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Help seeking behaviour in women diagnosed with gynaecological cancer: a systematic review

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Title: Help seeking behaviour in women diagnosed with gynaecological cancer: a systematic review.

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Abstract

Background: Identifying what prompts or hinders women's help seeking behaviour (HSB) is essential to ensure timely diagnosis and management of gynaecological cancers.

Aim: To understand the factors that influence HSB of women diagnosed with gynaecological cancer.

Design and Setting: Systematic review and narrative synthesis of studies from high-income settings.

Method: Five databases were searched for studies, of any design, that presented factors related to HSB of women diagnosed with gynaecological cancer. Data from the papers were extracted and presented using narrative synthesis which was inductive and also deductive, using the COM-B behaviour change model as a framework.

Results: There were 21 included studies. Inductive synthesis presented three main themes of factors related to HSB of women diagnosed with gynaecological cancer. Namely, patient factors such as knowledge of symptoms; emotional factors, including previous health care experience, embarrassment and trust; and practical factors, including time and resources. Deductive synthesis demonstrated that: capability, namely symptom knowledge; opportunity, having the required time, overcoming the cultural taboos surrounding gynaecological symptoms and motivation, believing that seeking help is beneficial, are all required to initiate HSB.

Conclusion: Help seeking behaviour of women with symptoms diagnosed with gynaecological cancer, whilst a journey of defined steps, is influenced by personal and

societal factors. Interventions to improve help seeking will need to address the identified factors as well as capability, opportunity and motivation.

How this fits in: Reducing diagnostic delay, by improving patients' help seeking behaviour, may reduce the UK's excess gynaecological cancer mortality. This review identifies that symptom knowledge is not enough to initiate help seeking; patients must also have the time or means to attend health care and be motivated enough, by previous experience, to overcome any fear or embarrassment they may have.

Key words: gynaecological cancer; delays in care; systematic review; patient's perspective; help seeking behaviour; general practice

Introduction

Almost one in eight cases of cancer affecting women in the UK will be one of the five gynaecological cancers, namely, endometrial, cervical, ovarian, vulval or vaginal. Despite UK survival rates improving, more than doubling in some cases, cancer survival in the UK lags behind other European Countries. It has been suggested that differences in survival are due to late stage presentation as a result of patient delay (1).

Any diagnostic journey begins with a patient seeking help from health care. It is known that embarrassment, fear of cancer and poor symptom knowledge may impact how quickly patients would present to healthcare should they develop symptoms of a gynaecological cancer (2) (3) (4) but there has been limited exploration of patient related delays in women who have been diagnosed with a gynaecological cancer (5) (6) (7).

The importance of cultural issues on detecting cancer early has been highlighted by the James Lind Alliance (8). There are cultural issues surrounding the intimate nature of gynaecological cancer symptoms and the investigation and examination necessary to diagnose gynaecological cancers; it is not yet known to what degree these cultural issues influence patient help seeking behaviour (HSB) and potential diagnostic delay.

Identifying what prompts or hinders patients' HSB when they have symptoms of gynaecological cancers, using the COM-B behaviour change model (Figure 1) (9) has the potential to identify targets for intervention with the aim of more timely help seeking. This model suggests that behaviour consists of three components: capability, the knowledge and skills needed to engage in HSB; opportunity, the external factors which influence help seeking and motivation, the internal processes which influence help seeking.

Identifying the factors associated with patients' HSB is important and may lead to the development of effective interventions which have the potential to shorten diagnostic delay. This narrative review aimed to understand what factors affect the HSB of women diagnosed with gynaecological cancer.

Figure 1: The COM-B model (9)

Method

A systematic review was conducted and the protocol was registered on PROSPERO: CRD42020197677. The 'Preferred Reporting Items for Systematic reviews and Meta-Analyses' (PRISMA) criteria have been followed (10). Initially performed in June 2020, the search was repeated in March 2022.

Search Strategy

The search strategy included two terms, their synonyms and MeSH terms: healthcare seeking and gynaecological cancer (Supplementary Box 1: search strategy). Searches were conducted in five databases: Cochrane Library, MEDLINE, CINAHL, EMBASE and Web of Science from inception to present. In addition, the citation lists of identified articles were searched manually. The search strategy was developed with input from a medical librarian.

Inclusion and exclusion criteria

All original research papers from 1996 to June 2020 were included; controlled and uncontrolled quantitative studies; and qualitative studies. Inclusion and exclusion criteria included particpants aged 18 or over who had been diagnosed with or who had symptoms of a gynaecological cancer and studies which reported HSB. Papers were excluded if they were not conducted in a high-income country. Full inclusion and exclusion criteria are listed in Supplementary Box 2.

Study selection

The outputs from the searches were imported into ENDNOTE were duplicates were removed. All titles, abstracts and full papers were assessed independently at all stages by

two researchers (PW, MCR or LH) using DistillerSR computer software. All titles were screened against the inclusion and exclusion criteria. The remaining abstracts were assessed for eligibility. Any disagreements were resolved by discussion between the researchers. Full texts were obtained for all abstracts which met the inclusion and exclusion criteria.

Data extraction and synthesis

Data from the full papers selected was extracted independently by two reviewers (PW, MCR or LH). Synthesis was narrative and followed the recommended sequence described by Popay (11). Data were analysed using thematic analysis (12) and Framework analysis (13). Thematic analysis enabled the emergence of themes and subthemes, while Framework analysis was based on the concepts of the COM-B behaviour change model (9). Detailed methodology can be seen in Supplementary Box 3.

Assessment of data quality

Independent dual (PW, SM, MCR) quality assessment of each included paper was performed using the relevant validated Critical Appraisal Skills Programme (CASP) tool (14) and poor study quality did not affect papers' inclusion.

Results

A PRISMA diagram is shown in Figure 2. The search identified 2296 titles. 2019 records (titles and abstracts) were excluded. 291 full text articles were assessed with 21 meeting the inclusion criteria described in Supplementary Box 2. The reasons for full paper exclusions are shown in Figure 2.

Figure 2. PRISMA flowchart

Eight studies were conducted in the UK; five in the USA; two in both New Zealand and Canada and one in each of Germany, Australia, Denmark with one multi centre study conducted in both Switzerland and Germany. Nine papers used qualitative methodology; 7 were cohort studies;2 used mixed methods: there were 2 systematic reviews and one cross-sectional study. A summary of results can be seen in Supplementary table 1. Quality assessment is shown in Supplementary tables 2-4: quality assessment of included papers.

Main emergent themes

Initial reading of the data identified three themes. Second level analysis identified subthemes. A summary of these can be seen in Table 1.

Table 1: Summary of themes and subthemes

Patient factors

Bodily sensations need to be considered a symptom in order to seek help. Sensations that can be understood in the context of a patient's life are not determined as symptoms (15) (16) (17) (18). When sensations persist, are painful, worsen, interfere with daily life, or have increased permanency, visibility, or palpability they are more likely to be determined as symptoms (5) (16) (17) The years of normal blood loss through menstruation or even post-partum can lead to some women normalising abnormal vaginal bleeding (17) (19).

Thirteen papers highlighted the influence of symptom knowledge (20) (21) (22) (23) (24) (5) (25) (15) (26) (27) (17) (28) (19). Some women had not heard of the cancer they were diagnosed with (21) (17) (28) while many reported poor symptom knowledge and health literacy (22) (26) (27) (17) (28) Symptom misattribution was common, especially in those with vague symptoms or who were diagnosed with ovarian cancer (19) (23) (24) (5) (25) (15).

Five studies reported an association between demographic factors and HSB (29) (15) (27) (30) (22) Multiborbidity increased delay (30) as did a divorced or widowed marital status (30). Younger women exhibited a delay in a study of women diagnosed with cervical cancer (27). Higher socio-economic status is associated with less delay (15). Ashing-Giwa and Lawton

described the influence of ethnicity on HSB, with delay seen in women of Latina origin in America and Maori women in New Zealand (29) (22).

Emotional factors

Fear of finding cancer is an important contributor to delay (31) (29) (32). Taught negative attitudes towards gynaecological symptoms contributes to avoidance of HSB and these attitudes can cultivate embarrassment with perceived associations between sexuality and gynaecological symptoms (21) (17). Concern about the discomfort associated with the examination can deter help seeking (31) Stigmatisation by clinicians of women who are overweight or attribution of health complaints to obesity can lead to avoidance of healthcare (17) (28). However, the influence of family and friends is important, and their encouragement can promote HSB (18) (16). The legitimisation of symptoms by clinicians is also important; not explaining about possible causes of symptoms, or alternative diagnoses and lack of advice if symptoms persists can contribute to patient delay (33). A lack of trust in clinicians can also impair HSB (30) But women also fear embarrassment from being considered a hypochondriac or time waster, and again this can contribute to delayed HSB (18) (32) (33). Previous benign diagnoses can also contribute to delay (32) (33) as can a lack of trust in clinicians (30) and concerns about painful or uncomfortable examination (31).

Practical factors

Caring responsibilities, inconvenient clinic times, being busy and short of time can lead to avoidance of HSB (18) (31) (17). The pressure of time required during a consultion to discuss symptoms of what some felt was a private matter also delayed HSB(17). In a study of African American women, having a self-reported barrier to seeking care was associated with prolonged symptom duration prior to presentation, although there was no description of these barriers (30). Prioritisation of others' health delays HSB (16) (24). In countries with insurance based health care, cost can be a deterrent (31).

Framework analysis based on the COM-B behaviour change model

Capability

Capability refers to whether patients have the knowledge, skills and abilities required to engage in help seeking. It has two components: psychological and physical.

Patients need to know what the symptoms of a disease are. Without this, women lack the capability to initiate help seeking (19) (20) (21) (22) (28)(17) (27). Many symptoms of gynaecological cancers, especially ovarian cancer, can be vague with misattribution of these symptoms as non-serious contributing to delay (23) (25) (15) (24) (5). Additionally, while vaginal bleeding can indicate an underlying malignancy, it is a normal physiological process; greater delay has been observed in women with vaginal bleeding compared to those with urinary bleeding, which is considered non physiological (26).

Opportunity

While capability initiates HSB, women must have the opportunity to access health care services in which they have trust. In the context of this model, opportunity refers to the external factors which make help seeking possible and again, has two components: physical e.g., time and social e.g., cultural norms.

Lack of time and being busy can delay help seeking (17) as can lack of trust in physicians (30). Social responsibilities such as prioritising family members can also lead to delay (31) (16) (24) (18). Opportunity is also determined by social influencers. Taboo and embarrassment about the association between gynaecological symptoms and sexuality can lead to delay (21) (17). Additionally, not wanting to be seen as a time waster or hypochondriac also contribute to delay (18) (33) (5). Discussion with family and friends can reinforce the belief that symptoms are worthy of health care seeking (18) (16). Difficulty navigating a health care system e.g. cost, getting to the clinic deters HSB (31).

Motivation

Motivation refers to the internal processes which influence a patient's decision to seek help. Its two components are: reflective e.g., previous experience and automatic e.g., fear and inhibition.

Fear of finding cancer is an important demotivator to help seeking (31) (32) (29). Moreover, previous health care experience of stigmatisation and discrimination can reduce motivation, leading to delay (28) (17) (30). Examination or symptoms that have previously been reassuring or suggestive of benign disease can decrease motivation (19) (33) (32) (18) as can concerns about painful examination (31).Renzi et al also reported that a lack of explanation for symptoms or lack of advice about what to do if symptoms persist can also contribute to delay (33).

Discussion

Main findings

Help seeking behaviour is complicated. This narrative review has identified patient, emotional, and practical factors which influence help seeking. While symptoms and symptom knowledge were highlighted as being key, it is clear that knowledge alone is not sufficient. Patients must be motivated to seek help in terms of previous experiences while the opportunity to seek help must be available; health care must be trustworthy, while social responsibilities such as employment and caring roles must not impede access. The review identifies individual factors but also contextualises them to reflect the behaviour change tool, COM-B, to allow for an overall assessment of help seeking (Figure 3).

Figure 3: Factors that influence a patient's help seeking behaviour

Strengths and limitations

This review has been systematically conducted and is the first to examine the HSB of women diagnosed with a gynaecological cancer using the COM-B framework. The data presented provides a comprehensive summary of the available evidence as well as highlighting the gaps in knowledge. The combination of thematic and framework analysis has added robustness to the results.

The studies were mostly observational and paper quality varied (Supplementary tables 2-4). The studies were heterogeneous. Cancer types and research methods varied, and outcomes were self reported and descriptive. There was also heterogeneity in study participants and health care systems investigated. The lack of commonality does not permit definitive conclusions.

Comparison with existing literature

Patients are aware that early diagnosis is important (34). Symptom knowledge is a key element of help-seeking behaviour and others have reported that lack of knowledge can lead to delay (6) (3) (35) with increased knowledge positively influencing help seeking (36)

(37) (38). Women's interpretation of gynaecological cancer symptoms as normal or trivial or attributing them to preexisting illness can lead to delay in help seeking (18) (37). While symptom knowledge has been associated with higher income and higher educational attainment, it has been reported as being lower in older women (39). The effect of competing demands has also been described previously (40) (18) as has the influence of friends and family (41) The positive effect of social support was confirmed by Whitaker et al (37). The COVID-19 pandemic appeared to alter HSB, with evidence that concerns about overburdening an overstretched health care system affected patients' decision to seek help (42). It is unclear if these changes will persist or change as the course of the pandemic changes.

Worrying about wasting GP time is a known concern for patients and can cause help seeking delay (26) (37) (43). Lack of trust in the healthcare system have also been observed to cause delay (37). Fear can both prompt and delay help seeking (6) (44) (37).

Implications for research and practice

Many health-promotion interventions focus on improving knowledge but do not result in improved cancer diagnosis (45). While symptom knowledge is important, women's decisions to seek help are also influenced by societal norms and previous experiences of help seeking.

The review highlights areas of patient behaviour that have potential for intervention. Societal demands, e.g., care responsibilities are difficult to influence. Time pressures during consultations and fragmentation of primary care contribute to decreased patient centeredness, which is associated with reduced symptom reporting (43) (46). The Royal Colleges of General Practitioners and Obstetricians and Gynaecologists suggest that primary care consultations should be increased to 15 minutes (47)(48), but the mismatch between resource and demand makes this a challenging target. When asked what they believed were the biggest barriers to presentation for women with gynaecological cancer symptoms, GPs cited lack of awareness and vagueness of symptoms i.e. capability, suggesting that reluctance to present was best managed by patient education. Only 14% of GPs questioned felt improving access to healthcare would reduce presentation delay (49).

In the same study by Evans et al, GPs also cited embarrassment as a barrier to presentation (49). Reluctance to discuss health concerns is associated negatively with help seeking (50). However, while we know many women are embarrassed to discuss gynaecological health with clinicians, much of the evidence is anecdotal or from third sector surveys (51). More research is needed to explore the influence of embarrassment and societal and cultural influences surrounding gynaecological cancer and its symptoms on patient behaviour and help seeking.

Conclusion

Help seeking behaviour of women with symptoms diagnosed with gynaecological cancer, whilst a journey of defined steps, is influenced by personal and societal factors. Interventions to improve help seeking will need to address the identified factors as well as capability, opportunity and motivation.

Disclosure of interests

There were no conflicts of interest.

Contribution to authorship

PW contributed to the conception and design of the work, acquired and interpreted the data for the work, drafted the manuscript and revised it for important intellectual content, provided final approval for publication and agreed to be accountable for all aspects of the work. SM interpreted the data for the work, drafted the manuscript and revised it for important intellectual content, provided final approval for publication and agreed to be accountable for all aspects of the work. MCR and LH assisted with the selection of studies, data extraction and quality assessment, interpreted the data for the work, revised the manuscript for important intellectual content, provided final approval for publication and agreed to be accountable for all aspects of the work.

Details of ethics approval

Ethical approvals were not required for this work.

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Tables and Figures

Figure 1: The COM-B model (48)

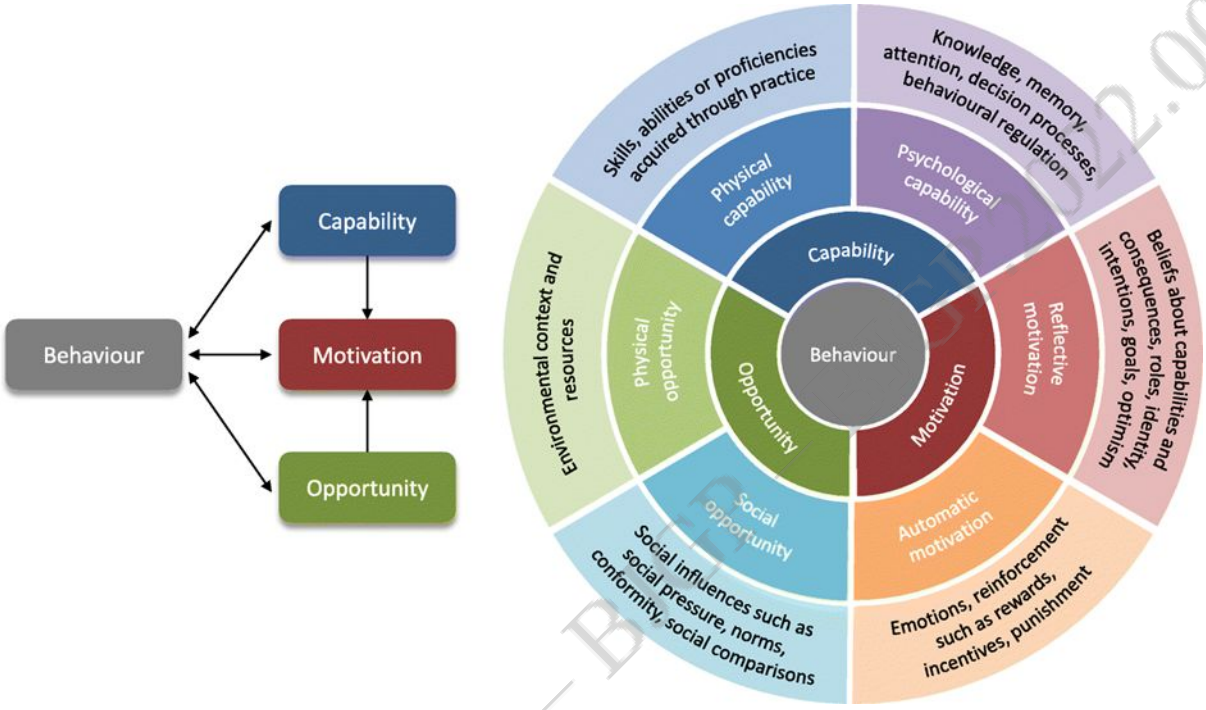

Figure 2. PRISMA flowchart

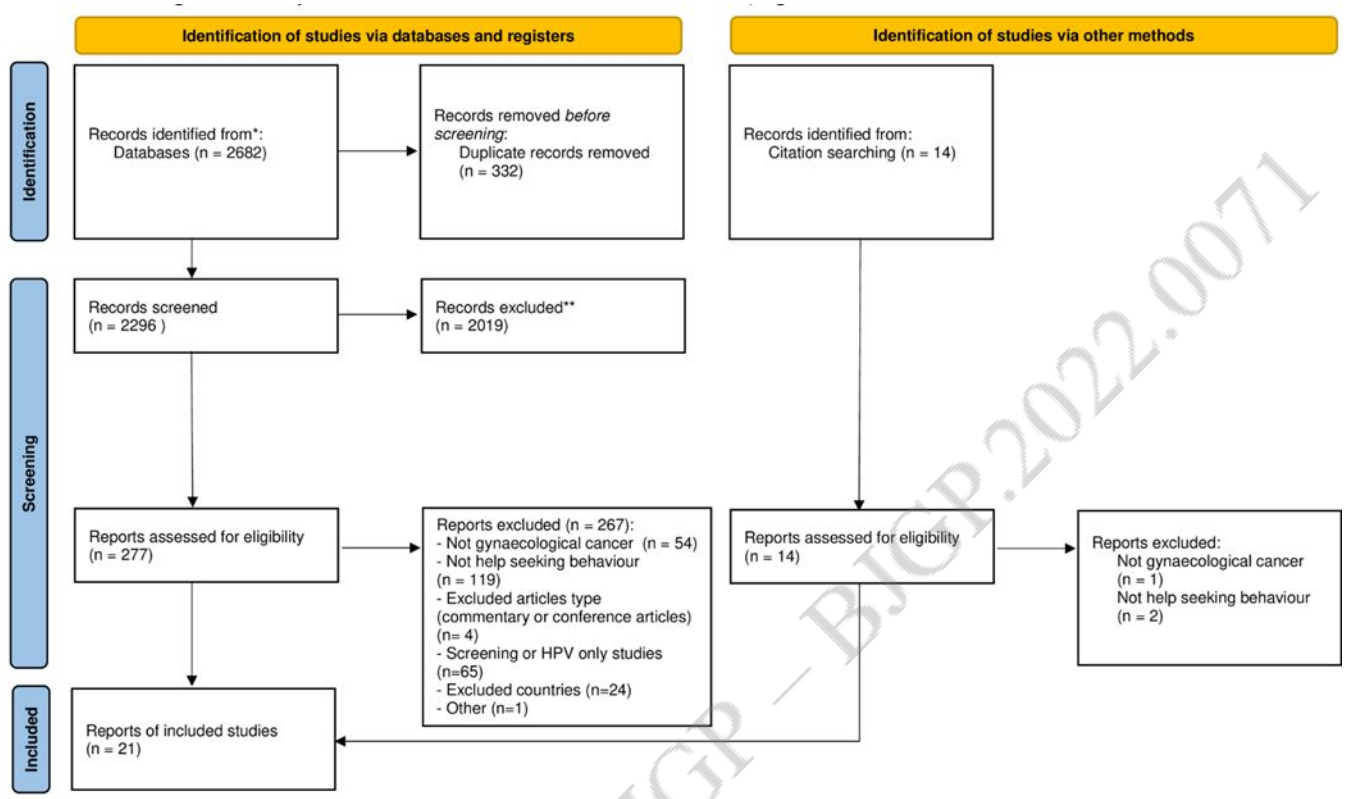

Figure 3: Factors that influence a patient's help seeking behaviour

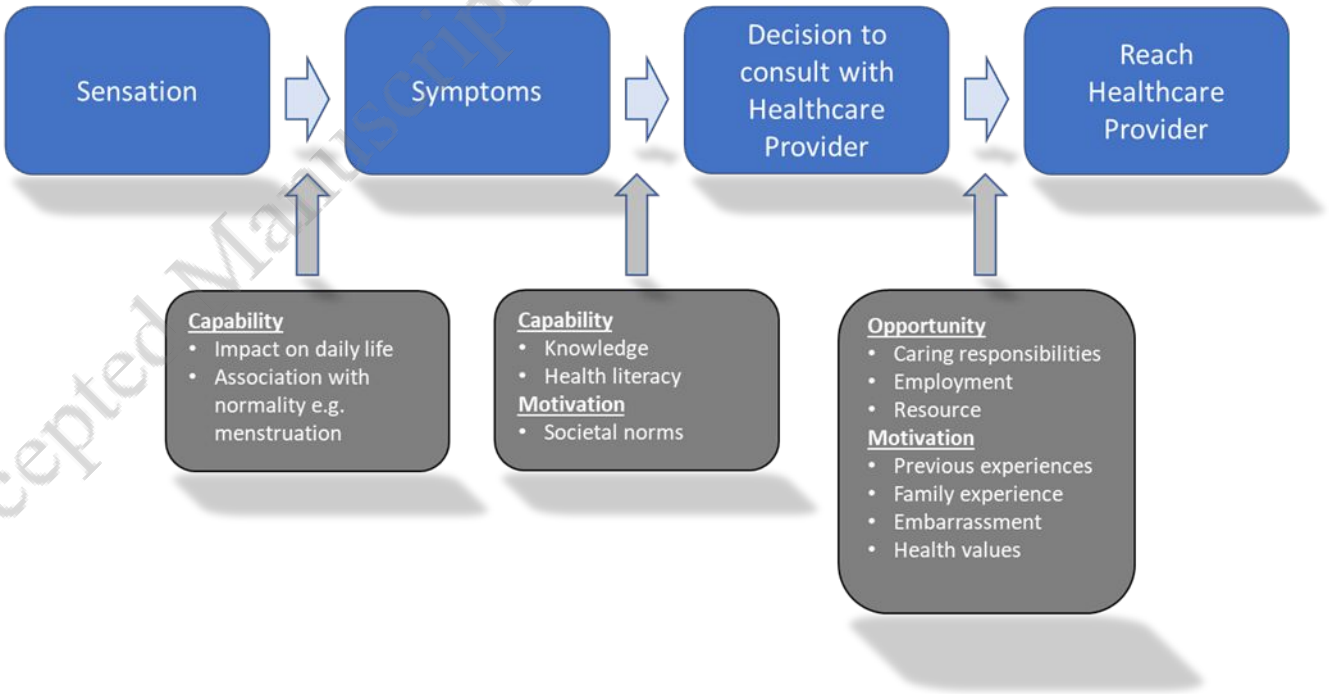

Table 1: Summary of themes and subthemes

Theme	Subtheme
Patient Factors	Symptoms and symptom knowledge
	Interpretation of bodily sensation as symptoms
	Patient demographics
Emotional Factors	Fear of finding cancer
	Taboo
	Previous stigmatisation/discrimination
	Legitimisation of symptoms
	Lack of trust in physicians
	Embarrassment
	Previous benign disease
Practical factors	Pressures of time at consultation
	Competing social responsibilities