Experiences of women with ovarian cancer in 22 low-income and middle-income countries (Every Woman Study LMICs): a cross-sectional study

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Summary

Background Around 70% of ovarian cancers occur in low-income and middle-income countries (LMICs), but little is known about the experiences of women with ovarian cancer in this setting. We aimed to describe the experiences and priorities of women with ovarian cancer in LMICs, and to identify potentially modifiable factors linked to these experiences.

Methods We did a cross-sectional, survey-based study in LMICs, recruiting women with ovarian cancer from 82 hospitals in 22 countries. Women diagnosed with ovarian cancer (primary malignancy of the ovary, fallopian tube, or peritoneum, including borderline tumours) at a study site within the past 5 years (2017–24), who were aged 18 years or older, were eligible for inclusion. Participants completed a 59-item survey at a single timepoint up to 5 years after their diagnosis, which collected information on demographics and cancer experiences. Survey data collection ran from June 14, 2022, to May 13, 2024. Data on cancer histology and stage at diagnosis were collected from medical records. Countries were grouped according to the four Human Development Index (HDI) levels (low, medium, high, and very high). The primary study outcomes were self-reported knowledge of ovarian cancer before diagnosis and the extent of any financial impact of having ovarian cancer. Based on survey responses, knowledge of ovarian cancer was ordered from low (had never heard of it) to high (had heard of it and knew something about it), and extent of financial impact from low (not at all) to high (a great extent). Random-effects ordered logistic regression was used to investigate the association of participant-reported variables and country HDI group with each primary outcome.

Findings We analysed data from 2446 women with ovarian cancer (mean age at diagnosis 49·9 years [SD 13·6]). 631 (26·1%) of 2421 participants who reported on their knowledge of ovarian cancer before diagnosis reported that they had heard of ovarian cancer and knew something about it (range: three [3·3%] of 90 participants in Nepal to 92 [63·4%] of 145 in Uzbekistan). In multivariable regression analyses of 2133 participants with relevant data on model variables, lower education level (no formal education *vs* tertiary or higher education, odds ratio [OR] 3·41, 95% CI 2·38–4·89, p<0·0001; and primary or secondary education *vs* tertiary or higher education, OR 1·96, 1·56–2·47, p<0·0001), lower household income (self-perceived as below *vs* above average for the country, OR 1·79, 1·28–2·50, p=0·0006), and lower HDI group (low *vs* very high HDI group, OR 2·32, 1·06–5·04, p=0·034; and medium *vs* very high HDI group, OR 1·88, 1·04–3·42, p=0·038) were associated with a decrease in ovarian cancer knowledge by one category level. 1105 (45·9%) of 2406 participants who reported on the extent of financial impact of ovarian cancer indicated that their financial situation had been affected to a great extent (range: 16 [15·2%] of 105 in Argentina to 46 [83·6%] of 55 in Uganda). In multivariable regression analyses of 2099 participants, lower household income (self-perceived as below *vs* above average for the country, OR 3·64, 2·58–5·14, p<0·0001; and average *vs* above average for the country, OR 1·78, 1·31–2·41, p=0·0002) and lower HDI group (low *vs* very high HDI group, OR 3·70, 1·10–12·45, p=0·035; and medium *vs* very high HDI group, OR 3·47, 1·40–8·59, p=0·0072) were associated with an increase in financial impact by one category level.

Interpretation We have identified factors associated with ovarian cancer knowledge, experiences, and outcomes across LMICs, which could inform policy and the development of interventions to improve patient care. Given variation in patient experiences and outcomes between LMICs, interventions should be tailored to local needs and priorities.

Funding International Gynecologic Cancer Society and the World Ovarian Cancer Coalition.

Research in context

Evidence before this study

We reviewed published literature on the experiences of women with ovarian cancer, searching PubMed for studies published from Jan 1, 2000, to Nov 5, 2024, using the search terms "ovarian cancer" and synonyms, terms relating to patient experiences ("patient experience", "patient journey", "patient satisfaction", "patient involvement", "patient engagement", and "patient-reported outcomes"), and terms relating to questionnaire-based or interview-based studies including "patient survey" and "interview-based". We identified survey and qualitative studies exploring patient experiences of ovarian cancer, including symptom perception, barriers to care access and diagnosis, treatment preferences, patient information, and care needs, and the impact of the disease on patient quality of life. However, most studies were done in a single high-income country (HIC) and focused on a single aspect of patient experience. A 2020 international survey by the World Ovarian Cancer Coalition (the Every Woman Study) examined women's experiences related to ovarian cancer across 44 countries including low-income and middle-income countries (LMICs), but 95% of respondents were from HICs. No LMIC-specific studies were identified.

Added value of this study

To our knowledge, this study is the first to collect detailed information on the experiences of women with ovarian cancer in LMICs. We explored experiences related to the diagnosis and treatment of ovarian cancer, including knowledge of ovarian cancer and symptom perception before diagnosis, financial impact of the disease, and patient priorities to improve diagnosis and care, in 22 countries across different geographical regions and Human Development Index (HDI) levels. We defined a symptom profile experienced by women before ovarian cancer diagnosis, identified factors associated with knowledge of the disease before diagnosis (education level, household income, and country HDI level), stage at diagnosis (age at diagnosis, education level, and country HDI level), and extent of financial impact of the disease (household income and country HDI level). We also identified the key priorities of participants for improving diagnosis and care, which were broadly similar across countries, with the most commonly cited priorities overall relating to improved diagnosis (development of screening programmes and free access to diagnostic tests).

Implications of all the available evidence

Although the types of symptoms that women had prior to an ovarian cancer diagnosis in our study were similar to those identified in studies in HICs, symptoms including persistent bloating and/or abdominal distension, abdominal and/or pelvic pain, and urinary symptoms were more common in our study than in those conducted in HICs, indicating that women might present differently in the two settings. Some aspects of patient experience in LMICs, including knowledge of ovarian cancer before diagnosis and financial impact of the disease, were context-specific, with differences by HDI level and between individual countries, but the priorities of patients with regard to improving diagnosis and care were similar across LMICs. Collectively, this evidence could help policymakers and health-care systems target interventions to improve care.

Introduction

In 2022, ovarian cancer was the eighth most common cancer in women worldwide with more than 300 000 new diagnoses.[1] The disease is one of the leading causes of cancer mortality in women globally, resulting in an estimated 207 000 deaths in 2022.[2] The global incidence of ovarian cancer is predicted to increase from this level by 55% by 2050, driven largely by population expansion and increasing population age in low-income and middle-income countries (LMICs).[3]

Understanding the experiences of women before, during, and after an ovarian cancer diagnosis is essential to identify opportunities to improve care and set clinical and public health priorities. However, studies to date have predominantly focused on women living in high-income countries (HICs), including our examination of the experiences of 1531 women with ovarian cancer in 44 countries (the Every Woman Study).[4,5] This work found wide variation between countries in patient's knowledge of ovarian cancer, help-seeking behaviours, and need for and access to emotional support. A key limitation of this work was that only 78 (5·1%) of 1531 of respondents were from LMICs.

In the present study, we aimed to address this evidence gap by collecting data on experiences related to ovarian cancer among women living in LMICs. We sought to explore experiences across LMICs, along with associated factors, and patient priorities for improving care, to identify potential opportunities to improve care at the local, national, regional, and international levels. Our findings are intended to inform policy and direct interventions tailored to the needs of women in LMICs.

Methods

Study design and participants

We did a cross-sectional, survey-based study of women with ovarian cancer, recruited across 82 hospital sites in 22 countries classified by the World Bank as low-income or middle-income as of June, 2021 (appendix p 4).[6] Two countries (Ghana and Mozambique) showed interest in participating, but did not join the study. Because the study was cross-sectional, data were obtained from women at a single timepoint via a participant survey, with survey data collected by local clinical staff, researchers, and social workers. Additional information was extracted on site from medical records by local

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See Online for appendix

clinicians. Survey data collection ran from June 14, 2022, to May 13, 2024. A lead clinician in each country coordinated in-country activity. The study protocol has been published.[7]

Study countries were chosen to obtain a geographically, culturally, and economically diverse pool, utilising the networks of the International Gynecologic Cancer Society. Women diagnosed with ovarian cancer (defined as a primary malignancy of the ovary, fallopian tube, or peritoneum—including borderline tumours) at a study site within the past 5 years (2017–24), aged 18 years or older, and able to provide informed consent were eligible for study inclusion. Additional details on participant eligibility criteria are provided in the appendix (p 5). Eligible women were provided with details of the study and written or digital informed consent obtained at the start of the survey (appendix pp 8–9).

Appropriate ethical approvals were secured in all countries and sites before commencing research at a given location (appendix pp 6–7). In Uganda and Malawi, ethics approvals required a payment to each participant, in local currency, equivalent to US$8 and $10, respectively (appendix p 63). An oversight committee comprising clinicians, patient and lived-experience advocates, and methodologists, most of whom were co-authors, monitored research conduct across the Every Woman Study LMICs programme (appendix p 62).

Procedures

An existing tool from our previous study on ovarian cancer experiences, developed by clinicians, patients, and patient advocates and informed by interviews with eight women with a history of ovarian cancer,[4] was adapted for the LMIC setting. All questions and responses from the original tool, including priorities for action, were reviewed by the oversight committee. The response options were refined and tested with eight women with ovarian cancer from LMICs. The survey was written in English and professionally translated from English into 28 languages (appendix p 4) and piloted before deployment. The final 59-item survey is reported in the appendix (pp 10–25) and covered: (1) demographics and background information, (2) family history of cancer, (3) journey to diagnosis (including symptoms and help seeking), (4) experience during treatment for ovarian cancer, (5) emotional, practical, and information support needs, and (6) quality of life and research and clinical priorities. A separate data extraction template was used by local clinicians to collect information on cancer diagnosis (including histology and stage at diagnosis) from patient medical records (appendix pp 26–31).

Potential participants diagnosed with ovarian cancer in the 5 years before survey administration were identified from clinic lists. Three main approaches to participant recruitment were employed: (1) review records to identify women with a diagnosis of ovarian cancer in the past 5 years and contact these potential participants (via telephone, email, letter, or WhatsApp); (2) review individuals who had attended clinics, starting with those who had attended most recently, and contact these potential participants (via telephone, email, letter, or WhatsApp), or (3) review individuals who were due to attend clinics and approach them in the clinic. Other methods for recruitment included approaching inpatients or those attending for imaging in a small number of patients (n=15). Methods of recruitment by country were recorded (appendix p 32).

Given the wide variation in health-care systems, internet access, literacy levels, and distance from study sites across countries, some participants completed a paper or electronic survey themselves while others had the survey administered by the study team in person. Pseudonymised data were transferred onto REDCap (version 13.5.4; (hosted by the International Gynecologic Cancer Society) for secure data storage and management.[8,9]

Participant-reported variables used in analyses included education level (tertiary or higher, primary or secondary as a combined category, or no formal education), self-perceived household income (above average, average, or below average for the country, or prefer not to say), knowledge of ovarian cancer before diagnosis (had heard of it and knew something about it, had heard of it but knew nothing about it, had never heard of it, or did not know or could not remember), method of payment for medical or ovarian cancer care (private insurance, state insurance, both private and state insurance, or other), symptoms before diagnosis (11 prespecified potential symptoms, grouped into seven prespecified symptom categories), extent of any impact on their financial situation due to having ovarian cancer (impacted to a great extent, to some extent, not much, or not at all, or prefer not to say), and participant priorities for investment to improve diagnosis and care in their country (up to three selected by each participant from 11 prespecified categories). Variables from medical records relevant for analyses comprised age at diagnosis (recorded as a continuous variable and categorised as <40, 40–59, or ≥60 years), type of ovarian cancer (high-grade serous, other epithelial, epithelial [unspecified], non-epithelial, borderline, or other [unspecified] or missing) and stage at diagnosis (early [stage I–II] or late [III–IV], or clinician-recorded stage unknown). Definitions and categorisations of all variables are included in the appendix (pp 33–35). Participant demographic and clinical characteristics were categorised by grouping participating countries into the four Human Development Index (HDI) levels (low, medium, high, and very high, as per country HDI classifications in 2021–22).[10] Country HDI group was also included as a participant-level variable in analyses.

Outcomes

The study was designed to describe the experiences of women with ovarian cancer across LMICs, and identify participant-related and country-related factors associated

with these experiences. Self-reported knowledge of ovarian cancer before diagnosis and the extent of any financial impact of the disease were chosen as primary outcomes, and stage at diagnosis was a post-hoc exploratory outcome. Participant priorities to improve diagnosis and care in their country was a prespecified descriptive outcome.

Statistical analysis

Recruitment targets for each country were informed by national 5-year ovarian cancer prevalence estimates as of 2021, derived from GLOBOCAN (appendix p 4). Variables included in each analysis were prespecified by the oversight committee. Participants with missing or unknown data on independent or dependent variables for a particular analysis were excluded from that analysis. Additionally, participants who responded "do not know or cannot remember" when asked about knowledge of ovarian cancer before diagnosis, those who responded "prefer not to say" when asked about household income, and those who responded "prefer not to say" when asked about the extent of any financial impact of having ovarian cancer were excluded from analyses incorporating these variables.

We fitted random-effects regression models with country of origin included as a random effect throughout. Random-effects ordered logistic regression was used to investigate factors associated with decreasing knowledge of ovarian cancer before diagnosis and increasing financial impact of the disease. Likelihood ratio tests were used to assess whether each variable significantly improved the fit of the final model, and variables with global p values of less than 0·05 in univariable analyses were simultaneously added to a multivariable model. p values comparing each variable category to the reference category for that variable were also computed using two-tailed Wald tests to determine whether each individual predictor variable had a significant effect on the log-odds of being in a higher outcome category. For both primary outcomes, the effect of including participants who responded "prefer not to say" when asked about household income was examined in sensitivity analyses.

Random-effects logistic regression was used in post-hoc analyses to investigate demographic factors and categories of symptoms before diagnosis associated with higher stage at diagnosis (III–IV *vs* I–II). Borderline tumours were excluded from these analyses. Participants with other (unspecified) subtypes or missing subtypes were retained in the analyses.

A post-hoc analysis was also done using random-effects ordered logistic regression to investigate demographic and clinical factors associated with an increasing number of categories of symptoms before diagnosis. For these regression models, the number of reported symptom categories was designated as none, one, or multiple. When a patient reported more than one symptom in a given symptom category (eg, pelvic pain and abdominal pain), this was counted as one symptom category (pain) for the purposes of this analysis (see appendix pp 33–34 for symptoms and symptom categories).

Participant priorities for improving the diagnosis and care of women with ovarian cancer within their country were summarised overall and by HDI group.

Statistical analyses were done with Stata (release 17). A p value of less than 0·05 was considered as the threshold for statistical significance in all analyses.

Role of the funding source

Authors associated with the funders of the study were included in the oversight committee and had a role in study design, data collection, data interpretation, and writing of the report. The funders of the study had no role in data analysis.

Results

2531 women with ovarian cancer consented to participate across the 82 sites in the 22 study countries. 29 did not complete the survey or submitted blank surveys, and, on reviewing responses and clinical records, 55 did not meet inclusion criteria. One participant withdrew. Consequently, 2446 participants across the 82 study sites were included in our analyses (appendix p 35). Two countries were categorised in the low HDI group, eight in the medium HDI group, nine in the high HDI group, and three in the very high HDI group (appendix p 36). Among the 2446 participants, mean age at diagnosis was 49·9 years (SD 13·6), which ranged from 45·2 years (15·6) in the low HDI group to 52·5 years (12·6) in the very high HDI group (table 1). The proportion of women reporting no formal education and below-average household income for their country was greater in low and medium HDI countries than in high and very high HDI countries (table 1).

High-grade serous epithelial cancer was the most common subtype of ovarian cancer in all HDI groups except in the low HDI group, in which more than a third of malignancies were of unspecified epithelial origin (table 1, appendix p 37). Staging data were unknown or missing in 140 (5·7%) participants overall (range: 11 [2·1%] of 517 in the very high HDI group to 45 [13·6%] of 330 participants in the low HDI group). Of the 2446 women included in the study, 1348 (55·1%) had late-stage (III–IV) ovarian cancer at diagnosis (range: 105 [31·8%] of 330 in the low HDI group to 428 [64·3%] of 666 in the medium HDI group; table 1). When examined by country, marked variation in disease characteristics was noted within the HDI groups (appendix pp 38–42). 278 (11·4%) of 2446 participants reported a family history of ovarian cancer (range: 17 [5·2%] of 330 in the low HDI group to 127 [13·6%] of 933 in the high HDI group; appendix p 43). Additional demographic data including parity and menopausal status are provided in the appendix (pp 43–44).

	Low HDI (n=330)	Medium HDI (n=666)	High HDI (n=933)	Very high HDI (n=517)	Total participants (n=2446)
Age at diagnosis, years					
Mean age (SD)	45·2 (15·6)	47·8 (13·6)	51·5 (12·8)	52·5 (12·6)	49·9 (13·6)
<40	116 (35·2%)	174 (26·1%)	167 (17·9%)	74 (14·3%)	531 (21·7%)
40–59	144 (43·6%)	365 (54·8%)	500 (53·6%)	287 (55·5%)	1296 (53·0%)
≥60	69 (20·9%)	124 (18·6%)	262 (28·1%)	156 (30·2%)	611 (25·0%)
Missing	1 (0·3%)	3 (0·5%)	4 (0·4%)	0 (0·0%)	8 (0·3%)
Education level*					
Tertiary or higher	43 (13·0%)	77 (11·6%)	189 (20·3%)	201 (38·9%)	510 (20·9%)
Primary or secondary	223 (67·6%)	413 (62·0%)	685 (73·4%)	299 (57·8%)	1620 (66·2%)
No formal education	63 (19·1%)	174 (26·1%)	51 (5·5%)	8 (1·5%)	296 (12·1%)
Missing	1 (0·3%)	2 (0·3%)	8 (0·9%)	9 (1·7%)	20 (0·8%)
Household income (self-perceived)†					
Above average for the country	18 (5·5%)	39 (5·9%)	90 (9·6%)	60 (11·6%)	207 (8·5%)
Average for the country	156 (47·3%)	278 (41·7%)	441 (47·3%)	278 (53·8%)	1153 (47·1%)
Below average for the country	140 (42·4%)	333 (50·0%)	342 (36·7%)	91 (17·6%)	906 (37·0%)
Prefer not to say	14 (4·2%)	10 (1·5%)	48 (5·1%)	73 (14·1%)	145 (5·9%)
Missing	2 (0·6%)	6 (0·9%)	12 (1·3%)	15 (2·9%)	35 (1·4%)
Method of payment for medical or ovarian cancer care					
Private insurance	7 (2·1%)	38 (5·7%)	125 (13·4%)	142 (27·5%)	312 (12·8%)
State insurance	16 (4·8%)	227 (34·1%)	388 (41·6%)	210 (40·6%)	841 (34·4%)
Private and state insurance	0 (0·0%)	19 (2·9%)	21 (2·3%)	4 (0·8%)	44 (1·8%)
Other (self or family funded or other)‡	263 (79·7%)	373 (56·0%)	387 (41·5%)	147 (28·4%)	1170 (47·8%)
Missing	44 (13·3%)	9 (1·4%)	12 (1·3%)	14 (2·7%)	79 (3·2%)
Subtype§					
High-grade serous	73 (22·1%)	365 (54·8%)	424 (45·4%)	243 (47·0%)	1105 (45·2%)
Other epithelial	87 (26·4%)	141 (21·2%)	270 (28·9%)	147 (28·4%)	645 (26·4%)
Epithelial, unspecified	116 (35·2%)	35 (5·3%)	69 (7·4%)	50 (9·7%)	270 (11·0%)
Non-epithelial	40 (12·1%)	81 (12·2%)	73 (7·8%)	45 (8·7%)	239 (9·8%)
Borderline	4 (1·2%)	16 (2·4%)	73 (7·8%)	21 (4·1%)	114 (4·7%)
Other, unspecified	10 (3·0%)	23 (3·5%)	22 (2·4%)	11 (2·1%)	66 (2·7%)
Missing	0	5 (0·8%)	2 (0·2%)	0	7 (0·3%)
Stage at diagnosis					
I	94 (28·5%)	138 (20·7%)	252 (27·0%)	166 (32·1%)	650 (26·6%)
II	86 (26·1%)	62 (9·3%)	90 (9·6%)	70 (13·5%)	308 (12·6%)
III	75 (22·7%)	345 (51·8%)	363 (38·9%)	234 (45·3%)	1017 (41·6%)
IV	30 (9·1%)	83 (12·5%)	182 (19·5%)	36 (7·0%)	331 (13·5%)
Unknown or missing	45 (13·6%)	38 (5·7%)	46 (4·9%)	11 (2·1%)	140 (5·7%)

Data are n (%) unless otherwise stated. Additional participant characteristics including parity, menopausal status, and family history of ovarian cancer are presented in the appendix (pp 43–44). HDI=Human Development Index. *Highest level of education, with education levels defined in the appendix (p 10); secondary education included post-secondary non-tertiary education (eg, technical or community college). †In response to the survey question "Just before you were diagnosed, in your view what was your household income?" ‡All survey response options on method of payment are listed in the appendix (p 11). §A further breakdown of histology is provided in the appendix (pp 37–40).

Table 1: **Demographic and clinical characteristics of participants by country HDI group**

2421 (99·0%) of the 2446 participants responded to the question on their knowledge of ovarian cancer before diagnosis. Of these 2421 participants, 631 (26·1%) reported having heard of ovarian cancer and knowing something about it (range: three [3·3%] of 90 participants in Nepal to 92 [63·4%] of 145 in Uzbekistan; appendix p 49), while 930 (38·4%) participants had heard of the disease but knew nothing about it (range: ten [16·7%] of 60 in Zambia to 16 [61·5%] of 26 in Egypt; appendix p 50). 2133 participants (87·2% of the total 2446 study participants) with relevant data on model variables, including age at diagnosis, household income, and education level, were included in random-effects ordered logistic regression analyses (table 2). In multivariable analysis, lower education level (no formal education *vs* tertiary or higher education, odds ratio [OR] 3·41, 95% CI 2·38–4·89, p<0·0001; and primary or secondary education *vs* tertiary or higher education, OR 1·96,

	Univariable analysis*			Multivariable analysis*		
	OR (95% CI)	p value†	Global p value‡	OR (95% CI)	p value†	Global p value‡
Age group at diagnosis, years	..	..	0·34	..	..	..
<40 (n=475)	1 (ref)	..	..	..	..	..
40–59 (n=1138)	1·12 (0·91–1·38)	0·29	..	..	..	..
≥60 (n=520)	1·20 (0·94–1·53)	0·15	..	..	..	..
Education level	..	..	<0·0001	..	..	<0·0001
Tertiary or higher (n=443)	1 (ref)	..	..	1 (ref)	..	..
Primary or secondary (n=1432)	2·30 (1·85–2·87)	<0·0001	..	1·96 (1·56–2·47)	<0·0001	..
No formal education (n=258)	4·60 (3·25–6·51)	<0·0001	..	3·41 (2·38–4·89)	<0·0001	..
Household income (self-perceived)	..	..	<0·0001	..	..	<0·0001
Above average for the country (n=196)	1 (ref)	..	..	1 (ref)	..	..
Average for the country (n=1077)	1·32 (0·98–1·77)	0·071	..	1·08 (0·80–1·46)	0·62	..
Below average for the country (n=860)	2·65 (1·92–3·64)	<0·0001	..	1·79 (1·28–2·50)	0·0006	..
Country Human Development Index	..	..	<0·0001	..	..	0·0007
Very high (n=394)	1 (ref)	..	..	1 (ref)	..	..
High (n=841)	0·89 (0·47–1·69)	0·73	..	0·67 (0·38–1·20)	0·18	..
Medium (n=606)	2·88 (1·51–5·52)	0·0014	..	1·88 (1·04–3·42)	0·038	..
Low (n=292)	3·38 (1·44–7·95)	0·0052	..	2·32 (1·06–5·04)	0·034	..

After excluding participants with missing information on the independent or dependent variables, we further excluded individuals who responded that they "do not know or cannot remember" when asked how much they knew, if anything, about ovarian cancer before their diagnosis, and individuals who responded "prefer not to say" when asked about household income (appendix p 52). The final number of participants included in this analysis was 2133. OR=odds ratio. *The outcome was decreasing knowledge of ovarian cancer before diagnosis (categorised as: had heard of it and knew something about it; had heard of it but knew nothing about it; and never heard of it), with ORs representing a decrease in knowledge by one category level. †p values obtained from two-tailed Wald tests. ‡Global p values obtained from the likelihood ratio test.

Table 2: **Factors associated with decreasing knowledge of ovarian cancer before diagnosis**

1·56–2·47, p<0·0001), lower household income (self-perceived as below *vs* above average for the country, OR 1·79, 1·28–2·50, p=0·0006), and lower HDI group (low *vs* very high HDI group, OR 2·32, 1·06–5·04, p=0·034; and medium *vs* very high HDI group, OR 1·88, 1·04–3·42, p=0·038) were significantly associated with a decrease in knowledge by one category level. A sensitivity analysis, in which the participant response of "prefer not to say" was included as a category for household income, produced similar results (appendix p 53).

Among 2406 women who reported on the extent of any financial impact of their ovarian cancer, 1105 (45·9%) reported that their financial situation had been impacted to a great extent, and 709 (29·5%) to some extent. The proportions impacted varied by country (range for proportion impacted to a great extent: 16 [15·2%] of 105 in Argentina to 46 [83·6%] of 55 in Uganda; appendix p 61). 2099 participants (85·8% of the total 2446 participants) with relevant data, including age at diagnosis, household income, education level, and payment method for medical or ovarian cancer care, were included in multivariable regression analysis (table 3). Decreasing level of household income (self-perceived as below *vs* above average for the country, OR 3·64, 95% CI 2·58–5·14, p<0·0001; and average *vs* above average for the country, OR 1·78, 1·31–2·41, p=0·0002), and lower HDI group (low *vs* very high HDI group, OR 3·70, 1·10–12·45, p=0·035; and medium *vs* very high HDI group, OR 3·47, 1·40–8·59, p=0·0072) were significantly associated with an increase in financial impact by one category level. A sensitivity analysis, in which the participant response of "prefer not to say" was included as a category for household income, generally produced similar results albeit with some differences in associations for age group and HDI group (appendix pp 54–55). Of the participants who reported that their finances had been impacted to any extent by their diagnosis (those affected to a great extent, some extent, or not much, n=1995), 720 (36·1%) indicated that their household income had fallen below the level they needed to live on when asked how their financial situation had been impacted, although marked variation in this proportion was noted by country (from three [4·6%] of 65 in Argentina to 127 [65·1%] of 195 in Mexico; appendix p 56).

In post-hoc multivariable analysis including 1929 women with an invasive ovarian tumour (82·7% of 2332 participants with an ovarian tumour other than borderline) for whom the required model data were available, categorical age at diagnosis, education level, and HDI group were significantly associated with ovarian cancer stage at diagnosis (table 4). Increasing age group at diagnosis was associated with higher odds of late-stage (III–IV) diagnosis (40–59 years *vs* <40 years, OR 1·93, 95% CI 1·51–2·48, p<0·0001; and ≥60 years *vs* <40 years, OR 3·61, 2·67–4·89, p<0·0001). Compared

	Univariable analysis*			Multivariable analysis*		
	OR (95% CI)	p value†	Global p value‡	OR (95% CI)	p value†	Global p value‡
Age group at diagnosis, years	..	..	0·0001	..	..	0·0001
<40 (n=450)	1 (ref)	..	..	1 (ref)	..	..
40–59 (n=1130)	1·28 (1·03–1·60)	0·027	..	1·22 (0·97–1·53)	0·083	..
≥60 (n=519)	0·83 (0·64–1·06)	0·14	..	0·78 (0·60–1·01)	0·061	..
Education level	..	..	0·0001	..	..	0·34
Tertiary or higher (n=442)	1 (ref)	..	..	1 (ref)	..	..
Primary or secondary (n=1385)	1·34 (1·08–1·66)	0·0090	..	1·02 (0·81–1·28)	0·90	..
No formal education (n=272)	2·09 (1·48–2·95)	<0·0001	..	1·28 (0·88–1·86)	0·20	..
Household income (self-perceived)	..	..	<0·0001	..	..	<0·0001
Above average for the country (n=195)	1 (ref)	..	..	1 (ref)	..	..
Average for the country (n=1063)	1·84 (1·37–2·47)	0·0001	..	1·78 (1·31–2·41)	0·0002	..
Below average for the country (n=841)	3·94 (2·85–5·45)	<0·0001	..	3·64 (2·58–5·14)	<0·0001	..
Method of payment for medical or ovarian cancer care	..	..	0·019	..	..	0·54
Private insurance (n=272)	1 (ref)	..	..	1 (ref)	..	..
State insurance (n=731)	1·50 (1·09–2·06)	0·012	..	1·21 (0·88–1·66)	0·25	..
Private and state insurance (n=40)	1·46 (0·75–2·85)	0·26	..	1·50 (0·77–2·93)	0·24	..
Other (self or family funded or other; n=1056)	1·68 (1·21–2·32)	0·0018	..	1·21 (0·87–1·69)	0·25	..
Country Human Development Index	..	..	0·018	..	..	0·077
Very high (n=386)	1 (ref)	..	..	1 (ref)	..	..
High (n=824)	2·70 (1·02–7·11)	0·045	..	2·28 (0·94–5·54)	0·068	..
Medium (n=631)	4·65 (1·73–12·47)	0·0023	..	3·47 (1·40–8·59)	0·0072	..
Low (n=258)	4·59 (1·23–17·20)	0·024	..	3·70 (1·10–12·45)	0·035	..

After excluding participants with missing information on the independent or dependent variables, we further excluded individuals who responded "prefer not to say" when asked about the extent of any impact on their financial situation due to having ovarian cancer, and individuals who responded "prefer not to say" when asked about household income (appendix p 52). The final number of participants included in this analysis was 2099. OR=odds ratio. *The outcome was increasing financial impact of ovarian cancer (categorised as being impacted to a great extent; some extent; not much; and not at all), with ORs representing an increase in financial impact by one category level. †p values obtained from two-tailed Wald tests. ‡Global p values obtained from the likelihood ratio test.

Table 3: **Factors associated with increasing financial impact of ovarian cancer**

with participants reporting tertiary or higher education, those reporting primary or secondary education had lower odds of late-stage diagnosis (OR 0·74, 0·57–0·96, p=0·022). In comparison with the very high HDI group, the medium HDI group had increased odds of having late-stage diagnosis (OR 2·13, 1·27–3·58, p=0·0042). Overall, knowledge of ovarian cancer before diagnosis and household income were not significantly associated with stage at diagnosis on univariable analysis.

Of women who responded to the question on specific symptoms (n=2428), 2223 (91·6%) reported one or more prespecified symptoms of possible ovarian cancer before diagnosis (appendix p 46). More than half of respondents reported abdominal and/or pelvic pain (n=1594, 65·7%) and increased abdominal size and/or persistent bloating (n=1422, 58·6%), more than a quarter reported feeling full and/or difficulty eating (n=827, 34·1%), and one in five reported urinary urgency and/or frequency (n=488, 20·1%). The symptoms reported were similar in women with epithelial and non-epithelial cancers (appendix p 45). Symptoms were common across HDI levels and all cancer stages, with at least one symptom reported in 552 (85·6%) of 645 participants with stage I cancer and 316 (95·5%) of 331 with stage IV cancer (figure). Of the participants reporting symptoms (n=2223), 1739 (78·2%) reported having multiple symptoms (median of 2 symptoms [IQR 2–4; range 1–7]). In post-hoc univariable logistic regression models, four categories of symptoms were more strongly associated with late-stage (III–IV) diagnosis, namely eating-related symptoms, bloating, weight loss, and bowel-related symptoms (appendix p 47). Further post-hoc univariable regression analyses, including 2121 women with relevant data on model variables (86·7% of the total 2446 study participants), indicated that respondents with late-stage diagnoses were significantly more likely to report an increasing number of symptom categories than those with early-stage diagnoses (appendix p 48).

2415 women responded when asked to select up to three priorities most in need of improvement if money could be invested in improving the diagnosis and care of women with ovarian cancer in their country. Development of a screening programme (n=1513, 62·7%) and free

	Univariable analysis*			Multivariable analysis*		
	OR (95% CI)	p value†	Global p value‡	OR (95% CI)	p value†	Global p value‡
Age group at diagnosis, years	..	..	<0·0001	..	..	<0·0001
<40 (n=408)	1 (ref)	..	..	1 (ref)	..	..
40–59 (n=1038)	1·92 (1·50–2·45)	<0·0001	..	1·93 (1·51–2·48)	<0·0001	..
≥60 (n=483)	3·55 (2·63–4·79)	<0·0001	..	3·61 (2·67–4·89)	<0·0001	..
Education level	..	..	0·0023	..	..	0·0040
Tertiary or higher (n=401)	1 (ref)	..	..	1 (ref)	..	..
Primary or secondary (n=1290)	0·83 (0·65–1·07)	0·16	..	0·74 (0·57–0·96)	0·022	..
No formal education (n=238)	1·50 (1·01–2·24)	0·046	..	1·18 (0·78–1·78)	0·42	..
Household income (self-perceived)	..	..	0·50	..	..	..
Above average for the country (n=176)	1 (ref)	..	..	..	..	..
Average for the country (n=978)	1·02 (0·72–1·44)	0·91	..	..	..	..
Below average for the country (n=775)	1·16 (0·80–1·67)	0·44	..	..	..	..
Knowledge of ovarian cancer before diagnosis	..	..	0·071	..	..	..
Had heard of it and knew something about it (n=516)	1 (ref)	..	..	..	..	..
Had heard of it but did not know anything about it (n=780)	1·21 (0·95–1·55)	0·12	..	..	..	..
Had never heard of it (n=633)	1·37 (1·04–1·78)	0·023	..	..	..	..
Country Human Development Index	..	..	0·0003	..	..	0·0013
Very high (n=369)	1 (ref)	..	..	1 (ref)	..	..
High (n=744)	1·49 (0·86–2·59)	0·15	..	1·57 (0·96–2·58)	0·074	..
Medium (n=559)	1·88 (1·07–3·29)	0·028	..	2·13 (1·27–3·58)	0·0042	..
Low (n=257)	0·48 (0·23–1·00)	0·050	..	0·55 (0·28–1·05)	0·072	..

Participants with borderline ovarian cancers were excluded from this analysis, while participants with other (unspecified) subtypes or missing subtypes were retained in the analysis. A further breakdown of histology is provided in the appendix (pp 37–40). After excluding participants with missing or unknown information on the independent or dependent variables, we further excluded individuals who responded that they "do not know or cannot remember" when asked how much they knew, if anything, about ovarian cancer before their diagnosis, and individuals who responded "prefer not to say" when asked about household income (appendix p 52). The final number of participants included in this analysis was 1929. OR=odds ratio. *The outcome was late-stage diagnosis, with ORs representing the odds of late stage (III–IV) versus early stage (I–II) cancer at diagnosis. †p values obtained from two-tailed Wald tests. ‡Global p values obtained from the likelihood ratio test.

Table 4: **Post-hoc analysis of factors associated with higher ovarian cancer stage (III–IV *vs* I–II) at diagnosis**

access to diagnostic tests (n=1301, 53·9%) were priorities for the majority of women, and in around a third of women, selected priorities were reducing delays in diagnosis (n=746, 30·9%), raising awareness of ovarian cancer and the symptoms (n=759, 31·4%), and free access to treatments (n=822, 34·0%). These top five priorities were the same across all HDI groups (table 5). The top priorities by country are presented in the appendix (pp 57–60).

Discussion

In this study, we described the characteristics, experiences, and priorities of 2446 women diagnosed with ovarian cancer in 22 LMICs across four continents, and identified potentially modifiable factors associated with disease awareness, stage at diagnosis, and the financial impact of the condition on participants.

To our knowledge, this is the largest study to report the symptoms of ovarian cancer experienced by women before diagnosis and the first conducted in the LMIC setting. Our findings indicate that symptoms are common in women diagnosed with both early-stage (I–II) and late-stage (III–IV) ovarian cancer within LMICs. Although ovarian cancer has often been termed a silent killer, studies in HICs have identified a symptom profile for the disease.[11–13] As in these studies, we found that most women had symptoms before diagnosis and that abdominal and/or pelvic pain was the most commonly reported symptom.[11,12] Additionally, the median number of symptoms reported in our study was two, consistent with a large US survey-based study.[13] However, symptoms including persistent bloating and/or abdominal distension, abdominal and/or pelvic pain, and urinary symptoms were more common in our population than in the previous studies based in the UK and USA.[11,13] Although some symptoms, including abdominal distention (which might be related to ascites) and systemic symptoms, such as weight loss, were more strongly associated with late-stage disease, they were still reported in substantial numbers of women with early-stage disease. A recent UK study found that 77 (64·7%) of 119 women with high-grade serous ovarian cancer detected via a symptom-triggered rapid diagnostic cancer pathway

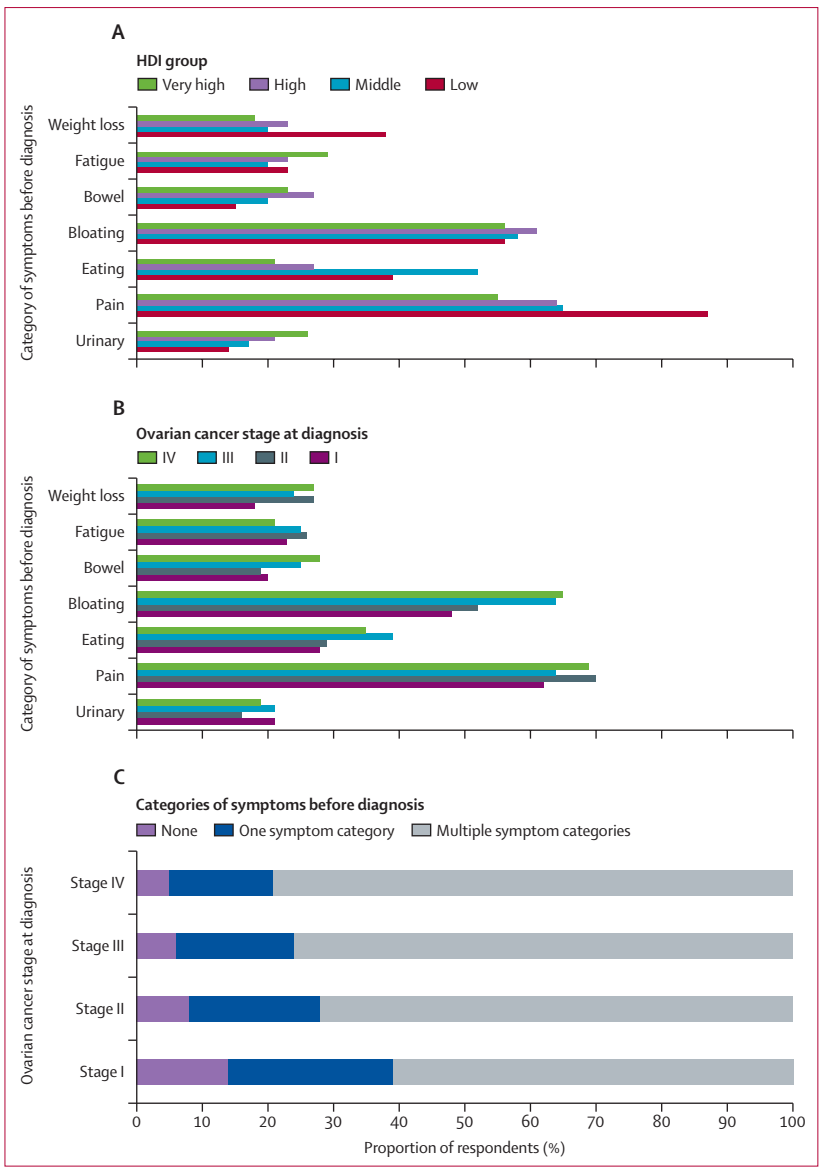

Figure: **Symptoms reported before diagnosis (all ovarian cancers)**
(A) Proportion of respondents reporting symptoms within seven symptom categories by HDI group (n=2428). (B) Proportion of respondents reporting symptoms within seven symptom categories by cancer stage at diagnosis (n=2290). (C) Proportion of respondents reporting no, one, or multiple symptom categories by cancer stage at diagnosis (n=2290). In plots A and B, the seven symptom categories represent 11 prespecified potential symptoms, as follows: abdominal and/or pelvic pain (pain); persistent bloating and/or increased abdominal size (bloating); difficulty eating and/or feeling full (eating); urinary frequency and/or urinary urgency (urinary); changes in bowel habit (bowel); extreme fatigue (fatigue); and unexplained weight loss (weight loss). In plot C, if a participant reported more than one symptom in a given category (eg, pelvic pain and abdominal pain), this was counted as one symptom category (pain). HDI=Human Development Index.

were reported as having low-to-moderate-extent disease, and 30 (25·2%) were diagnosed at stage I–II disease.[14] Although the majority of women in our study (55·1%) had late-stage disease at diagnosis, the high frequency of multiple symptoms among women diagnosed at an early stage suggests that targeted symptom-triggered detection approaches could serve a role in aiding earlier diagnosis in LMICs.

A minority (26·1%) of participants in this study had knowledge of ovarian cancer before their diagnosis. This finding is consistent with research from HICs, in which knowledge of ovarian cancer before diagnosis was low among survey respondents.[4,15,16] The finding that a decreasing level of knowledge of ovarian cancer was associated with lower education level, lower HDI level, and lower household income indicates that knowledge might be expected to increase with an increase in country HDI level or an individual's wealth. However, we observed marked variation among individual countries in terms of participants' knowledge of ovarian cancer between and within HDI groups (appendix pp 49–51). Research to understand why knowledge is high in some countries could help to support the development of strategies to promote awareness in other LMICs. We did not find a statistically significant association between knowledge of the disease and stage at diagnosis. To date, only small studies have examined the effect of symptom awareness strategies in HICs and have not shown a stage shift.[17] However, the Canadian DOvE study, in which a proactive approach was taken with symptomatic women recruited through a number of approaches, including self-referral following a media campaign, resulted in ovarian cancer diagnoses with lower symptom burdens compared with the usual care pathway.[18] It is possible that symptom awareness approaches might lead to more timely ovarian cancer diagnosis; however, given that most patients with symptoms of ovarian cancer do not have the disease, any campaigns in LMICs would need to be carefully targeted and designed so as not to unduly burden patients or health-care systems. Having relatives with ovarian cancer could affect knowledge and experience of the disease, and such patients might represent a higher-risk population for targeted education or interventions, but further research is needed to explore this within LMICs.

The odds of late-stage diagnosis were higher in the medium HDI group than in the very high HDI group. However, the low HDI group had the lowest odds of late-stage diagnosis, albeit without a significant difference versus the very high HDI group; this finding might be due to women with advanced cancer in low HDI countries being too unwell or not surviving long enough to be included in our study, which is supported by feedback from clinical researchers in those countries.[19] Although the odds of late-stage diagnosis were slightly higher in participants who reported below-average household income than in those reporting above-average household income in univariable analysis, this was not statistically significant. By contrast, in England, which has a universal health-care system, previous research has identified an association between socioeconomic status and stage at diagnosis.[20] Research is needed to examine the relationship between income, other socioeconomic factors, and outcomes including stage at diagnosis in LMICs. Regarding tumour subtypes, more than a third of

	Low HDI (n=330)	Medium HDI (n=658)	High HDI (n=922)	Very high HDI (n=505)	Total respondents (n=2415)
Development of a screening programme	213 (64·5%)	367 (55·8%)	688 (74·6%)	245 (48·5%)	1513 (62·7%)
Free access to diagnostic tests	197 (59·7%)	404 (61·4%)	507 (55·0%)	193 (38·2%)	1301 (53·9%)
Free access to treatments	129 (39·1%)	282 (42·9%)	257 (27·9%)	154 (30·5%)	822 (34·0%)
Raising awareness of ovarian cancer and the symptoms	120 (36·4%)	263 (40·0%)	218 (23·6%)	158 (31·3%)	759 (31·4%)
Reducing delays in diagnosis	66 (20·0%)	245 (37·2%)	307 (33·3%)	128 (25·3%)	746 (30·9%)
Access to new drugs approved in high-income countries	21 (6·4%)	74 (11·2%)	100 (10·8%)	97 (19·2%)	292 (12·1%)
Increasing the number of experienced surgeons	9 (2·7%)	70 (10·6%)	101 (11·0%)	71 (14·1%)	251 (10·4%)
Women at risk due to family history identified	17 (5·2%)	24 (3·6%)	95 (10·3%)	67 (13·3%)	203 (8·4%)
Funding for research	7 (2·1%)	17 (2·6%)	68 (7·4%)	45 (8·9%)	137 (5·7%)
Access to clinical trials	4 (1·2%)	12 (1·8%)	26 (2·8%)	23 (4·6%)	65 (2·7%)
Other	10 (3·0%)	2 (0·3%)	11 (1·2%)	39 (7·7%)	62 (2·6%)

Priorities were selected from a prespecified list of 11 priorities; participants could select up to three priorities (appendix p 25). HDI=Human Development Index.

Table 5: **Priorities for improving ovarian cancer diagnosis and care by country HDI group**

tumours in the low HDI group were recorded as epithelial, unspecified, while the proportion of high-grade serous tumours was lower in the low HDI group than in the other HDI groups. Lack of accurate and specific histopathology information could have implications for patient outcomes, as this information is important when considering treatment options and prognosis.

The substantial financial burden that cancer diagnoses have on patients and their families, due to diagnostic and treatment costs, travel costs, and lost income through reduced productivity, has been described in HICs.[4,21] However, we are not aware of any studies exploring financial toxicity in women with ovarian cancer in LMICs. Previous studies on multiple cancers have identified low income as a key risk factor for financial toxicity in the USA,[21] which is consistent with our study, in which both lower household income (in comparison with participant-perceived national average) and lower HDI level were associated with increasing financial impact. In LMICs, where welfare support is often limited, diagnosis and care is frequently self-funded, and new treatments might be unaffordable to many individuals, an ovarian cancer diagnosis can have a profound financial impact. Concerningly in our study, more than a third of participants who reported a financial impact of ovarian cancer also reported that their household income had fallen below the level required to live on due to their diagnosis.

In LMICs, understanding the priorities of patients is key to tailor improvements in research and care. For women within this study, opportunities for improved diagnosis, through the development of screening programmes and through free access to diagnostic tests, were the most important priorities across all HDI levels. Studies have not found a significant survival benefit through screening, and national screening programmes are not recommended.[22,23] However, the UK National Institute for Health and Care Excellence now recommends surveillance in asymptomatic women who are at high risk due to *BRCA1/2* mutations.[24] In addition, blood tests, such as for cancer antigen 125, and transvaginal ultrasound are recommended in many countries as first-line investigations in symptomatic women.[25,26] Free access to such tests would address patient priorities and support ovarian cancer detection, but would need to be considered within the context of health demands within each country.

This study has several limitations. Firstly, we have only captured the experiences of women who could afford to undergo ovarian cancer diagnosis, and the results might exclude those in greatest poverty. Local clinical researchers in low and middle HDI settings in our study highlighted that in some countries, there is only one ovarian cancer centre and only patients with the necessary resources can travel for treatment. This might explain the finding that a primary or secondary level of education, versus a tertiary or higher level of education, was associated with reduced odds of late-stage diagnosis, as lower education is often associated with lower income. Recruitment varied by country, with some countries contributing relatively few participants and not meeting recruitment targets. Including all participants, even when country-level sample size was small, enabled us to capture the experiences of women from a range of large and small countries, but means caution is required when generalising findings to inform priority setting or develop interventions at the national level. We have provided country-level descriptive data to support interpretation and guide further research (appendix pp 38–42, 49–51, 56–61). Given the diverse health-care systems, follow-up schedules, staff resources, literacy rates, and access to technology in the different countries, it was necessary to employ several approaches to recruitment and data collection. These approaches maximised inclusion but added heterogenicity. Additionally, the total numbers of women approached were not captured and thus recruitment rates could not be determined. Furthermore, the cross-sectional nature of the

study means that results are subject to recall bias (eg, recall of knowledge of ovarian cancer before diagnosis). Cohort studies recruiting at the point of cancer diagnosis could further improve understanding of women's knowledge of ovarian cancer and their experiences over time, and enable assessment of outcomes such as relapse rates. We also acknowledge that, although we examined factors associated with early-stage and late-stage diagnosis, results are likely to be affected by survivorship bias, as patients who were too sick or who died soon after diagnosis will not have been included. We present these analyses as, given the absence of cancer registries in most LMICs, the data provide the best available information on patient factors associated with ovarian cancer stage in the LMIC setting. Nonetheless, a small proportion of data were missing for participant-reported variables and for variables extracted from notes (appendix p 52). Furthermore, participants who responded but selected "do not know or cannot remember" for prediagnosis ovarian cancer knowledge or "prefer not to say" for household income and financial impact were excluded from analyses, which could bias our findings. These data might be missing not at random and so approaches such as multiple imputation were not employed. However, including "prefer not to say" as a category for household income within sensitivity analyses generally had little influence with small differences in effect estimates.

Given the finding that medium country HDI status and lower education level (no formal education *vs* tertiary or higher) were associated with late-stage diagnosis in this study, the projected rise in ovarian cancer incidence rates in LMICs over the next 15 years[3] has the potential to deepen inequalities in ovarian cancer diagnosis and outcomes, disproportionately affecting women in countries with lower socioeconomic development. The ovarian cancer symptoms described in this study, particularly abdominal and/or pelvic pain and abdominal distension and/or persistent bloating which occurred frequently in women with both early-stage and late-stage disease, could be used to support patient awareness and symptom-triggered testing approaches in LMICs, which would fit with the priorities of women affected by the disease in these settings. However, any interventions would need to take account of the specific resources and socioeconomic, cultural, and geographical factors within a given country. To support next steps, detailed reports have been made available to each country team, and survey data made available to support further research to improve care for women with ovarian cancer in LMICs.

Contributors

GF: writing (original draft), conceptualisation, formal analysis, methodology, writing (review/editing); TA: conceptualisation, formal analysis, investigation, methodology, writing (review/editing); RSA: conceptualisation, methodology, writing (review/editing); CEA: investigation, writing (review/editing); RB: conceptualisation, investigation, methodology, writing (review/editing); RCWC: conceptualisation, methodology, writing (review/editing); RC: conceptualisation, methodology, writing (review/editing); ME: funding, resources, software, project administration; DK: conceptualisation, investigation, methodology, writing (review/editing); KK: data curation, formal analysis, data access and verification, visualisation, writing (review/editing); IL: conceptualisation, methodology, writing (review/editing); CM: funding, resources, software, project administration; PTM: investigation, writing (review/editing); EM: data curation, formal analysis, data access and verification, visualisation, writing (review/editing); AsM: conceptualisation, investigation, methodology, writing (review/editing); AiM: investigation, writing (review/editing); SN: investigation, writing (review/editing); FN: conceptualisation, formal analysis, investigation, methodology, writing (review/editing); MO: conceptualisation, investigation, methodology, writing (review/editing); JP: investigation, writing (review/editing); SP: investigation, writing (review/editing); NP: conceptualisation, investigation, methodology, writing (review/editing); RR-M: investigation, writing (review/editing); BR: conceptualisation, investigation, methodology, writing (review/editing); JR: investigation, writing (review/editing); AFS: investigation, writing (review/editing); IS: investigation, writing (review/editing); E-MS: conceptualisation, methodology, writing (review/editing); S-YY: investigation, writing (review/editing); NZ: investigation, writing (review/editing); FR: conceptualisation, methodology, project administration, supervision, writing (review/editing). All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Declaration of interests

The following authors declare payments of US$500 from the funders of the study (World Ovarian Cancer Coalition and the International Gynecologic Cancer Society) to their institutions as a country lead site: AiM, AsM, BR, DK, FN, JP, RR-M, NP, AFS, and NZ. CEA, in addition to the honorarium payment of $500 from the study funders to his institution, declares payment from AstraZeneca for lectures given at regional AstraZeneca meetings. RB and JR declare payments of $300 from the study funders to their institutions as participating sites. MO declares payment from the study funders of $7343 as required by the Uganda National Council for Science and Technology to cover honorarium payments at three sites, supervision, printing, and fees for researchers, participants, and ethics approvals. PTM declares payment of $6675 from the study funders as required by the Malawi National Health Sciences Research Committee to cover honorarium payments at three sites, printing, translation, and fees for researchers, participants, and ethics approvals. ME is employed by the International Gynecologic Cancer Society. FR and CM are employed by the World Ovarian Cancer Coalition. KK declares ownership of Novartis stock and worked for Novartis from April, 2013 to March, 2025. Novartis was not involved in this research and KK contributed to the research as a volunteer for the World Ovarian Cancer Coalition, as part of a volunteering scheme through the Novartis Foundation. All other authors declare no competing interests. Where authors are identified as personnel of the International Agency for Research on Cancer, the authors alone are responsible for the views expressed in this Article, and they do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer.

Data sharing

Aggregated data, including country-level data for figures included in the appendix, will be shared via Queen Mary Research Online (https://qmro.qmul.ac.uk/xmlui/) on publication. Anonymised participant-level survey data are available from the authors on written request to the corresponding author, which will be reviewed by the oversight committee of the Every Woman Study LMICs programme. Access to the participant-level data will require the signing of a data sharing agreement. The participant information and consent form is provided in the appendix (pp 8–9). The study protocol has been published (*PLoS One* 2024; **19:** e0298154).

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References

1 Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2024; **74:** 229–63.

2 WHO. Mortality, both sexes, in 2022. https://gco.iarc.fr/today/en/dataviz/tables?mode=cancer&cancers=39&types=1&group_populations=1&multiple_populations=1 (accessed March 28, 2025).

3 WHO. Estimated number of new cases from 2022 to 2050, both sexes, age [0–85+]. 2024. https://gco.iarc.fr/tomorrow/en/dataviz/isotype?cancers=25&single_unit=10000&years=2050&types=0 (accessed March 28, 2025).

4 Reid F, Bhatla N, Oza AM, et al. The World Ovarian Cancer Coalition Every Woman Study: identifying challenges and opportunities to improve survival and quality of life. *Int J Gynecol Cancer* 2021; **31:** 238–44.

5 Tone A, Boghosian T, Ross A, et al. Understanding the experience of Canadian women living with ovarian cancer through the Every Woman Study. *Curr Oncol* 2022; **29:** 3318–40.

6 The World Bank. World Bank Country and Lending Groups. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups (accessed Oct 28, 2025).

7 Reid F, Adams T, Adel RS, et al. The Every Woman Study Low- and Middle-Income Countries Edition protocol: a multi-country observational study to assess opportunities and challenges to improving survival and quality of life for women with ovarian cancer. *PLoS One* 2024; **19:** e0298154.

8 Harris PA, Taylor R, Minor BL, et al, and the REDCap Consortium. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform* 2019; **95:** 103208.

9 Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009; **42:** 377–81.

10 United Nations Development Programme. Human development report 2021–22. 2022. https://hdr.undp.org/content/human-development-report-2021-22 (accessed Oct 28, 2025).

11 Hamilton W, Peters TJ, Bankhead C, Sharp D. Risk of ovarian cancer in women with symptoms in primary care: population based case-control study. *BMJ* 2009; **339:** b2998.

12 Lim AWW, Mesher D, Gentry-Maharaj A, et al. Predictive value of symptoms for ovarian cancer: comparison of symptoms reported by questionnaire, interview, and general practitioner notes. *J Natl Cancer Inst* 2012; **104:** 114–24.

13 Goff BA, Mandel LS, Melancon CH, Muntz HG. Frequency of symptoms of ovarian cancer in women presenting to primary care clinics. *JAMA* 2004; **291:** 2705–12.

14 Kwong FLA, Kristunas C, Davenport C, et al, and the ROCkeTS collaborators. Symptom-triggered testing detects early stage and low volume resectable advanced stage ovarian cancer. *Int J Gynecol Cancer* 2024; published online Sept 25. https://doi.org/10.1136/ijgc-2024-005371.

15 Low EL, Waller J, Menon U, Jones A, Reid F, Simon AE. Ovarian cancer symptom awareness and anticipated time to help-seeking for symptoms among UK women. *J Fam Plann Reprod Health Care* 2013; **39:** 163–71.

16 Radu CA, Matos de Melo Fernandes N, Khalfe S, Stordal B. Awareness of ovarian cancer symptoms and risk factors in a young ethnically diverse British population. *Cancer Med* 2023; **12:** 9879–92.

17 Cancer Research UK. Evaluation of the Be Clear on Cancer ovarian cancer awareness campaign. March, 2015. https://assets.publishing.service.gov.uk/media/5a74e1ace5274a59fa715b08/CRUK_Report_Local_Ovarian_130315_CT_GW_final.pdf (accessed Oct 28, 2025).

18 Gilbert L, Basso O, Sampalis J, et al, and the DOvE Study Group. Assessment of symptomatic women for early diagnosis of ovarian cancer: results from the prospective DOvE pilot project. *Lancet Oncol* 2012; **13:** 285–91.

19 Bajwa A, Chidebe RCW, Adams T, et al. Challenges and opportunities in ovarian cancer care: a qualitative study of clinician perspectives from 24 low- and middle-income countries. *J Cancer Policy* 2025; **44:** 100582.

20 Barclay ME, Abel GA, Greenberg DC, Rous B, Lyratzopoulos G. Socio-demographic variation in stage at diagnosis of breast, bladder, colon, endometrial, lung, melanoma, prostate, rectal, renal and ovarian cancer in England and its population impact. *Br J Cancer* 2021; **124:** 1320–29.

21 Smith GL, Lopez-Olivo MA, Advani PG, et al. Financial burdens of cancer treatment: a systematic review of risk factors and outcomes. *J Natl Compr Canc Netw* 2019; **17:** 1184–92.

22 Menon U, Gentry-Maharaj A, Burnell M, et al. Ovarian cancer population screening and mortality after long-term follow-up in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS): a randomised controlled trial. *Lancet* 2021; **397:** 2182–93.

23 Pinsky PF, Yu K, Kramer BS, et al. Extended mortality results for ovarian cancer screening in the PLCO trial with median 15 years follow-up. *Gynecol Oncol* 2016; **143:** 270–75.

24 National Institute for Health and Care Excellence. Ovarian cancer: identifying and managing familial and genetic risk. NICE guideline. NG241. March 21, 2024. https://www.nice.org.uk/guidance/ng241/chapter/Recommendations#assessing-the-risk-of-developing-ovarian-cancer (accessed Nov 4, 2025).

25 Funston G, Van Melle M, Baun M-LL, et al. Variation in the initial assessment and investigation for ovarian cancer in symptomatic women: a systematic review of international guidelines. *BMC Cancer* 2019; **19:** 1028.

26 Funston G, Hamilton W, Abel G, Crosbie EJ, Rous B, Walter FM. The diagnostic performance of CA125 for the detection of ovarian and non-ovarian cancer in primary care: a population-based cohort study. *PLoS Med* 2020; **17:** e1003295.