zealand Gynaecological Oncology Group (ANZGOG), NHMRC Clinical Trials Centre, The University of Sydney, Camperdown, Australia

^g Department of Medical Oncology, Prince of Wales Hospital, Randwick, Australia

HIGHLIGHTS

- In the last year of life, ovarian cancer caregivers have higher distress and lower QOL than age-matched norms.
- Cancer services need to address caregiver, as well as patient, needs.

ARTICLE INFO

Article history:

Received 27 November 2013

Accepted 5 January 2014

Available online 11 January 2014

Keywords:

Caregivers
Ovarian cancer
End of life
Quality of life
Unmet needs
Prospective

ABSTRACT

Purpose. Caregiver burden, quality of life (QOL) and unmet needs are poorly understood, particularly at the end of life. We explored these issues in caregivers of women with ovarian cancer.

Patients and methods. The Australian Ovarian Cancer Study (AOCS) is a prospective population-based study of women newly diagnosed with primary epithelial ovarian cancer. Ninety-nine caregivers of women participating in the AOCS QOL sub-study (88% response rate) rated their QOL (SF-12), psychological distress (HADS), optimism (LOT), social support (Duke) and unmet needs (SCNS-carers), and patients rated their QOL (FACT-O), every three months for two years. This analysis included measurements in the patient's last year of life.

Results. Caregivers had significantly lower mental and physical QOL than population norms ($p < 0.01$). Mean distress ($p = 0.01$) and unmet needs increased over time, however social support remained constant. In linear mixed models, (using scores for each psychosocial variable over time), optimism ($p < 0.0001$), social support ($p < 0.0001$), higher unmet needs ($p = 0.008$), physical wellbeing ($p < 0.0001$), and time to death ($p < 0.0001$) but not patient QOL, predicted caregiver mental well-being and distress. Highest unmet needs in the last 6 months related to managing emotions about prognosis, fear of cancer spread, balancing one's own and the patient's needs, impact of caring on work and making decisions in the context of uncertainty.

Conclusions. Aspects of caregiver functioning, rather than patient quality of life, predict caregiver quality of life and distress. Caregivers need help with managing emotions about prognosis, balancing their own and the patient's needs, work, and decision-making when there is uncertainty.

© 2014 Elsevier Inc. All rights reserved.

[☆] Funding: This study was funded by the Cancer Council New South Wales and the Queensland Cancer Fund (RG 36/05). Financial support for the parent study was provided by the U.S. Army Medical Research and Materiel Command under DAMD17-01-1-0729, the National Health and Medical Research Council of Australia (400413 and 400281) and the Cancer Councils of New South Wales, Queensland, South Australia, Tasmania and Victoria and the Cancer Foundation of Western Australia. Additional recruitment was conducted under the Australian Cancer Study (Ovarian Cancer), funded by the National Health and Medical Research Council of Australia (199600). P Butow is supported by the National Health and Medical Research Council of Australia Principal Research Fellowship (211199, 457093). PW is supported by a Senior Research Fellowship from the National Health and Medical Research Council of Australia.

* Corresponding author at: Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), School of Psychology, Transient Building (F12) The University of Sydney, Sydney, 2006 Australia. Fax: +61 2 90365292.

E-mail address: phyllis.butow@sydney.edu.au (P.N. Butow).

Introduction

Ovarian cancer places a particularly significant burden on patients and their family members, due to its high mortality rate and complex, prolonged, multimodal treatments [1]. It is a disease characterised by multiple recurrences and many lines of chemotherapy, with decreasing duration of benefit over time.

Family members are often called upon to provide emotional and practical support, and physical care [1]. Caregivers often feel unprepared for this role [1], and can also experience financial stress if unable to maintain income-generating activity, existential distress and anxiety related to future uncertainty [1]. Studies have documented higher levels of distress and poorer quality of life in caregivers compared to controls, and significant needs for informational, practical and emotional support [2]. Further, poorer physical health due to the strain of caregiving can increase caregivers' own risk of mortality [3,4].

Predictors of high caregiver distress include other life stresses [5], poorer social support [6], lower social economic status and younger age [7,8], lower carer optimism [9] and a closer caregiver–patient relationship [8]. Caregiver distress also increases with greater patient physical impairment and need for palliative care [10]. Thus supporting carers during the final months of illness is particularly important. Despite this, little research has focused on caregiver experiences at this time, with very few studies specifically focused on caregivers of women with ovarian cancer. Caregivers of women with ovarian cancer may have unique concerns, give that they are primarily male (husbands), and given the complex, repeated treatment regimens and high symptom burden in the last year of life in ovarian cancer.

Only two quantitative studies have explored caregiver QOL in ovarian cancer. One cross-sectional study found significantly higher anxiety and depression in 373 caregivers compared to controls [11]. Another study [12] of 30 caregivers found their QOL improved on completion of chemotherapy, regardless of the patient's tumour response. Caregiver QOL was correlated with patient worry, distress and functioning. Neither of these studies focused specifically on issues for caregivers at the end of life.

Therefore the aims of this longitudinal study were, in the patient's last year of life, to:

- 1.) Describe the QOL of caregivers of women with ovarian cancer
- 2.) Describe the most frequent and severe unmet needs in caregivers
- 3.) Identify caregiver and patient predictors of caregiver quality of life

Methods

Participants and procedures

Participants included in this analysis were women taking part in the Australian Ovarian Cancer Study QOL study (AOCS-QOL) and their nominated primary support person (caregiver). AOCS is a prospective population-based study that recruited women aged 18–79 years newly diagnosed with primary epithelial ovarian cancer (including fallopian tube and primary peritoneal cancers) between 2002 and 2006 [13]. Women were recruited through major treatment centres and state-based cancer registries. The AOCS has collected detailed epidemiological, pathology and initial treatment data, as well as ongoing treatment and clinical outcome data [13].

The AOCS-QOL study investigated the role of psychosocial factors in predicting patient and caregiver outcomes, recruiting AOCS participants who were alive in May 2005 or recruited to AOCS after this date [14]. Initial contact was made by AOCS to preserve confidentiality. Consenting women were mailed an information statement, consent form, questionnaire booklet and a reply paid envelope, and a request to invite their primary caregiver (over the age of 18) to also participate in the study. Women were 3–55 months post-diagnosis (mean 25.8 months) at study entry [13,14].

Measures of quality of life, psychological distress, optimism, social support, and unmet needs were collected by validated measures from both patients and caregivers at three-monthly intervals for up to two years. If more than one item on any questionnaire was missing, the participant was contacted; missing psychosocial data are therefore minimal.

The current analyses include 99 caregivers who completed at least one assessment within the last year of life of the woman for whom they were caring. The study was approved and conducted in accordance with the ethical standards of The University of Sydney, Queensland Institute of Medical Research Human Research Ethics Committees and all participating sites across Australia.

Measures

Primary outcome variable

The primary outcome variable is caregiver QOL, measured using the 12-item Short Form – version 2 (SF-12v2) of the Health Survey [15]. The SF-12v2 is the most widely used health related QOL measure in the general population and consists of two components, physical health (PCS) and mental health (MCS). Higher scores indicate better QOL. Australian population norms for the SF-12v2 were obtained from the Australian Bureau of Statistics, collected in 1997.

Demographic and treatment variables

Carer age, gender, education, marital status, occupational status and relationship to the patient were self-reported via questionnaire. Place of residence (major city or regional/remote) was determined from residential postcodes. Date of patient's cancer diagnosis was obtained through the AOCS. Current treatment data (on chemotherapy/radiotherapy or not) was self-reported with each patient questionnaire.

Carer psychosocial variables

Hospital anxiety and depression scale (HADS) [16]. The 14-item HADS measures anxiety (7 items) and depression (7 items). Total scores (combining sub-scales) measure distress. Higher scores indicate greater morbidity.

Duke-UNC functional social support questionnaire [17]. This 8-item scale, developed for use in general practice settings, measures satisfaction with the functional and affective aspects of social support. Higher scores indicate better social support.

Life orientation test-revised (LOT-R) [18]. This 10-item scale measures dispositional optimism; higher scores indicate greater optimism.

Supportive care needs survey (SCNS)-carers version [19]. This 44 item questionnaire was adapted from a measure developed for caregivers of cancer survivors. Respondents indicate on a 5-point scale whether they have a need, and if so, how strong that need is. Higher scores indicate greater need.

Patient quality of life

Functional Assessment of Cancer Therapy-Ovarian scale (FACT-O version 4) [20]. This ovarian cancer-specific QOL instrument assesses the four core QOL domains of physical (7 items), social (7 items), emotional (6 items) and functional wellbeing (7 items), together with 11 additional items assessing disease and treatment issues specific to ovarian cancer (symptom burden). Higher scores indicate better QOL.

Statistical methods

Patient and caregiver data were merged by patient ID and by matching caregiver assessment date to the closest patient assessment date within 1 month. Months to patient death were calculated as the date of death minus the patient's assessment date, rounded to the nearest month.

Download English Version:

<https://daneshyari.com/en/article/6182829>

Download Persian Version:

<https://daneshyari.com/article/6182829>

[Daneshyari.com](https://daneshyari.com)