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Impact of disease recurrence on the supportive care needs of patients with ovarian cancer and their caregivers

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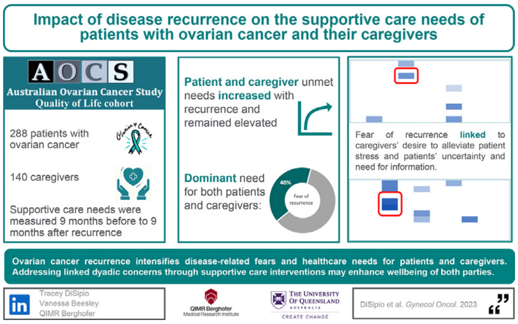
HIGHLIGHTS

- Ovarian cancer recurrence imposes enduring psychological, service and information needs for patients and caregivers.
- Patients additionally experience an increase in physical and care needs with recurrence.
- At recurrence, the most prevalent unmet need for both patients and caregivers revolved around fear of cancer metastasis.
- Coupled with this fear is caregivers' desire to alleviate patient stress and patient uncertainty and need for information.
- Patients also worry about loved ones, while caregivers struggle with adjusting expectations about patient recovery.

GRAPHICAL ABSTRACT



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ABSTRACT

Objective. We aimed to explore the supportive care needs of ovarian cancer patients and their caregivers before and after the first cancer recurrence, the top unmet needs after recurrence, and the relationship between patient and caregiver needs at recurrence.

Methods. Participants were 288 patients and 140 caregivers from the Australian Ovarian Cancer Study-Quality of Life (AOCS-QoL) cohort. They completed Supportive Care Needs Surveys (patients: SCNS-SF34, caregivers: SCNS-P&C44) every three-to-six months for up to two years. Linear mixed models tracked changes in needs over time. We calculated the percentage reporting moderate-to-high needs after recurrence. LASSO regression analysed patient-caregiver need relationships.

Results. Both patients' and caregivers' psychological, health system/service and information needs increased with recurrence along with patients' support and physical needs. These remained stable at nine months after recurrence. Dominant patient needs post-recurrence included 'fear of recurrence' (38%) and 'concerns about the worries of those close' (34%), while caregivers expressed 'concerns about recurrence' (41%) and 'recovery of the patient not turning out as expected' (31%). Among dyads, when patients had 'fears about the cancer spreading' this was associated with caregivers having a need for help with 'reducing stress in the patients' life'; when

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caregivers had concerns about ‘recurrence’ this was associated with patients needing help with ‘uncertainty about the future’ and ‘information about things they can do to help themselves'.

Conclusions. Recurrent ovarian cancer intensifies disease-related fears and concerns for patients and loved ones. Addressing dyadic concerns through supportive care interventions may enhance cohesion during the challenging journey of recurrent disease.

1. Introduction

Globally, >300,000 females are diagnosed with ovarian cancer every year [1]; most are diagnosed at an advanced stage of disease and approximately 70% will experience recurrence within 12 to 18 months of primary treatment [2,3]. The main objective of follow-up after primary treatment is monitoring for disease progression although follow-up consultations also offer continuity of care and support by providing the opportunity for patients to talk about their concerns [4]. The goals of treatment for recurrent ovarian cancer shift from cure to delaying further disease progression and addressing patient physical symptoms and psychological needs [5].

Recurrence can have a devastating effect on patients, partners, and family caregivers, having a negative effect on quality of life, raising existential issues, as well as causing new symptoms [6,7]. While the focus of treatment for recurrent disease is to improve palliation, only 40% of patients who receive chemotherapy for recurrent ovarian cancer report improved symptom management, and even fewer report improved quality of life [8].

Supportive care is therefore important to address a range of changing needs after recurrence [9]. It is essential not only for managing physical symptoms but also for addressing emotional, psychological, and social aspects of living with cancer recurrence. Involving caregivers and loved ones in the care process can ensure that crucial emotional and practical support is provided to the whole family during this difficult time.

Supportive care needs can vary widely depending on factors including the type of cancer, its stage and the treatments received. For women with ovarian cancer, data from the Australian Ovarian Cancer Study Quality of Life (AOCS-QoL) cohort has already shown that information, care, and sexuality needs are largely resolved after primary treatment but psychological and physical needs can persist for many years during the recurrence-free period [10]. Data from an internet-based questionnaire indicates that physical needs are higher still in women with recurrent ovarian cancer compared to without recurrent disease [11], although the cross-sectional study design was limited in its ability to explore outcomes over time, and the sample may have been biased towards more healthy women (possible selection bias exists for healthier recurrent cancer patients to participate) since the median time since diagnosis was 5.1 years among those with recurrent ovarian cancer in that survey.

The supportive care needs of patients and their caregivers at the time of recurrence may differ from the initial needs at primary treatment or during the recurrence-free period. However, no prospective studies have specifically measured the needs of patients with ovarian cancer and their caregivers before and after the time of first recurrence. We used population-based longitudinal data from ovarian cancer patient-caregiver dyads to (1) describe changes in supportive care needs from before to after a diagnosis of recurrent ovarian cancer, (2) identify the top moderate-to-high unmet needs after recurrence, and (3) explore the relationship between unmet needs of patients and their caregivers.

2. Methods

2.1. Study design

The AOCS-QoL study was a longitudinal population-based mail survey. Ethics approval was obtained from The University of Sydney and QIMR Berghofer Medical Research Institute Human Research Ethics Committees and all participating sites.

2.2. Participants and procedures

The AOCS recruited patients aged 18–79 years with invasive epithelial ovarian cancer diagnosed between January 2002 and June 2006 through major treatment centres and state-based cancer registries in all Australian states and territories. AOCS study methodology has been described in detail [12]. AOCS participants who were alive in May 2005 or recruited after this date were contacted by letter to participate in the AOCS-QoL sub-study. Consenting patients were asked to invite their familial or voluntary caregiver into the study. Patients and their caregivers were mailed QoL study materials separately at sub-study entry (which ranged from 3 to 55 months after patient diagnosis) and at three to six monthly intervals for up to two years [12,13].

The current analysis includes participants from the AOCS-QoL sub-study who were diagnosed with a recurrence during the study period, and their nominated caregiver. Participants contributed to analysis if they had data for at least one assessment after their first recurrence. Data within 12 months of initial diagnosis was excluded to preclude the late-effects of first-line treatment, and data from six months after recurrence was excluded if patients were on treatment at that time (as a proxy for a second recurrence). This was to provide information about the timeframe in which patients' and caregivers' needs related to the initial relapse and return to pre-recurrence levels.

2.3. Data collection

2.3.1. Outcome measures

Supportive care needs for patients and their caregivers were measured using the Supportive Care Needs Survey-Short Form (SCNS-SF34) and the SCNS-Partners and Caregivers (SCNS-P&C44), respectively [14,15]. The SCNS-SF34 assesses 34 need items across five domains: psychological (10 items), health system and information (11 items), physical and daily living (5 items), patient care and support (5 items), and sexuality (3 items). The SCNS-P&C44 is a 44-item questionnaire that measures needs across four domains: health care service (13 items), psychological and emotional (14 items), work and social (10 items), and information needs (7 items). Patient and caregiver respondents rate their level of need on each item over the past month on a five-point scale (1 = not applicable, 2 = need satisfied, 3 = low unmet need, 4 = moderate unmet need, 5 = high unmet need). Summated domain and global Likert scale scores are standardised (range 0–100) according to the guidelines for patients and caregivers [15,16]. Higher scores reflect greater need.

2.3.2. Demographic and treatment variables

Demographic information (age, gender, education level and marital status, residential location) were self-reported at AOCS enrolment for patients and at sub-study entry for caregivers (additionally, caregivers self-reported their relationship to the patient). Residential location was classified according to the Accessibility/Remoteness Index of Australia using each participant's postcode [17]. Patients also self-reported current treatment (chemotherapy/radiotherapy) at each survey. Stage of disease at diagnosis (International Federation of Gynaecological and Obstetrics, FIGO) was extracted from medical records.

2.4. Statistical analyses

Participant characteristics were summarised as proportions for categorical variables and means and standard deviations (SD) for continuous variables.

To describe changes in needs from before to after a diagnosis of recurrent ovarian cancer (*aim one)*, six time intervals were defined relative to the recurrence date as follows: 6–9 months before (T1), 3–6 months before (T2), 0–3 months before (T3), 0–3 months after (T4, referred to as the recurrence interval), 3–6 months after (T5), and 6–9 months after (T6) recurrence. Linear mixed models were used to investigate changes in needs over these time intervals, using all available data, accounting for the correlation within participant, and allowing for individual rate of change. Models were fitted for patients and caregivers separately, and for each domain and for global needs. Models were fitted with a random intercept and random slope to describe change in needs using the least squares mean scores (95% confidence interval, CI). Pre-specified models were fitted based on covariates expected to affect scores based on theoretical and background knowledge (including age, marital status or relationship to patient, residential location, treatment status) with an unstructured covariance matrix specified. A minimally important difference (MID) of five points on the standardised 0–100 need domains and global scales was defined a priori as a clinically meaningful change between time intervals, based on the MID of the FACT-G which has similar constructs (convergent validity) to the SCNS [18].

To identify the top moderate-to-high unmet needs after recurrence (*aim two)*, the first available survey after recurrence was selected and individual need items were dichotomised into no-to-low unmet need versus moderate-to-high unmet need. The proportion of participants reporting moderate-to-high unmet need on each item was calculated and the top 10 (or more if tied) unmet needs after recurrence were identified overall and stratified by treatment status.

Logistic least absolute shrinkage and selection operator (LASSO) regression was used to examine the relationship between the top 10 prevalent moderate-to-high unmet patient need items and the top 10 prevalent moderate-to-high unmet caregiver need items after recurrence to identify important sets of need associations (*aim three*). First each patient need was regressed against the top 10 caregiver needs to identify caregiver needs associated with the patient need. Then each caregiver need was regressed against the top 10 patient needs to identify patient needs associated with the caregiver need. The Bayesian Information Criterion (BIC) was used in the Lasso model to select regressors. The strength of an individual association is depicted by standardised (centered and scaled) coefficients displayed in heat maps of patient versus caregiver needs and caregiver versus patient needs. Positive associations for high unmet needs among dyads are identified.

Statistical analyses for aims one and two were performed in Stata version 18 [19] and in JMP Pro Version 17 [20] for aim three.

2.4.1. Missing data analysis

To assess the impact of missing data on the prevalence of moderate-high unmet needs, stratified by treatment status, we compared participant characteristics after recurrence to determine if demographic differences might confound needs reported on and off treatment. We also compared the characteristics of patients included versus excluded from aim three analyses, i.e., patients with and without a matched caregiver.

3. Results

3.1. Sample characteristics

The flow of participant recruitment is summarised in Supplementary Material S1. Of the 798 patients who participated in the AOCS-QoL study, 288 experienced a recurrence during the study period, completed at least one assessment after recurrence, and contributed to the analysis for aim one, describing changes in needs over time, and aim two, identifying the top moderate-to-high unmet needs after recurrence. Of the 423 nominated caregivers who participated in the AOCS-QoL study, 140 completed at least one assessment after the patient's recurrence and contributed to the analysis for aims one and two. One hundred and thirty-one patient-caregiver dyads contributed to analyses for aim three exploring the relationship between unmet needs of patients and their caregivers.

On average, patients in our analysis experienced a recurrence 15 months (SD = 8) following their initial diagnosis of ovarian cancer, were 60 years of age (SD = 10) at first recurrence, approximately three-quarters (74%) had a current partner, half (51%) had completed further education after high school, 64% lived in a major city, and 92% were diagnosed with stage III/IV disease at the time of study entry (Table 1). Caregivers were, on average, 58 years of age (SD = 14), most (86%) had a current partner, three-quarters (75%) completed further education after high school, two-thirds (66%) lived in a major city, 69% were the husband or partner of the patient, and 71% were male (Table 1).

3.2. Missing data results

Participant characteristics were stratified by treatment status and this analysis showed that while age, marital status and caregiver relationship to the patient and gender of the caregiver were similar

Table 1
Characteristics of patients with a recurrence and their caregiver at study entry.

	N (%) except where otherwise specified[a]	
	Patients (*n* = 288)	Caregivers (*n* = 140)
Age at recurrence (years), mean (SD)	60 (10)	58 (14)
Disease stage (FIGO) at diagnosis		
Stage I/II	24 (9)	
Stage III/IV	260 (92)	
Time to recurrence from diagnosis (months), mean (SD)	15 (8)	
Marital status		
Current partner	208 (74)	121 (86)
Not partnered	74 (26)	19 (14)
Education level		
High school or less	141 (50)	35 (25)
College, diploma, trade	85 (30)	64 (46)
University	59 (21)	39 (28)
Residential location		
Major city	184 (64)	91 (66)
Inner regional	72 (25)	32 (23)
Outer regional/remote	32 (11)	16 (12)
Caregiver relationship to patient		
Husband or partner		97 (69)
Daughter or son		27 (19)
Other		16 (11)
Gender		
Male		99 (71)
Female		41 (29)

[a] With at least one assessment after recurrence.

between the treatment groups there were some differences (Supplementary Material S2). Slightly lower proportions of city dwelling patients (59% versus 68%) and patients with a matched caregiver (57% versus 72%) were receiving treatment versus not receiving treatment for recurrence. There was also a lower proportion of university-educated caregivers of patients receiving treatment (20% versus 31%, respectively).

Next, analysis of patients with and without a matched caregiver (Supplementary Material S3) showed that age, caregiver gender and relationship to the patient were similar between the groups. A higher proportion of patients without a matched caregiver did not have a partner compared to patients with a matched caregiver (32% versus 19%, respectively). Only nine caregivers (6%) did not have matched patient data available for aim three and therefore their exclusion was unlikely to bias the results.

3.3. Domain and global needs over time

There were clinically meaningful increases in mean scores (≥5 points) for patients on the psychological (9.2 points), health system/information (13.6 points), physical/daily living (6.6 points), care/support (11.4 points), and global (10.0 points) need domains with the T4 recurrence event, and scores remained elevated (Fig. 1). Reported needs in the psychological domain also increased between T1 and T3, i.e., before the recurrence (7.2 points).

Caregivers reported increases in health care service (5.9 points), psychological/emotional (5.9 points), and information (5.6 points) needs with the T4 recurrence event, and these needs remained elevated until the end of the observation period (Fig. 2). An increase in caregiver work/social needs was observed over a longer time interval, between T3 and T6 (8.2 points), including time leading up to and the time following

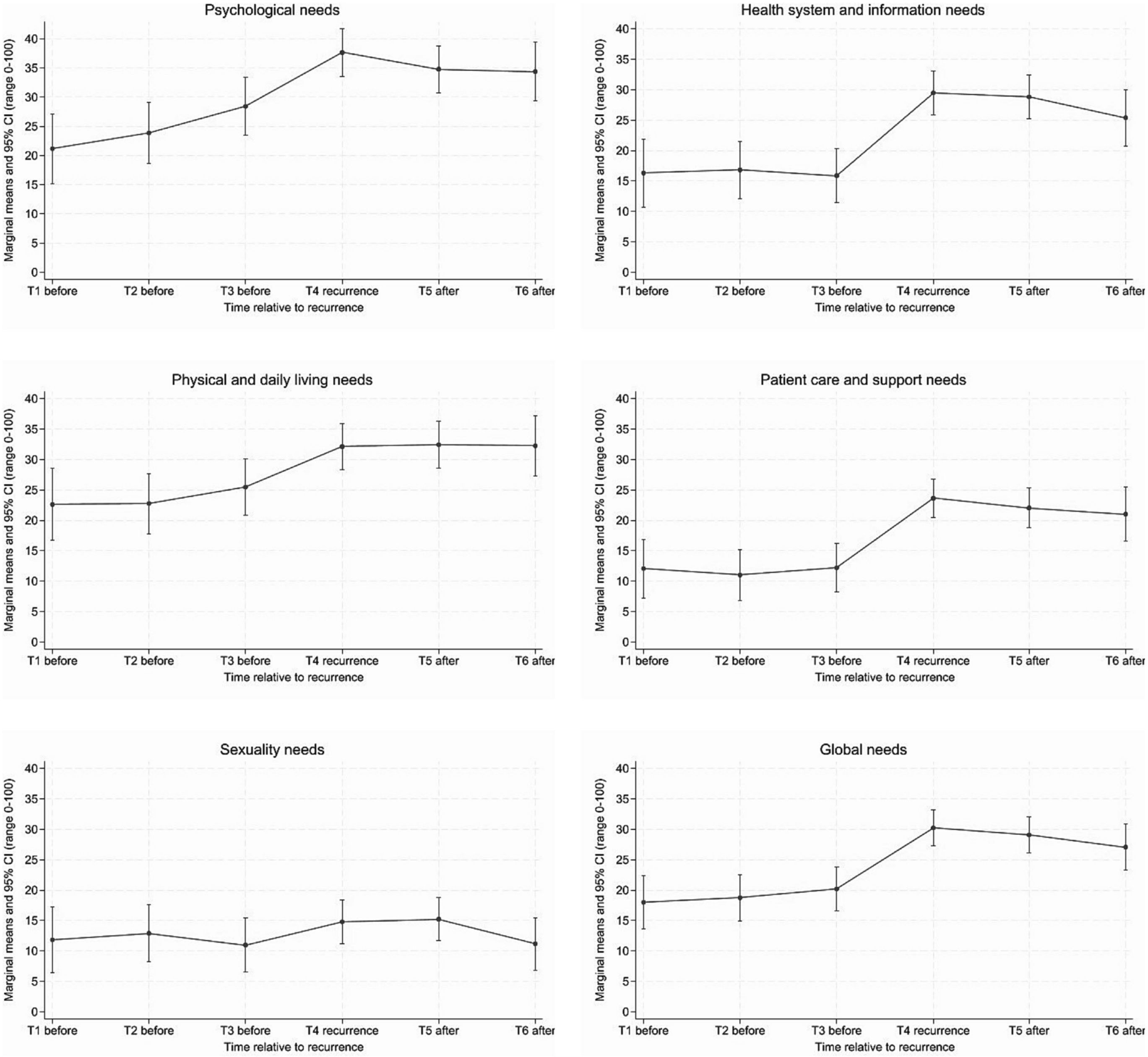

Fig. 1. Predicted marginal means (95% Confidence Intervals) of standardised (range 0–100) need domains and global scores among ovarian cancer **patients** over time.
Footnotes: T1: 6–9 months before; T2: 3–6 months before; T3: 0–3 months before; T4 0–3 months after (recurrence interval); T5: 3–6 months after; T6: 6–9 months after recurrence.

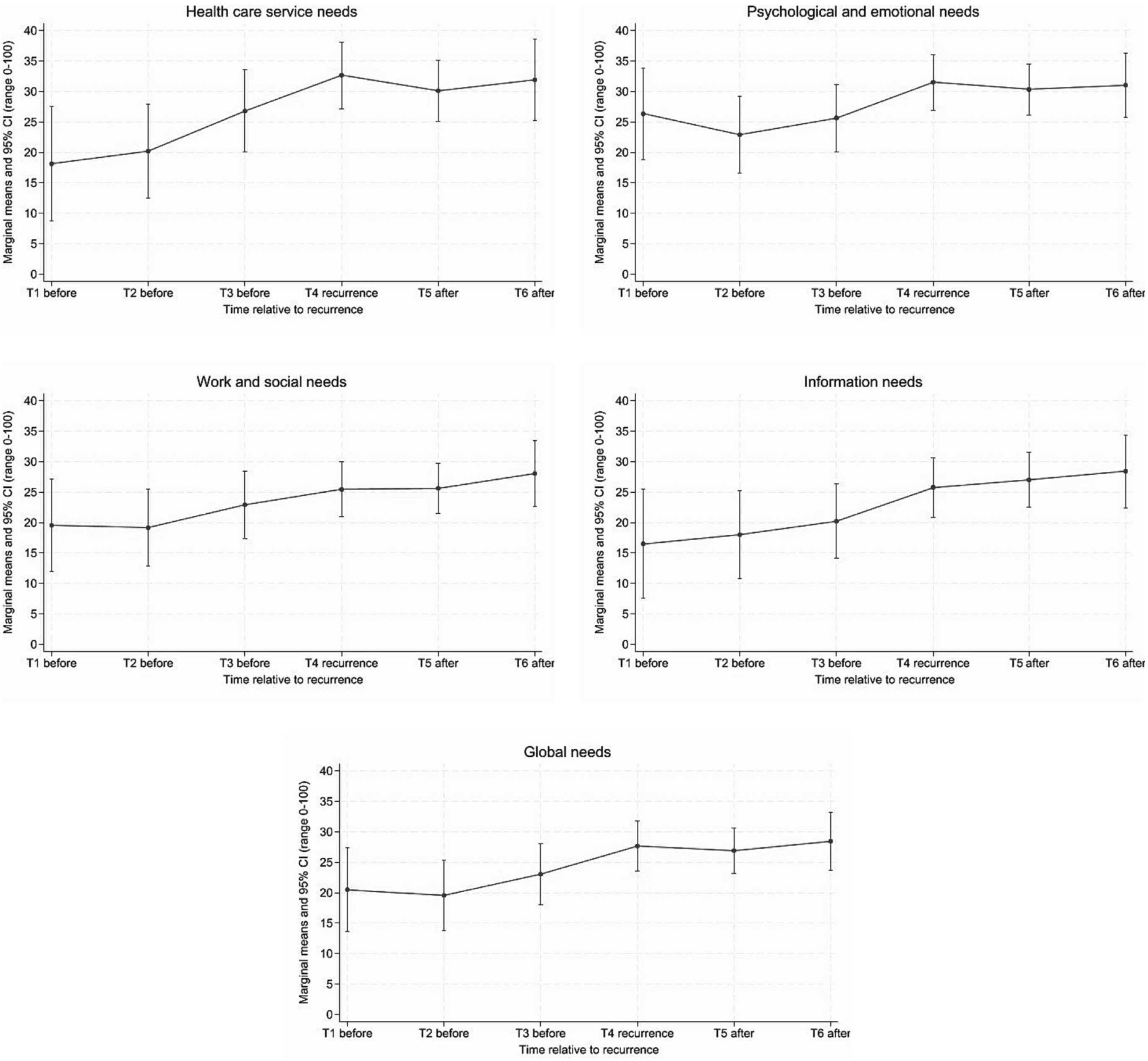

Fig. 2. Predicted marginal means (95% Confidence Intervals) of standardised (range 0–100) need domains and global scores among ovarian cancer **caregivers** over time.
Footnotes: T1: 6–9 months before; T2: 3–6 months before; T3: 0–3 months before; T4 0–3 months after (recurrence interval); T5: 3–6 months after; T6: 6–9 months after recurrence.

recurrence. Prior to recurrence, there was also an increase in health care service needs between T2 and T3 (6.6 points).t

3.4. Prevalence of unmet need items after recurrence

Two thirds ($n = 189$; 66%) of patients and caregivers ($n = 96$; 69%) reported at least one moderate-to-high unmet need at their first survey following recurrence. For patients, 'fear about the cancer spreading' was the number one moderate-to-high unmet need reported by approximately 40% of patients irrespective of whether they were on or off treatment for recurrence (Table 2). The next top needs for patients were also in the psychological domain: 'concerns about the worries of those close to you' (34%); 'uncertainty about the future' (33%); and 'worry that the results of treatment are beyond your control' (30%). Three physical needs and one information need were also among the top ten patient needs after recurrence. In general, unmet needs were more prevalent among women receiving treatment for recurrence compared to those not on treatment; however, the difference was only statistically significant for 'worry that the results of treatment are beyond your control' (36% versus 24%; $p = 0.04$).

For caregivers, the most prevalent moderate-to-high unmet need was 'concern about recurrence' (41%), followed by 'recovery not as expected' (31%). The following three items tied with a prevalence of 28% each: 'information on prognosis'; 'reduce stress for the patient'; and 'decision making in the context of uncertainty' (Table 2). When unmet needs were stratified by treatment status, few differences were identified.

3.5. Relationship between needs of patients and their caregivers

Among patient-caregiver dyads we found patients' need for help with 'fear about the cancer spreading' and patients' 'uncertainty about

Table 2
Top ten most prevalent[a] moderate-to-high unmet supportive care need items among patients with ovarian cancer and their caregivers after first recurrence (overall and stratified by treatment status).

Domain	Unmet need item	After recurrence (T4)		On treatment for recurrence	Not on treatment
Patients		$N = 278–288$		$N = 127–134$	$N = 141–145$
		Rank	n (%)	n (%)	n (%)
Psychological	Fears about the cancer spreading	1	108 (38)	54 (41)	51 (35)
Psychological	Concerns about the worries of those close to you	2	97 (34)	47 (36)	46 (32)
Psychological	Uncertainty about the future	3	94 (33)	48 (36)	44 (30)
Psychological	Worry that the results of treatment are beyond your control	4	86 (30)	48 (36)*	35 (24)*
Physical	Lack of energy/tiredness	5	73 (26)	39 (30)	31 (21)
Physical	Not being able to do the things you used to do	6	65 (23)	31 (23)	33 (23)
Information	Being informed about things you can do to help yourself to get well	7	63 (22)	33 (25)	27 (19)
Psychological	Learning to feel in control of your situation	8	58 (20)	29 (22)	27 (19)
Physical	Work around the home	9	56 (20)	32 (24)	24 (17)
Psychological	Feelings about death and dying	10	53 (19)	30 (23)	22 (15)
Caregivers		$N = 136–140$		$N = 52–54$	$N = 73–75$
		Rank	n (%)	n (%)	n (%)
Psychological	Concerns about recurrence	1	56 (41)	19 (35)	33 (45)
Psychological	Recovery not as expected	2	43 (31)	19 (35)	22 (30)
Information	Information on prognosis	3	39 (28)	13 (24)	24 (32)
Health care	Reduce stress for patient	3	38 (28)	17 (31)	19 (25)
Psychological	Decision making in uncertainty	3	39 (28)	18 (33)	18 (24)
Health care	Best medical care for patient	6	36 (26)	12 (22)	20 (27)
Health care	Fears about patient deterioration	6	37 (26)	14 (26)	20 (27)
Information	Information on patient physical needs	8	35 (25)	15 (28)	17 (23)
Psychological	Feelings about death	8	35 (25)	18 (33)	14 (19)
Health care	Discuss concern with doctor	10	33 (24)	14 (26)	16 (21)

* *P*-value (Fisher's exact, two-sided) <0.05 on versus not on treatment for recurrence.
[a] Prevalence among non-missing observations.

the future' were associated with caregivers having a need for help with 'reducing stress in the patient's life' (Fig. 3). Patients' need for help with 'tiredness' and 'learning to feel in control' were associated with caregivers reporting a need for help with 'fear about the patient's physical or mental deterioration'. For patients wanting help with 'feelings about death', there was also an association with caregivers needing help to cope with the 'patient's recovery not turning out as expected' and 'fear about the patient's physical or mental deterioration'.

In caregiver models (Fig. 4), caregivers' need for help with 'concerns about recurrence' were associated with patients' 'uncertainty about the future' and patients' need for 'information about things they can do to help themselves'. Caregivers' need for help with the 'patients' recovery not turning out as expected' was associated with patients' 'uncertainty about the future' and patients' 'tiredness'. Caregivers need for help with 'reducing stress in the patient's life' and 'making decisions about life in the context of uncertainty' were associated with patients' wanting

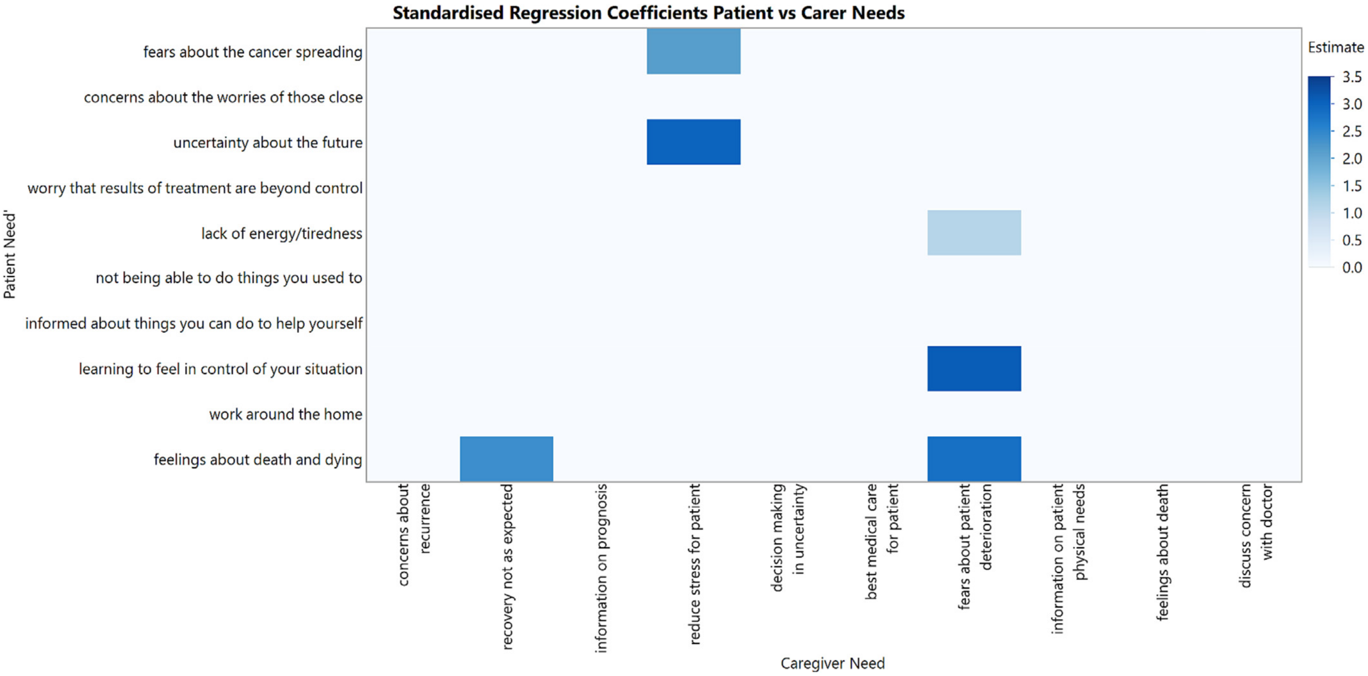

Fig. 3. Associations between the top ten most prevalent unmet supportive care needs among **patients with ovarian cancer** after recurrence and caregiver needs.

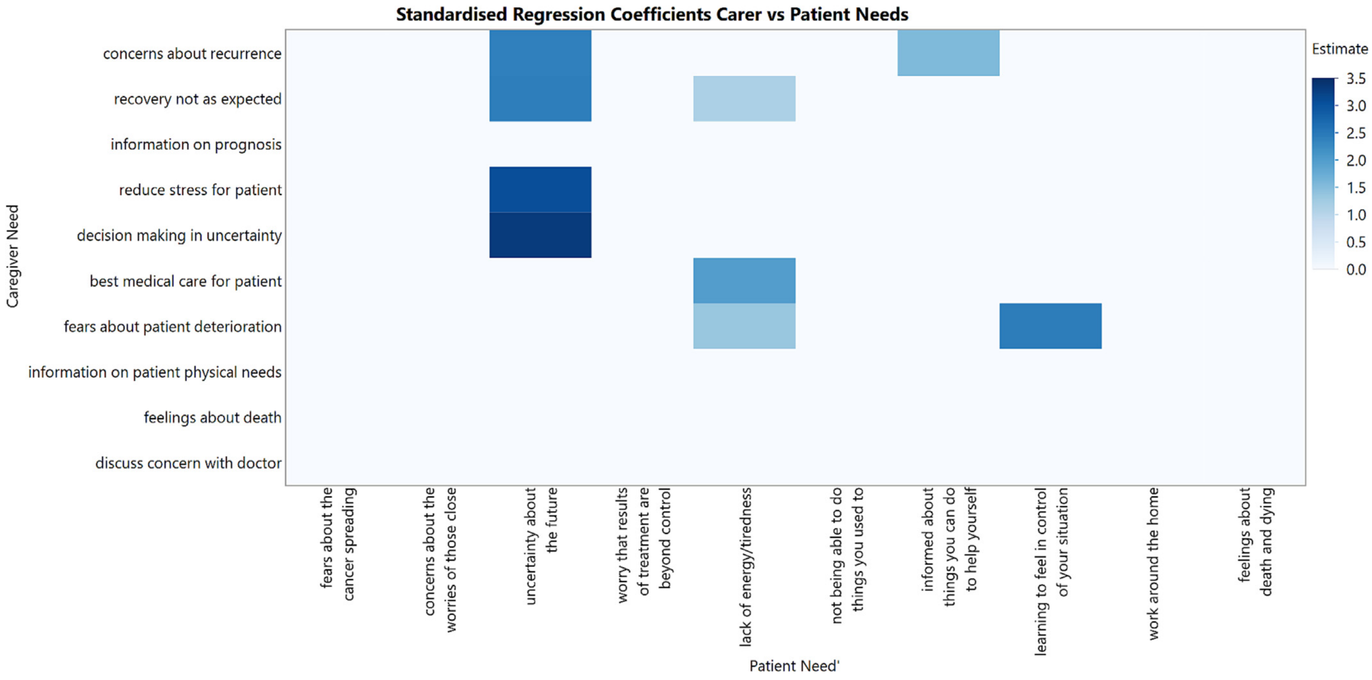

Fig. 4. Associations between the top ten most prevalent unmet supportive care needs among **caregivers** after recurrence of ovarian cancer in patients and patient needs.

help with 'uncertainty about the future'. Caregivers' need for 'medical care for the patient' was associated with patients' 'tiredness' and, for caregivers' 'fears about the patient deteriorating' and, for caregivers' 'fears about the patient deteriorating' there was also an association with patients' need to 'learn to feel in control of their situation'.

4. Discussion

This national prospective study investigated the impact of recurrence on the supportive care needs of patients with ovarian cancer and their caregivers. Results highlight increased needs with the recurrence interval that persisted for many months; this pattern was observed across multiple need domains for both patients and caregivers. Patients' psychological needs had the largest increase of any domain, with clinical increases in need seen even *before* recurrence. The same pattern was observed for caregiver health care service needs which also increased from *before* recurrence. After recurrence, need items in the psychological domain dominated the top ten most prevalent moderate-to-high unmet needs for both patients and caregivers, in addition to health care needs for caregivers. In particular, fear of cancer spreading was the most prevalent moderate-to-high unmet need among patients (38%) and caregivers (41%), regardless of treatment status. When patients feared cancer spreading, caregivers wanted help with ways to reduce the patient's stress. Conversely, when caregivers worried about recurrence, patients wanted guidance to cope with uncertainty and learn self-help strategies for the future. The next dominant patient need post-recurrence was concerns about the worries of those close, highlighting the important link between the dyad. The next most prevalent caregiver need was recovery of the patient not turning out as expected, indicating the pressing importance of tailored support for managing unforeseen outcomes and facilitating adaptation within the caregiving process.

Most recurrences are diagnosed based on an asymptomatic rise in CA125 levels however imaging techniques are often needed to confirm disease recurrence [3]. This might explain why patient psychological need scores, and caregiver health care service need scores increased *prior* to recurrence. There is likely increased contact with the health care service as CA125 levels are monitored closely causing psychological distress with escalating levels. A study conducted in Australia and Canada found that over half of study participants reported abdominal (pain/discomfort/cramps or swelling/bloating/fullness) and psychological (anxiety/feeling worried or depression/feeling sad) symptoms before starting chemotherapy for recurrent ovarian cancer [8]. In our study, three of the top 10 moderate-to-high unmet patient needs at recurrence were from the physical domain. Together, findings indicate that a proportion of patients will experience disease-related symptoms of progression at or soon after clinical detection.

There is limited research specific to the needs of caregivers of patients with recurrent ovarian cancer beyond the AOCS study [13,21]. International research among caregivers of patients with lung, urological or gastrointestinal cancer (29% progressive disease; 62% female patients) reported many of the same unmet needs as those found here [22]. The greatest unmet needs were within the health care service domain and the information domain (four items and two items, respectively, featuring in the top 10 moderate-to-high unmet needs in our study), and the most prevalent single needs were fears about patient deterioration followed by managing concerns about recurrence (sixth and first most prevalent in our study, respectively) [22]. There is a clear need for care that addresses these identified unmet needs.

Our research delved into the intricate dynamics between patient and caregiver unmet needs, revealing significant associations. We discovered that several of the primary needs expressed by patients were linked to caregivers' concerns regarding the patient's deteriorating health and their strong inclination to alleviate the patient's stress. Conversely, many of the key needs expressed by caregivers were intertwined with the uncertainty and fatigue experienced by patients, along with the patients' keen interest in acquiring self-help techniques and a sense of control. These correlations underscore the importance of dyadic supportive care interventions aimed at addressing the interconnected needs of both patients and caregivers, emphasising the significance of coping strategies tailored to needs at recurrence that encompass the holistic wellbeing of the patient-caregiver dyad.

Similar research among ovarian cancer patients and caregivers is limited. Some studies have reported on anxiety and depression outcomes of couples with equivocal results [23,24]. Others (not ovarian cancer) have reported that unmet needs in patients and caregivers' anxiety predicted unmet caregiver needs [22]. Together these studies suggest that patients and caregivers influence each other, and that interventions to help both may be useful. A review of survivorship interventions for women with gynaecological cancer and their caregivers found only one trial included caregivers and concluded that further research is required to explore the patient-partner dynamics [25].

4.1. Strengths and limitations

This analysis utilised an Australia-wide, population-based sample and longitudinal assessment of unmet needs using valid and reliable measures and, importantly, acknowledges the role of the caregiver. Another strength and novelty is the exploration of the patient-caregiver relationship of unmet needs. As only nine caregivers who were not linked to cases and therefore excluded from analyses, the dyad results were unlikely biased. Patients excluded from analyses were more likely not to have a partner, a factor that has been associated with higher unmet needs among ovarian cancer survivors [26] so findings may underestimate the prevalence of needs following recurrence among patients. While this was a population-based sample, there is potential for some selection bias, whereby healthier cancer patients may have been more likely to enrol and/or remain in the study after recurrence, further underestimating the prevalence of needs.

Data were collected between 2005 and 2007 and it is possible that there have been advances in supportive care practices since this time which may affect contemporary relevance. However, an Australian study from a few years ago showed that only 34% of health professionals caring for women with gynaecological cancer had a documented needs assessment protocol for patients and 10% did so for caregivers, indicating that there is a long way to go until care is optimised [27]. The results presented here relate to the needs of women and caregivers in a high-income country and may not be as relevant to those in lower- and middle-income countries. For instance, 50% of our patient sample and 75% of our caregiver sample completed further education after high school. As 84% of the global population live in low- and middle-income countries the characteristics of our cohort do not mirror the global population [28]. As higher education may impact needs and patient care [26], and given that health systems vary by country, there is a need for similar research to be conducted in low-to-middle income countries.

4.2. Implications for research and practice

In Australia, clinical practice guidelines for the management of patients with epithelial ovarian cancer were developed in 2004 and superseded with specific guidelines on follow-up in 2012 [4]. It was acknowledged at that time that further research was required for alternate models of follow-up care and evaluation of follow-up interventions on survivorship issues. Recent reviews of observational studies to identify supportive care needs and intervention trials of survivorship care among patients with gynaecological cancer and their caregivers continue to highlight the need for further research to explore the dynamics of the patient-caregiver dyad [25,29]. While interventions for nurse-led follow-up care to improve care coordination and psychological wellbeing are promising, trials specific to recurrent cancer and for caregivers are limited [25]. Patient navigation services, encompassing tailored assistance to meet the needs of patients and caregivers, can overcome barriers and facilitate timely access to care through all phases of the cancer experience [30].

5. Conclusion

This study aimed to bridge a critical gap in the literature by identifying the impact of ovarian cancer recurrence on the specific unmet needs and supportive care requirements for both patients and their caregivers. Results clearly demonstrate the substantial and lasting burden of recurrence on the support demands of patients and their caregivers. It is evident that ongoing unmet needs persist, affecting two in three patients and caregivers, prompting the necessity for additional assistance and concern, particularly with fear of cancer spreading. Meeting the joint needs of the patient-caregiver dyad or the needs of just one of these groups holds the potential to improve the quality of life of both parties. However, given ovarian cancer is typically diagnosed at an advanced stage and most patients will relapse, integrating strategies to alleviate the burden of unmet needs for both patients and caregivers is optimal as a comprehensive cancer care approach.

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Author contributions

TD drafted the manuscript. TD and GH conducted the analyses. All authors contributed to the study conception and/or analysis protocol, interpretation of data and critically reviewed the manuscript and approved the final version.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Ethics approval was obtained from The University of Sydney and QIMR Berghofer Medical Research Institute (P845) Human Research Ethics Committees and all participating sites.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publish

Not applicable; no individual-level data has been reported in this manuscript.

CRediT authorship contribution statement

Tracey DiSipio: Formal analysis, Writing – original draft, Writing – review & editing, Conceptualization. **Gunter Hartel:** Formal analysis, Writing – review & editing, Conceptualization. **Phyllis Butow:** Conceptualization, Writing – review & editing. **Penelope M. Webb:** Conceptualization, Writing – review & editing. **Vanessa L. Beesley:** Conceptualization, Writing – review & editing.

Data availability

The datasets generated during and/or analysed during the current study are available from Vanessa Beesley on reasonable request and with appropriate Human Research Ethics Committee approval and data transfer agreements in place.

Declaration of competing interest

The authors have no relevant financial or non-financial interests to disclose.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ygyno.2024.02.012.

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