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Women's interpretation of and responses to potential gynaecological cancer symptoms: a qualitative interview study

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page number
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	4-5
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	N/A
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	N/A
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A

Continued on next page

Results			Page number
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5
		(b) Give reasons for non-participation at each stage	5
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	N/A
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(b) Report category boundaries when continuous variables were categorized	N/A
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-16
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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11 **Women's interpretation of and responses to potential gynaecological cancer**
12 **symptoms: a qualitative interview study**
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15 Low EL¹, Whitaker KL², Simon AE³, Sekhon M³, Waller J^{1*}.
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ABSTRACT

Objective: To explore women's experiences of symptoms potentially indicative of gynaecological cancer, without imposing a cancer perspective.

Design: A qualitative interview study with thematic analysis of transcripts.

Participants: 26 women aged ≥ 30 years, who had experienced a symptom that might indicate gynaecological cancer in the past 3 months, were recruited using a screening questionnaire distributed online and in community settings.

Setting: London, UK

Results: Women attributed gynaecological symptoms to existing illnesses/conditions or considered themselves to be predisposed to them, either through their 'genes' or previous personal experience. Normalising symptoms by attributing them to demographic characteristics (e.g. age, sex) was common, as was considering them a side-effect of hormonal contraception. When cancer was raised by women as a possible cause, it was often dismissed as unlikely. Responses to symptoms included self-management (e.g. self-medicating, making lifestyle changes), adopting a 'lay system of care', or consulting a health care professional. Triggers to help-seeking included persistent, painful or debilitating symptoms, concern about symptom seriousness, and feeling that help-seeking was legitimised. Barriers to help-seeking included lack of concern, vague symptoms, unusual symptom location, competing time demands, previous negative experiences with the healthcare system, and not wanting to be perceived as a time-waster.

Conclusions: Attributions of symptoms potentially indicative of a gynaecological cancer were varied, but most often involved women fitting symptoms into their expectations of what was 'normal'. People responded to symptoms with self-management, seeking help from friends/family or consulting health care professionals. An important trigger for consulting a health care professional was feeling that it was an appropriate course of action.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first qualitative, community-based study to assess how women interpret and respond to symptoms possibly indicative of a gynaecological cancer outside the cancer context.
- The Model of Pathways of Treatment was used to frame the interview schedule and interpret the findings to allow for comparison with other research.
- Women often interpreted their symptoms as 'normal', attributing them to their gender, age or to the use of hormonal contraception. Responses to symptoms included self-management, adopting a lay system of care or consulting a health care professional.
- The sample was homogenous; most of the women were white and from relatively high socioeconomic backgrounds.
- Larger and more demographically diverse studies are needed to clarify how women interpret and respond to symptoms possibly indicative of gynaecological cancer.

INTRODUCTION

Gynaecological cancers have a combined annual incidence second only to breast cancer in UK women.¹⁻⁴ There is increasing evidence that earlier diagnosis of gynaecological cancers could contribute to improving the survival gap between the UK and other countries with similar healthcare systems.^{5,6} One avenue for earlier diagnosis is encouraging prompt help-seeking.⁷ Retrospective evidence from gynaecological cancer patients suggests that symptoms that are 'alarming' such as bleeding or pain trigger help-seeking, while non-recognition of symptom seriousness, misattributing symptoms to a non-serious cause, lack of awareness, fear, and worry about wasting the doctor's time act as barriers.⁸⁻¹⁰ In one of these studies, a 'triggering process' was described where the normality of novel bodily sensations was challenged, transforming them into symptoms in need of care. Important elements in this process included normalising, level of severity and interference, competing social responsibilities, and social legitimisation.¹⁰

However, retrospective evidence from women with a cancer diagnosis, while important, may not wholly reflect how people respond to symptoms when they first occur. Community-based studies have found that although intention to seek help is high in women who anticipate having a symptom of a gynaecological cancer,^{11;12} actual help-seeking is lower in women with the same symptoms, when they are asked about it without mentioning cancer.¹³ Findings from this population-based survey also showed that there were potentially many more women in the population with possible gynaecological cancer symptoms than are seeking help for them.

To date, in-depth research to explore how women interpret and respond to bodily changes - as they are experienced - has been limited. A previous focus group study explored some of these issues in women and found the most common reason for foregoing medical help-seeking was the belief the symptom was benign.¹⁴ However, anticipated and actual help-seeking were not always differentiated and the study was conducted in the US, which has a different healthcare system to the UK.

We used the Model of Pathways to Treatment (MPT) as a theoretical framework in the present study, which identifies contributing factors that may influence a patient's pathway to treatment. The model describes events, processes and intervals; from detecting bodily changes (appraisal), perceiving a reason to contact a healthcare professional (help-seeking), through to first consultation, diagnosis and the start of treatment.¹⁵ The present study was

novel in its exploration of recently experienced gynaecological symptoms reported by women in the community, discussed without imposing a 'cancer' frame.

METHODS

Participant selection and recruitment

We recruited participants in London through an online and paper-based screening questionnaire in non-medical settings during 2012. Women were asked if they had experienced any of 14 gynaecological symptoms identified through NHS and cancer charity websites (see Table 1) in the past 3 months. Screening packs included an information sheet, reply sheet and return envelope. We aimed for a varied sample of women of different ages and from different social backgrounds and ethnic groups. Inclusion criteria for the interviews were: experience of at least one of 14 gynaecological cancer symptoms in the past 3 months and aged 30 years or over. Seventy women returned a completed screening questionnaire, and 26 eligible women were interviewed (37%) until data saturation was achieved.

Interviews

ELL conducted the interviews either face to face at University College London (n=10) or on the phone (n=16). The average duration of the interviews was 35 minutes. A semi-structured topic guide, underpinned by the Model of Pathway to Treatment (MPT),¹⁵ was used to explore themes related to symptom appraisal and help-seeking. Women were probed about what they thought caused the symptom (with no mention of cancer by the interviewer), and what action they took. The interviews were digitally recorded and were transcribed verbatim by a professional freelance transcription service. Transcripts were checked against portions of each digital recording for accuracy.

Analysis

Transcripts were analysed thematically using guidelines outlined in Braun and Clarke,¹⁶ within the NVivo software package. ELL and MS read and re-read the transcripts and generated initial codes. These were discussed in frequent meetings with ELL and JW. Themes were further categorised into the appraisal and help-seeking intervals defined in the MPT, with agreement from all co-authors. The coding framework was refined a total of eight times in an iterative process. Within the final framework, three broad themes were identified, each with a number of sub-themes (see Box 1).

RESULTS

Demographic characteristics of the sample are shown in Table 1. The most common symptoms reported by women were pain in abdomen, lower back or pelvis (reported by 56% of women) and increased need to empty bladder (50%). The majority of women reported more than one symptom (mean (M)=3, range=1-8).

Box 1 Thematic structure mapped on to appraisal and help-seeking intervals of the Model of Pathways to Treatment.¹⁵

Interpretation of symptoms (Appraisal interval)	Response to symptoms (Help-seeking interval)
<i>Patient factors</i>	<i>Patient factors</i>
Normalising	Self-management Adopting a lay system of care Competing demands
<i>Disease factors</i>	<i>Disease factors</i>
Existing illnesses/predisposed	Perceived seriousness
Cancer as a possible cause	Persistence Previous symptom experience
	<i>Healthcare provider and system factors</i>
	Worry about wasting the GPs time Difficulty in getting an appointment Gender of the GP

Interpretation of gynaecological symptoms

Patient factors

Normalising

Women often appraised their bodily changes as normal, and simply a consequence of diet, being female or “down to age” (OL02, bleeding after sex, age 50).

“that’s probably, again, linked to my periods because it’s worse at certain times of the month ... I’ve just always thought that maybe it’s, kind of, diet and, kind of, linked with my periods. A lot of my friends ... complain a bit as well so I just, kind of, think that it’s

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3 something that's fairly common ... It was just, kind of, one of those things that you just think,
4 well, that's part of being a woman, really. (OL02, abdominal bloating, age 46)
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8 "I'm right in the process of kind of menopausal ... periods are getting less and less and
9 less and less. So I think they're sort of departing. They may even have gone by now, I may
10 actually have had the last one. So it's a very.. it's actually really difficult to discern kind of
11 what's bleeding and what's period residue." (OL01, bleeding after sex, age 50)
12
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14
15 Other normalising explanations included using hormonal contraception. In these cases a
16 number of women had already been warned that their symptom may be a side effect of the
17 medication they were taking. Therefore, when they did experience that symptom, it was
18 logical for them to attribute it to the medication.
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23 "I have a contraceptive implant which can cause irregular bleeding and I have had it since
24 April. It never caused me any trouble and suddenly all this. So that could be one of the
25 reasons. That would be the obvious reason." (OL37, heavier or longer periods than normal,
26 age 30)
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28

29 30 31 **Disease factors**

32 Existing illnesses/predisposed

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34 Women often attributed their symptom to an existing or past condition, illness, disease,
35 surgery or injury. These attributions suggest that women will attempt to 'fit' new symptoms to
36 existing illness schemas, at least in the first instance.
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40
41 "I probably blame the fibroids ... These things are, kind of, crowding me out, I can't eat, I
42 can't hold my urine, I can't do anything, I'm heavy, I'm bloated. So I guess the fibroids are
43 what I would, kind of, blame logically first" (OL04, heavier or longer periods than normal,
44 increased abdominal size, discomfort in the abdomen, increased need to empty bladder
45 more often or urgently and difficulty eating, age 46)
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50 One woman referred to her previous experience of bleeding easily when interpreting
51 bleeding during sex.
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55 "I think skin sensitivity, I honestly do. I feel that this is minor bleeding on the inside of the
56 vagina. I ... have excessively sensitive skin on the outside and also in my nose and I know
57 that sounds weird but it seems to me that if you're kind of sensitive on the outside, why might
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3 you not be on the inside? You know, if I blow my nose here, it will bleed. I mean, I often get
4 blood there. Not nose bleeds, but just blood. It's, so going back to vaginal bleeding, you can
5 see why it's not something that would disturb me unduly." (OL01, bleeding during sex, age
6 50)
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10 Women described feeling predisposed to experiencing symptoms and this was related to
11 their family history. "I think it's hereditary, you see, because my mother had this problem as
12 well" (OL01, increased need to empty bladder, age 50).
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15
16
17 "Just like my mum and my auntie, we are all a bit of a likeness that way. ... because
18 members of your family have experienced the same sort of problem as they have got older
19 and it hasn't meant anything, you know, there's been no problem associated with it, you
20 think, oh I'm just getting older and it's a family thing and I don't worry about it." (OL33,
21 increased wind, age 60)
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25
26 Stories of the influence of family history were sometimes quite elaborate, and were not
27 always based on a previous diagnosis or condition. For example, one woman who reported
28 pelvic pain around the time of her period disclosed that dizygotic twins ran in her family. In
29 this context, she believed that the pain was caused by the release of two eggs during
30 ovulation. This attribution was then further cemented by information from her grandmother.
31
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35 "My nan reckons that eggs are released from both sides or a double egg comes from one
36 side every other month ... She says that's why twins run in the family ... everybody was
37 really surprised when I was pregnant that I ... didn't have twins because ... I had got those
38 pains ... That's why I have been told that I get those pains, because I get a bad pain on my
39 left-hand side every other month." (OL26, pelvic pain, age 34)
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45 Cancer as a possible cause

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47 When cancer was raised as a possible cause, the attribution often formed part of a cycle of
48 possible attributions and was dismissed as unlikely. Women doubted their cancer
49 attributions, concerned that they were over-reacting.
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53 "I don't know, if I have stomach cancer or, I don't know, anything like that, because
54 everything seemed to be getting better and I, kind of, thought it was probably to do with the
55 uterus and the fibroids. Whether I should have gone and spoken to the doctor about things
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3 as well? I don't know. I don't like going to the doctor more than I need to." (OL04, increased
4 abdominal size, discomfort in the abdomen, age 46)
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8 "I am either going through the menopause or I have got cervical cancer. And then, for some
9 reason, I decided that I could possibly have chlamydia, not that that's got anything to do with
10 your periods or the fact that I was at risk of getting it but I'm just, erm, a bit of a worrywart,
11 really." (OL16, heavier or longer periods than normal, age 41)
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15 The unusual location of reported lumps also led women to dismiss cancer as a possible
16 cause, as it didn't ring "alarm bells".
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20 "I wasn't particularly concerned about it ... if I find a lump in my breast, then alarm bells start
21 ringing and you start going, oh my gosh, I've got to see the doctor straight away... it maybe
22 fleetingly went through my mind that it would be something that ... needed investigation,
23 yeah, a bad lump, a cancerous lump or something like that ... it's not causing any problems
24 ... it hadn't made alarm bells ring in my mind so I just want to see what happens to it, rather
25 than rushing to the doctor and freaking out." (OL06, lump on vulva, age 34).
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32 Responses to gynaecological symptoms

33 Patient factors

34 Self-management

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36 Self-management was a common response to symptoms and an alternative to seeking
37 medical help, although the reasons or justifications women gave for these decisions varied.
38 The language used by some women suggested that they viewed their symptoms with a 'stiff
39 upper lip', deciding that they shouldn't let them interfere with their lives, even if they were
40 causing discomfort or concern.
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47 "I would say in my mid-40s it started to bother me. I mean, it is a bother but, you know, you
48 just put up with it, don't you?" (OL21, increased wind, age 62)
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52 Other women described self-management as a way of ruling things out, or deciding whether
53 medical attention was needed.
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3 *"I took some motilium and, kind of, moved on with my life and, sort of, figured if it went on for*
4 *any longer then I probably would go and see my GP because that would be worrying"* (OL07,
5 increased abdominal size that does not go away (including bloating), age 33)
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9 Some of these women had an idea about what might have caused their symptoms, which
10 appeared to influence their response to it.
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13 *"I think I'd probably try and sort myself out first with eating and say, right, okay, that's enough*
14 *of dairy ... and then I'd see how it went from there and then if I thought I needed to go to my*
15 *GP, I'd head off there."* (OL27, increased abdominal size, age 52)
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19 For a few women, their decision to put up with their symptom or ignore it seemed to be
20 related to the impact it had on their lives.
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23 *"it's not frequent enough, it doesn't give me any trouble, so, as I say, I'm inclined just to*
24 *ignore it."* (OL33, increased wind, age 60)
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28 However, even symptoms that were considered quite interfering would be self-managed,
29 with some women setting high 'tipping-points' for when they would consider it time to contact
30 a health care professional:
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33 *"Once the pain has gone, you just tend to think, well, okay, there's not really any point. If I*
34 *get it again, the third time will definitely be the cut-off and I will go and see if they can refer*
35 *me on."* (OL02, lower back pain, age 46)
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37

38
39 *"It would have to go on for a lot longer and be a lot more urgent ... And if I was wetting*
40 *myself or, you know, partially wetting myself then I would be conscious of smelling or things*
41 *like that. I wouldn't, sort of, suffer in silence but perhaps having to get up every hour in the*
42 *night or ... if it's twice a night then I can put up with it."* (OL10, increased need to urinate
43 more frequently and urgently, age 39).
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49
50 One of the most common non-medical self-management techniques that women mentioned
51 was to manage their symptoms with food or drink remedies, including avoiding certain foods
52 or drinks or introducing others into their diets. Women who reported using these self-
53 management techniques mostly did so in response to changes in their bowel habits, or a
54 persistently increased abdominal size, including bloating. This suggests that women
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3 believed that their symptoms were related to their digestive system, and that they could be
4 resolved by altering their eating or drinking habits.
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8 *"I don't take laxatives or anything like that. I try to do it through what I eat, through roughage.
9 I don't know whether it's a lazy gut or whatever because sometimes it can be violent and
10 other times.."* (OL43, changes in bowel habit, including constipation, age 64)
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14 *"in order to really make sure that I've eaten lots of good solid food that's going to keep me
15 strong and keep me moving around, cos I walk and .. I do a lot of stuff. I really do rely on
16 fairly kind of high fat stuff."* (OL01, difficulty eating, age 50).
17
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19 Adopting a lay system of care

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21 Women talked about seeking help via the 'lay system of care',¹⁷ which included family,
22 friends and others in their social network. Some women described how the experiences of
23 others influenced their appraisals and subsequent decision to seek help. For example, one
24 woman suspected that her irregular bleeding was caused by her contraceptive implant, and
25 described seeking advice from a friend who had the same contraceptive device fitted.
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30 *"I spoke to my friend who had it as well and she said, "Oh, just take [the contraceptive
31 implant] out, it will stop." So it has, hopefully."* (OL37, heavier or longer periods than normal,
32 age 30)
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36 Although the 'lay system of care' describes help-seeking from various social connections,
37 women appeared to be particularly influenced by close family members. Their advice
38 perhaps gave more depth to the potential consequences of a bodily change or symptom
39 compared to non-relatives possibly because of shared genes. For example one woman
40 talked about the importance of seeking advice from close relatives so as to gauge the level
41 of health threat:
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47 *"I talked to my mum and my sister about it and my mum said, oh yeah, it's cystitis, cystitis.
48 And I said, it's not ... I think it's hereditary ... I just tend to think that it's always worth asking
49 your mother and your sister about these things because a lot of these things are quite similar
50 within families and if they appear to have the same thing and they're still alive, why should I
51 not be?"* (OL01, increased need to empty bladder, age 50).
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55 Competing demands

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3 Other common reasons for avoiding seeking help included not prioritising help-seeking or
4 putting it off. Competing demands included other, more immediate health care needs, or
5 wanting to put others first. One woman talked about having several other ailments that
6 required her attention and prevented her from seeking help for vaginal bleeding:
7

8
9 *"I have the procession of minor ailments permanently, that are really annoying and*
10 *sometimes really quite debilitating ... it's all these things that there's always something more*
11 *immediate ... that's what stops me. It's not to do with not wanting to tell the GP ... it keeps*
12 *moving down the list of priorities cos something else takes precedence."* (OL01, vaginal
13 bleeding after sex, age 50)
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18 As well as other ailments acting as competing priorities, people discussed putting other
19 people first, which outweighed seeking help for their own bodily changes.
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23 *"My husband is being investigated for prostate cancer ... he comes first for something like*
24 *this. His needs would be beyond mine ... in terms of supporting him ... that would be a*
25 *barrier ... his needs along with the needs of my children would come first."* (OL14, Increased
26 wind, increased abdominal size, changes in bowel habit, age 46)
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30 31 32 **Disease factors**

33 Disease-related factors that influenced help-seeking were perceived seriousness,
34 persistence, and previous symptom experience.
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37 38 Perceived seriousness

39 If a symptom was perceived to be getting worse, this was sometimes a trigger to seeking
40 medical help.
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44 *"I basically went back recently because of how bad it had got ... I would say over the last*
45 *year it was probably getting slightly worse each time ... Tiredness, and headaches I was*
46 *getting as well, so, sort of, just generally feeling really out of sorts for a good few days each*
47 *month and beforehand, sort of, mood swings ... and I think they [periods] were getting*
48 *heavier, or it felt like they were."* (OL03, heavier or longer periods than normal, age 34).
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53 Social comparison could also serve to reinforce the perceived seriousness of symptoms and
54 legitimise help-seeking:
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3 *"I ... saw other people's experiences and that ... persuaded me that mine was bad enough*
4 *to actually do something about it and that I wasn't just making a fuss about nothing ... I, sort*
5 *of, realised yes, it probably is quite bad ... that was probably a factor in doing something*
6 *about it as well."* (OL03, heavier or longer periods than normal, age 34).
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9
10 Awareness that a symptom could be indicative of cancer was also a trigger for help-seeking:
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13 *"I had read that if you get bloating and it doesn't go away, that is usually a sign maybe that's*
14 *cancer. If it went down, which happens to me, it probably isn't ... There is quite a history of*
15 *cancer in my family ... I was frightened so it prompted me ... I think I am probably like a lot of*
16 *people who think, oh it will go away, it will be fine, don't worry, but it didn't and ... I got*
17 *scared."* (OL43, persistent bloating, age 64)
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20
21 Conversely, for those not perceiving their symptom as serious, they did not perceive value
22 in contacting a health care professional because they felt that what they were experiencing
23 was something that just 'happens':
24
25

26
27 *"I guess I have not thought enough to be able to actually go and get it sorted out or, you*
28 *know, speak to anybody about it, I just, kind of, assumed, you know, that might be what*
29 *happens."* (OL24, bleeding between periods, age 35).
30
31
32

33 Persistence

34
35 Symptoms that weren't persistent or long-lasting prevented women from help-seeking, and
36 this was linked to concern about bothering the GP unnecessarily.
37
38

39
40 *"I think it would have to be more persistent and last for longer for me to think it was*
41 *worthwhile to bother the GP. You always feel apologetic when you see a GP."* (OL31,
42 describing constipation, age 62)
43
44
45

46 Previous symptom experience

47
48 A final reason for putting off seeking medical attention was comparing the symptom with
49 previous experiences. For example, one woman had previously experienced severe
50 pancreatitis. This previous experience of a painful and acute illness influenced her
51 judgement of later symptoms.
52
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54
55 *"I have been with the pancreatitis, that was drastic ... obviously, that's immediate. Whereas*
56 *this isn't quite immediate and I think, actually, that's a bad thing for me because I tend to*
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3 *judge everything by that previous experience, say, well if it's not like that, it's not as urgent,*
4 *it's not as important, which isn't a good thing ... I have been blowing it off a bit" (OL14,*
5 *heavier or longer periods than normal, age 40).*
6
7

8
9 Previous negative test results could also lead women to feel that their symptom was not
10 important, and prevent help-seeking:
11

12
13 *"Given that, you know, I have had so many tests that were negative in the past, it's again this*
14 *issue - am I going to bother the GP with something that's going to come up negative again?*
15 *So I probably wouldn't go."* (OL31, describing discharge that smells unpleasant, age 62).
16
17
18

21 **Healthcare provider and system factors**

22 Women reported visiting several types of healthcare professional (HCP) including GPs,
23 pharmacists, Genitourinary Medicine (GUM) clinics or Accident and Emergency (A&E)
24 departments. A number of barriers to seeking medical help were raised, and are described
25 below
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30 **Difficulty making an appointment**

31 For this woman, making an appointment was so difficult, and time with the GP so short that
32 she had not sought help for her symptom:
33
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35
36 *"It would have to be easier to get an appointment with the GP. It really is that, that is such a*
37 *bloody drama. And you get you know, thirty seconds with you GP and you're allowed to talk*
38 *about one thing" (OL01, vaginal bleeding after sex, age 50)*
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40
41

44 **Wasting the doctor's time**

45 Another barrier that women mentioned was a concern about wasting GP time. For most of
46 these women this stemmed from a belief that their symptoms weren't serious enough, or
47 there was inadequate justification to *"bother the doctor"* (OL36, increased wind, age 53).
48
49

50
51 *"I would do. I'm sensible. I'm not going to be stupid about it, but, on the other hand, I don't*
52 *want to bother people because there are people who are really ill" (OL28, itching, pain or*
53 *soreness of vulva, age 57).*
54
55

58 **Gender of the GP**

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3 Finally, for a number of women in this study, the gender of their GP was mentioned as a
4 contributing factor:
5
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8 *"It's important because I think you need to be able to say... like you can sit down and explain*
9 *things when they are sometimes quite embarrassing, to this person."* (OL30, lump on vulva,
10 age 32).
11

12
13 Other women discussed visiting a male GP as a last resort because they would feel
14 embarrassed about talking to a man about their symptoms:
15
16

17
18 *"I think it would have to become really bad. Because he's the male GP as well and I would*
19 *feel a bit embarrassed talking to him in a way."* (OL36, increased wind, age 53)
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22 23 24 **DISCUSSION**

25 This is the first qualitative study to explore how British women appraise and respond to
26 changes in their bodies that may indicate gynaecological cancer. Attributions of bodily
27 changes were often aligned to women's expectations, either based on previous illness
28 experience, perceived hereditary conditions or their expectations of getting older or being a
29 woman. These findings are consistent with evidence from interviews with cervical cancer
30 patients,⁹ and support previous research in patients with melanoma, where prior beliefs and
31 experience were important determinants of help-seeking. For example, if a change in a mole
32 did not meet patients' expectations of a 'bad' sign (e.g. bleeding, itchy mole), the appraisal
33 interval was prolonged (i.e. time from noticing a bodily change to deciding to consult a health
34 care professional).¹⁸
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42 For bodily sensations that were not consistent with expectations, women sometimes
43 mentioned cancer as a possible cause, but it often formed a cycle of changing attributions,
44 and was usually dismissed as unlikely. For others, unexpected symptoms were often not
45 attributed to anything specific, and were dismissed as trivial and not worthy of further
46 consideration, mirroring findings from clinical samples.^{8,9} Symptom attribution was
47 associated with women's responses to their symptoms. If symptoms were considered
48 'normal' the typical response was to self-manage. Women also relied on their lay networks
49 for support and guidance in respect of their symptoms, particularly from close family
50 members. A similar theme was recently observed in a qualitative study with cervical cancer
51 patients in Uganda; conversations with husbands, relatives and friends reinforced women to
52 seek medical help.¹⁹ The importance of social networks has previously been highlighted,²⁰
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3 and may be a promising avenue for intervention work aimed at encouraging help-seeking
4 across socio-demographic groups.²¹
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7 Consulting a health care professional was discussed in terms of triggers and barriers.
8 Symptom severity and persistence triggered help-seeking from a health care professional,
9 while non-recognition of seriousness and previous symptom experience could undermine it.
10 These findings echo those from clinical samples, particularly the intermittent/vague nature of
11 symptoms.²² They also support a recent review of the literature highlighting the possible
12 impact of previous symptom experiences on subsequent help-seeking.²³ System barriers
13 were also similar to those found in previous research, including difficulty making
14 appointments and worry about wasting the doctor's time.²⁴
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21 There was evidence of high tolerance of symptoms which has also been observed in
22 previous studies.²⁴ Women reported setting themselves a 'tipping point' of when a bodily
23 sensation would trigger help-seeking and this could be extreme, for example, waking up
24 every hour through the night to go to the toilet.
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29 Women also described the role of competing demands, which led to avoidance of help-
30 seeking. These varied from having other more urgent health needs or prioritising the health
31 needs of others. Competing family and work demands have also been given as reasons by
32 women for not seeking help for breast cancer symptoms.^{25,26} One possibility is that women
33 may 'contain' or side line bodily changes to prevent them from interfering with normal life.²⁷
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38 Strengths and weaknesses

39 One of the main strengths of this study lies in the exploration of symptom appraisal and help-
40 seeking outside of the context of cancer and in non-medical settings. This is also the first
41 time symptom research with a community sample has focused on a specific group of
42 cancers. The exploration of these processes in this way may have led to these findings
43 more closely reflecting real life responses than research in which women are aware that the
44 symptoms being explored may indicate cancer. The present study explored help-seeking for
45 symptoms potentially indicative of all five gynaecological cancers, which provides a basis for
46 future, larger, quantitative research in this area.
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53 There is very little research which has drawn on a theoretical model to guide the research
54 design and interpretation of the findings.²⁸ The current study drew on the Model of
55 Pathways to Treatment, which allowed us to map our findings in a structured way, which in
56 turn, will allow for comparison with future research, and aid the development of future
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3 interventions targeting specific barriers to earlier presentation. Most of the women in our
4 sample were white, educated and came from relatively high socioeconomic status (SES)
5 backgrounds. Although SES may not be associated with differences in help-seeking,²⁴ we
6 cannot rule out the possibility that different themes would have emerged had we been able
7 to recruit a sample that was more diverse with respect to SES and ethnicity.
8
9

10 11 Implications

12 The findings from the present study progress our understanding of how women interpret and
13 respond to symptoms that may be indicative of a gynaecological cancer. However, there is
14 evidence that some of these symptoms can be common,^{13;29} and most are likely to be
15 indicative of benign disease, rather than cancer.³⁰ Encouraging all women with these
16 symptoms to seek help because of a potential risk of cancer may lead to unnecessary levels
17 of fear. Evidence suggests that GPs have concerns over encouraging help-seeking among
18 all women with symptoms that may potentially indicate a gynaecological cancer due to
19 associated increased costs and demand on resources, as well as the emotional impact on
20 the patient.³¹ Future research might explore how GPs can encourage appropriate help-
21 seeking in those women at higher risk, in particular by challenging 'normalising' behaviour.
22 On the other hand, help-seeking for symptoms that do indicate a benign condition may be
23 beneficial in its own right, by providing women with reassurance or treatment for other
24 conditions.
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34 35 Conclusion

36 The current research demonstrates that women will adopt alternative strategies to cope with
37 symptoms that are potentially indicative of a gynaecological cancer. Among the most
38 common response was to use self-management techniques and to adopt a lay system of
39 care. The main triggers for contacting a healthcare professional were severity and
40 persistence, which also related to social sanctioning by people in women's networks.
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44

45 **Author contributions:** ELL, AES and JW conceived of the study and developed the
46 discussion guide. ELL conducted the interviews. ELL and MS checked the transcripts and
47 carried out the initial coding of the data. All the authors were involved in the discussion and
48 refinement of the thematic framework and in the drafting of the paper. JW is the guarantor.
49 All authors have read and approved the final manuscript.
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53

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Competing interests: We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

Patient consent: Obtained

Ethics approval: The study was approved by the UCL Research Ethics Committee (reference: 2734/001).

Data sharing statement: No additional data available. The discussion guide and anonymised transcripts will be made available (on request) to interested researchers.

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Table 1 Demographic characteristics and symptom reporting of women interviewed (n=26)

	n	%*
Age group		
30-39	9	35
40-49	6	23
50-59	5	19
60-69	6	23
Ethnicity		
White British	22	85
White Other	4	15
Non-White	0	0
Education level		
Degree or higher degree	16	61
Higher education qualification below degree level	2	8
A-levels or Highers	2	8
ONC/BTEC	2	8
O Level or GCSE equivalent	3	11
No formal qualifications	0	0
Other	1	4
Car ownership		
None	7	27
One or more	19	73
Home ownership		
Own outright	7	27
Own with mortgage	12	46
Rent from Local Authority/Housing Association	2	8
Rent privately	4	15
Other (e.g. living with family/friends/squatting)	1	4
Symptoms reported		
Pain in abdomen/lower back/pelvis	14	54
Increased abdominal size	12	46
Increased need to empty bladder more	13	50

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2			
3	often/urgently		
4			
5	Increased wind or constipation	12	46
6	Difficulty eating/feeling full quickly	6	23
7	Heavier/longer periods	11	42
8	Changes in bowel habit	10	38
9	Pain/discomfort during sex	7	27
10	Itching, pain or soreness of vulva	7	27
11	Bleeding between periods	6	23
12	Discharge that smells unpleasant or is blood	7	27
13	stained		
14			
15	Bleeding during/after sex	6	23
16	Growth/lump/sore/ulcer on skin of vulva	7	27
17	Bleeding after menopause	0	0
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Women's interpretation of and responses to potential gynaecological cancer symptoms: a qualitative interview study

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11 **Women's interpretation of and responses to potential gynaecological cancer**
12 **symptoms: a qualitative interview study**
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15 Low EL¹, Whitaker KL², Simon AE³, Sekhon M³, Waller J^{1*}.
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ABSTRACT

Objective: To explore women's experiences of symptoms potentially indicative of gynaecological cancer in a community-based sample without imposing a cancer perspective

Design: A qualitative interview study with thematic analysis of transcripts.

Participants: 26 women aged ≥ 30 years, who had experienced a symptom that might indicate gynaecological cancer in the past 3 months, were recruited using a screening questionnaire distributed online and in community settings.

Setting: London, UK

Results: Women attributed gynaecological symptoms to existing illnesses/conditions or considered themselves to be predisposed to them, either through their 'genes' or previous personal experience. Normalising symptoms by attributing them to demographic characteristics (e.g. age, sex) was common, as was considering them a side-effect of hormonal contraception. When women raised cancer as a possible cause, they often dismissed it as unlikely. Responses to symptoms included self-management (e.g. self-medicating, making lifestyle changes), adopting a 'lay system of care', or consulting a health care professional. Triggers to help-seeking included persistent, painful or debilitating symptoms, concern about symptom seriousness, and feeling that help-seeking was legitimised. Barriers to help-seeking included lack of concern, vague symptoms, unusual symptom location, competing time demands, previous negative experiences with the healthcare system, and not wanting to be perceived as a time-waster.

Conclusions: Attributions of symptoms potentially indicative of a gynaecological cancer were varied, but most often involved women fitting symptoms into their expectations of what was 'normal'. Normalising acted as a barrier to seeking help from a healthcare professional, alongside competing time demands and negative attitudes towards help-seeking. These barriers may lead to later diagnosis and poorer cancer survival. Our findings could be used to inform the development of interventions to encourage appropriate help-seeking.

ARTICLE SUMMARY**Strengths and limitations of this study**

- This is the first qualitative, community-based study to assess how women interpret and respond to symptoms possibly indicative of a gynaecological cancer outside the cancer context.
- The Model of Pathways of Treatment was used to frame the interview schedule and interpret the findings to allow for comparison with other research.
- Women often interpreted their symptoms as 'normal', attributing them to their gender, age or to the use of hormonal contraception. Responses to symptoms included self-management, adopting a lay system of care or consulting a health care professional.
- The sample was homogenous; most of the women were white and from relatively high socioeconomic backgrounds.
- Larger and more demographically diverse studies are needed to clarify how women interpret and respond to symptoms possibly indicative of gynaecological cancer.

INTRODUCTION

Gynaecological cancers have a combined annual incidence second only to breast cancer in UK women.¹⁻⁴ There is increasing evidence that earlier diagnosis of gynaecological cancers could contribute to improving the survival gap between the UK and other countries with similar healthcare systems.^{5,6} Routes to earlier diagnosis of gynaecological cancers are currently limited, with screening only available for cervical, but not other forms of gynaecological cancer.⁷ Therefore, one avenue for earlier diagnosis is encouraging prompt help-seeking.⁸ Retrospective evidence from gynaecological cancer patients suggests that symptoms that are 'alarming' such as bleeding or pain trigger help-seeking, while non-recognition of symptom seriousness, misattribution of symptoms to non-serious or benign causes, lack of awareness, fear, and worry about wasting the doctor's time act as barriers.⁹⁻¹³ In one of these studies, a 'triggering process' was described where the normality of novel bodily sensations was challenged, transforming them into symptoms in need of care. Important elements in this process included normalising, level of severity and interference, competing social responsibilities, and social legitimisation.¹¹

However, retrospective evidence from women with a cancer diagnosis, while important, may not wholly reflect how people respond to symptoms when they first occur. Community-based studies have found that although intention to seek help is high in women who anticipate having a symptom of a gynaecological cancer^{14,15} actual help-seeking is lower in women with the same symptoms, when they are asked about it without mentioning cancer.¹⁶ Findings from this population-based survey also showed that there were potentially many more women in the population with possible gynaecological cancer symptoms than are seeking help for them.

To date, in-depth research to explore how women interpret and respond to bodily changes - as they are experienced - has been limited. A previous focus group study explored some of these issues in women and found the most common reason for foregoing medical help-seeking was the belief the symptom was benign.¹⁷ However, anticipated and actual help-seeking were not always differentiated and the study was conducted in the US, which has a different healthcare system to the UK.

We used the Model of Pathways to Treatment (MPT) as a theoretical framework in the present study, which identifies contributing factors that may influence a patient's pathway to treatment. The model describes events, processes and intervals; from detecting bodily changes (appraisal), perceiving a reason to contact a healthcare professional (help-seeking),

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3 through to first consultation, diagnosis and the start of treatment.¹⁸ The present study was
4 novel in its exploration of recently experienced gynaecological symptoms reported by
5 women in the community, discussed without imposing a 'cancer' frame.
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8 9 **METHODS**

10 11 **Participant selection and recruitment**

12 We recruited participants in London through an online screening questionnaire disseminated
13 to women via non-medical settings during 2012. Online settings included the Mumsnet and
14 Streetlife websites. In addition, posters displaying the web address of the screening
15 questionnaire were displayed in a range of locations including job centres, libraries and
16 community centres. We aimed to recruit a varied sample of women of different ages and
17 from different socioeconomic backgrounds and ethnic groups. Potential participants were
18 told that the study was about women's health and were invited to complete the screening
19 questionnaire.
20
21

22 The questionnaire asked about women's experiences of 14 gynaecological symptoms
23 identified as possibly indicative of cancer through NHS and cancer charity websites (see
24 Table 1) in the past 3 months. Women also provided demographic information. At the end of
25 the questionnaire, women were asked whether they would be willing to be contacted about
26 taking part in an interview to explore their health experiences in more depth. Interested
27 women provided their contact details.
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30 A total of 123 women responded to the screening questionnaire, of whom 70 reported at
31 least one eligible symptom in the last 3 months, and agreed to an interview. From this pool,
32 purposive sampling was used to select women from a range of age, ethnic and
33 socioeconomic status (SES) backgrounds. Most women who responded were, in fact, white,
34 educated to a mid- or high-level and from high SES groups (indexed by home and car
35 ownership). In total, 26 were interviewed (37% of those identified as eligible). We had
36 originally planned to interview 20 high- and 20 low-SES women, but were unable to recruit
37 more women from low SES groups, and chose not to interview more women from similar
38 backgrounds to the higher SES participants as we had reached data saturation within that
39 group.
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42 The study was approved by the UCL Research Ethics Committee (reference: 2734/001). At
43 the end of the interview women were encouraged to contact their doctor if they had any
44 persistent symptoms.
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Interviews

ELL conducted the interviews. Participants chose either a face to face interview at University College London (UCL) (n=10), a neutral location where they could discuss their (potentially sensitive) symptoms, or a phone interview (n=16) if they felt uncomfortable either speaking about their symptoms face to face or were unable or unwilling to travel to UCL. All travel expenses were reimbursed.

The average duration of the interviews was 35 minutes. A semi-structured topic guide, underpinned by the Model of Pathway to Treatment, was used to explore themes related to symptom appraisal and help-seeking. Women were probed about what they thought caused the symptom (with no mention of cancer by the interviewer), and what action they took. The interviews were digitally recorded and were transcribed verbatim by a professional freelance transcription service. Transcripts were checked against portions of each digital recording for accuracy. Once transcription was finished, ELL read and re-read the transcripts to check the integrity of the data.

Analysis

Transcripts were analysed thematically using guidelines outlined in Braun and Clarke,¹⁹ within the NVivo software package. ELL and MS read and re-read the transcripts and generated initial codes. These were discussed in frequent meetings with ELL and JW. Themes were further categorised into the appraisal and help-seeking intervals defined in the MPT, with agreement from all co-authors. The coding framework was refined a total of eight times in an iterative process. Within the final framework, two broad themes were identified, each with a number of sub-themes (see Box 1 below).

RESULTS

Sample characteristics

Demographic characteristics of the sample are shown in Table 1. A broad range of age-groups were represented, with 35% in the 30-39 year age group, 23% in the 40-49 year age group, 19% in the 50-59 year age group and 23% in the 60-69 year age group. The majority of women were White British (85%) and most were educated to degree level or higher (61%). The most common symptoms reported by women were pain in abdomen, lower back or pelvis (reported by 56% of women) and an increased need to empty bladder (50%). The majority of women reported more than one symptom (mean=3, range=1-8).

Box 1 Thematic structure mapped on to appraisal and help-seeking intervals of the Model of Pathways to Treatment.¹⁸

Interpretation of symptoms (Appraisal interval)	Response to symptoms (Help-seeking interval)
<i>Patient factors</i>	<i>Patient factors</i>
Normalising	Self-management Adopting a lay system of care Competing demands
<i>Disease factors</i>	<i>Disease factors</i>
Existing illnesses/predisposed Cancer as a possible cause	Perceived seriousness Persistence Previous symptom experience
	<i>Healthcare provider and system factors</i>
	Worry about wasting the GPs time Difficulty in getting an appointment Gender of the GP

Interpretation of gynaecological symptoms

Patient factors

Normalising

Women often appraised their bodily changes as normal, and simply a consequence of diet, being female or “down to age” (OL02, bleeding after sex, age 50).

“That’s probably, again, linked to my periods because it’s worse at certain times of the month ... I’ve just always thought that maybe it’s, kind of, diet and, kind of, linked with my periods. A lot of my friends ... complain a bit as well so I just, kind of, think that it’s something that’s fairly common ... It was just, kind of, one of those things that you just think, well, that’s part of being a woman, really. (OL02, abdominal bloating, age 46)

1
2
3 *"I'm right in the process of kind of menopausal ... periods are getting less and less and*
4 *less and less. So I think they're sort of departing. They may even have gone by now, I may*
5 *actually have had the last one. So it's a very... it's actually really difficult to discern kind of*
6 *what's bleeding and what's period residue."* (OL01, bleeding after sex, age 50)
7
8

9
10 Other normalising explanations included using hormonal contraception. In these cases a
11 number of women had already been warned that their symptom may be a side effect of the
12 medication they were taking. Therefore, when they did experience that symptom, it was
13 logical for them to attribute it to the medication.
14

15
16
17
18 *"I have a contraceptive implant which can cause irregular bleeding and I have had it since*
19 *April. It never caused me any trouble and suddenly all this. So that could be one of the*
20 *reasons. That would be the obvious reason."* (OL37, heavier or longer periods than normal,
21 age 30)
22
23

24 25 26 27 **Disease factors**

28 Existing illnesses/predisposed

29 Women often attributed their symptom to an existing or past condition, illness, disease,
30 surgery or injury. These attributions suggest that women will attempt to 'fit' new symptoms to
31 existing illness schemas, at least in the first instance.
32
33

34
35
36
37 *"I probably blame the fibroids ... These things are, kind of, crowding me out, I can't eat, I*
38 *can't hold my urine, I can't do anything, I'm heavy, I'm bloated. So I guess the fibroids are*
39 *what I would, kind of, blame logically first"* (OL04, heavier or longer periods than normal,
40 increased abdominal size, discomfort in the abdomen, increased need to empty bladder
41 more often or urgently and difficulty eating, age 46)
42
43
44

45
46 One woman referred to her previous experience of bleeding easily when interpreting
47 bleeding during sex.
48

49
50 *"I think skin sensitivity, I honestly do. I feel that this is minor bleeding on the inside of the*
51 *vagina. I ... have excessively sensitive skin on the outside and also in my nose and I know*
52 *that sounds weird but it seems to me that if you're kind of sensitive on the outside, why might*
53 *you not be on the inside? You know, if I blow my nose here, it will bleed. I mean, I often get*
54 *blood there. Not nose bleeds, but just blood. It's, so going back to vaginal bleeding, you can*
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3 see why it's not something that would disturb me unduly." (OL01, bleeding during sex, age
4 50)
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7
8 Women described feeling predisposed to experiencing symptoms and this was related to
9 their family history. "I think it's hereditary, you see, because my mother had this problem as
10 well" (OL01, increased need to empty bladder, age 50).
11
12

13
14 "Just like my mum and my auntie, we are all a bit of a likeness that way. ... because
15 members of your family have experienced the same sort of problem as they have got older
16 and it hasn't meant anything, you know, there's been no problem associated with it, you
17 think, oh I'm just getting older and it's a family thing and I don't worry about it." (OL33,
18 increased wind, age 60)
19
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21

22
23 Stories of the influence of family history were sometimes quite elaborate, and were not
24 always based on a previous diagnosis or condition. For example, one woman who reported
25 pelvic pain around the time of her period disclosed that dizygotic twins ran in her family. In
26 this context, she believed that the pain was caused by the release of two eggs during
27 ovulation. This attribution was then further cemented by information from her grandmother.
28
29
30

31
32 "My nan reckons that eggs are released from both sides or a double egg comes from one
33 side every other month ... She says that's why twins run in the family ... everybody was
34 really surprised when I was pregnant that I ... didn't have twins because ... I had got those
35 pains ... That's why I have been told that I get those pains, because I get a bad pain on my
36 left-hand side every other month." (OL26, pelvic pain, age 34)
37
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41 42 Cancer as a possible cause

43
44 When cancer was raised as a possible cause, the attribution often formed part of a cycle of
45 possible attributions and was dismissed as unlikely. Women doubted their cancer
46 attributions, concerned that they were over-reacting.
47
48

49
50 "I don't know, if I have stomach cancer or, I don't know, anything like that, because
51 everything seemed to be getting better and I, kind of, thought it was probably to do with the
52 uterus and the fibroids. Whether I should have gone and spoken to the doctor about things
53 as well? I don't know. I don't like going to the doctor more than I need to." (OL04, increased
54 abdominal size, discomfort in the abdomen, age 46)
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"I am either going through the menopause or I have got cervical cancer. And then, for some reason, I decided that I could possibly have chlamydia, not that that's got anything to do with your periods or the fact that I was at risk of getting it but I'm just, erm, a bit of a worrywart, really." (OL16, heavier or longer periods than normal, age 41)

The unusual location of reported lumps also led women to dismiss cancer as a possible cause, as it didn't ring "alarm bells".

"I wasn't particularly concerned about it ... if I find a lump in my breast, then alarm bells start ringing and you start going, oh my gosh, I've got to see the doctor straight away... it maybe fleetingly went through my mind that it would be something that ... needed investigation, yeah, a bad lump, a cancerous lump or something like that ... it's not causing any problems ... it hadn't made alarm bells ring in my mind so I just want to see what happens to it, rather than rushing to the doctor and freaking out." (OL06, lump on vulva, 34).

Responses to gynaecological symptoms

Patient factors

Self-management

Self-management was a common response to symptoms and an alternative to seeking medical help, although the reasons or justifications women gave for these decisions varied. The language used by some women suggested that they viewed their symptoms with a 'stiff upper lip', deciding that they shouldn't let them interfere with their lives, even if they were causing discomfort or concern.

"I would say in my mid-40s it started to bother me. I mean, it is a bother but, you know, you just put up with it, don't you?" (OL21, increased wind, age 62)

Other women described self-management as a way of ruling things out, or deciding whether medical attention was needed.

"I took some motilium and, kind of, moved on with my life and, sort of, figured if it went on for any longer then I probably would go and see my GP because that would be worrying" (OL07, increased abdominal size that does not go away (including bloating), age 33)

1
2
3 Some of these women had an idea about what might have caused their symptoms, which
4 appeared to influence their response to it.
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6

7
8 *"I think I'd probably try and sort myself out first with eating and say, right, okay, that's enough*
9 *of dairy ... and then I'd see how it went from there and then if I thought I needed to go to my*
10 *GP, I'd head off there."* (OL27, increased abdominal size, age 52)
11

12
13
14 For a few women, their decision to put up with their symptom or ignore it seemed to be
15 related to the impact it had on their lives.
16

17
18 *"it's not frequent enough, it doesn't give me any trouble, so, as I say, I'm inclined just to*
19 *ignore it."* (OL33, increased wind, age 60)
20
21

22
23 However, even symptoms that were considered quite interfering would be self-managed,
24 with some women setting high 'tipping-points' for when they would consider it time to contact
25 a health care professional:
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28
29 *"Once the pain has gone, you just tend to think, well, okay, there's not really any point. If I*
30 *get it again, the third time will definitely be the cut-off and I will go and see if they can refer*
31 *me on."* (OL02, lower back pain, age 46)
32
33

34
35 *"It would have to go on for a lot longer and be a lot more urgent ... And if I was wetting*
36 *myself or, you know, partially wetting myself then I would be conscious of smelling or things*
37 *like that. I wouldn't, sort of, suffer in silence but perhaps having to get up every hour in the*
38 *night or ... if it's twice a night then I can put up with it."* (OL10, increased need to urinate
39 more frequently and urgently, age 39).
40
41
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43

44
45 One of the most common non-medical self-management techniques that women mentioned
46 was to manage their symptoms with food or drink remedies, including avoiding certain foods
47 or drinks or introducing others into their diets. Women who reported using these self-
48 management techniques mostly did so in response to changes in their bowel habits, or a
49 persistently increased abdominal size, including bloating. This suggests that women
50 believed that their symptoms were related to their digestive system, and that they could be
51 resolved by altering their eating or drinking habits.
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3 *"I don't take laxatives or anything like that. I try to do it through what I eat, through roughage.*
4 *I don't know whether it's a lazy gut or whatever because sometimes it can be violent and*
5 *other times.."* (OL43, changes in bowel habit, including constipation, age 64)
6
7

8
9 *"in order to really make sure that I've eaten lots of good solid food that's going to keep me*
10 *strong and keep me moving around, cos I walk and .. I do a lot of stuff. I really do rely on*
11 *fairly kind of high fat stuff."* (OL01, difficulty eating, age 50).
12
13

14 15 16 17 Adopting a lay system of care

18 Women talked about seeking help via the 'lay system of care'²⁰ which included family,
19 friends and others in their social network. Some women described how the experiences of
20 others influenced their appraisals and subsequent decision to seek help. For example, one
21 woman suspected that her irregular bleeding was caused by her contraceptive implant, and
22 described seeking advice from a friend who had the same contraceptive device fitted.
23
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26
27 *"I spoke to my friend who had it as well and she said, "Oh, just take [the contraceptive*
28 *implant] out, it will stop." So it has, hopefully."* (OL37, heavier or longer periods than normal,
29 age 30)
30
31

32
33 Although the 'lay system of care' describes help-seeking from various social connections,
34 women appeared to be particularly influenced by close family members. Their advice
35 perhaps gave more depth to the potential consequences of a bodily change or symptom
36 compared to non-relatives possibly because of shared genes. For example one woman
37 talked about the importance of seeking advice from close relatives so as to gauge the level
38 of health threat:
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43
44 *"I talked to my mum and my sister about it and my mum said, oh yeah, it's cystitis, cystitis.*
45 *And I said, it's not ... I think it's hereditary ... I just tend to think that it's always worth asking*
46 *your mother and your sister about these things because a lot of these things are quite similar*
47 *within families and if they appear to have the same thing and they're still alive, why should I*
48 *not be?"* (OL01, Increased need to empty bladder, age 50).
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52 53 54 Competing demands

55 Other common reasons for avoiding seeking help included not prioritising help-seeking or
56 putting it off. Competing demands included other, more immediate health care needs, or
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3 wanting to put others first. One woman talked about having several other ailments that
4 required her attention and prevented her from seeking help for vaginal bleeding:
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7 *"I have the procession of minor ailments permanently, that are really annoying and*
8 *sometimes really quite debilitating ... it's all these things that there's always something more*
9 *immediate ... that's what stops me. It's not to do with not wanting to tell the GP ... it keeps*
10 *moving down the list of priorities cos something else takes precedence."* (OL01, vaginal
11 bleeding after sex, age 50)
12
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15
16 As well as other ailments acting as competing priorities, people discussed putting other
17 people first, which outweighed seeking help for their own bodily changes.
18
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20
21 *"My husband is being investigated for prostate cancer ... he comes first for something like*
22 *this. His needs would be beyond mine ... in terms of supporting him ... that would be a*
23 *barrier ... his needs along with the needs of my children would come first."* (OL14, Increased
24 wind, increased abdominal size, changes in bowel habit, age 46)
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30 **Disease factors**

31 Disease-related factors that influenced help-seeking were perceived seriousness,
32 persistence, and previous symptom experience.
33
34

35 Perceived seriousness

36
37 If a symptom was perceived to be getting worse, this was sometimes a trigger to seeking
38 medical help.
39
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41
42 *"I basically went back recently because of how bad it had got ... I would say over the last*
43 *year it was probably getting slightly worse each time ... Tiredness, and headaches I was*
44 *getting as well, so, sort of, just generally feeling really out of sorts for a good few days each*
45 *month and beforehand, sort of, mood swings ... and I think they [periods] were getting*
46 *heavier, or it felt like they were."* (OL03, heavier or longer periods than normal, age 34).
47
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51 Social comparison could also serve to reinforce the perceived seriousness of symptoms and
52 legitimise help-seeking:
53
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55
56 *"I ... saw other people's experiences and that ... persuaded me that mine was bad enough*
57 *to actually do something about it and that I wasn't just making a fuss about nothing ... I, sort*
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3 of, realised yes, it probably is quite bad ... that was probably a factor in doing something
4 about it as well.” (OL03, heavier or longer periods than normal, age 34).
5
6

7 Awareness that a symptom could be indicative of cancer was also a trigger for help-seeking:
8
9

10
11 *“I had read that if you get bloating and it doesn’t go away, that is usually a sign maybe that’s*
12 *cancer. If it went down, which happens to me, it probably isn’t ... There is quite a history of*
13 *cancer in my family ... I was frightened so it prompted me... I think I am probably like a lot of*
14 *people who think, oh it will go away, it will be fine, don’t worry, but it didn’t and ... I got*
15 *scared.”* (OL43, persistent bloating, age 64)
16
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20 Conversely, for those not perceiving their symptom as serious, they did not perceive value
21 in contacting a health care professional because they felt that what they were experiencing
22 was just something that just ‘happens’:
23
24

25
26 *“I guess I have not thought enough to be able to actually go and get it sorted out or, you*
27 *know, speak to anybody about it, I just, kind of, assumed, you know, that might be what*
28 *happens.”* (OL24, bleeding between periods, age 35).
29
30
31

32 Persistence

33 Symptoms that weren’t persistent or long-lasting prevented women from help-seeking, and
34 this was linked to concern about bothering the GP unnecessarily.
35
36
37

38 *“I think it would have to be more persistent and last for longer for me to think it was*
39 *worthwhile to bother the GP. You always feel apologetic when you see a GP.”* (OL31,
40 describing constipation, age 62)
41
42
43

44 Previous symptom experience

45 A final reason for putting off seeking medical attention was comparing the symptom with
46 previous experiences. For example, one woman had previously experienced severe
47 pancreatitis. This previous experience of a painful and acute illness influenced her
48 judgement of later symptoms.
49
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52

53 *“I have been with the pancreatitis, that was drastic ... obviously, that’s immediate. Whereas*
54 *this isn’t quite immediate and I think, actually, that’s a bad thing for me because I tend to*
55 *judge everything by that previous experience, say, well if it’s not like that, it’s not as urgent,*
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3 *it's not as important, which isn't a good thing ... I have been blowing it off a bit*" (OL14,
4 heavier or longer periods than normal, age 40).
5
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7
8 Previous negative test results could also lead women to feel that their symptom was not
9 important, and prevent help-seeking:
10

11
12 *"Given that, you know, I have had so many tests that were negative in the past, it's again this*
13 *issue - am I going to bother the GP with something that's going to come up negative again?*
14 *So I probably wouldn't go."* (OL31, describing discharge that smells unpleasant, age 62).
15
16

17 18 19 **Healthcare provider and system factors**

20
21 Women reported visiting several types of healthcare professional (HCP) including GPs,
22 pharmacists, Genitourinary Medicine (GUM) clinics or Accident and Emergency (A&E)
23 departments. A number of barriers to seeking medical help were raised, and are described
24 below
25
26

27 28 **Difficulty making an appointment**

29
30 For this woman, making an appointment was so difficult, and time with the GP so short that
31 she had not sought help for her symptom:
32
33

34
35 *"It would have to be easier to get an appointment with the GP. It really is that, that is such a*
36 *bloody drama. And you get you know, thirty seconds with your GP and you're allowed to talk*
37 *about one thing"* (OL01, vaginal bleeding after sex, age 50)
38
39

40 41 **Wasting the doctor's time**

42
43 Another barrier that women mentioned was a concern about wasting GP time. For most of
44 these women this stemmed from a belief that their symptoms weren't serious enough, or
45 there was inadequate justification to *"bother the doctor"* (OL36, increased wind, age 53).
46
47

48
49 *"I would do. I'm sensible. I'm not going to be stupid about it, but, on the other hand, I don't*
50 *want to bother people because there are people who are really ill"* (OL28, itching, pain or
51 soreness of vulva, age 57).
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3 Gender of the GP

4 Finally, for a number of women in this study, the gender of their GP was mentioned as a
5 contributing factor:
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9 *"It's important because I think you need to be able to say... like you can sit down and explain*
10 *things when they are sometimes quite embarrassing, to this person."* (OL30, lump on vulva,
11 age 32).
12
13

14
15 Other women discussed visiting a male GP as a last resort because they would feel
16 embarrassed about talking to a man about their symptoms:
17
18

19
20 *"I think it would have to become really bad. Because he's the male GP as well and I would*
21 *feel a bit embarrassed talking to him in a way."* (OL36, increased wind, age 53)
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26 DISCUSSION

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28
29 This is the first qualitative study to explore how British women appraise and respond to
30 changes in their bodies that may indicate gynaecological cancer, outside the cancer context.
31 Attributions of bodily changes were often aligned to women's expectations, either based on
32 previous illness experience, perceived hereditary conditions or their expectations of getting
33 older or being a woman. These findings are consistent with evidence from interviews with
34 cervical cancer patients¹⁰ and support previous research in patients with melanoma, where
35 prior beliefs and experience were important determinants of help-seeking. For example, if a
36 change in a mole did not meet patients' expectations of a 'bad' sign (e.g. bleeding, itchy
37 mole), the appraisal interval was prolonged (i.e. time from noticing a bodily change to
38 deciding to consult a health care professional).²¹
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46 For bodily sensations that were not consistent with expectations, women sometimes
47 mentioned cancer as a possible cause, but it often formed a cycle of changing attributions,
48 and was usually dismissed by women as unlikely. For others, unexpected symptoms were
49 often not attributed to anything specific, and were dismissed as trivial and not worthy of
50 further consideration, mirroring findings from studies with cancer patients.^{9;10;12} Symptom
51 attribution was associated with women's responses to their symptoms. If symptoms were
52 considered 'normal' the typical response was to self-manage. Women also relied on their lay
53 networks for support and guidance in respect of their symptoms, particularly from close
54 family members, which has long been recognised as a trigger to consultation.²² A similar
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3 theme was recently observed in a qualitative study with cervical cancer patients in Uganda;
4 conversations with husbands, relatives and friends reinforced women to seek medical help.²³
5
6 The importance of social networks for prompting help-seeking has previously been
7 highlighted,²⁴ and may be a promising avenue for intervention work aimed at encouraging
8 help-seeking across socio-demographic groups.²⁵
9
10

11 Consulting a health care professional was discussed in terms of triggers and barriers.
12 Symptom severity and persistence triggered help-seeking from a health care professional,
13 while non-recognition of seriousness and previous symptom experience could undermine it.
14 These findings echo those from studies of people with a cancer diagnosis, particularly the
15 intermittent/vague nature of symptoms.²⁶ They also support a recent review of the literature
16 highlighting the possible impact of previous symptom experiences on subsequent help-
17 seeking.²⁷ System barriers were also similar to those found in previous research, including
18 difficulty making appointments and worry about wasting the doctor's time.²⁸
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26 There was evidence of high tolerance of symptoms which has also been observed in
27 previous studies.²⁸ Women reported setting themselves a 'tipping point' of when a bodily
28 sensation would trigger help-seeking and this could be extreme, for example, waking up
29 every hour through the night to go to the toilet.
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33 Women also described the role of competing demands, which led to avoidance of help-
34 seeking. These varied from having other more urgent health needs or prioritising the health
35 needs of others. Competing family and work demands have also been given as reasons by
36 women for not seeking help for breast cancer symptoms.^{29;30} One possibility is that women
37 may 'contain' or side line bodily changes to prevent them from interfering with normal life.³¹
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43 **Strengths**

44 One of the main strengths of this study lies in the exploration of symptom appraisal and help-
45 seeking outside of the context of cancer and in non-medical settings. This is also the first
46 time symptom research with a community sample has focused on a specific group of
47 cancers. The exploration of these processes in this way may have led to these findings
48 more closely reflecting real life responses than research in which women are aware that the
49 symptoms being explored may indicate cancer. The present study explored help-seeking for
50 symptoms potentially indicative of all five gynaecological cancers, which provides a basis for
51 future, larger, quantitative research in this area.
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3 There is very little research in this area which has drawn on a theoretical model to guide the
4 research design and interpretation of the findings.³² The current study drew on the Model of
5 Pathways to Treatment, which allowed us to map our findings in a structured way, which in
6 turn, will allow for comparison with future research, and aid the development of future
7 interventions targeting specific barriers to earlier presentation.
8
9

10 11 12 **Limitations**

13 Most of the women in our sample were white, educated and came from relatively high SES
14 backgrounds, and therefore we cannot rule out the possibility that different themes would
15 have emerged had we been able to recruit a sample that was more diverse with respect to
16 SES and ethnicity. However, we did reach data saturation within our relatively homogenous
17 sample.
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22 23 **Implications**

24 The findings from the present study progress our understanding of how women interpret and
25 respond to symptoms that may be indicative of a gynaecological cancer. However, there is
26 evidence that some of these symptoms can be common,^{16;33} and most are likely to be
27 indicative of benign disease, rather than cancer,³⁴ so women, in the main, were correctly
28 attributing their bodily changes to benign conditions. Encouraging all women with these
29 symptoms to seek help because of a potential risk of cancer may lead to unnecessary levels
30 of fear. Evidence suggests that GPs have concerns over encouraging help-seeking among
31 all women with symptoms that may potentially indicate a gynaecological cancer due to
32 associated increased costs and demand on resources, as well as the emotional impact on
33 the patient³⁵. Future research might explore how GPs can encourage appropriate help-
34 seeking in those women at higher risk, in particular by challenging 'normalising' behaviour.
35 On the other hand, help-seeking for symptoms that do indicate a benign condition may be
36 beneficial in its own right, by providing women with reassurance or treatment for other
37 conditions.
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47 48 **Conclusion**

49 The current research demonstrates that women will adopt alternative strategies to cope with
50 symptoms that are potentially indicative of a gynaecological cancer. Among the most
51 common response was to use self-management techniques and to adopt a lay system of
52 care. The main triggers for contacting a healthcare professional were severity and
53 persistence, which also related to social sanctioning by people in women's networks.
54 Understanding the barriers and triggers to help-seeking at a cancer specific level is crucial to
55 developing interventions aimed at improving earlier diagnosis.
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3 **Author contributions:** ELL, AES and JW conceived of the study and developed the
4 discussion guide. ELL conducted the interviews. ELL and MS checked the transcripts and
5 carried out the initial coding of the data. All the authors were involved in the discussion and
6 refinement of the thematic framework and in the drafting of the paper. JW is the guarantor.
7 All authors have read and approved the final manuscript.
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14

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16
17 **Competing interests:** We have read and understood BMJ policy on declaration of interests
18 and declare that we have no competing interests.
19

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21 **Patient consent:** Obtained
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24 **Ethics approval:** The study was approved by the UCL Research Ethics Committee
25 (reference: 2734/001).
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29 **Data sharing statement:** The discussion guide and anonymised transcripts will be made
30 available to interested researchers.
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Table 1 Demographic characteristics and symptom reporting of women interviewed (n=26)

	n	%*
Age group		
30-39	9	35
40-49	6	23
50-59	5	19
60-69	6	23
Ethnicity		
White British	22	85
White Other	4	15
Non-White	0	0
Education level		
Degree or higher degree	16	61
Higher education qualification below degree level	2	8
A-levels or Highers	2	8
ONC/BTEC	2	8
O Level or GCSE equivalent	3	11
No formal qualifications	0	0
Other	1	4
Car ownership		
None	7	27
One or more	19	73
Home ownership		
Own outright	7	27
Own with mortgage	12	46
Rent from Local Authority/Housing Association	2	8
Rent privately	4	15
Other (e.g. living with family/friends/squatting)	1	4
Symptoms reported		
Pain in abdomen/lower back/pelvis	14	54
Increased abdominal size	12	46
Increased need to empty bladder more often/urgently	13	50
Increased wind or constipation	12	46
Difficulty eating/feeling full quickly	6	23
Heavier/longer periods	11	42
Changes in bowel habit	10	38
Pain/discomfort during sex	7	27

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Itching, pain or soreness of vulva	7	27
Bleeding between periods	6	23
Discharge that smells unpleasant or is blood stained	7	27
Bleeding during/after sex	6	23
Growth/lump/sore/ulcer on skin of vulva	7	27
Bleeding after menopause	0	0

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page number
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	4-5
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	N/A
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	N/A
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A

Continued on next page

Results			Page number
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5
		(b) Give reasons for non-participation at each stage	5
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	N/A
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(b) Report category boundaries when continuous variables were categorized	N/A
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-16
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.