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Full title: Changes in supportive care needs after first-line treatment for ovarian cancer: identifying care priorities and risk factors for future unmet needs.

Short title: Supportive care needs after first-line treatment for ovarian cancer

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Abstract

Objective: To determine changes in supportive care needs after first-line treatment for ovarian cancer and identify risk factors for future unmet needs.

Methods: 219 women with ovarian cancer were asked to complete a baseline survey 6-12 months after diagnosis then follow-up surveys every 6 months for up to 2 years. The validated SCNS-SF34 measured 34 needs across 5 domains. Logistic regression identified baseline variables associated with future needs.

Results: At baseline, standardized median scores (possible range 0-100, least-to-greatest need) within the psychological, system/information, physical, patient care and sexuality need domains were 25, 20, 15, 15 and 8, respectively. The most frequently reported moderate-to-high unmet needs at baseline were needing help with fear about cancer spreading (25%), concerns about worries of those close (20%), being informed about things to help get well (20%), uncertainty about future (19%) and lack of energy (18%). All except the item about being informed were still reported as unmet needs by $\geq 15\%$ of women 2 years later. Median health system/information, patient care and sexuality need scores decreased over 2 years ($p < 0.05$), whereas psychological and physical scores remained constant. Risk factors for having ≥ 1 moderate-to-high unmet overall, psychological or physical need 1-2 years after baseline included older age, advanced disease, unmet need, anxiety, depression, insomnia and less social support at baseline.

Conclusion: Women with ovarian cancer report needing ongoing assistance to deal with psychological and physical needs over the first 2 years after first-line treatment. Targeting individuals at risk of future unmet needs should be prioritized.

Key words: ovarian cancer, oncology, needs assessment, supportive care, risk factors

Introduction

Most women with ovarian cancer have advanced disease at diagnosis [1]. They are typically treated with surgery and six three-weekly cycles of adjuvant chemotherapy. While most women initially respond to treatment, 80% experience disease recurrence and go on to have multiple courses of chemotherapy over several years, before succumbing to their disease [1]. Survival is an important objective of treatment but, in the context of advanced disease and the debilitating side-effects of ongoing treatment, maximising quality of life is also a priority issue. Comprehensive care involves not only curative efforts, but also attention to a whole range of patient needs [2]. It is through meeting these needs that we can improve overall quality of life [3].

Needs assessment tools explicitly assess the stated desire for some action or resource that will help the patient attain optimal well-being [4]. Such tools directly measure the gap between a person's experience of a service and the actual service required [5], highlighting deficiencies in service delivery. Little information is available about the specific needs of women with ovarian cancer. The only **published** study to date, a cross-sectional single clinic sample of 50 women, reported that the most frequently reported needs were psychosocial, such as fear about the cancer returning or spreading [6]. While other studies include women with ovarian cancer among heterogeneous gynecological samples, these have been cross-sectional, mainly longer-term survivors [7-9] and/or convenience samples [9, 10] and do not separately report on women with ovarian cancer. The needs of women with ovarian cancer are likely to differ from those of other gynecological cancer subgroups, due to their predominantly late stage diagnosis and ongoing courses of chemotherapy.

Some support needs are also likely to change over time. Studies of women with ovarian cancer have shown that compared to women undergoing first-line chemotherapy, those post-treatment have significantly higher physical and functional wellbeing [11], lower depression and better quality of life [12]. After initial treatment-associated clinical care, some needs may be resolved, or addressed by family, friends or community organisations, while others may remain unmet [13]. Only one longitudinal study has **been published that** assessed unmet needs of

cancer patients beyond the end of primary treatment. In this study, 30% of a mixed cancer group (including breast, prostate, colorectal, and gynecological cancer and non-Hodgkin's lymphoma survivors) who were treated with curative intent reported more than five unmet needs at the end of treatment, and for 60% of these participants the situation did not improve by the 6 month post-treatment follow-up assessment [14].

To date, younger age [5, 14-18], not living with a partner [7], living in rural areas [7, 16], later stage disease [7, 8, 15], more extensive surgery [7], ever receiving chemotherapy [7, 16], radiotherapy [16], or hormone treatment [14, 18], less time since diagnosis/treatment [5, 17-19], less social support [18], anxiety [8, 14], depression [8, 14, 18], insomnia [20] and lower physical or mental quality of life [8, 21] have been associated with greater levels of unmet need among cancer patients. However, these mostly cross-sectional studies cannot identify determinants of future unmet needs. The two studies that have reported on risk factors for future unmet needs are unlikely to apply to women with ovarian cancer as they have included heterogeneous samples of cancer patients who were either treated with curative intent [14] or were 1 to 1057 weeks after diagnosis at baseline and excluded patients if they commenced additional treatment [18].

Our aim was to assess the prevalence of, and changes in, unmet supportive care needs after first-line treatment among women diagnosed with ovarian cancer and to identify factors at the end of first-line treatment that predict future unmet needs.

Methods

The study was a longitudinal population-based mail survey with five repeated measures of unmet supportive care needs. Ethics approval for the study was obtained from The University of Sydney and Queensland Institute of Medical Research Human Research Ethics Committees and all participating sites across Australia.

Participants and procedures

The flow of participant recruitment is outlined in Figure 1. Australian women with

invasive ovarian cancer diagnosed between 2002 and 2006 participating in the population-based case-control Australian Ovarian Cancer Study (AOCS) [22, 23] were invited to participate in a quality of life sub-study (AOCS-QoL). Women alive in May 2005 and women who joined AOCS after this date were contacted by letter. Consenting women were mailed identical 'quality of life' questionnaires at 6-monthly intervals for a period of 2 years [12, 20]. Thus there were five assessment points: Time 1 (baseline); Time 2 = 6 month follow-up; Time 3 = 12 month follow-up; Time 4 = 18 month follow-up; Time 5 = 24 month follow-up.

The current analysis includes women who completed the baseline AOCS-QoL questionnaire within 6-12 months after their cancer diagnosis, a point that approximated the end of first-line treatment, and who **remained active in the study for at least 12 months (n=185)**. The follow-up time period of ≥ 12 and ≤ 24 months was selected as the focus of this analysis as it reflects medium-term survival, where initial unmet supportive care needs may become satisfied by available support or become non-existent due to recovery from or adjustment to cancer. It is also the time when ovarian cancer recurrence and further chemotherapy are most likely to occur.

Outcome measure

The Supportive Care Needs Survey-Short Form (SCNS-SF34) was used to assess unmet needs across five domains: psychological (10 items); physical and daily living (5 items); health system and information (11 items); patient care and support (5 items); and sexuality (3 items). This tool asks participants to rate their need for help with each item over the past month on a 5-point scale where 1 = not applicable (no need), 2 = satisfied (need was met), 3 = low unmet need, 4 = moderate unmet need, and 5 = high unmet need. Summated Likert scale scores are standardized (range 0 to 100) to allow comparison across need domains [24]. The SCNS-SF34 is a validated measure of unmet needs within the cancer population. Its five domains collectively accounted for 73% of the variance, with Cronbach's alpha for individual domains ranging from 0.86 to 0.96 [24]. Individual needs items can be dichotomized into no need, need met, low unmet need (1-3) versus moderate-to-high unmet need (4-5) to assess the proportion of patients reporting individual unmet needs.

Potential risk factor variables measured

Demographics:

Age, marital status and education level were self-reported at recruitment for AOCS. Each participant's postcode, accessed through AOCS records, was used to classify her as residing in a major city, or an inner regional, outer regional, remote or very remote area using the Accessibility/Remoteness Index of Australia [25].

Disease and cancer symptom burden:

- i) Disease stage (FIGO - International Federation of Gynecology and Obstetrics) at diagnosis was extracted from medical records as part of the AOCS.
- ii) Ovarian cancer symptom burden was assessed using the 12-item additional concerns subscale of the Functional Assessment of Cancer Therapy–Ovarian (FACT-O) [26]. Scores range between 0-44, with higher scores indicating lower symptom burden.
- iii) Participants also self-reported whether they were receiving chemotherapy at the time of each survey.

Psychological distress and insomnia:

- i) Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS) [27]. Two sub-scales distinguish between 'normal' (0–7), 'sub-clinical' (8–10), and 'clinical' (11–21) anxiety and depression.
- ii) Insomnia was measured using the 7-item Insomnia Severity Index (ISI) [28]. Scores are classified as 'normal' (0-7), 'sub-clinical' (8-14), and 'clinical' (15-28) insomnia [20].

Social support and use of support services/mental health treatment:

- i) Social support was assessed using the Duke University of North Carolina Functional Social Support Questionnaire [29]. Higher scores indicate greater support.
- ii) Patients were asked if they had had any treatment for mental health problems (seen a psychologist or psychiatrist, had medication, counseling/cognitive behavioral therapy) and if they had seen or attended any additional support services (social worker, other health professionals, support groups, education programs,

relaxation/meditation) in the past 3 months. Responses were recoded as “yes” or “no/don’t know.”

Statistical analysis

Analyses were conducted to compare representativeness of baseline characteristics and needs of women with and without follow-up data at 12 months. These included t-test for normally distributed continuous variables, chi-square test for categorical variables and Wilcoxon-Mann-Whitney test for not normally distributed continuous variables.

Since 13 to 59% of women (depending on domain) had standardised need score of 0 at follow-up, these variables were not normally distributed or transformable. Hence standardized medians were used to compare the level of need (possible range 0-100) in each domain at each time point. We explored change over time by comparing baseline to each follow-up point using Wilcoxon signed ranks test. Fifteen women (8%) had missing data at 1 or 2 of the 3 follow-up time-points analysed but remained active in the study (n=8 at 12 months, n=6 at 18 months and n=6 at 24 months). Missing scores for these women were imputed as the average of their scores before and after the missing time-point(s).

To identify priority need items, the point prevalence of individual items with moderate-to-high levels of unmet needs was calculated.

To identify baseline risk factors associated with reporting at least one moderate or high unmet need at any time within the 12-24 month follow-up period, we used backwards stepwise logistic regression. Parametric models of continuous outcomes were not appropriate as not normally distributed data caused heteroscedastic residuals. We considered any report of need during a single follow-up period to avoid multiple analyses and thus the potential of type I error. Initial logistic regression models included all potential baseline risk factors and were adjusted for whether the woman was on chemotherapy at follow-up. Then, similarly to others [7], variables that were not statistically (p-value <0.05) or contextually significant were removed, where contextual significance was pre-specified as an odds ratio ≥ 2 or ≤ 0.5 or, for ordinal variables, a monotonic relationship with the outcome. This process was

repeated until only statistically or contextually significant variables remained. Then, for the final models, ordinal variables with a monotonic relationship to the outcome were fitted as continuous variables and adjacent levels of categorical variables were collapsed when the effects were similar. All models were adjusted for baseline needs in that domain.

Results

Participants

Of the 798 women who participated in the AOCS-QoL study, 219 were recruited within 6-12 months after diagnosis (Figure 1). Eighty-four percent (n=185) of these women remained active in the study at the 12 month follow-up and contributed to the current analysis. Death was the primary reason for women dropping out (Figure 1).

On average, women in our analysis were 59 years of age at diagnosis (SD = 10), most (76%) were married or living with their partner, over half (57%) had completed further education after high school, and lived in a major city (61%) and three-quarters (76%) were diagnosed with late stage disease (Table 1). The demographic characteristics of the 34 women who died or withdrew before the 12 month follow-up, and thus were not included in the analysis, were similar to those who were included, with the exception that they were more likely to have had higher baseline physical needs ($p<0.01$) (Table 1).

Needs within the five domains over time

At baseline, the standardized median scores (possible range 0 to 100) within the psychological, system/information, physical and patient care need domains were 25, 20, 15 and 15, respectively (Figure 2). Sexuality needs were less common (median score = 8). Over the two year follow-up period, median psychological and physical need scores remained fairly constant, whereas median scores in the other domains decreased over time (Figure 2). On average, sexuality and patient care needs were either non-existent or completely met by 12 months and 24 months after baseline, respectively ($p<0.001$, $p=0.011$ for change over time, respectively). The level of system/information needs decreased to a median score of 11 by 24 months after baseline ($p<0.001$).

At baseline, 59% of women reported having at least one moderate or high unmet supportive care need (median 2, range 0-26). Two-thirds (65%) reported at least one unmet need at the 12, 18 or 24 month follow-up (median 2, range 0-33). Depending on the domain, 25%-60% of women who reported needs at the 12, 18 or 24 month follow-up had not reported them at baseline.

Priority unmet need items

Items reported with moderate-to-high levels of unmet need by 15% or more women at baseline are presented in Table 2. With the exception of 'lack of energy/tiredness' which belongs to the physical domain, the top unmet need items all came from within the psychological and system/information domains. The trajectories of individual items over time were similar to their corresponding domain scores. Items that were still reported as moderate-to-high unmet needs by at least 15% of women two years after baseline were: fear about their cancer spreading, concerns about the worries of those close, uncertainty about the future, lack of energy/tiredness, anxiety and worry that results of treatment are beyond their control.

Baseline risk factors for having at least one moderate-to-high unmet need within the 12-24 month follow-up period

Statistically and/or contextually significant risk factors at baseline for having at least one moderate-to-high unmet need within the 12-24 month follow-up period, overall and in each supportive care need domain, are presented in Table 3. Overall, the risk factors were reporting any unmet need at baseline, being diagnosed with late stage disease, anxiety, insomnia and having a lower level of social support. As psychological and physical needs were the highest and remain constant over time, risk factors for these specific domains are also of importance. Risk factors for psychological needs were having an unmet psychological need at baseline, late stage disease, insomnia and having a lower level of social support. Risk factors for physical needs were having an unmet physical need at baseline, older age, late stage disease, depression and insomnia.

Discussion

Our study is the first to consider the level of supportive care needs of cancer patients at more than two time points. Importantly, we discovered that women with ovarian cancer report consistent levels of psychological and physical needs and declining levels of system/information, patient care and sexuality needs over the two year period after first-line treatment. The persistence of psychological and physical needs may be due to women experiencing one or more disease recurrences and receiving follow-up chemotherapy [1], which can amplify physical and psychosocial issues [30]. This is confirmed in our sample with women who were on chemotherapy having higher odds of unmet needs.

Our study also indicates that a substantial proportion of women with ovarian cancer report having unmet needs; 3 out of 5 women reported having moderate-to-high unmet needs at the end of first-line treatment and 2 out of 3 reported having moderate-to-high unmet needs 1 to 2 years later. Consistent with Armes et al's study [14], scores at the end of first-line treatment were highest for the psychological and system/information need domains. Further, our study suggests that women with ovarian cancer appear to have higher levels of supportive care needs than women with other types of gynecological cancer (standardized median scores 0-25 vs 0-8 [7]). This disparity is likely due to more women with ovarian cancer being diagnosed with late stage disease.

In particular, we found that many women with ovarian cancer reported needing more psychological support to help them manage their worries about the cancer spreading, their family's worries, and their future. They also frequently reported an ongoing need for help with their lack of energy. These care priorities are consistent with those identified in cross-sectional studies [5, 7, 15], and in the first prospective study that followed patients for 6 months after first-line treatment [14].

Like most other studies we found the risk factors for unmet supportive care needs varied across need domains, demonstrating the distinct nature of these constructs. However, we identified that current unmet needs, late stage disease, anxiety, insomnia and minimal social support at the end of first-line treatment could be used

as a set of screening variables to identify women with ovarian cancer who are likely to have unmet needs in the future. In addition, we showed that older age and depression at the end of first-line treatment are also important risk factors for future unmet physical needs.

Screening, assessment and management of patients with cancer who experience emotional and/or social deficits is currently recommended in guidelines to ensure patients have the ability to cope [31]. Prospective evidence of the link between patient characteristics and future unmet needs is important, not just for supporting guidelines for targeted management of individuals experiencing anxiety, depression or a lack of social support, but also for the potential resource- and cost-saving effect on health care provisions.

This study suggests a broader range of variables could be incorporated in screening. Identifying older women and those with late stage disease makes sense as they may have reduced physical capabilities, making the demands of daily living and their ability to cope in the context of advancing disease a more pertinent concern. The relationship of insomnia to unmet needs is a new and noteworthy finding as it remained significant after adjustment for anxiety, depression and symptom burden, issues it is known to be associated with [32]. Poor sleep is reported to affect daytime functioning via a clustering of symptoms including decreased mood and cognitive abilities (concentration, memory, attention), elevated anxiety, fatigue and physical pain/discomfort [32]. Thus it is not surprising that individuals suffering from a chronic sleep problem have, as we identified, ongoing needs for help with psychological, physical and patient care needs. With almost half (44%) of women with ovarian cancer reporting insomnia [20], screening for and addressing this risk factor has the potential to make a huge impact on reducing future needs.

This was an Australia-wide population-based study that used a valid and reliable unmet needs assessment tool. It was the first study to track changes over time specifically in an ovarian cancer population. However, due to the nesting of this study within a larger study, the baseline survey was completed over a wide interval (6-12 months after diagnosis). Our results represent the average experience of a group of women, some of whom may have adjusted to their diagnosis while others

may have experienced a recurrence. The nature of ovarian cancer is reflected in many of our participants experiencing disease progression and some dying during the course of the study. Another 15% of participants missed some assessments but remained active in the study. For these women, we imputed an average of their scores before and after the missing time-point(s). Our results therefore assume the individuals' trend over time. As needs decrease or remain constant this imputation may under represent needs at follow-up points. To more accurately measure changes in needs over time we limited the sample to women who **remained active in the study** 1 year after baseline. This also allowed for complete outcome data when modelling risk factors for unmet needs reported 1 to 2 years after baseline. The women who died or withdrew before the 1 year follow-up were more likely to have higher baseline **physical** needs. Our results are therefore likely to under represent the level of unmet **physical** needs as patients get sicker. While our sample characteristics are representative of Australian women with ovarian cancer [33], we had a limited sample size for multivariable modelling. Like others we used backwards stepwise logistic regression to limit over-specification of the final models [14] and considered the point estimates, not just p-values, to ensure that potentially important factors were not missed [7].

In conclusion, our results suggest that health professionals and service providers should consider how to improve their care of psychological concerns and reduce fatigue in women with ovarian cancer beyond the end of primary treatment. Development of individualized care plans based on risk assessment for future needs and patient choice could be implemented at the end of first-line treatment. Future research is however required to identify the optimal tools for this and to test their implementation and cost-effectiveness in a clinical setting. Importantly, our supportive care needs study is one of the first with a longitudinal design and a focused sample of women with ovarian cancer. It provides evidence of what factors are likely to predict the risk of experiencing unresolved needs in this group who mostly experience advanced disease.

Conflict of interest statement

The authors declare that there are no conflicts of interest.

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Table 1. Demographic and clinical characteristics and supportive care needs of participants at baseline (6-12 months after diagnosis)

	Completed ≥12 month follow-up assessment and were included in these analyses (n=185)	Did not complete ≥12 month follow-up assessment and were not included in these analyses (n=34)	Difference between women with and without follow-up data at 12 months p-value ^a
Age (years), mean (SD)	59 (10)	60 (10)	0.55
Marital status			
Current partner	76%	74%	0.98
Separated/divorced	18%	19%	
Never married/partner	7%	6%	
Education level			
High school or less	43%	45%	0.94
TAFE/college	39%	39%	
University educated	17%	15%	
Remoteness Areas Classification			
Major city	61%	71%	0.29
Inner regional	26%	29%	
Outer regional	10%	0%	
Remote/very remote	3%	0%	
Disease stage (FIGO) at diagnosis			
Early (I-II)	24%	15%	0.27
Late (III-IV)	76%	85%	
Psychological needs ^b	25	33	0.46
Physical needs ^b	15	35	<0.01
System/information needs ^b	20	25	0.48
Patient care needs ^b	15	25	0.11
Sexuality needs ^b	8	8	0.99

^a Values based on t-test for means, chi-square test for categorical variables and Wilcoxon-Mann-Whitney test for medians

^b Standardized median score (possible range from 0-100)

Table 2. Supportive Care Needs Survey items with a moderate or high unmet need reported by 15% or more women at baseline (6-12 months after diagnosis) and their trajectory over time.

Rank	Item	Baseline	Follow-up		Domain
		0 months	12 months	24 months	
1	Fear about the cancer spreading	25%	16%	21%	Psychological
2	Concerns about the worries of those close to you	20%	16%	18%	Psychological
3	Being informed about things you can do to help yourself get well	20%	11%	6%	System/Information
4	Uncertainty about the future	19%	16%	19%	Psychological
5	Lack of energy/tiredness	18%	15%	15%	Physical
6	Anxiety	17%	11%	15%	Psychological
7	Worry that results of treatment are beyond your control	16%	13%	18%	Psychological
8	Being informed about cancer that is under control or diminishing	16%	10%	5%	System/Information
9	Having one member of staff with whom you can talk about all aspects of your condition, treatment, and follow-up	16%	7%	4%	System/Information
10	Being informed about your test results as soon as feasible	16%	9%	3%	System/Information
11	Keeping a positive outlook	15%	8%	10%	Psychological
12	Feelings of sadness	15%	7%	12%	Psychological
13	Being treated like a person not just another case	15%	3%	4%	System/Information

Note: ranking based on baseline then subsequent time-points

Table 3. Statistically and/or contextually^a significant risk factors for moderate/high unmet needs at 12-24 months after baseline (T1)^b (n=169^c)

	Odds ratio (95% confidence interval)	p-value
Overall needs		
T1 any need: moderate/high vs no/met/low need	2.9 (1.2, 6.6)	0.01
FIGO stage at diagnosis: III-IV vs I-II	2.5 (0.9, 6.4)	0.07
On chemotherapy during any follow-up: yes vs no	6.1 (2.4, 15.5)	<0.01
T1 anxiety: sub-clinical/clinical vs normal	2.9 (1.0, 8.3)	0.04
T1 insomnia: sub-clinical/clinical vs normal	2.1 (0.9, 4.9)	0.10
T1 social support: per unit change	0.91 (0.84,0.98)	0.02
Psychological needs		
T1 psychological need: moderate/high vs no/met/low need	4.7 (2.2, 10.0)	<0.01
FIGO stage at diagnosis: III-IV vs I-II	2.9 (1.2, 6.9)	0.02
T1 insomnia: sub-clinical/clinical vs normal	2.0 (1.0, 4.1)	0.07
T1 social support: per unit change	0.92 (0.86, 0.98)	0.01
Physical needs		
T1 physical need: moderate/high vs no/met/low need	2.4 (1.0, 5.7)	0.04
Age, years: per unit change	1.03 (0.99, 1.07)	0.13
FIGO stage at diagnosis: III-IV vs I-II	2.2 (0.8, 6.4)	0.14
On chemotherapy during any follow-up: yes vs no	4.7 (2.1, 10.4)	<0.01
T1 depression: sub-clinical/clinical vs normal	3.5 (1.1, 11.4)	0.04
T1 insomnia: sub-clinical/clinical vs normal	2.9 (1.4, 6.4)	0.01
System/information needs		
T1 system/information need: moderate/high vs no/met/low need	4.1 (1.8, 9.1)	<0.01
Marital status: current partner vs no partner	2.3 (0.8, 6.0)	0.11
Education: further education vs high school or less	2.2 (0.9, 5.1)	0.07
FIGO stage at diagnosis: III-IV vs I-II	2.6 (0.8, 8.0)	0.10
T1 cancer symptoms burden: top third vs rest	2.4 (1.0, 5.8)	0.05
On chemotherapy during any follow-up: yes vs no	2.8 (1.2, 6.5)	0.02
T1 social support: per unit change	0.92 (0.86, 0.99)	0.02
Patient care needs		
T1 patient care need: moderate/high vs no/met/low need	4.5 (1.6, 12.3)	<0.01
T1 cancer symptoms burden: top third vs rest	2.1 (0.8, 5.6)	0.13
T1 insomnia: sub-clinical/clinical vs normal	2.0 (0.8, 5.5)	0.16
T1 social support: per unit change	0.94 (0.88, 1.01)	0.07
Sexuality needs		
T1 sexuality need: moderate/high vs no/met/low need	5.4 (1.8, 16.4)	<0.01
T1 anxiety: sub-clinical/clinical vs normal	3.2 (1.1, 9.0)	0.03
T1 social support: per unit change	0.95 (0.88, 1.02)	0.17
T1 support service use/mental health treatment: yes vs no	3.3 (1.2, 9.1)	0.03

^a Contextually significant = odds ratio ≥ 2 or ≤ 0.5 or, for ordinal variables, a monotonic relationship with the outcome.

^b Baseline/T1 = 6-12 months after diagnosis

^c 16 participants with missing values across covariates

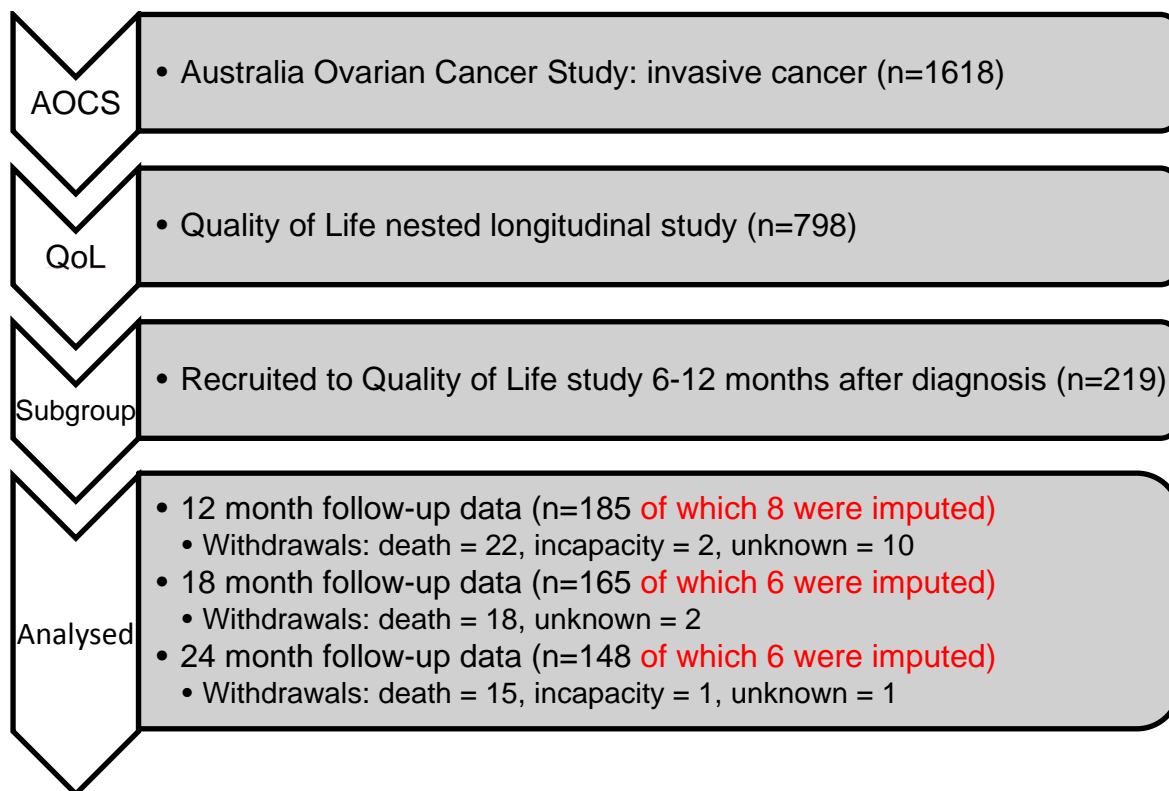


Figure 1 Flow of participant recruitment

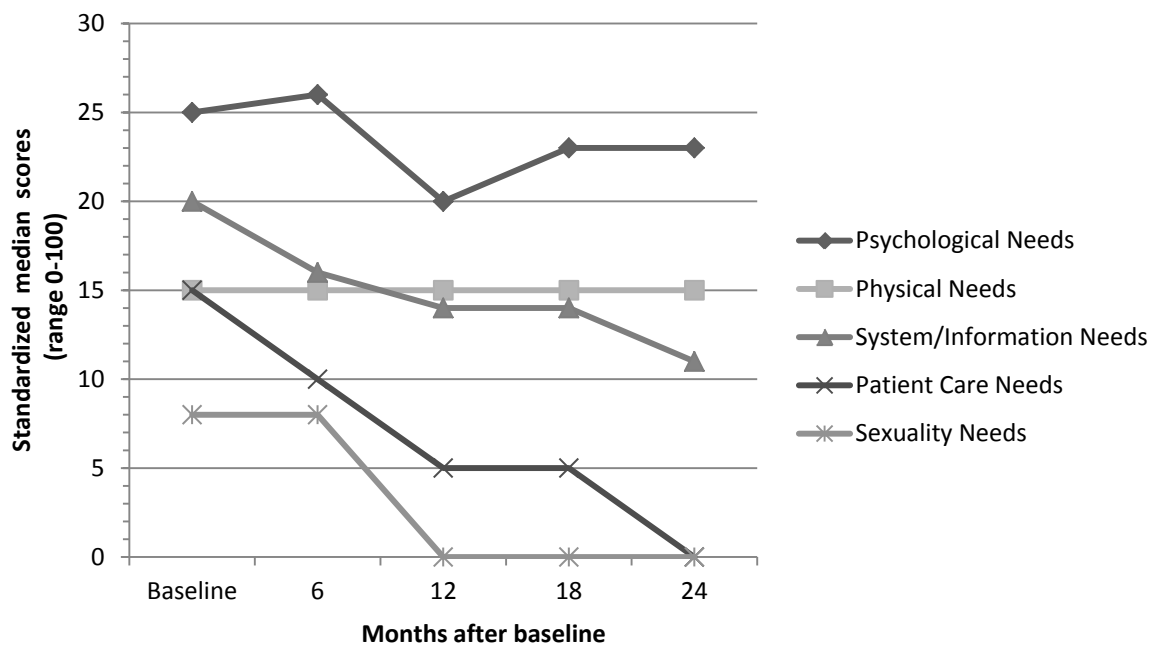


Figure 2. Standardized need domain scores over time after baseline (6-12 months after diagnosis)