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Psychosocial influences on help-seeking behaviour for cancer in low-income and lower middle-income countries: a mixed-methods systematic review

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ABSTRACT

Introduction Starting cancer treatment early can improve outcomes. Psychosocial factors influencing patients' medical help-seeking decisions may be particularly important in low and lower middle-income countries (LMIC) where cancer outcomes are poor. Comprehensive review evidence is needed to understand the psychosocial influences on medical help-seeking for cancer symptoms, attendance for diagnosis and starting cancer treatment.

Methods Mixed-methods systematic review registered on PROSPERO (CRD42018099057). Peer-reviewed databases were searched until April 2020 for studies assessing patient-related barriers and facilitators to medical help-seeking for cancer symptoms, diagnosis and treatment in adults (18+ years) living in LMICs. Quality of included studies was assessed using the Critical Appraisal Skills Programme tool. Data were synthesised using meta-analytic techniques, meta-ethnography or narrative synthesis as appropriate.

Results Of 3963 studies identified, 64 were included. In quantitative studies, use of traditional, complementary and alternative medicine (TCAM) was associated with 3.60 higher odds of prolonged medical help-seeking (95% CI 2.06 to 5.14). Qualitative studies suggested that use of TCAM was a key barrier to medical help-seeking in LMICs, and was influenced by causal beliefs, cultural norms and a preference to avoid biomedical treatment. Women face particular barriers, such as needing family permission for help-seeking, and higher stigma for cancer treatment. Additional psychosocial barriers included: shame and stigma associated with cancer such as fear of social rejection (eg, divorce/disownment); limited knowledge of cancer and associated symptoms; and financial and access barriers associated with travel and appointments.

Conclusion Due to variable quality of studies, future evaluations would benefit from using validated measures and robust study designs. The use of TCAM and gender influences appear to be important barriers to help-seeking in LMIC. Cancer awareness campaigns developed with LMIC communities need to address cultural influences on medical help-seeking behaviour.

Key questions

What is already known?

- Most reviews/studies of influences on medical help-seeking for cancer have focused on high-income countries (HIC), and report barriers such as low cancer awareness and negative beliefs about cancer.
- Most relevant reviews that included studies only conducted in low and lower middle-income countries (LMICs) (n=3) and reviews with a global focus including studies conducted in both LMICs and HICs (n=4) focused on specific tumour sites and/or synthesised their data narratively.
- No mixed-methods systematic reviews with meta-analysis and meta-ethnography have been conducted to explore the patient-related psychosocial influences on medical help-seeking for cancer symptoms, attendance for diagnosis or the start of treatment in LMICs.

What are the new findings?

- We found a relatively high prevalence of use of traditional, complementary and alternative medicine (TCAM) which was associated with prolonged help-seeking.
- Women faced particularly high levels of barriers, such as needing family permission to seek medical help, and gender-related stigma (eg, for breast cancer treatment).
- Our review also identified critical research design limitations reducing the utility of the literature (eg, use of different time lengths to define 'delay' in cancer help-seeking).

INTRODUCTION

Early cancer diagnosis and treatment are key to effective and efficient treatment.¹ Cancer disproportionately affects low and lower middle-income countries (LMIC) with rapidly increasing incidence² and poorer survival¹ when compared with high-income countries (HIC). Earlier stage cancer at diagnosis has a significant impact on survival, particularly

Key questions

What do the new findings imply?

- Many studies used non-standardised measures/designs, increasing the difficulty integrating findings across studies.
- Future evaluations should use robust study designs and validated measures that have been translated and pilot tested.
- Our results suggest that barriers such as low symptom knowledge and negative beliefs about cancer may be universal barriers to help-seeking, whereas the use of TCAM and female-specific barriers to medical help-seeking may be more prevalent in LMICs.
- Our findings provide a basis for development of interventions to encourage medical help-seeking in the earlier, more treatable cancer stages to reduce the burden of cancer in LMICs.

in LMICs where advanced technology critical for treatment at later cancer stages is generally less available.^{3 4} One factor related to access to early treatment is prompt medical help-seeking for potential cancer symptoms.⁵ Early cancer detection and treatment are seen by the WHO as major public health and economic issues.⁶

Following the Aarhus statement,^{7 8} the cancer early diagnosis field has moved from describing the medical help-seeking process in terms of 'patient delay', with its connotations of blame, to using time intervals as set out in the Model of Pathways to Treatment (MPT⁹; eg, 'patient interval'). The MPT describes processes underlying medical help-seeking for cancer symptoms and accessing treatment. The model delineates the time between a person first noticing a change in their body and the beginning of cancer treatment into four intervals (figure 1^{9 10}): (1) the appraisal interval (from noticing a

bodily change to perceiving a reason to seek help); (2) the help-seeking interval (from perceiving a reason to seek help to first contact with the medical professional); (3) the diagnostic interval (from first contact with the healthcare professional to diagnosis of cancer); (4) the pretreatment interval (from formal diagnosis to the start of cancer treatment). The patient interval combines both the appraisal and help-seeking intervals. In the current article we refer to longer and shorter intervals for the patient (medical help-seeking for cancer symptoms), diagnostic and pretreatment intervals (attendance for investigations or starting treatment). Although the MPT was designed to be applicable globally,⁹ there are few examples of the model being applied to LMIC contexts.¹¹⁻¹³

Most research on cancer symptom appraisal and help-seeking has been conducted in HIC. In two previous systematic reviews of psychosocial influences on help-seeking for cancer symptoms, only 10%¹⁴ and 15%¹⁵ of studies were conducted in LMICs. Previous systematic reviews conducted in LMICs have focused on understanding barriers to help-seeking for breast or head and neck cancer using narrative data synthesis.¹⁶⁻¹⁹ To date, no mixed-methods systematic review has investigated patient-related influences on medical help-seeking for cancer symptoms, attendance for examination or the start of cancer treatment in LMICs. Review of existing evidence regarding the psychosocial influences on cancer help-seeking in LMICs is essential, in order to develop effective interventions to facilitate earlier diagnosis and treatment.^{1 6}

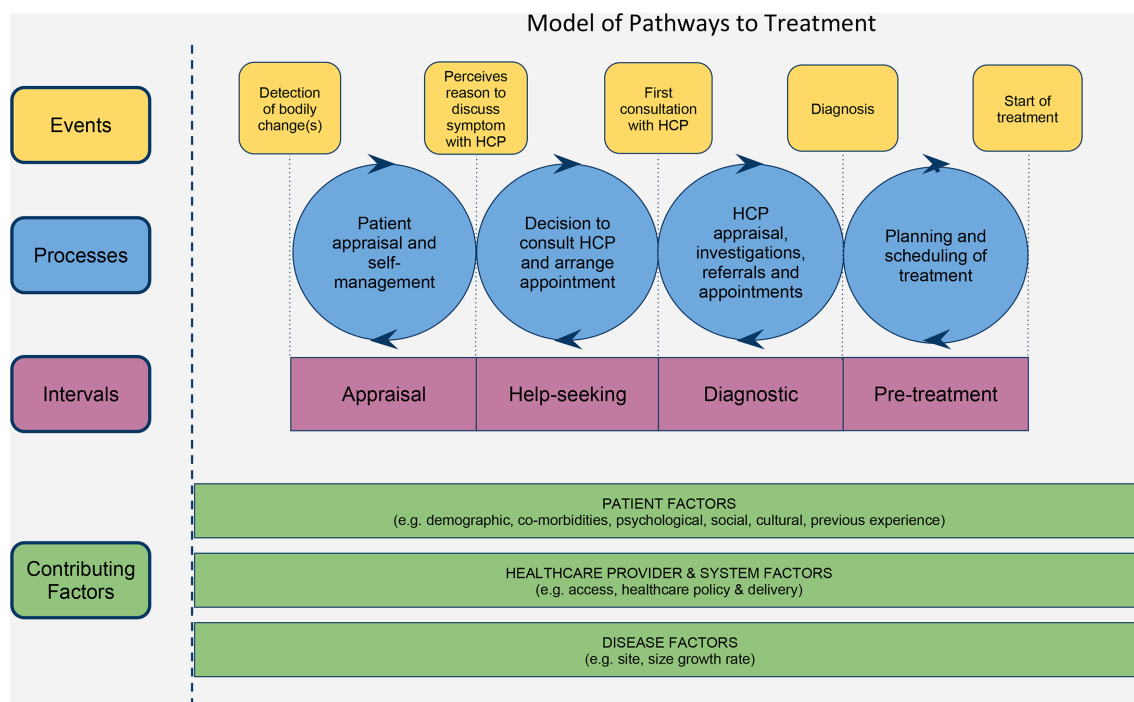


Figure 1 Model of Pathways to Treatment. HCP, healthcare professional. Reprinted with permission from Walter F, Webster A, Scott S, *et al*. The Andersen model of total patient delay: a systematic review of its application in cancer diagnosis. *J Health Serv Res Policy* 2012;17:110–8.

How patients appraise and act on potential cancer symptoms varies by tumour site and symptom type.^{20 21} The current systematic review therefore included all cancer types to examine the patient-related psychosocial influences on help-seeking for cancer during the patient interval and decisions to attend healthcare during the diagnostic and pretreatment intervals in LMICs. Diverse study designs were included to identify predictors of help-seeking using meta-analytic techniques for the quantitative studies, and to gain an in-depth understanding of barriers and facilitators to help-seeking through a meta-ethnography²² of qualitative studies. Quantitative data were analysed narratively to identify barriers and facilitators, including data not able to be included in the meta-analysis, to ensure results were comprehensive. Data were synthesised to form overarching conclusions and recommendations.

METHODS

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines²³ (online supplemental file 1).

Search strategy and selection criteria

We conducted a mixed-methods systematic review of qualitative, quantitative and mixed-methods studies to explore patient-related barriers and facilitators to medical help-seeking behaviour for cancer symptoms and decisions to attend healthcare for diagnosis and start of cancer treatment. The review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) prior to study selection (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=99057).

Inclusion criteria

Studies written in English that assessed (A) patient-related (B) barriers/facilitators to medical help-seeking for cancer symptoms, diagnosis and the start of treatment (C) in adults (18+ years) (D) living in LMICs were included. LMIC was defined as low-income or lower middle-income countries as classified by the World Bank (<https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>), correct at the time of protocol development (May 2018). There were no limits on date of publication or study methodology. Study designs that assessed and reported observed help-seeking behaviour (retrospectively reported actual help-seeking behaviour in patients with cancer or symptomatic participants) or hypothetical help-seeking behaviour (anticipated help-seeking in asymptomatic community or population samples) were included.

Qualitative studies that did not include time to help-seeking but where participants described their reasons for longer patient, diagnostic or pretreatment intervals were included. Included studies were required to report the

contribution of one or more of the following influences on help-seeking: symptom knowledge, symptom interpretation, social influences, use of traditional or complementary medicine, cancer beliefs, competing priorities, expectations/beliefs about care seeking, availability and access to care, financial barriers, understanding/navigating the health system, cultural barriers and cancer treatment beliefs. Variables were selected based on our previous review¹⁵ and extensive scoping searches.

Exclusion criteria

Studies that were not about cancer and/or were conducted in high-income or upper middle-income economy countries were excluded. Studies that were not written in English, review papers, policy documents and conference abstracts were excluded, although relevant review papers were reviewed to identify studies for potential inclusion. Studies were excluded if they did not focus on (1) barriers to cancer help-seeking, (2) adult participants' perspectives, or were (3) low-quality studies²⁴ as evaluated by the Critical Appraisal Skills Programme (CASP) tool.

Search strategy

Peer-reviewed literature in the electronic databases of Cochrane Library, MEDLINE (1946–2020), Global Health (1910–2020) and PsycINFO (1806–2020) was searched by TD and GMC up to April 2020. Initial searches were conducted in May 2018, and updated in June 2019 and April 2020. A comprehensive search strategy was developed by the study team and a subject librarian with expertise in literature searching²⁴ to retrieve all studies relevant to the research question. Search terms relating to *LMICs*, *symptomatic help-seeking*, *decisions to initiate treatment*, *cancer* and *barriers to help-seeking* were used to search for relevant studies (online supplemental file 2 for full list of terms). Study authors were emailed by BW if additional information was required.

Titles and abstracts of studies were reviewed against the inclusion and exclusion criteria by TD and GMC. Full texts of included studies were reviewed for inclusion or exclusion by TD and GMC (figure 2). Reference lists of included studies were checked manually by GMC for additional studies. Ten per cent of studies at each stage were independently reviewed for inclusion by GMC, HQS and KB, with good agreement (93%). All discrepancies were resolved through discussion.

Data analysis

Data were analysed using a parallel results convergent design,²⁵ where qualitative and quantitative findings were analysed separately and integrated in the discussion.

Data extraction

Data from all included studies were extracted onto an Excel sheet (online supplemental file 3 for full list of extracted variables). Country classifications by income group were determined by data collection year and the World Bank (<https://datahelpdesk.worldbank.org/>

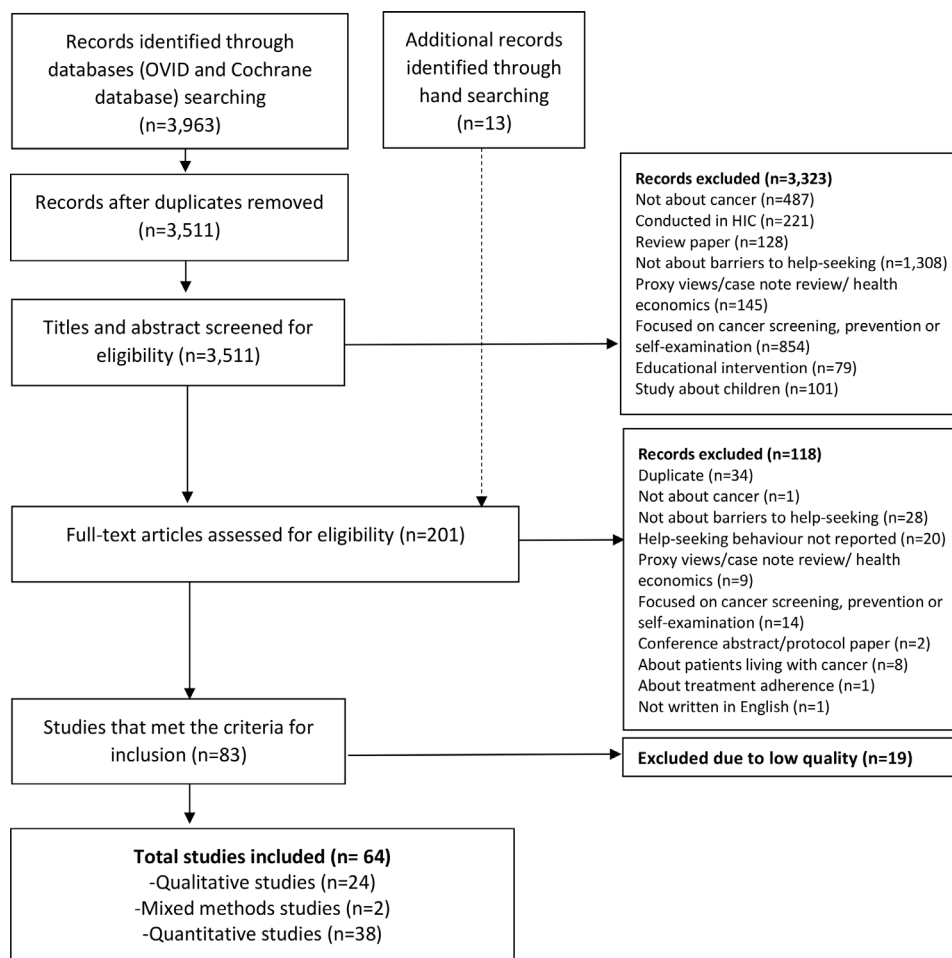


Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart of study selection. HIC, high-income countries.

knowledgebase/articles/906519-world-bank-country-and-lending-groups).

Quality appraisal

The CASP (www.casp-uk.net) tools were used to assess quality of studies in the following domains: validity of results, research design, participant recruitment, data collection, ethical issues, data analysis and reporting, and consideration of the contribution of their research. The tools were adapted to include questions to assess the quality of the patient interval.^{7 8} When assessing the quality of the reported patient interval the following were considered: the length of time from cancer diagnosis to data collection; whether self-report patient interval data were triangulated with medical records; how the patient/diagnosis/pre-treatment interval was classified and how the patient interval was analysed.^{7 8} Quality was rated as low, medium or high. Low-quality studies were excluded. The main reasons for exclusion included insufficient information provided about data collection procedures (n=18), or where intervals were measured but not reported or defined (n=7).

Quantitative summarisation

All included quantitative studies were discussed in detail during team meetings (BW, GMC, AD, YD, HH). Due

to the high level of heterogeneity in study measures and research designs within the context of relatively few studies, a formal meta-analysis was not feasible for most variables. However, meta-analytic techniques were used to quantitatively summarise study results regarding use of traditional, complementary and alternative medicine (TCAM) (eg, traditional healers, herbal medication, prayer camps, spiritual healers) as a predictor of help-seeking in the patient interval because TCAM use was consistently reported between studies and a high proportion of quantitative studies reported TCAM use. We first summarised the proportion of research participants who used TCAM in the patient interval, weighting studies by the square root of their sample size (proportional to the inverse of the SE for that sample's parameter estimate). We then assessed the proportion of participants who experienced significantly longer patient intervals, defined as a patient interval of 3 months or longer. Third, we summarised within-study statistics of relations between TCAM use and the probability of a longer patient interval. We extracted from the report (or computed if not reported) the OR for the effect of TCAM on 'delay', calculated as the odds of having a longer patient interval if a participant had used TCAM, over the odds of having a longer

Table 1 Noblit and Hare's seven-stage meta-ethnographic approach

Stages in Noblit and Hare ²²	Activity
1. Development of the research question	Align with the overarching research question of the review: 'What are the patient-reported influences on medical help seeking in the patient, diagnostic and pre-treatment intervals in LMICs?'.
2. Scope of synthesis	Define scope of the meta-ethnography to align with the overarching scope of the review: (1) focus on medium and high-quality studies; (2) focus on data related to patient-reported influences on medical help-seeking in the patient, diagnostic and pretreatment intervals; (3) do not include data from proxies (eg, spouses, children healthcare professionals) due to the focus on patient-reported influences.
3. Develop main concepts	Familiarisation with studies. Develop main concept grid with main and subconcepts and description. Refine main concept grid.
4. Determine how studies are related	Extract and separate first-order data (participant quotes) and second-order data (authors' narrative interpretations) from included studies into NVivo (GMC). Code data under each of the main concepts (GMC). Dual code at least 20% of included studies (HQS and KB). Discuss and resolve discrepancies in coding (GMC, KB, HQS).
5. Translate studies	Create a matrix on Excel to summarise study characteristics, first and second-order data under each of the main concepts and subconcepts (GMC).
6. Synthesise translations	Three researchers (GMC, KB, HQS) to independently review the main concept matrix of included first and second-order data to generate an overarching summary of each main concept (third-order data). Workshop-style analysis meeting to discuss how studies relate, and to identify areas of accordance and discordance. Discuss overall interpretations and conclusions and how main concepts relate with one another.
7. Dissemination	Express the synthesis through dissemination.

LMICs, low and lower middle-income countries.

patient interval given a participant had not used TCAM. The mean OR, weighted by the square root of each study's sample size, was computed. Subgroup analyses were conducted for TCAM use as a function of the region in which the studies were conducted (Africa vs Asia) and type of cancer (breast cancer vs non-breast cancer). All other quantitative data were analysed narratively.²⁶

Qualitative summarisation

Qualitative data from all qualitative and mixed-methods studies were synthesised using Noblit and Hare's²² seven-stage meta-ethnographic approach (table 1). Meta-ethnography reporting guidance²⁷ was used.

Patient and public involvement

Patients and public were not directly involved in this review.

RESULTS

Of the 3511 studies screened for inclusion in the review, 64 met the inclusion criteria (figure 2).

As shown in table 2, data were collected using quantitative survey methods (n=38), qualitative interviews or focus groups (n=24) and mixed-methods (n=2) to assess observed (n=46), hypothetical (n=16) and both observed and hypothetical (n=2) help-seeking behaviours.

Thirty-five studies were conducted in sub-Saharan Africa (Uganda, n=7; Nigeria, n=6; Ghana, n=5; Ethiopia, n=4; Kenya, n=3; Mali, n=2; multiple countries, n=2; Cameroon, n=2; Rwanda, n=1; Burkina Faso, n=1; Malawi,

n=1; Sudan, n=1). Fourteen studies were conducted in South Asia (India, n=6; Pakistan, n=5; Bangladesh, n=2; Nepal, n=1). Ten studies were conducted in the Middle East and North Africa (Jordan, n=5; Egypt, n=4; Morocco, n=1). Four studies were conducted in East Asia and Pacific (Indonesia, n=4). One study was conducted in Latin America and Caribbean (Haiti, n=1).

Most studies focused on breast cancer (n=44). The remaining 20 studies focused on the following cancer sites: colorectal (n=3), multiple sites (n=6), cervical (n=4), oral (n=2), ovarian (n=1), prostate (n=1), lung (n=1), nasopharyngeal carcinoma (n=1) and Kaposi carcinoma (n=1). Studies focused on the patient interval (n=54), diagnostic interval (n=10) and pretreatment interval (n=21).

Of the included studies, 11 were high quality and 53 were medium quality.

Quantitative studies

TCAM. Frequency of TCAM use in the patient interval was reported in 11 studies (n=2415 participants; 10 breast cancer studies, 1 non-breast cancer study), and the mean proportion of TCAM use across the studies was 0.20 (95% CI 0.09 to 0.31).²⁸⁻³⁸ The mean proportion of TCAM use in the patient interval in African studies (n=7) was 0.23 (95% CI 0.07 to 0.40), and 0.17 (95% CI -0.08 to 0.42) in Asian studies (n=4). Five studies (n=953 participants; 4 African studies, 1 Asian study) assessed the association between TCAM use and a longer patient interval, with a mean OR of 3.60 (95% CI 2.06

Table 2 Characteristics of included studies

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Abu-Helalah <i>et al</i> ⁴⁰	189 participants: men (n=87); women (n=91). Mean age: 57.5 years. Marital status: married (n=152); single (n=4); widow/divorced (n=22). Education: illiterate (n=30); primary school (n=48); secondary school (n=61); college (n=15); university (n=25). Employment: employed full time (n=22); employed part-time (n=8); housewife (n=62); retired (n=48); unemployed (n=40). Income (family): <JD399 (n=113); >JD400 (n=63). Area of residence: city (n=113); town (n=30); village (n=34).	Observed; cross-sectional survey of patients with colorectal cancer	Jordan (UM)	Colorectal	Authors developed survey measure	PI (>3 months: 33.9%; TI (>1 month: 32.6%)	Medium
Agbokey <i>et al</i> ⁶²	20 women. Median age: 52.5 years (range: 29–80 years). Marital status: married (n=18); widowed (n=2). Education: no formal education (n=4); basic (n=12); secondary (n=1); tertiary (n=3). Employment: farming (n=5); teaching (n=3); trading (n=11); nursing (n=1).	Observed; in-depth qualitative interviews with patients with breast cancer	Ghana (LM)	Breast	N/A	PI (3 months: –)	High
Ahmad <i>et al</i> ⁶¹	100 women. Mean age: 41 years (range: 18–67 years). Marital status: married (n=76); not married (n=23). Education: less than grade 10 (n=17); grade 10/university/college (n=31); postgraduate education (n=52). Employment: employed (n=66); not employed (n=34). Income (annual household): below average (n=26); above average (n=74).	Hypothetical; vignette survey of a community sample recruited from community venues	Bangladesh (LM)	Breast	Vignette survey of women with a breast lump developed by authors	PI (binary; 79% would seek help with symptoms)	Medium
Al Qadire <i>et al</i> ⁴⁸	241 participants: male (n=106); female (n=135). Mean age: 27.9 years (range: 18–47). Marital status: married (n=125); not married (n=116). Education: secondary or lower (n=177); diploma or more (n=31). Employment: working (n=40); not working (n=201). Income (monthly family): low (<US\$845, n=210); high (>US\$845, n=31).	Hypothetical; cross-sectional survey of Syrian refugees living in Jordan	Jordan (UM)	All cancers	Adapted version of the Cancer Awareness Measure	PI (2 weeks; 24.9%)	Medium
Al Qadire ⁴⁹	2292 participants: male (n=1206); female (n=1073); missing (n=13). Mean age: 30.5 years (range: 18–81). Marital status: married (n=1108); not married (n=1169); missing (n=15). Employment: working (n=1013); not working (n=1247); missing (n=32). Income (monthly family): low (<US\$845, n=1646); high (>US\$845, n=320); missing (n=326).	Hypothetical; population-based cross-sectional survey	Jordan (UM)	All cancers	Adapted version of the Cancer Awareness Measure	PI (2 weeks; 34.3%)	Medium
Asoogo and Duma ⁶³	30 women. Age range: 35–67 years (60% aged 40+ years). Education: illiterate/never been to school (n=2); primary education (n=7); secondary education (n=16); tertiary education (n=5).	Observed; semistructured qualitative interviews with patients with stage II and III breast cancer	Ghana (L)	Breast	N/A	PI (–)	Medium
Aziato and Clegg-Lamprey ⁷¹	12 women. Age range: 31–60 years. Marital status: married (n=9); separated (n=2); single (n=1).	Observed; semistructured qualitative interviews with patients with late-stage breast cancer	Ghana (LM)	Breast	N/A	TI (–)	Medium
Basharat <i>et al</i> ⁶²	14 participants: male (n=10); female (n=4). Age range: 43–68 years.	Observed; in-depth qualitative interviews with patients with oral cancer	Pakistan (LM)	Oral	N/A	PI (1 month; 100%)	Medium
Bonsu and Ncama ⁶⁴	11 women. Age range: 32–70+ years. Marital status: married (n=5); divorced (n=3); single (n=2); widowed (n=1). Employment: unemployed (n=3); trader (n=5); self-employed (n=2); retired teacher (n=1). Education: secondary (n=3); middle (n=7); tertiary (n=1).	Observed; in-depth qualitative interviews with patients with breast cancer and advanced stage disease	Ghana (LM)	Breast	N/A	PI (3 months; 91%)	High

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
De Boer <i>et al</i> ²⁸	161 participants: male (n=11); female (n=50). Mean age: 34 years. Education: primary (n=83); secondary (n=58); tertiary/degree (n=20).	Observed: cross-sectional survey of patients with AIDS-associated Kaposi sarcoma diagnosed within 6 months of the study	Uganda (L)	Kaposi sarcoma	Authors developed and piloted survey measure	PI (3 months; 45.3%)	Medium
Deliana <i>et al</i> ⁶⁸	15 participants: male (n=2); female (n=13). Age categories: 17–35 years (n=1); 36–45 years (n=5); 46–55 years (n=6); 56–65 years (n=2); 65+ years (n=1). Stage: III (n=10); IV (n=5).	Observed: in-depth qualitative interviews with patients with cancer and advanced stage disease (stages III and IV)	Indonesia (LM)	Multiple (cervical, n=5; colon, n=2; breast, n=6; ovary, n=1; skin, n=1)	N/A	TI (–)	Medium
Dereje <i>et al</i> ³⁹	237 women. Mean age: 52.6 years (range: 23–86 years). Marital status: married (n=96); single (n=11); divorced (n=36); widowed (n=88). Education: unable to read or write (n=89); primary (n=85); secondary (n=42); diploma (n=15). Employment: housewife (n=144); government employed (n=29); privately employed (n=23); merchant (n=10); daily labourer (n=13); pensioner (n=8); other (n=4). Income (family): <3201 Ethiopian birr (approximately US\$100) (n=157); >3201 Ethiopian birr (n=74).	Observed: cross-sectional survey of patients with cervical cancer (diagnosed within 68 days of the study)	Ethiopia (L)	Cervical	Questionnaire adapted from previous studies	PI (90 days; 23.4%); DI (30 days; 80.5%)	High
Desalu <i>et al</i> ³⁰	1125 participants: male (n=578); female (n=546). Mean age: 33 years (SD: 10 years). Marital status: married (n=647); not married (n=478). Education: none/primary (n=293); secondary (n=364); tertiary (n=468). Income: low (n=883); middle-high (n=242). Smoking status: current (n=124); former (n=35); never (n=1006).	Hypothetical; population representative cross-sectional survey	Nigeria (LM)	Lung	Lung Cancer Awareness Measure	PI (2 weeks; 33.2%)	High
Dye <i>et al</i> ⁶⁴	55 women. Marital status: most were married (n: –).	Observed: qualitative interview study of patients with breast cancer	Ethiopia (L)	Breast	N/A	PI (ignored first signs; 69.6%)	Medium
El-Shinawi <i>et al</i> ⁶²	45 women. Median age: 47 years. Education: illiterate (42.2%); literate (57.8%).	Observed: cross-sectional survey of patients with breast cancer (diagnosed within 6 months of the study)	Egypt (LM)	Breast	Authors developed and piloted survey measure	PI (1 month; 53%)	Medium
Fles and Bos ⁶⁵	12 participants: male (n=8); female (n=4). Mean age: 44 years. Marital status: married (n=9); not married (n=2); widowed (n=1). Education: completed primary school or below (n=6); completed high school or above (n=6). Employment: housewife (n=3); employed (n=8); student (n=1). Stage of disease: III (n=1); IV (n=1).	Observed: in-depth semistructured qualitative interviews with patients with histologically confirmed nasopharyngeal carcinoma	Indonesia (LM)	Nasopharyngeal carcinoma	N/A	PI (median PI=5.5 months)	Medium
Foerster <i>et al</i> ⁵⁶	1325 women. Mean age: 50.7 years (SD: 13.6 years). Employment: skilled/not applicable (n=923). Socioeconomic group: low (n=600); middle (n=438); high (n=288). Area of residence: urban (n=681); rural (n=645).	Observed: cross-sectional survey of patients with breast cancer	Sub-Saharan Africa (Namibia (UM), Nigeria (LM) and Uganda (L))	Breast	Authors developed survey measure	TI (12 months; 17%)	High

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Grosse Frie <i>et al</i> ¹¹	25 women (demographics reported by focus group). Group 1 (breast cancer survivors, n=8). Mean age: 48 years (range: 35–61 years). Marital status: married (n=8). Education: most had secondary education (n: –). Group 2 (community members, n=12). Mean age: 42 years (range: 20–65 years). Marital status: married (n=12). Education: none (n=6); primary/secondary (n=6). Group 3 (community members, n=5). Mean age: 41 years (range: 22–45 years). Marital status: married (n=4); single (n=1). Education: none (n=4); some formal education (n=1).	Observed and hypothetical; three focus groups; one with breast cancer survivors and two community members	Mali (L)	Breast	N/A	PI (–); DI (–); TI (–)	Medium
Grosse Frie <i>et al</i> ³²	64 women. Marital status: married (n=45); not married (n=19). Employment: housewife (n=34); working (n=30). Size of tumour: T0/T1/T2 (n=15); T3/T4 (n=49).	Observed; cross-sectional survey of women diagnosed with breast cancer	Mali (L)	Breast	Survey measure developed from previous study and pilot tested by authors	PI (mean=11.6 months; median=4.8 months); DI (mean=6.4 months; median=0.9 months); TI (mean=2.5 months; median=1.3 months)	Medium
Freij <i>et al</i> ⁵¹	896 women. Mean age: 41 years (range: 18–85 years). Marital status: single (n=181); married (n=618); divorced/widowed (n=89); not given (n=8). Education: secondary school and below (n=399); diploma and above (n=497). Employment: full time (n=705); not working or retired (n=191). Income (family): <JD1000 (n=751); >JD1000 (n=145).	Hypothetical; cross-sectional survey of women with no previous diagnosis of ovarian cancer	Jordan (UM)	Ovarian	Ovarian Cancer Awareness Measure	PI (2 weeks; 20.8%)	High
Gadgil <i>et al</i> ²⁹	389 women. Mean age: 48 years (range: 30–69 years). Income: high (n=147); middle (n=140); low (n=82).	Hypothetical; cross-sectional postal survey of middle-class urban women living in Mumbai	India (LM)	Breast	Questionnaire developed and validated International Agency for Research on cancer and translated into Hindi	PI (binary; 5% would not seek medical help)	Medium
Gakunga <i>et al</i> ⁷⁶	6–11 women in each group. Age range: 30–60 years. Socioeconomic status: group 1 (breast cancer diagnosis; high SES); group 2 (breast cancer diagnosis; low SES); group 3 (no breast cancer diagnosis; high SES); group 4 (no breast cancer diagnosis; low SES).	Hypothetical and observed; four focus group discussions; two groups with women diagnosed with breast cancer and two groups with women in the community without a diagnosis of breast cancer	Kenya (LM)	Breast	N/A	PI (–); TI (–)	Medium
Gabremariam <i>et al</i> ⁴¹	441 women. Mean age: 44.4 years (SD: 12.2 years). Marital status: married (n=55); widowed (n=73); single (n=67); divorced (n=46). Education: not attended school (n=87); primary school (n=112); secondary school (n=142); diploma and above (n=100). Employment: housewife (n=217); employed outside the home (n=198); retired (n=13); not employed (n=13). Income (family monthly): <US\$161.94 (n=325); >US\$161.94 (n=106); no income (n=3); missing (n=7).	Observed; cross-sectional survey of newly diagnosed patients with breast cancer	Ethiopia (L)	Breast	Questionnaire adapted from previous study	PI (90 days; 34%); DI (30 days; 69%)	Medium

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Getachew et al ⁶⁵	12 women. Age range: 26–65 years. Marital status: married (n=9); widowed (n=3). Education: illiterate (n=5); primary (n=3); secondary (n=1); diploma and above (n=3). Employment: housewife (n=2); farmer (n=6); merchant (n=1); government employee (n=3). Area of residence: urban (n=4); rural (n=8).	Observed: in-depth qualitative interviews with patients with breast cancer	Ethiopia (L)	Breast	N/A	PI (–)	Medium
Grunfield and Kohli ³⁰	685 women. Mean age: 49 years (range: 16–84). Marital status: married (n=530); not married (n=155). Education: no education (n=253); primary/middle education (n=130); high school (n=50); graduate (n=252). Area of residence: urban (n=367); rural (n=318).	Hypothetical; cross-sectional survey study to explore anticipated breast cancer symptom presentation in urban and rural women with no previous diagnosis of breast cancer	India (LM)	Breast	Survey adapted from a survey developed in the UK	PI (1 month; 44%)	High
Iskandarsyah et al ⁷⁷	50 women. Age range: 34–65 years. Marital status: married (n=44); widowed (n=6). Education: none (n=3); elementary school (n=23); junior high school (n=13); senior high school (n=11). Employment: housewife/unemployed (n=42); labourer/irregular job (n=7); private employee (n=1). Stage of disease: I (n=0); II (n=18); III (n=29); IV (n=3).	Observed: 50 semistructured qualitative interviews with patients with breast cancer	Indonesia (LM)	Breast	N/A	PI (3 months; 70%); TI (3 months; 42%)	Medium
Iskandarsyah et al ⁸¹	70 women. Mean age: 45.6 years (range: 28–66). Marital status: married (n=57); widowed (n=11); single (n=2). Education: none (n=7); elementary school (n=36); junior high school (n=11); senior high school (n=10); college or university (n=6). Employment: housewife/unemployed (n=46); labourer/regular job (n=18); private employee (n=1); government officer (n=5). Income (family): <\$200 (n=53); \$200–\$300 (n=13); >\$300 (n=4). Health insurance: yes (n=14); no (n=56). Stage of disease: I (n=3); II (n=37); III (n=16); IV (n=14).	Observed: cross-sectional survey of patients undergoing cancer treatment	Indonesia (LM)	Breast	Five questionnaires: Breast Cancer Knowledge Test, Brief Illness Perception Questionnaire, Multidimensional Health Locus of Control Scales, Satisfaction with Cancer Information, Distress Thermometer	PI (–); TI (3 months; 24%)	High
Kaninjing et al ⁷⁵	25 men. Mean age: 57.3 years. Marital status: married (n=20); single (n=5). Education: less than high school (n=15); high school (n=4); university (n=6). Employment: employed (n=12); retired (n=10); unemployed (n=3). Income: low (n=15); middle (n=6); high (n=2); missing (n=2).	Hypothetical; focus groups with a community sample of men with no previous diagnosis of prostate cancer	Cameroon (LM)	Prostate	N/A	PI (–)	Medium
Khan et al ⁶⁴	315 women. Age: <40 years (n=54); >40 years (n=111). Marital status: married (n=294); not married (n=21). Education: under 8 years (n=234); over 8 years (n=81). Socioeconomic status: poor/low (n=269); medium/high (n=46).	Observed: cross-sectional survey of patients with breast cancer	Pakistan (LM)	Breast	Authors developed survey measure	PI (3 months; 39%)	Medium
Hameed Khaliq et al ⁶¹	200 women. Marital status: married (n=169); not married (n=31). Median age: 45 years (range: 22–70). Education: median 2 years (range 0–16 years). Employment: self-employed (n=19); employed (n=35); housewife (n=146). Income (monthly; PKR): median 15250 (range 1000–150000). Area of residence: urban (n=95); rural (n=105). Stage: I (n=56); II (n=36); III (n=108); IV (n=56).	Observed: cross-sectional survey of patients with breast cancer	Pakistan (LM)	Breast	Survey measure developed from previous study and pilot tested by authors	PI (median through primary care–89 days)	Medium

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Kishore <i>et al</i> ⁶⁰	95 participants: equal number of males and females (actual number: –). Mean age: 52 years. Employment: semiskilled (54.7%); skilled (20%); other (%: –).	Observed: cross-sectional survey of patients recently diagnosed with cancer (within 1 month)	India (L)	All cancer	Pretested 42-item questionnaire	PI (mean=24 months)	Medium
Kohler <i>et al</i> ⁷⁰	20 women. Median age: 47 years. Age group: 25–40 (n=9); 41–55 (n=4); 56+ (n=7). Marital status: married (n=15); single/divorced (n=2); widowed (n=3). Education: no formal schooling (n=5); some primary schooling (n=8); some secondary schooling (n=7).	Observed: in-depth qualitative interviews with patients with breast cancer	Malawi (L)	Breast	N/A	PI; DI; TI (total time range: few weeks to few years)	Medium
Kumar <i>et al</i> ⁶⁷	Quantitative component: 269 women. Age group: 25–44 (n=90); 45–64 (n=162); 65+ (n=17). Marital status: married (n=235); unmarried (n=16); widowed (n=18). Education: no formal education (n=70); primary (n=34); middle (n=43); secondary (n=58); higher secondary (n=36); graduate and above (n=26%); missing (n=1). Employment: home maker (n=230); daily wage (n=5); farmer (n=1); salaried (n=16); business (n=5); other (n=9); missing (n=3). Area of residence: urban (n=73); rural (n=195); missing (n=1). Socioeconomic status: lower class (n=74); middle class (n=67); upper class (n=128). Qualitative component: 15 women. Age range: 35–65 years.	Observed: mixed-methods study with (A) cross-sectional survey of patients with breast cancer; and (B) in-depth qualitative interviews with patients with breast cancer with a patient interval of 3 months or longer	India (LM)	Breast	Authors developed survey measure	PI; TI (total interval 3 months; 53.1%)	Medium
Maghous <i>et al</i> ⁴⁵	137 women. Mean age: 48.3 years. Marital status: married (n=77); single (n=26); widowed/divorced (n=34). Education: illiterate (n=115); primary (n=14); secondary/higher (n=8). Employment: no employment (n=23); housewife (n=102); full time employed (n=10); part-time employed (n=2). Area of residence: rural (n=48); urban (n=89).	Observed: cross-sectional survey of patients with advanced stage breast cancer with a PI of 3 months or longer	Morocco (LM)	Breast	Authors developed survey measure	PI (median=6 months); DI (median=1 month)	High
Leng <i>et al</i> ⁶⁷	186 participants: male (n=58); female (n=127). Median age: 50 years (range: 19–79 years). Marital status: married (n=162); divorced/separated (n=2); widowed (n=12); never married (n=10). Education: none (n=20); primary (n=46); secondary (n=52); vocational/technical (n=18); polytechnic/OND/some college (n=15); bachelor's degree (n=24); postgraduate degree (n=9). Employment: none (n=37); trader (n=68); farmer (n=9); artisan (n=23); professional (n=38); other (n=11).	Observed: cross-sectional survey of patients with cancer attending radiotherapy clinics	Nigeria (LM)	Multiple	Questionnaire adapted from two questionnaires from previous studies	TI (–)	Medium
Malik and Gopalan ³²	138 women. Mean age: 46 years. Marital status: married (n=132); single (n=4); divorced/widowed (n=2). Education: illiterate (n=43); high school (n=61); college or above (n=33). Employment: home maker (n=125); teacher (n=8); other (n=5). Stage: I–II (n=90); III–IV (n=48).	Observed: cross-sectional survey of recently diagnosed (<3 months) patients with breast cancer presenting with a lump	Pakistan (L)	Breast	Authors developed survey measure	PI (1 month; 52.9%)	Medium
Manir <i>et al</i> ⁴⁶	212 women. Median age: 24 years (range 21–54 years). Education: postgraduate (n=129); undergraduate (n=83).	Hypothetical; cross-sectional survey of urban highly educated women	India (LM)	Breast	Adapted version of the Cancer Awareness Measure	PI (1 month; 48.6%)	Medium
Martei ⁷²	31 women. Mean age: 47 years (range: 25–85).	Observed: semistructured qualitative interviews with women undergoing breast cancer treatment	Ghana (L)	Breast	N/A	PI (–)	Medium
McEwan <i>et al</i> ⁸³	15 women (additional demographics: –).	Observed: structured qualitative interviews with patients with breast cancer	Egypt (LM)	Breast	N/A	PI (3 months: 60%); DI (3 months: 53%); TI (3 months: 33%)	Medium

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Meacham <i>et al</i> ⁷⁸	20 women. Age range: 35–67 years. Age group: 30–39 (n=1); 40–49 (n=8); 50–59 (n=6); 60–69 (n=5). Marital status: married (n=11); separated/divorced (n=2); widowed (n=4); single (n=3). Education: primary (n=1); secondary (n=4); university (n=15). Stage: I (n=7); II (n=11); III (n=4).	Observed; semistructured qualitative interviews with breast cancer survivors (defined as being in remission for 1+ years)	Uganda (L)	Breast	N/A	TI (–)	Medium
Mhaidat <i>et al</i> ⁸³	807 participants: male (n=568); female (n=233). Marital status: married (n=29); single (n=772). Mean age: 20.36 years (range: 18–37 years). Age group: <20 years (n=295); >20 years (n=506). Education: medical-related degree (n=146); non-medical-related degree (n=655).	Hypothetical; cross-sectional survey of undergraduate university students from five universities	Jordan (UM)	Colorectal	Adapted version of the Cancer Awareness Measure	PI (2 weeks; 27.4%)	Medium
Muthoni and Miller ⁷³	6–7 participants in each of eight focus groups (exact number: –). Age range: 20–60 years.	Hypothetical; eight focus groups (two in a middle-income urban area; two in a low-income urban area; two in rural area and ethnically Kikuyu Kiambu districts; and two in rural area and ethnically Kamba Machakos districts)	Kenya (L)	Breast	N/A	PI (–)	Medium
Mwaka <i>et al</i> ¹²	149 women. Mean age: 48 years. Age group: 18–29 (n=7); 30–44 (n=52); 45–59 (n=63); 60+ (n=25); missing (n=2). Education: no formal education (n=67); primary (n=72); secondary (n=7); tertiary (n=2); missing (n=1). Employment: housewife/peasant (n=132); petty trader (n=10); formally employed (n=4); missing (n=3). Stage: I (n=17); II (n=29); III (n=67); IV (n=31); missing (n=5).	Observed; cross-sectional survey of patients with cervical cancer	Uganda (L)	Cervical	Authors developed survey measure guided by the Model of Pathways to Treatment	PI (3 months; 55%)	Medium
Mwaka <i>et al</i> ⁷⁹	Total number of participants: –. Age range: 18–59.	Hypothetical. Twenty-four focus groups with members of the community living in rural (12 focus groups) or urban areas (12 focus groups)	Uganda (L)	Cervical	N/A	TI (–)	High
Mwaka <i>et al</i> ¹³	18 women. Mean age: 42 years (range: 35–56). Employment: subsistence farmers (n=15); small-scale business workers (n=2); formally employed as an office worker (n=1).	Observed; in-depth qualitative interviews with patients with cervical cancer	Uganda (L)	Cervical	N/A	PI+DI (median PI+DI: 20 months; range 2–140 months)	High
Ntiringanya <i>et al</i> ³³	136 women. Country: Sierra Leone (n=57); Rwanda (n=79). Median age: Sierra Leone (31 years); Rwanda (43 years). Education: none (n=71); primary school (n=47); secondary school (n=16); tertiary school (n=2). Employment: none (n=19); home maker (n=7); domestic helper (n=2); farmer (n=96); self-employed/small business (n=12).	Observed; cross-sectional survey to assess self-reported current breast masses in women and help-seeking/barriers to help-seeking in those reporting a lump symptom	Sierra Leone (L) and Rwanda (L)	Breast	Surgeons Overseas Assessment of Surgical Need (SOSAS) survey	PI (binary; 6.2% did not seek medical help)	Medium
Odongo <i>et al</i> ³⁴	162 women. Mean age: 45 years. Marital status: married (n=87); single (n=20); widowed (n=25); divorced (n=28). Education: none (n=15); primary (n=54); secondary (n=57); tertiary (n=36). Employment: unskilled worker (n=36); subsistence farmer (n=53); formal employment (n=29); unemployed (n=44). Income (monthly): <93 750 shillings (US\$36; n=91). Area of residence: rural (n=142); urban (n=20). Stage: II (n=6); III (n=17); IV (n=139).	Observed; cross-sectional survey of female patients with breast cancer	Uganda (L)	Breast	Previously validated questionnaire	PI (3 months; 89%)	Medium

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Okobia <i>et al</i> ⁶⁹	1000 women. Mean age: 29 years (range 15–91). Marital status: married (n=484); single (n=451); divorced/separated (n=21); widowed (n=23); missing (n=21). Education: primary (n=222); secondary (n=442); NCE/polytechnic (n=113); university (n=108); other (n=23); missing (n=92).	Hypothetical; cross-sectional survey of women living in an urban community	Nigeria (LM)	Breast	Authors developed survey measure	TI (binary; 54.7% would not accept treatment)	Medium
Olarewaju <i>et al</i> ⁴²	275 women. Age group: 25–35 (n=30); 36–46 (n=102); 47–57 (n=66); 58–68 (n=49); 69–79 (n=28). Marital status: single (n=12); married (n=193); divorced/separated (n=19); widowed (n=51). Education: primary (n=46); secondary (n=87); tertiary (n=142). Employment: unemployed (n=124); employed (n=151). Income: <18 000 (below national minimum wage; n=99); >18 000 (above national minimum wage; n=176).	Observed; cross-sectional survey of patients with breast cancer attending surgical and oncology clinics	Nigeria (LM)	Breast	Authors developed survey measure	PI (3 months; 35.3%); DI (8 weeks; 30.5%)	Medium
Pace <i>et al</i> ⁶⁵	144 women. Median age: 49 years. Marital status: married (n=71); single/widowed/divorced (n=73). Education: none/primary (n=108); secondary/university (n=36). Stage: I or II (n=35); III (n=75); IV (n=34).	Observed; cross-sectional survey of patients with breast cancer	Rwanda (L)	Breast	Adapted questionnaire used in another study	PI (6 months; 45%)	Medium
Price <i>et al</i> ⁶⁸	79 participants: male (n=20); female (n=59). Mean age: 46 years (range: 29–75 years).	Observed; cross-sectional survey of patients with cancer	Cameroon (LM)	Breast lymphoma (n=50), Kaposi sarcoma (n=10)	Authors developed and pilot tested survey measure	PI (3 months; 40%); TI (1 week; 16%)	Medium
Pruitt <i>et al</i> ⁷⁴	31 women. Mean age: 51 years (range: 28 to 80+). Education: no formal education (n=7); university or polytechnic degree (n=9); intermediate education (n=15).	Observed; semistructured qualitative interviews with patients with breast cancer	Nigeria (LM)	Breast	N/A	PI (-); TI (-)	Medium
Salih <i>et al</i> ⁴³	63 women. Mean age: 46.89 (range: 22–91). Marital status: married (n=7); single (n=56). Education: illiterate (n=22); literate (n=41). Employment: unemployed (n=53); employed (n=10). Income (annual): <GDP per capita (n=53); >GDP per capita (n=10). Area of residence: rural (n=19); urban (n=44).	Observed; cross-sectional survey of patients with breast cancer	Sudan (L)	Breast	Authors developed survey measure guided by Anderson Model of Total Patient Delay	PI (3 months; 75%)	Medium
Sanuade <i>et al</i> ⁶⁹	20 women. Age group: <40 years (n=2); 40–49 years (n=8); 50–59 years (n=6); 60+ years (n=4). Marital status: married (n=16); widowed (n=2); separated (n=2). Education: none (n=2); primary (n=2); middle (n=4); secondary (n=4); tertiary (n=4); missing (n=4). Employment: unemployed (n=2); trader (n=11); other (n=7). Stage: I and II (n=13); III and IV (n=7).	Observed; four focus groups with patients with breast cancer	Ghana (LM)	Breast	N/A	TI (1 month; 78.9%)	Medium
Sayed <i>et al</i> ³⁷	697 survey participants. Female participants (n=442). Median age: 22 years (range: 19–25 years). Marital status: married (n=307); single (n=70); widowed (n=40); divorced (n=17). Education: none (n=212); primary (n=182); secondary (n=30); tertiary (n=8); adult educated/unemployed (n=5). Employment: farmer (n=136); trader (n=47); housewife (n=77); other (n=76); none (n=102). Male participants (n=237). Median age: 31 years (range: 24–43 years). Marital status: married (n=173); single (n=49); widowed (n=8); divorced (n=5). Education: none (n=48); primary (n=133); secondary (n=44); tertiary education (n=2). Employment: farmer (n=90); trader (n=36); other (n=30); none (n=30).	Hypothetical; mixed-methods study involving a cross-sectional survey of men and women recruited from the community and six focus groups with a community sample	Kenya (LM)	Breast	Authors developed survey measure	PI (1 week; 9.3%)	Medium

Continued

Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Sharma <i>et al</i> ⁴⁴	90 women. Mean age: short PI group (45 years); long PI group (49 years). Marital status: married (n=36); not married (n=35); missing (n=19). Education: none (n=16); primary (n=32); secondary (n=22); university (n=6); missing (n=14). Employment: unemployed (n=58); employed (n=29); missing (n=3).	Observed; cross-sectional survey of female patients with breast cancer	Haiti (L)	Breast	Authors developed survey measure	PI (3 months; 42%)	Medium
Sharp <i>et al</i> ⁴⁷	347 women. Age group: 25–39 (n=182); 40–49 (n=89); 50–74 (n=70). Marital status: married/living with significant partner (n=207); single (n=129). Education: primary (n=236); above primary (n=104). Employment: full time employed/student (n=235); not in full-time employment/not full-time student (n=99); missing (n=7). Income: <500 000 shillings (n=125); >500 001 shillings (n=127). Area of residence: urban (n=83); rural (n=258).	Hypothetical; cross-sectional survey of community sample of women without breast cancer	Uganda (L)	Breast	Attitudes on Breast Cancer Surveillance and Knowledge survey	PI (binary; 15.5% had a recent breast examination)	Medium
Stapleton <i>et al</i> ⁴⁵	343 women. Mean age: 49 (range: 22–81). Stage: I and II (n=185); III and IV (n=158). Education: no formal schooling (n=201); completed primary school (n=63); completed secondary school (n=78). Employment: unemployed (n=207); employed (n=35).	Observed; cross-sectional survey of female patients with breast cancer	Egypt (LM)	Breast	Authors developed survey measure	PI (3 months; 11.7%)	Medium
Steiness <i>et al</i> ⁶¹	43 women. Mean age: 34.7 years (range: 18–60). Marital status: married (n=34); separated (n=4); divorced (n=1); widowed (n=3); never married (n=1). Education: none (n=10); primary (n=8); secondary (n=19); college+ (n=6). Perceived wealth in comparison to neighbours: 'better than neighbours' (n=8); 'same as neighbours' (n=12); 'worse than neighbours' (n=23).	Observed; qualitative interviews with women with breast cancer symptoms (but no formal diagnosis of cancer)	Bangladesh (L)	Breast	N/A	PI	Medium
Strobele <i>et al</i> ⁶⁴	996 women. Mean age: 33.4 years (range: 18–86). Marital status: married (n=795); not married (n=201). Education: none (n=557); elementary (n=192); secondary (n=134); tertiary (n=57, 5.7%); university (n=55); missing (n=7). Employment: housewife (n=167); farmer (n=369); business (n=323); public service (n=25); student (n=47); other (n=38).	Observed; population representative cross-sectional survey to assess current or former breast symptoms in women, help-seeking in those reporting symptoms and barriers to help-seeking	Burkina Faso (L)	Breast	SOSAS survey	PI (binary; 30% sought medical advice)	Medium
Tessler <i>et al</i> ⁶⁸	1942 participants (18+; age and gender of sample: –). Of the 38 who had experienced rectal bleeding: male (n=21); female (n=17).	Observed; population representative cross-sectional survey to assess current or former rectal bleeding in the population, help-seeking in those reporting symptoms and barriers to help-seeking	Nepal (L)	Colorectal	SOSAS survey	PI (binary; 60% sought medical advice)	Medium
Uddin <i>et al</i> ⁶⁰	48 women. Marital status: married (n=43); not married (n=5). Mean age: 37.5 years (range: 20–66). Education: illiterate (n=9); less than high school (n=7); high school (n=17); bachelor's degree (n=14); graduate degree (n=1). Employment: unemployed (n=39); employed (n=9).	Hypothetical; six focus groups conducted in urban (n=2) and rural (n=4) communities	Egypt (LM)	Breast	N/A	PI	Medium
Ukwanya <i>et al</i> ⁶⁸	117 women. Median age (split by group): 'short interval' (50 years); 'long interval' (43 years). Marital status: married (n=97); not married (n=14). Education: illiterate/primary (n=59); secondary/tertiary (n=52). Stage: I (n=10); II (n=18); III (n=37); IV (n=46).	Observed; cross-sectional survey of women undergoing treatment for breast cancer	Nigeria (LM)	Breast	Authors developed survey measure	PI+DI+TI (1 month; 89.2%)	Medium

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Table 2 Continued

Study	Population	Study type	Country (country classification*)	Tumour site	Measures	Interval†	Quality appraisal
Zahid et al ⁶³	190 participants: men (n=119); women (n=71). Mean age: 48.3 years. Marital status: married (n=136); not married (n=54). Education: <grade 5 (n=161); grades 5–10 (n=19); >grade 10 (n=10). Income (monthly): <PKR10 000 (n=156); PKR10 001–PKR20 000 (n=31); >PKR20 000 (n=3).	Observed; cross-sectional survey of patients with oral cancer	Pakistan (LM)	Oral	Authors developed survey measure	TI (mean=6.3 days)	Medium

The symbol (–) refers to not applicable or data not available.

*Country classification in final year of data collection as defined by the World Bank (<https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>).

†The number of days/weeks in brackets denotes the cut-off for a long interval versus short interval and the % of participants with a long interval. Mean/median/binary interval times are given in some studies.

DI, diagnostic interval; GDP, gross domestic product; JD, Jordanian dinar; L, low-income economy; LM, low/middle-income economy; N/A, not applicable; NCE, Nigeria Certificate of Education; ; OND, Ordinary National Diploma; PI, patient interval; PKR, Pakistani rupee; SES, socioeconomic status; TI, pretreatment interval; UM, upper/middle-income economy.

to 5.14).^{28 32 34 35 39} The mean OR was 4.32 (95% CI 1.54 to 7.11) for breast cancer studies (n=3) and 2.58 (95% CI 1.39 to 3.77) for non-breast cancer studies (n=2). Nine studies (eight African studies, one Asian study) assessed the proportion of participants who used TCAM who also had patient intervals greater than 3 months, with the mean proportion equal to 0.45 (95% CI 0.29 to 0.61).^{28 34 36 39–44} The proportion of participants who used TCAM who had patient intervals longer than 3 months was 0.51 (95% CI 0.27 to 0.76) in breast cancer studies (n=6) and 0.33 (95% CI 0.06 to 0.60) in non-breast cancer studies (n=3).

Gender roles. In five female-only observed studies of patients with breast cancer, competing priorities such as housework or childcare were reported as a barrier in the patient interval in Pakistan³² and in African countries^{35 41 42 45} (table 3). In three breast cancer studies, women reported embarrassment about the medical examination as an actual⁴⁵ or anticipated^{46 47} barrier to help-seeking in the patient interval in India⁴⁶ and in African countries^{45 47} (table 3).

Cancer knowledge. Lower cancer symptom knowledge was associated with longer anticipated patient intervals in three hypothetical studies with various cancers in Jordan^{48 49} and lung cancer in Nigeria,⁵⁰ while one hypothetical study found no association between ovarian cancer symptom knowledge and anticipated time to help-seeking in Jordan.⁵¹ In hypothetical studies, good lung cancer symptom knowledge was associated with higher educational attainment and higher income in Nigeria,⁵⁰ while good ovarian cancer symptom knowledge was associated with higher income, but not educational attainment in Jordan.⁵¹ Living in an urban area in India was associated with good breast cancer symptom knowledge in one hypothetical study.³⁰

Misattribution of symptoms^{12 32 34 40 44 45 52} was associated with a longer patient interval in seven observed studies of patients with breast,^{38 44 45 52} colorectal,⁴⁰ cervical³⁹ and oral⁵³ cancers (table 3). Absence of pain was reported as a barrier to help-seeking in the patient interval in four observed studies of patients with breast cancer^{45 54 55} or Kaposi sarcoma²⁸ (table 3).

Emotional barriers to help-seeking. Fear of cancer was a barrier to help-seeking in the patient interval in five observed studies of patients with breast^{32 35 42 44} and oral cancers⁵³ in African, Asian and Caribbean countries (table 3). Fear of breast cancer surgery was not associated with longer patient intervals in one observed study conducted in Uganda.³⁴ Concerns about escalation of their cancer and a negative impact on relationships led to refusal of treatment in two observed studies of patients with breast cancer conducted in African countries.^{38 56}

Access barriers. In four observed studies, long travel times to hospital were reported in African countries^{35 36 57} and in Indonesia³¹ (table 3). In two hypothetical studies conducted in Jordan, participants anticipated difficulty in arranging transport as a possible barrier in the patient interval^{48 49} (table 3).

Table 3 Summary of narrative synthesis for quantitative studies

Measure	% of participants endorsed— observed studies	% of participants endorsed— hypothetical studies
Patient interval		
Cancer knowledge		
Initially unaware their symptoms could indicate cancer	23% ³² , 40% ¹² , 47% ⁴⁴ , 59% ⁴⁰ , 66% ⁴⁵ , 69% ³⁴ , 78% ⁵²	—
Absence of pain	4% ⁵⁵ , 17% ⁵⁴ , 42% ⁴⁵ , 48% ²⁸	—
Emotional barriers to help-seeking		
Fear of cancer	6% ³² , 6% ³⁵ , 11% ⁴⁴ , 38% ⁵³ , 71% ⁴²	—
Access barriers		
Anticipated difficulty in arranging transport	—	29% ⁴⁹ , 49% ⁴⁸
Financial barriers		
Anticipated medical costs	—	42% ⁴⁸ , 68% ⁴⁷ , 83% ⁴⁹
Financial barriers	2% ⁴¹ , 3% ⁵⁸ , 6% ³⁹ , 7% ⁴⁵ , 14% ³⁵ , 17% ⁴³ , 21% ⁴⁴ , 24% ⁵⁷ , 25% ⁵⁴ , 25% ¹² , 32% ²⁸ , 35% ³³ , 75% ³⁶ , 75% ⁵³ , 76% ⁴²	—
Cancer beliefs		
Aware of the benefits of early breast cancer diagnosis	77% ⁵³	41% ⁵⁹ , 58% ³⁷ , 83% ²⁹
Belief that breast cancer is incurable	63% ⁶⁰	53% ³⁷
Belief that cancer is curable	93% ⁵⁷	—
Belief that cancer is caused by evil spirits	60% ⁶⁰	40% ⁵⁹
Belief that rituals and worshipping could cure cancer	35% ⁶⁰	—
Gender roles		
Competing priorities (eg, housework or childcare)	7% ⁴⁵ , 7% ³² , 7% ³⁵ , 12% ⁴¹ , 77% ⁴²	—
Embarrassment about the examination	6% ⁴⁵	7% ⁴⁷ , 15% ⁴⁶
Pretreatment interval		
Fear of escalation	25% ³⁸	—
Fear that treatment would have a negative impact on their relationship	21% ³⁸	—
Refusal of treatment due to emotional barriers	31% ⁵⁶	—
Access barriers		
2+ hours' travel time to the hospital	19% ³⁵ , 50% ⁵⁷ , 69% ³¹	—
4+ hours' travel time to the hospital	43% ³⁶	—
Financial barriers		
Financial barriers	47% ⁵⁶ , 75% ³⁶	—
Reliance on family and friends to fund treatment costs	61% ⁵⁷ , 75% ³⁶	—

The symbol (—) refers to not applicable or data not available.

Financial barriers. In three hypothetical studies^{47–49} and 15 observed studies of patients with breast^{33 35 41–45 54} and non-breast^{12 28 36 39 53 57 58} cancer conducted in African, Asian and Caribbean countries, participants cited financial barriers as major contributors to longer patient intervals or not seeking medical help for symptoms^{33 58} (table 3). In two observed studies conducted in African countries, patients with breast cancer refused⁵⁶ or postponed treatment³⁶ due to financial issues (table 3). Participants in observed studies conducted in African countries

reported having to rely on gift/loans from friends and family during the pretreatment interval to fund treatment for various cancers^{36 57} (table 3).

Cancer beliefs. Three hypothetical studies conducted in India²⁹ and in African countries^{37 59} reported awareness of the benefits of early breast cancer diagnosis. One hypothetical breast cancer study conducted in Kenya³⁷ and one observed study conducted in India with various cancers⁶⁰ reported beliefs that cancer was incurable (table 3). Negative breast cancer beliefs were more prevalent in women

living in urban areas in Morocco in one observed study⁴⁵; conversely, one hypothetical study reported higher negative beliefs about breast cancer among women living in rural areas in India.³⁰ Participants in an observed study in India with various cancers believed that cancer was caused by evil spirits and could be cured by rituals and worshipping.⁶⁰ In one hypothetical study conducted in Nigeria, women believed that breast cancer was caused by evil spirits.⁵⁹ In an observed study of multiple cancers conducted in India, over half of the sample thought that cancer was contagious or were unsure, with those from lower socioeconomic groups more likely to believe that cancer was contagious.⁶⁰

Social influences. In two observed studies of patients with oral⁵³ and breast⁶¹ cancers conducted in Pakistan, encouragement to seek medical help from their social network promoted help-seeking in the patient interval^{53 61} and attendance for diagnostic appointments in the diagnostic interval.⁶¹ However, one observed study conducted in Pakistan found that patients with breast cancer who disclosed symptoms to their social network experienced longer patient intervals.³² One observed study conducted in Uganda found that patients with breast cancer with no social support experienced longer patient intervals.³⁴

Qualitative studies: meta-ethnography

Narrative summary data (third order) are presented below. Supporting illustrative participant quotes (first-order data) are presented in [table 4](#).

TCAM. Most studies reported that the use of TCAM lengthened the patient, diagnostic and pretreatment intervals. In observed studies in Indonesia and in African countries, TCAM was typically sought prior to modern medicine in the patient interval,^{62–67} after diagnosis in the pretreatment interval^{68 69} or both⁷⁰ highlighting that help-seeking and accessing healthcare is a non-linear process.

In hypothetical and observed studies mostly conducted in African countries, it was common to believe that breast^{11 64 66 67 69 71–74} and prostate⁷⁵ symptoms were caused by evil spirits, a spell, or witchcraft or a benign cause (eg, ‘a boil’).^{66 72 73} Beliefs about causality generally prompted participants to visit TCAM healers in the patient interval in observed studies of patients with breast cancer in African countries.^{62 64 69 72 74 76} Due to causal beliefs, TCAM was seen as a logical option to resolve symptoms and treat the perceived underlying cause in the patient interval, and was strongly influenced by cultural norms around TCAM use in Indonesia^{68 77} and in African countries.^{64 66 69 75 78} In hypothetical^{73 79} and observed^{63 65 66} studies conducted in African countries and Indonesia, participants reported beliefs that traditional medicine could cure breast,^{63 66 73} nasopharyngeal⁶⁵ and cervical⁷⁹ cancers; whereas Egyptian participants in a hypothetical breast cancer study tended to believe that traditional medicine could only cure non-cancer conditions such as coughs and colds.⁸⁰

Help-seeking from TCAM practitioners after diagnosis substantially lengthened the pretreatment interval. In

African countries and in Indonesia, TCAM was commonly sought after diagnosis in patients with breast^{62 64 66 69 78} and non-breast^{65 68} cancer. In these studies, use of TCAM in the pretreatment interval was usually encouraged by friends/family due to perceived affordability,^{37 62 65 68 69 78} easier access^{37 65} and more trusted care^{64–66 68 79} when compared with modern medicine. In observed studies of patients with breast cancer conducted in African countries, TCAM was sought in the pretreatment interval to avoid mastectomy, thereby preserving breasts to avoid social exclusion.^{63 66 69 77} In African patients with breast cancer, biomedical cancer treatment was sought in the pretreatment interval when symptoms did not resolve or worsened, typically at an advanced cancer stage.^{63 64 66 78}

Gender effects. In observed studies of patients with breast^{62 63 74 81} and oral⁸² cancers, and hypothetical breast cancer studies^{37 73} conducted in African and Asian countries, it was common for women to require permission from the family, usually their husband, prior to help-seeking in the patient interval^{37 62 63 73 74 81 82} and for husbands to make the final decision regarding treatment in the pretreatment interval.⁷⁴ In observed breast cancer studies conducted in African and Asian countries, husbands were a key influence on either prompting help-seeking or refusing permission to seek medical help in the patient interval or treatment in the pretreatment interval.^{62 63 69 74 81} However, sometimes the husband's decision was over-ridden by the extended family.^{63 81} Breast examination by a male doctor was reported to be a key barrier in the patient and diagnostic intervals for Indian,⁶⁷ Egyptian^{80 83} and Bangladeshi⁸¹ women due to cultural beliefs about modesty.^{67 80 81 83}

As primary caregivers, women in observed and hypothetical studies conducted in Indonesia and African countries reported prioritising family and work commitments over their personal health as barriers to help-seeking for breast^{64 66 67 70 73 78} and non-breast^{13 68 79} cancer symptoms in the patient interval. Medical help was sought in exceptional circumstances, typically if they were in pain and could not carry out domestic or childcare responsibilities.^{70 80} Limited financial resource meant that healthcare costs for women were often lower in priority, and when women in breast cancer studies eventually sought medical help/treatment in all intervals, some described feeling guilty about using limited financial resources towards medical costs.^{72 73 77}

Cancer knowledge. Knowledge of breast^{63 64 73 76 80 83} and non-breast⁶⁵ cancer was generally obtained from social networks, although some participants in African^{13 64 71–73} and Egyptian⁸⁰ breast cancer studies described the influence of cancer awareness campaigns. The point of diagnosis for some African patients with breast cancer^{63 64 66} and Indonesian patients with nasopharyngeal⁶⁵ cancer in observed studies was the first time they had heard of cancer.

In observed and hypothetical studies conducted in Asian and African countries, breast,^{80 81} cervical,¹³ prostate⁷⁵ and oral⁸² cancer symptom knowledge was poor

Table 4 Supporting quotes (first-order data) from meta-ethnography

Theme Subtheme	Example quotations
Patient interval	
Knowledge of cancer	
Symptom detection	'After work, I came back home and while eating my second spoon, suddenly, as we say, an ant bit me in my breast. I stood up and removed my clothes. And automatically I saw a lump which I had never noticed before.' (Breast cancer, observed, Mali ¹¹)
Self-examination behaviour/ source of symptom knowledge	'Based on the education for frequent checks of the breast for cancer lumps, I developed the routine checks daily. It was during one of those checks for lumps that I identified the lump in my breast the very first month I had my menopause.' (Breast cancer, observed, Ghana ⁷¹)
Symptom knowledge restricted to lumps	'Lump—the only one known—there could be other signs but lump is all that is known.' (Breast cancer, hypothetical and observed, Kenya ⁷⁶)
Pain as a motivator for help-seeking	'I came with my sister. She told me she had a lump on her breast about two years back. We were not worried that much because it was painless. But, starting last year, the lump become painful and we took her to [a clinic].' (Breast cancer, observed, Ethiopia ⁸⁴)
Change in symptoms as a motivator for help-seeking	'About 2 years back, I found a small hard lump over my left breast, but since it was small and I had no pain, I was not that much concerned about it. But it kept getting bigger and bigger...' (Breast cancer, observed, Ethiopia ⁸⁴)
Lack of knowledge of cancer as a disease	'I had absolutely no idea what breast cancer was or any knowledge about the disease and symptoms before my diagnoses. I was totally ignorant about what was going on in my breast. Therefore, I did not take any action earlier.' (Breast cancer, observed, Ghana ⁶⁴)
Low knowledge of the aetiology of disease	'I have never seen someone with this disease before in my home. How would I have known that it was a bad disease, cancer? I just thought it would go away.' (Breast cancer, observed, Ghana ⁶³)
Knowledge of cancer obtained from social networks	'This disease is very dangerous; I have seen my relatives and my neighbor who had breast cancer. They did not recover and finally died.' (Breast cancer, observed, Indonesia ⁷⁷)
Educational cancer awareness programmes	'They come and tell us in the church, before I know that there is something like that [breast cancer] to check the breasts.' (Breast cancer, observed, Ghana ⁷²)
Reliance on traditional, complementary and alternative medicine (TCAM)	
Use of TCAM due to beliefs about causality	'I had a prophecy at church some months ago that a family witch (evil spirit) has bought breast cancer for me; just to destroy and kill me. I got delivered spiritually though. Hence, when it manifested physically as a lump in the breast, I took the spiritual route; I went for prayers. I deemed it as not a hospital disease; I ignored hospitals for more than a year.' (Breast cancer, observed, Ghana ⁶⁴)
Cease TCAM and seek medical help when TCAM was considered ineffective	'They [men] go first to the traditional healer because he or she is versed with the traditional treatment. If it doesn't work, then they go to the hospital.' (Prostate cancer, hypothetical, Cameroon ⁷⁵)
Stigma	
Fear of disownment/divorce if diagnosed with cancer	'Maybe if a girl is known to have breast cancer, one may be divorced if she is married. If a girl gets cancer and one of her breasts is removed obviously that one will be rejected. One time...a woman had cancer. The husband's family did not want her...They disowned her.' (Breast cancer, hypothetical, Kenya ³⁷)
Cancer fatalism	'For us cancer means death has arrived.' (Prostate cancer, hypothetical, Cameroon ⁷⁵)
Cancer fatalism	'When I hear the word cancer, I see death, I see a growth that leads to death.' (Breast cancer, hypothetical and observed, Kenya ⁷⁶)
Belief that their cancer was caused by a spell	'He said my husband fought with somebody and that, that person [cast a spell]... so the spell was meant for my husband but it did not get him so it attacked me.' (Breast cancer, observed, Ghana ⁷²)
Belief that their cancer was a spiritual attack	'My cancer is a spiritual attack, it is caused by witches and wizards, I [knew] it would happen. I was told that cancer arrow would be fashioned.' (Breast cancer, observed, Nigeria ⁷⁴)
Social influences	
Lay symptom disclosure facilitated symptom interpretation and promoted medical help-seeking	'After a year, I went to [Eastern Ethiopia] where my biggest child lives. I told him that I had a lump on my breast. I think he heard about breast cancer. He immediately took me to nearby clinic.' (Breast cancer, observed, Ethiopia ⁸⁴)
Lay symptom disclosure facilitated misattribution	'I showed it to many people, some said maybe you are approaching menopause, others said that it is nothing. After I saw two lumps appearing, without any pain but which were growing, I showed it to a pharmacist who called [name]. He told me it is a furuncle but taking antibiotics will prevent it from growing. I talked to my husband who said that I have nothing and that I talk too much.' (Breast cancer, observed, Mali ¹¹)
Seek symptom advice from religious leader	'I told my pastor and then he recommended Dr. X.' (Breast cancer, observed, Ghana ⁷²)
Husband prompted help-seeking	'I first told my husband. My husband told me to go to the hospital immediately.' (Cervical cancer, observed, Uganda ¹³)
Husband encouraged help-seeking from TCAM	'I told my husband. He told me that he has no money and that I should ask God for help and see a traditional healer. His younger brother also said someone has put a spell on me.' (Breast cancer, observed, Mali ¹¹)

Continued

Table 4 Continued

Theme Subtheme	Example quotations
Gender roles	
Women prioritise family and work commitments over their personal health	'Women have no time for themselves. You take care of the children; you take care of the husbands, the shamba [vegetable garden], and everything, even the [extended] family... In fact, there are few of us who take care of ourselves such as going for a walk or going for aerobics. If you take a holiday, people will look at you. You are seen as somebody who is not okay. It is not in our culture.' (Breast cancer, hypothetical, Kenya ⁷³)
Women typically suffer in silence	'A woman doesn't know how to be sickly or pity herself...If the husband falls sick, he exaggerates his illness, but the wife bears her sickness in silence and hides it.' (Breast cancer hypothetical, Kenya ⁷³)
Male health prioritised	'A woman can bear it if it is a serious disease but a man says "No I cannot, I must see a doctor quickly".' (Breast cancer, hypothetical, Egypt ⁸⁰)
Women's health relegated to second place	'Our society is male dominant, and here women are often neglected. It is the same for government and everyone else. This is one of the reasons why the awareness of this kind of disease [breast cancer] is almost non-existent.' (Breast cancer, observed, Bangladesh ⁸¹)
Diagnostic interval	
Difficulty navigating the healthcare system	'I went around looking for doctors, as I didn't know anything about this subject. Nor did I know what doctor to go to; should he be a surgeon or a medical doctor? All these things I knew very late.' (Breast cancer, observed, Egypt ⁸³)
Power imbalance between doctor and patient	'We listen to what the doctor says because the doctor knows, he was trained in many things. You don't know anything. So if he tells you to do something, you have to do it.' (Breast cancer, observed, Malawi ⁷⁰)
Embarrassment of examination from a male doctor	'It is embarrassing to have a breast examination by a male doctor.' (Breast cancer, hypothetical, Egypt ⁸⁰)
System barriers	'It took three years for me to know that it was cancer because they took it [sample] to Blantyre. In the first year, it got lost. They took another sample. It got lost again. During the third time, that was when they diagnosed cancer of the breast.' (Breast cancer, observed, Malawi ⁷⁰)
Pretreatment interval	
Reliance on TCAM	
Belief that TCAM can cure cancer	'There is a strongly held belief among men in Bamenda that diseases like prostate cancer need to be treated as a spiritual illness and traditional medicine is better suited for such.' (Prostate cancer, hypothetical, Cameroon ⁷⁵)
Use of TCAM due to fear of surgery	'I was really afraid of surgery, it was not wrong to try another treatment such as herbal medicine and another method of traditional treatment which were more comfortable for me.' (Breast cancer, observed, Indonesia ⁷⁷)
Use of TCAM as a cure for cancer and for perceived affordability	'I don't know the names of all the herbs; knowledge is inherited from previous generations, my grandparents [...] I'm using alternative treatment because I just want to be cured. Besides that, it is more affordable.' (Nasopharyngeal cancer, observed, Indonesia ⁶⁵)
Stigma	
Health professionals inform families of diagnosis rather than the patient	'It was my sister and her husband who were informed and they did not want to tell me because I tend to overreact.' (Breast cancer, observed, Mali ¹¹)
Fear of cancer stems from social networks	'I felt it was the end of the world, because I had not seen anyone who recovered from it.' (Breast cancer, observed, Uganda ⁷⁶)
Beliefs about cancer being contagious	'People say it is contagious, and some say not. They think that I should not make food for them. They are frightened of me. They fear me. I am frightened my children will get it. I feel as if I am a germ.' (Breast cancer, observed, Egypt ⁸³)
The need to refocus the mind to cope with a diagnosis of cancer	'Everything is from the mind; this is what I always say. If you tune your mind, you will be okay.' (Breast cancer, observed, Ghana ⁷¹)
Religious beliefs to cure cancer	'This cancer is my destiny; I just have to be patient, accept my condition and try to seek a treatment, but only God can heal.' (Breast cancer, observed, Indonesia ⁷⁷)
The need to maintain a positive attitude to cure cancer	'This cancer is painful, but I'm going to fight back. It is going to hurt me, but I am also going to fight back. I am not going to allow it to get over me. I decided to remain positive despite what has happened.' (Breast cancer, observed, Uganda ⁷⁶)
Fear of modern biomedical treatment	
Belief that modern medicine was ineffective and invasive	'I was told that cancer medicine kills everything—good and bad inside you. I decided to keep living and not kill myself with those dangerous medicines.' (Breast cancer, observed, Ghana ⁶³)
'External' cancers perceived as more treatable than 'internal' cancers	'The simplest form of cancer as far as I know is breast cancer. Someone who has colon cancer has lots of operations. When I had the operation, I felt that the operation recovered the person, and it was over in a certain period of time. Cancer of the lung very bad, cancer of the colon bad.' (Breast cancer, observed, Egypt ⁸³)
Preference to die from cancer than undergo mastectomy	'A woman's glory is her breast, so what is your use if one of your breasts is not there? I will rather die with my two breasts than live with one.' (Breast cancer, observed, Ghana ⁷²)
Divorce after mastectomy	'My husband even wanted a divorce because he said I had been maimed.' (Breast cancer, observed, Ghana ⁷²)

Continued

Table 4 Continued

Theme Subtheme	Example quotations
Removal of breasts considered to diminish a woman's sexual identity	'Some think that if you have no breast then your husband would not have something to hold; there are many places the man can play with; so one can still have a fulfilling relationship with a man.' (Breast cancer, observed, Ghana ⁷¹)
Modern biomedical medicine	
Suspicion about modern medicine	'They say medicines given from hospital here [to the community] could be family planning pills given secretly, and many of them are not ready to do family planning. Others even say that [community outreach] is an organization for devil worshippers.' (Breast cancer, hypothetical, Kenya ³⁷)
High financial cost of modern medicine	'If you don't have the financial power, neither you nor your husband, they don't care for you, even if you cry; but if they know you have money, they give you attention. That's why I am using traditional medicine.' (Breast cancer, observed, Mali ¹¹)
Reluctance to use government assistance for medical bills due to fear of mistreatment	'I would like to pay no matter what, my son told me not to use BPJS they would treat us like less important.' (Nasopharyngeal cancer, observed, Indonesia ⁶⁵)
Access problems	'I was worried about transport [...] If it was near, I could have been coming sooner.' (Breast cancer, observed, Malawi ⁷⁰)
Economic hardship	
High transportation costs	'We rely on farming in order to find money for transport...[we were] waiting until we sell tobacco to find money to use for transport to go.' (Breast cancer, observed, Malawi ⁷⁰)
Did not accept treatment due to cost	'Immediately I went to the lab and came here, they immediately scheduled me for surgery. I didn't have money so I went home and never came back because I didn't have money... I run away because of the money.' (Breast cancer, observed, Ghana ⁷²)
Prioritising educational bills over medical bills	'At the time I discovered this lump in my breast, my daughter had just been accepted into [university] to study nursing... I didn't come [follow up with treatment] because I wouldn't have been able to work to provide [financially] for my child and I would have destroyed her life... so I wanted to her to go because I knew that even if I had passed away, she would have entered the University.' (Breast cancer, observed, Ghana ⁷²)
Social influences	
Husband refused permission to seek medical; family over-rode decision	'My husband was against mastectomy, but my mother and uncle prevailed upon me to have it. I obeyed my mother and uncle and had the mastectomy even though I thought just removing the lump would be okay since the breast looked normal.' (Breast cancer, observed, Ghana ⁶³)
Husband refused permission for mastectomy	'A day to the operation, my husband decided not to allow the operation to come on. I was subsequently discharged even though the doctor wasn't happy about it. I was taken to a(n) herbalist. In fact, I went through a lot.' (Breast cancer, observed, Ghana ⁶³)
Accepting God's will	'According to the bible in Jeremiah 30:17; the word of God says that "I shall be whole again", I believe that they will not cut it and the lump will go.' (Breast cancer, observed, Nigeria ⁷⁴)

and mainly restricted to lumps as a cancer symptom.^{64 73 76}

In observed studies of patients with breast cancer, misattribution of symptoms contributed to longer patient intervals.^{11 63 64 66 70 72 74 76 77 81 82 84} Lack of pain was a key barrier to help-seeking in the patient interval in observed breast cancer studies conducted in African countries due to misattribution.^{62–64 66 70 72 74 84} Painless symptoms and/or symptoms that did not hinder daily functioning lengthened the patient interval in observed studies of African patients with breast cancer^{63 64 66 74 78 84} and Indonesian patients with nasopharyngeal⁶⁵ cancer. Symptoms that persisted, changed or became painful motivated help-seeking in the patient interval in observed studies of patients with breast^{62–64 70 78 83 84} and cervical¹³ cancers.

Stigma. In hypothetical and observed studies conducted in Asian and African countries, cancer was a source of shame and stigma^{72 75–77 82} that influenced help-seeking across all intervals due to fear of social rejection and treatment, and presumed death after diagnosis.^{37 62 75 81 82} In Indonesia and in African countries, cultural norms around cancer stigma and secrecy after breast^{63 72 74 76 77} and prostate⁷⁵ cancer diagnosis meant that there was a lack of exposure to cancer, and negative illness synonyms

such as 'the bad disease'^{63 64 76 80} were used. Cancer taboo was reinforced in hospital settings in African countries where health professionals referred to cancer as 'that disease' or 'the sickness',⁷² and commonly withheld details of the diagnosis from the patient.⁷⁴

In observed and hypothetical studies conducted in Asian and African countries, breast^{11 62 64 66 67 69 72 73 77 78 81} and oral⁸² cancer stigma stemmed from beliefs about the causes of cancer in general, where cancer was mainly viewed as a form of punishment, out of one's control or the patients' destiny.^{11 62 64 66 67 69 72 73 77 78 81 82} These beliefs lead to fear of disownment or mistreatment from family or the community in Asian and African countries.^{37 67 72 76–78 81 83} Participants in observed breast cancer studies reported that seeking social support after diagnosis in the pretreatment interval was potentially risky due to stigma associated with cancer.^{64 74} In observed studies, strong religious beliefs facilitated acceptance of the consequences of their cancer in Indonesian patients with nasopharyngeal cancer⁶⁵ and Ghanaian patients with breast cancer⁶³ leading to refusal of cancer treatment, accepting God's will or entrusting God to cure the cancer without the need for biomedical treatment.^{63–65 74 77 82}

Financial barriers. In hypothetical and observed studies, high medical and transportation costs were a major barrier in Asian and African studies across all intervals,^{11 13 62 63 65–78 80 81 83} particularly for patients living in rural areas. Many participants did not have healthcare insurance, or insurance coverage was limited to certain treatments.^{65 72 75 77 83} The pretreatment interval in Asian and African studies was lengthened while patients with breast^{11 62 70 77 81 83} and non-breast^{13 65 68} cancer in observed studies obtained the financial means to cover medical costs and/or transport, often using more affordable TCAMs. Patients in observed breast and non-breast cancer studies conducted in Indonesia and African countries^{11 62 70–72 74} relied on relatives, the community and the church for financial support for medical bills and transport costs which shortened the pretreatment interval.

Social influences. Social networks—family, friends, the local community, elders, the church—were found to play a pivotal role in help-seeking at all intervals. In observed studies conducted in African and Asian countries, typically spouses, close relatives or church leaders were consulted on discovery of a breast^{63 64 70–72 78 84} or non-breast^{13 65 82} symptom. Symptom disclosure could lengthen or shorten the patient interval in observed studies of patients with breast and non-breast cancer conducted in Asian and African countries depending on whether symptoms were attributed to cancer by friends and family^{11 13 63–65 69 70 72 74 78 82–84} and whether patients were encouraged to seek help from TCAM^{11 62–64 69 70 74} or modern medicine.^{11 13 64 65 70 72 74 78 82 84}

Beliefs about cancer. Most studies assessing fearful and fatalistic cancer beliefs found that these lengthened all intervals. In observed and hypothetical studies conducted in Asian and African countries, breast,^{37 62–64 66 67 73 74 76 77 80} nasopharyngeal,⁶⁵ oral⁸² and prostate⁷⁵ cancers were conceptualised as dangerous, painful and deadly. Negative beliefs were usually based on experiences of people within patients' social network with a cancer diagnosis.^{62–64 66 74–78 83} There were few accounts of positive survival stories.⁷⁴

For women in observed breast cancer studies conducted in African countries, the possibility of disfigurement lengthened the pretreatment interval or led to treatment refusal.^{63 69 72 74 78} In hypothetical and observed studies conducted in Indonesia⁷⁷ and in African countries,^{37 63 69 71 72 78} the removal of a woman's breasts through mastectomy was considered to diminish her sexual identity, self-worth, personal relationships and value in society. In hypothetical and observed breast cancer studies, women recounted examples of cancer diagnoses that resulted in divorce or social rejection.^{37 72 74 76 78 81}

Modern medicine. One hypothetical breast cancer study conducted in Egypt reported positive views towards modern cancer treatment,⁸⁰ although few women in hypothetical and observed breast cancer studies reported knowledge about the benefits of early diagnosis for breast cancer.^{62 72 73 76 80} In most observed and hypothetical studies conducted across African and Asian contexts, modern

biomedical treatment for breast^{63 64 66 67 70–72 77 81} and non-breast^{65 75 79} cancer was generally perceived as expensive, invasive and ineffective, with harmful side effects that destroy the body and/or lead to disfigurement and shame. In some hypothetical and observed studies conducted in African countries, breast cancer surgery was believed to escalate cancer progression.^{62 72 73 77}

Suspicion and mistrust of biomedical care in Asian and African countries lengthened the patient and pretreatment intervals in observed breast cancer studies, and prompted visits to TCAM practitioners.^{11 66 67 69 70 76 83} In hypothetical and observed studies conducted in African and Asian countries there was a perceived imbalance of power between doctors and patients, with reports of health professionals dominating discussions about treatment and lacking empathy.^{65–67 69 70 73 76 77 79 83} Patients with breast^{67 70 76 77} and nasopharyngeal⁶⁵ cancers in observed studies were reluctant to question their diagnosis or ask questions in Asian and African countries. This power imbalance was most prominent in uninsured, lower income, less educated and rural patients, where some studies reported instances of mistreatment or suboptimal treatment.^{11 65 76 77 79} In observed studies of patients with breast^{11 76 77} and nasopharyngeal⁶⁵ cancers, some low-income uninsured patients who were eligible for government assistance to cover healthcare costs sometimes described refusing the financial support due to fear of differential treatment by medically trained health professionals.

DISCUSSION

This was the first comprehensive review of psychosocial barriers to medical help-seeking behaviour for cancer symptoms and access to healthcare in LMICs. Use of TCAM was a key barrier to prompt medical help-seeking in LMICs. Consulting TCAM was influenced by causal beliefs about symptoms, familial pressure to visit a traditional healer, ease of access, affordability and a preference to avoid biomedical treatment. Biomedical treatment was perceived as invasive, disfiguring, ineffective and expensive, and in some contexts medically trained doctors were perceived as untrustworthy and corrupt. Fear, shame and stigma associated with cancer were a barrier to help-seeking that prompted refusal of treatment due to fear of social rejection. Women were seen as having particular high levels of challenges and barriers to prompt cancer help-seeking, such as needing permission from the husband or family to contact the medical system, their health being seen as lower value and female-specific stigma around breast cancer. The cost of travel and healthcare appointments/treatment was a key barrier across all intervals.

Consistent with previous narrative reviews and one meta-analysis conducted in HIC and/or LMIC contexts, low symptom knowledge,^{14 15 85} misattribution of symptoms,^{16 19 85} negative beliefs about cancer^{14 18 19} and fear of treatment^{17 86} were associated with longer patient intervals,

suggesting these are universal barriers to cancer help-seeking. Findings from our meta-ethnography indicate that cancer is highly stigmatised in LMICs partly due to beliefs about causation and low knowledge of the disease, and impacts help-seeking across all intervals. One review of breast cancer studies in LMIC contexts found fair to moderate evidence that the use of TCAM healers lengthened the patient interval,¹⁷ while our updated review covering all cancers found strong evidence that use of TCAM was prevalent and a key influence on help-seeking across all intervals. No review in HIC has reported use of complementary medicines, suggesting that TCAM use may be particularly important in LMICs.

Due to the predominance of breast cancer studies and patient interval studies, we were unable to draw strong conclusions in relation to help-seeking in the diagnostic and pretreatment intervals, or for non-breast tumours and male help-seeking. Additionally, some findings were presented descriptively, meaning it was not possible to assess their influence on time to help-seeking. Heterogeneity among the quantitative studies precluded a formal meta-analysis⁸⁷ due to inconsistencies in help-seeking thresholds (eg, definitions of 'delay' ranged from 2 weeks⁵⁰ to 6 months⁸⁴) and the use of a wide range of psychosocial measures, many of which were unvalidated, increasing the difficulty of integrating findings. There were additional inconsistencies in the reporting of statistical results, for example, not reporting non-significant findings and not providing full information needed to interpret statistical results. The quantitative study team met frequently to discuss each paper in detail and the data set as a whole to agree on which variables could be analysed using meta-analytic techniques. Due to consistency of reporting and the high number of studies that assessed TCAM use, TCAM use was the only variable that could be analysed using meta-analytic techniques. It is a limitation of our review that other non-TCAM variables could not be summarised using meta-analytic techniques for comparison. Due to small sample sizes, it was not possible to assess whether TCAM use varied as a function of region. There are methodological limitations associated with measuring observed and hypothetical help-seeking behaviour, with a possible intention-behaviour gap in hypothetical studies and recall bias in observed studies. We included both types of studies in our review to balance the limitations associated with each study design.

Future research on cancer help-seeking behaviour in LMICs should consider using validated measures^{7 8} with reporting of all statistical results (significant or not) and use of ORs, to allow for summarisation across studies. Freely available and validated measures include the Cancer Awareness Measure,⁸⁸ the Awareness and Beliefs about Cancer Measure,⁸⁹ and the Cancer-Symptom Interval Measure.⁹⁰ Pilot testing should be conducted with a sample of potential participants to ensure cultural relevance of translated or new survey items. A number of studies in our review included limited assessment of

TCAM, and further research is required to understand in depth the influences of TCAM on the patient interval.

Lack of symptom knowledge and negative beliefs about cancer appear to be universal barriers to cancer help-seeking behaviour, suggesting that elements of existing awareness campaigns (eg, Be Clear on Cancer; <https://www.cancerresearchuk.org/health-professional/awareness-and-prevention/be-clear-on-cancer>) could potentially be adapted for LMICs. Cultural and context-specific barriers reflecting TCAM use and gender influences on medical help-seeking are key barriers in LMICs that would need to be addressed sensitively and in collaboration with local communities.

CONCLUSION

With rapidly rising cancer incidence in LMICs, efforts to improve early cancer diagnosis and treatment through system-level interventions and individual behavioural interventions are critical to reduce cancer mortality. Interventions must address major barriers to medical help-seeking for symptoms and decisions to access healthcare for diagnosis and treatment in LMICs by raising cancer awareness, modifying negative beliefs and addressing cultural barriers such as TCAM use and barriers for women.

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