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Women's awareness of cancer symptoms: a review of the literature

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Abstract
Improvements in cancer detection and treatment have led to consistent declines in mortality from many cancers. However, many patients present for treatment at a point where more invasive treatment is required and/or treatment outcomes are less than optimal. One factor that has been consistently shown to be associated with late diagnosis and treatment is delay in seeking help for symptoms. This paper reviews the literature on women's awareness of cancer symptoms and aims to identify knowledge gaps that need to be addressed in order to improve help-seeking behaviors. The discovery of substantial gaps in awareness suggest a need for improved community education regarding cancer symptoms.

Keywords
women, awareness, cancer, review, symptoms, literature

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Women’s awareness of cancer symptoms: a review of the literature

Sandra C Jones*1 & Keryn Johnson1

Improvements in cancer detection and treatment have led to consistent declines in mortality from many cancers. However, many patients present for treatment at a point where more invasive treatment is required and/or treatment outcomes are less than optimal. One factor that has been consistently shown to be associated with late diagnosis and treatment is delay in seeking help for symptoms. This paper reviews the literature on women’s awareness of cancer symptoms and aims to identify knowledge gaps that need to be addressed in order to improve help-seeking behaviors. The discovery of substantial gaps in awareness suggest a need for improved community education regarding cancer symptoms.

While women’s decision to seek diagnosis and treatment for cancer are influenced by a complex interaction of demographic, clinical, cognitive, behavioral and social factors [1], awareness of symptoms is an important precursor to action. Poor awareness of cancer symptoms (i.e., not recognizing that the symptoms may represent a significant medical condition [2] – in this case, cancer) has been associated with patient delay in help-seeking; late diagnosis, in turn, is associated with reduced survival, the need for more aggressive treatment and fewer treatment choices [2–4].

The purpose of this current review is to examine the evidence on women’s awareness of cancer symptoms – to identify knowledge gaps and misperceptions and, thus, improve help-seeking behaviors (e.g., attending a medical practitioner for investigation of potential symptoms) at the early stages of disease.

Methods

The databases MEDLINE, ProQuest, Scopus, Web of Knowledge, Health Reference Centre, Informit and PsycINFO were searched using the following keywords: ‘cancer’ AND ‘knowledge’ OR ‘awareness’ OR ‘understanding’ AND ‘symptoms’ AND ‘women’. An additional search using the keywords ‘cancer’ AND ‘help-seeking’ OR ‘delay’ was also conducted. Literature was limited to English language, peer-reviewed journal articles from the year 2000 onwards. The search was conducted with a view to achieving a high sensitivity but low specificity, retrieving a high number of articles (n = 1332 titles retrieved). Titles were scanned to exclude content not relevant to cancer symptoms (reduced to 187 articles) and then abstracts reviewed with a further 94 papers excluded (review articles [n = 18], qualitative research [n = 42], content not specific to symptom awareness [n = 21], lack of symptom awareness measured outcomes [n = 6], dissertations [n = 2] or unrepresentative of general female populations [n = 2]). Reference lists from included articles and review articles were also reviewed for relevant papers, with 13 extra papers retrieved. These 106 full papers were then reviewed. Of these, 52 are included in this review. Those excluded from the review did not report measures on symptom awareness, were qualitative, did not report data separately for females, discussed treatment delay rather than delay in help-seeking, were datasets previously reported or discussed symptom experience rather than awareness.

Papers were included that quantified women’s knowledge of cancer symptoms, the factors associated with this knowledge, behavioral responses to potential symptoms and discussed factors associated with intending to or actually seeking help for cancer symptoms. Qualitative studies were excluded from the review. Where studies included male and female respondents, only the data from female respondents are included in this paper.

A number of papers were retrieved from non-western nations. These papers were included as the high levels of immigration into western developed countries means that awareness of immigrant women about cancer symptoms and issues surrounding help-seeking behaviors is particularly important for health service agencies that aspire to ensure equality in health across populations. For practical reasons, only papers written in English were included in the review.

The paper commences with an overview of the small number of studies that have addressed women’s awareness of a variety of cancer symptoms across all forms of cancer, followed by a
review of the literature on female cancers (breast then gynecological, then colorectal cancer). For each cancer type, the included papers are reviewed for: country of study, study method, population/sampling frame (e.g., general population, screening clinic attendees, cancer patients), sampling (e.g., method, sample size and response rate) and findings on symptom awareness.

The paper finishes with a summary of what is known, what the gaps are in the literature and recommendations for research and practice.

‘Cancer symptom’ awareness

Four studies were identified that assessed women’s awareness of cancer symptoms across all sites (all four studies included male and female respondents; only the data from female respondents are reported) three studies were from the UK [5–7] (note that Waller reports on the same dataset as Brunswick) and one from the Netherlands [8]. Two of the studies used recall (i.e., open-ended questions that asked women to name symptoms), whereas the other two used recognition (i.e., asking women to state whether they believed each of a list of items to be potential symptoms of cancer).

The first of the two ‘symptom recognition’ studies was conducted in the UK with a stratified probability sample that included 1854 women, with a response rate of 69% [5]; the second study was conducted in the Netherlands with a convenience sample of respondents to newspaper advertisements that included 1221 women with a mean age of 46 years [8]. When provided with a list of symptoms, the majority of the British [5] and Dutch respondents [8], respectively, recognized as ‘warning signs’ or symptoms of cancer: thickening/lump (84.0 and 56.0%); change in a mole or wart (79.0 and 82.3%); bleeding/discharge (74.3 and 62.6%; described as ‘unusual’ bleeding or discharge in the Dutch study); change in bowel or bladder habits (73.7%; separated in the Dutch study into bowel [44.6%] and urinary [32.0%]); and persistent cough or hoarseness (53.8 and 55.0%). Less than half responded affirmatively to a sore that does not heal (47.3 and 39.0%) and indigestion or difficulty swallowing (37.7 and 42.4%). Recognition of symptoms only included in the Dutch study was 61.9% for unusual weight loss and 58.8% for new warts.

The two recall studies were conducted in the UK with stratified probability samples that included 874 women aged 16–75 years [6], and 1240 women ranging from 16 years and over 65 years [7]. As expected, recall of symptoms was lower than recognition (note that the second paper did not report exact figures). Approximately three-quarters of women spontaneously mentioned thickening or a lump, less than half mentioned bleeding or discharge, less than one-third mentioned a change in a mole or wart or unusual weight loss, less than one-fifth mentioned a change in bowel or bladder habits or persistent cough or hoarseness, and less than one-tenth mentioned indigestion or difficulty swallowing or a sore that does not heal.

Higher levels of symptom awareness were associated with being older [5–7], having a higher level of education [5,6,8], higher socioeconomic status or income [5,7], being married [7] and being Caucasian [7].

Breast cancer

Breast cancer is the most commonly diagnosed cancer in women (excluding skin); accounting for 31% of diagnoses in the UK [9], 29% in the USA [10] and 30% in Australia (the Australian Institute of Health and Welfare report includes skin cancer; the figures were recalculated by the authors excluding skin cancer to enable comparison with the UK and US data) [11].

Thirty six articles were identified that addressed women’s awareness of breast cancer symptoms: the majority were from the UK (ten in total), with four from the USA [12–15], three each from Malaysia [16–18] and Iran [19–21], two each from the Republic of Ireland [22,23], India [24,25] and Nigeria [26,27], and one each from Canada [28], Australia [29], New Zealand [30], Germany [31], Singapore [32], Sierra Leone [33], Nepal [34], Turkey [35], Pakistan [36] and Myanmar [37].

Nineteen of the articles reported on surveys of asymptomatic women in the general population who were not undergoing cancer treatment, screening or education; an additional three articles reported on surveys of university students [26,27]. Among the 19 general population surveys (Table 1), sample sizes ranged from 50 [28] to 3005 [29], and response rates, for the ten which reported this data, ranged from 32% to 92% [14].

The majority of these studies targeted the female population as a whole and, thus, generally experienced the same limitations of generalizability, including under-representing women from minority groups and those with lower levels of education. However, this was addressed in a UK study, which stratified sampling by tertiles of deprivation and oversampled nonwhite ethnic groups [38]; a UK study, which oversampled for black and minority ethnic groups [39]; and an Indian study, which recruited a sample that
included 46% of respondents who were illiterate [25]. A further three studies sought specifically to explore cancer awareness among minority groups: Chinese–American women living in Chicago in the USA [15]; Tongan–American women in California in the USA [14]; and Iranian immigrant women in Toronto, Canada [28]. All but two of the surveys were conducted with the aim of exploring women’s general knowledge and beliefs regarding breast cancer symptoms and screening; these two studies sought to examine potential predictors of delay in seeking diagnosis and treatment (note that Grunfeld et al. reports on the same dataset) [12,40].

Twelve articles reported on surveys conducted with women who were diagnosed with breast cancer [13,31,41,42], attending for follow-up of symptoms [23,30,43,44], attending for breast screening [45,46] or attending a breast cancer educational program or information session (Table 2) [33,35].

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Sample size</th>
<th>Sampling method</th>
<th>Survey method</th>
<th>Age range (mean; years)</th>
<th>Response rate (%)</th>
<th>Ref.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al. (2010)</td>
<td>Australia</td>
<td>3005</td>
<td>Stratified random</td>
<td>CATI</td>
<td>30–69 (50)</td>
<td>32</td>
<td>[29]</td>
</tr>
<tr>
<td>Grunfeld et al. (2002)</td>
<td>UK</td>
<td>1830</td>
<td>Random representative</td>
<td>Face-to-face and phone</td>
<td>16–96 (47)</td>
<td>67</td>
<td>[47]</td>
</tr>
<tr>
<td>Linsell et al. (2008)</td>
<td>UK</td>
<td>712</td>
<td>Random representative</td>
<td>Postal</td>
<td>67–73 (N/S)</td>
<td>84</td>
<td>[48]</td>
</tr>
<tr>
<td>McMenamin et al. (2005)</td>
<td>Ireland</td>
<td>1250</td>
<td>Convenience (intercept)</td>
<td>Self-completed</td>
<td>16–50+ (N/S)</td>
<td>N/S</td>
<td>[22]</td>
</tr>
<tr>
<td>Forbes et al. (2011)</td>
<td>UK</td>
<td>1515</td>
<td>Stratified random</td>
<td>Face-to-face (researcher-completed)</td>
<td>30–65+ (N/S)</td>
<td>81</td>
<td>[38]</td>
</tr>
<tr>
<td>Facione et al. (2002)</td>
<td>USA</td>
<td>699</td>
<td>Convenience</td>
<td>Self-completed</td>
<td>19–99 (47)</td>
<td>N/S</td>
<td>[12]</td>
</tr>
<tr>
<td>Scanlon and Wood (2005)</td>
<td>UK</td>
<td>342 (general)</td>
<td>Representative, with quotas for seven BME groups</td>
<td>Phone (general) and face-to-face (BME)</td>
<td>18+ (N/S)</td>
<td>N/S</td>
<td>[39]</td>
</tr>
<tr>
<td>Yu et al. (2001)</td>
<td>USA</td>
<td>332</td>
<td>Purposive</td>
<td>Face-to-face (researcher-completed)</td>
<td>40–69 (54)</td>
<td>N/S</td>
<td>[15]</td>
</tr>
<tr>
<td>Tanjasiri et al. (2002)</td>
<td>USA</td>
<td>303</td>
<td>Convenience</td>
<td>Face-to-face (researcher-completed)</td>
<td>40–60+ (N/S)</td>
<td>92</td>
<td>[14]</td>
</tr>
<tr>
<td>Vahabi (2011)</td>
<td>Canada</td>
<td>50</td>
<td>Convenience</td>
<td>Face-to-face (researcher-completed)</td>
<td>29–66 (45)</td>
<td>80</td>
<td>[28]</td>
</tr>
<tr>
<td>Baig et al. (2011)</td>
<td>Malaysia</td>
<td>320</td>
<td>Random</td>
<td>Face-to-face (researcher-completed)</td>
<td>16–55 (27)</td>
<td>80</td>
<td>[17]</td>
</tr>
<tr>
<td>Okobia et al. (2006)</td>
<td>Nigeria</td>
<td>1000</td>
<td>Random</td>
<td>Face-to-face (researcher-completed)</td>
<td>15–91 (29)</td>
<td>N/A†</td>
<td>[26]</td>
</tr>
<tr>
<td>Montazeri et al. (2008)</td>
<td>Iran</td>
<td>1402</td>
<td>Cluster randomized</td>
<td>Face-to-face (researcher-completed)</td>
<td>20–80 (43)</td>
<td>N/S</td>
<td>[20]</td>
</tr>
<tr>
<td>Sim et al. (2009)</td>
<td>Singapore</td>
<td>1000</td>
<td>Convenience (intercept)</td>
<td>Self-completed</td>
<td>&lt;30–60+ (N/S)</td>
<td>N/S</td>
<td>[32]</td>
</tr>
<tr>
<td>Grunfeld and Kohli (2010)</td>
<td>India</td>
<td>685</td>
<td>Convenience (intercept)</td>
<td>Researcher-completed or self-completed</td>
<td>16–84 (49)</td>
<td>86</td>
<td>[24]</td>
</tr>
<tr>
<td>Bhatt et al. (2011)</td>
<td>Nepal</td>
<td>100</td>
<td>Convenience</td>
<td>Face-to-face (researcher-completed)</td>
<td>19–65 (37)</td>
<td>N/S</td>
<td>[34]</td>
</tr>
<tr>
<td>Hunter et al. (2003)</td>
<td>UK</td>
<td>546</td>
<td>Purposive (from random)</td>
<td>Postal</td>
<td>16–86 (47)</td>
<td>70</td>
<td>[40]</td>
</tr>
<tr>
<td>Mon et al. (2009)</td>
<td>Myanmar</td>
<td>400</td>
<td>N/S</td>
<td>N/S</td>
<td>40–60+ (48)</td>
<td>N/S</td>
<td>[37]</td>
</tr>
</tbody>
</table>

*BME: Black and minority ethnic; CATI: Computer-assisted telephone interview; N/A: Not applicable; N/S: Not stated.

†Replacement for nonresponse.
Sample sizes ranged from 69 [44] to 867 women [46]. Few of these articles reported response rates; those that did suggested that relatively higher response rates were achieved than with general population surveys, ranging from 59 [35] to 98% [43]. The four studies that were conducted with women diagnosed with breast cancer aimed to identify the predictors of delay in seeking diagnosis and treatment, as did three of the studies conducted with women presenting for investigation of symptoms [23,30,43]. The four studies conducted with women attending breast screening or information sessions were designed to assess the effectiveness of breast cancer education sessions.

**Awareness of symptoms**

While the studies included in this review differed in their methodologies, scope and, in some cases, purpose, the majority asked women to name potential symptoms of breast cancer. Again, it is important to note that some studies used recall while others used recognition.

The UK National Health Service (NHS) recommends that women see their family doctor if they notice any of the following:

- A lump or area of thickened tissue in either breast;
- A change in the size or shape of one, or both, breasts;
- A discharge from either nipple (which may be streaked with blood);
- A lump or swelling in either armpit;
- A dimpling on the skin of the breast;
- A rash on or around the nipple;
- A change in the appearance of the nipple, such as becoming sunken into the breast;
- Pain in either breast or armpit that is not related to the menstrual period [101].

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**Table 2. Surveys conducted in healthcare settings: breast cancer.**

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Sample</th>
<th>Sample size</th>
<th>Survey method</th>
<th>Age range (mean; years)</th>
<th>Ref.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pullyblank et al. (2002)</td>
<td>UK</td>
<td>Attending breast clinic</td>
<td>75</td>
<td>Researcher-administered, self-completed</td>
<td>N/S (46)</td>
<td>[44]</td>
</tr>
<tr>
<td>Linsell et al. (2009)</td>
<td>UK</td>
<td>Attending routine breast screening</td>
<td>867</td>
<td>Researcher-administered, self-completed</td>
<td>67–70 (N/S)</td>
<td>[46]</td>
</tr>
<tr>
<td>Burgess et al. (2008)</td>
<td>UK</td>
<td>Attending routine breast screening</td>
<td>292</td>
<td>Postal</td>
<td>N/S</td>
<td>[45]</td>
</tr>
<tr>
<td>Meechan et al. (2003)</td>
<td>New Zealand</td>
<td>Self-discovered breast symptoms referred to clinic</td>
<td>85</td>
<td>Nurse-administered, self-completed questionn followed by face-to-face interview with researcher</td>
<td>20–71 (39)</td>
<td>[30]</td>
</tr>
<tr>
<td>O’Mahony and Hegarty (2009)</td>
<td>Ireland</td>
<td>Self-discovered breast symptoms referred to clinic</td>
<td>99</td>
<td>Researcher-administered, self-completed</td>
<td>18–75 (40)</td>
<td>[23]</td>
</tr>
<tr>
<td>Nosarti et al. (2000)</td>
<td>UK</td>
<td>Referred to breast clinic</td>
<td>692</td>
<td>Face-to-face semistructured interview</td>
<td>40–75 (N/S)</td>
<td>[43]</td>
</tr>
<tr>
<td>Arndt et al. (2002)</td>
<td>Germany</td>
<td>Diagnosed with breast cancer</td>
<td>287</td>
<td>Face-to-face, researcher-completed</td>
<td>18–80 (57)</td>
<td>[31]</td>
</tr>
<tr>
<td>Burgess et al. (2006)</td>
<td>UK</td>
<td>Diagnosed with breast cancer</td>
<td>69</td>
<td>Face-to-face semistructured interview</td>
<td>65–96 (78)</td>
<td>[41]</td>
</tr>
<tr>
<td>Rauscher et al. (2010)</td>
<td>USA</td>
<td>Diagnosed with breast cancer</td>
<td>438</td>
<td>Face-to-face, researcher-completed</td>
<td>30–79 (N/S)</td>
<td>[13]</td>
</tr>
<tr>
<td>Budakoglu et al. (2007)</td>
<td>Turkey</td>
<td>Attending breast cancer education</td>
<td>462</td>
<td>Self-completed questionnaire and face-to-face interviews</td>
<td>40–80 (48)</td>
<td>[35]</td>
</tr>
<tr>
<td>Shepherd and McInerney (2006)</td>
<td>Sierra Leone</td>
<td>Attending breast cancer education</td>
<td>120</td>
<td>Face-to-face, researcher-completed</td>
<td>18–50+ (N/S)</td>
<td>[33]</td>
</tr>
<tr>
<td>Harirchii et al. (2005)</td>
<td>Iran</td>
<td>Advanced breast cancer</td>
<td>200</td>
<td>Face-to-face, researcher-completed</td>
<td>20–79 (47)</td>
<td>[19]</td>
</tr>
</tbody>
</table>

N/S: Not stated.
This list of symptoms is largely consistent with those of other national health authorities, albeit with some differences in wording. For example, the US National Cancer Institute combines the breast and armpit in a single descriptor, “A lump or thickening in or near the breast or in the underarm area” and refers to “dimpling or puckering in the skin of the breast” [102]. Perhaps the most notable difference is the inclusion of pain as a symptom in the UK NHS list (but not that of Cancer Research UK [103], the US National Cancer Institute [102] or the Canadian Cancer Society [104]); in Australia this is typically described as “an unusual pain that does not go away” [105].

Given that the majority of breast cancer awareness survey studies identified in this review were conducted in the UK, the UK NHS list of symptoms has been used as the organizing structure for the reporting of findings on symptom awareness.

Many of the studies did not report levels of awareness of individual symptoms, rather they reported on specific symptoms of interest to the researchers or on the number of symptoms identified. A UK study reported that only 18% of respondents recognized five or more nonlump symptoms of cancer from a list [38]; a US study found that 14% of respondents identified only a ‘lump’ as a symptom and only 10% identified all, or all but one, of the 15 symptoms correctly [12]; a UK study reported that at baseline, 42% could circle five symptoms or more from a list of 11 [46]; and another UK study found that the mean number of symptoms recognized from a list of 11 was 5.3 [45].

Eleven of the articles reported data for some or all of the listed symptoms in terms of the proportion of respondents who recalled or recognized these as potential symptoms of breast cancer (Table 3). It is clear that a breast lump is the most consistently identified symptom of breast cancer, with high levels of both recognition and recall (particularly in western countries). Other symptoms, such as a lump or swelling in the armpit, discharge from the nipple or a change in the size or shape of the breast, are recognized but not recalled (i.e., the majority of women agree when they are presented with a written list and asked whether these are symptoms, but do not spontaneously think of them when asked to name possible symptoms). A third group of symptoms, which includes dimpling of the skin and inversion of the nipple, are neither recalled nor recognized by the majority of women.

It is interesting to note the high ‘recognition’ of pain as a symptom of breast cancer, despite the absence of pain as a potential symptom in the materials developed and disseminated by many of the major cancer agencies as detailed previously. Among the studies described in this table, pain was recognized or recalled as a symptom of breast cancer by large proportions of respondents (often more than half). Similarly, 72% of a sample of Iranian women living in Canada [28] and 52% of Singaporean women [32] associated breast pain with early breast cancer.

Predictors of awareness
A number of demographic factors are consistently found to be associated with breast cancer awareness and, particularly, knowledge of symptoms and screening. Older respondents identify fewer symptoms [32,47] and hold more misconceptions about breast cancer [13]. Perhaps the biggest predictor is education, with studies consistently finding an association between increased education level and increased awareness of cancer symptoms [13,17,26,32,34,48]. For example, in a UK study, women with O-level qualification or above (ordinary [O] level is a standard qualification in the UK, usually taken at age 15–16 years), identified a median of seven symptoms compared with a median of five for women with no educational qualifications [48]; and in a US study women with some college education identified a mean of ten symptoms, compared with seven for those with only high-school completion and six for those with lower education [12]. Consistent with this, those in lower-skilled employment report lower cancer awareness [26,34,47], as do those with lower incomes [13,32].

Being part of an ethnic minority, or being a non-native language speaker, is associated with lower awareness of breast cancer symptoms. For example, a UK study found that south-Asian women were significantly less likely to recognize five or more symptoms (9.6%) than black women (15.9%), and both groups were less likely to do so than white women (22.1%) [38]; a US study found that African–Americans and Hispanics are significantly more likely to hold misconceptions about cancer than are white Americans (18 and 35% compared with 5%) [13]. This is even more evident when comparing between, rather than within, studies. For example, a survey of Iranians living in Canada reported that the majority did not know what symptoms to look for (data not provided) [28]; a survey of Chinese immigrants in Chicago found that, unprompted, 65% could not identify a single cancer symptom [15]; and a UK study...
reported that 38% of black and minority ethnic respondents stated that a lump is the only symptom, compared with 22% of the general population [38].

Studies from non-English speaking countries, and with rural populations, also found low levels of symptom awareness. For example, Indian respondents identified an average of three symptoms from a list of eight (and four distractors), with rural respondents being less likely to correctly identify symptoms [24]; only 42% of women attending a breast information session in Sierra Leone could name some symptoms [33]; and only 21.4% of a Nigerian sample were aware that breast cancer presents most commonly as a painless lump, with even fewer responding correctly to questions on other symptoms, including ulceration of the nipple (data not provided) [26].

Other factors found to be associated with breast cancer awareness include prior exposure to breast cancer via a family member or friend [32,44] and prior interactions with medical services. For example, in US studies, symptom awareness has been found to be associated with prior clinical breast examination or mammogram [14], although the direction of this relationship is unclear (i.e., it may be that awareness of symptoms increases the likelihood of screening, or that information provided by health professionals during screening increases symptom awareness), misconceptions about cancer have also been found to be associated with a lack of private health insurance and not having a regular doctor [13]. Similarly, in a Nepalese study, knowledge was related to prior discussions about breast cancer during clinic visits [34].

**Gynecological cancers**

While considered separately, each of the gynecological cancers is not in the top three cancers

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Method</th>
<th>Breast lump/thickening (%)</th>
<th>Change in size/shape (%)</th>
<th>Nipple discharge (%)</th>
<th>Arm pit lump/swelling (%)</th>
<th>Dimpling skin (%)</th>
<th>Rash (%)</th>
<th>Inversion of nipple (%)</th>
<th>Pain in breast (%)</th>
<th>NIL (%)</th>
<th>Ref.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grunfeld et al. (2002)</td>
<td>UK</td>
<td>Recognition</td>
<td>85</td>
<td>64</td>
<td>70</td>
<td>80</td>
<td>39</td>
<td>–</td>
<td>38</td>
<td>50</td>
<td>–</td>
<td>[47]</td>
</tr>
<tr>
<td>Linsell et al. (2008)</td>
<td>UK</td>
<td>Recognition</td>
<td>93</td>
<td>67</td>
<td>72</td>
<td>86</td>
<td>57</td>
<td>14</td>
<td>60</td>
<td>53</td>
<td>–</td>
<td>[48]</td>
</tr>
<tr>
<td>Montazeri et al. (2008)</td>
<td>Iran</td>
<td>Recognition</td>
<td>44</td>
<td>2</td>
<td>6–8</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>5</td>
<td>16</td>
<td>6</td>
<td>[20]</td>
</tr>
<tr>
<td>Akhtari-Zavare et al. (2011)</td>
<td>Malaysia</td>
<td>Recognition</td>
<td>62</td>
<td>63*</td>
<td>60</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>64</td>
<td>–</td>
<td>–</td>
<td>[16]</td>
</tr>
<tr>
<td>Hadi et al. (2010)</td>
<td>Malaysia</td>
<td>Recognition</td>
<td>72</td>
<td>82</td>
<td>75</td>
<td>79</td>
<td>59</td>
<td>–</td>
<td>–</td>
<td>79</td>
<td>–</td>
<td>[18]</td>
</tr>
<tr>
<td>Jones et al. (2010)</td>
<td>Australia</td>
<td>Recall</td>
<td>86</td>
<td>16</td>
<td>34</td>
<td>6</td>
<td>17</td>
<td>–</td>
<td>–</td>
<td>25</td>
<td>5</td>
<td>[29]</td>
</tr>
<tr>
<td>McMenamin et al. (2005)</td>
<td>Ireland</td>
<td>Recall</td>
<td>74</td>
<td>–</td>
<td>6</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>14</td>
<td>24</td>
<td>[22]</td>
</tr>
<tr>
<td>Pullyblank et al. (2002)</td>
<td>UK</td>
<td>Recall</td>
<td>75</td>
<td>–</td>
<td>48</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>[44]</td>
</tr>
<tr>
<td>Somdatta and Baridalyne (2008)</td>
<td>India</td>
<td>Recall</td>
<td>42‡</td>
<td>–</td>
<td>7</td>
<td>–</td>
<td>1.6</td>
<td>–</td>
<td>–</td>
<td>41</td>
<td>49</td>
<td>[25]</td>
</tr>
</tbody>
</table>

*Described as ‘swelling of all or part of the breast’.

†Only 5% knew that painless lump is a symptom of breast cancer. Other symptoms identified were fever, itching, weight loss, breast abscess and presence of breast ulcer.

NIL: None.
in most countries, but when combined they account for more cases of cancer in women than colorectal cancer. For example, uterine and ovarian cancer are the fourth and fifth most commonly diagnosed cancers in women in the UK [9] and the fifth and eighth in Australia [11]. In the USA, it is estimated that there will be 88,750 new cases of gynecological cancers in 2012 (including uterine, ovarian, cervical, vulval, vaginal and other genital) [10].

Eight articles were identified that addressed women’s awareness of gynecological cancer symptoms: three related to ovarian cancer [49–51]; two to cervical cancer [52,53]; one to endometrial cancer [54]; one to gynecological cancers in general [55]; and one to common female cancers (also discussed above regarding breast cancer) [37].

Five of the articles reported on population based surveys of cancer awareness among women without a cancer diagnosis; two from the USA [51,55] and one each from Australia [50], Myanmar [37] and Laos [53]. Sample sizes ranged from 400 [37] to 2991 [55]; response rates were not provided for the majority of studies (Table 4).

Both of the ovarian cancer surveys asked women whether a series of symptoms were potentially those of ovarian cancer, with six symptoms included in both studies. Weight changes – described as ‘putting on weight around the middle’ in the Australian study and ‘unexplained weight gain or loss’ in the US study – was recognized as a symptom by 30.6% of the Australian sample [50] and 35.9% of the US sample [51]; feeling full or bloated by 58.6% of the Australian and 47.2% of the US samples; and tiredness/ongoing unusual fatigue by 73.3% of the Australian and 35.8% of the US samples. Among the Australian sample, indigestion was recognized as a potential symptom by 17.7% and nausea by 68.9%; in the US study these were combined as ‘vague or persistent gastrointestinal upsets such as gas, nausea and indigestion’ and were recognized as a symptom by 29.2%. Levels of agreement with other symptoms asked in the Australian study were stomach pain (82.3%), changes in the menstrual cycle (91.6%) and backache (76.9%), and in the US study, frequency and/or urgency in urination (26.3%). To control for affirmative response bias (i.e., ticking yes to all items), both studies included items that were not potential symptoms of ovarian cancer. Levels of agreement that these were ovarian cancer symptoms in the Australian study were 31.0% for headache and 10.5% for chest pain, and 17.5% for continuous fever in the US study.

The other US study, which addressed gynecologic cancers more generally [55], did not ask about awareness of symptoms, but rather intention to seek help if experiencing specific symptoms. Women were more likely to report intending to seek help for postmenopausal bleeding (90.5%), vaginal itching (90.4%) and vaginal discharge (83.1%) than for bloating (41.0%) or feeling full after eating a small amount of food (37.2%).

The Laos study assessed awareness of cervical cancer symptoms; the Myanmar study included similar symptoms. Of the four symptoms included in both studies, abnormal vaginal bleeding was recognized as a symptom by 76.3% of respondents in Myanmar and 52% in Laos; bleeding after coitus by 42.1% in Myanmar and 33% in Laos; and vaginal discharge by 63.3% in Myanmar (question referred

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Sample size</th>
<th>Sampling method</th>
<th>Survey method</th>
<th>Age range (mean; years)</th>
<th>Response rate (%)</th>
<th>Cancer type(s)</th>
<th>Ref.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al. (2010)</td>
<td>Australia</td>
<td>2954</td>
<td>Stratified random</td>
<td>CATI</td>
<td>30–69 (48)</td>
<td>32%</td>
<td>Ovarian</td>
<td>[50]</td>
</tr>
<tr>
<td>Lockwood-Rayerman et al. (2009)</td>
<td>USA</td>
<td>1211</td>
<td>Random (from panel)</td>
<td>Email</td>
<td>40–60+ (N/S)</td>
<td>N/S</td>
<td>Ovarian</td>
<td>[51]</td>
</tr>
<tr>
<td>Trivers et al. (2011)</td>
<td>USA</td>
<td>2991</td>
<td>Stratified random</td>
<td>Mail</td>
<td>18–50+ (N/S)</td>
<td>77.1</td>
<td>Gynecologic</td>
<td>[55]</td>
</tr>
<tr>
<td>Mon et al. (2009)</td>
<td>Myanmar</td>
<td>400</td>
<td>N/S</td>
<td>N/S</td>
<td>40–60+ (48)</td>
<td>N/S</td>
<td>Common female cancers</td>
<td>[37]</td>
</tr>
<tr>
<td>Phongsavan et al. (2010)</td>
<td>Laos</td>
<td>800</td>
<td>Purposive</td>
<td>Face-to-face (interviewer-completed)</td>
<td>18–55 (34)</td>
<td>N/S</td>
<td>Cervical</td>
<td>[53]</td>
</tr>
</tbody>
</table>

*States that panel has approximately 1 million members, first 1235 were used.

CATI: Computer-assisted telephone interview; N/S: Not stated.
to ‘white’ discharge) and 64% in Laos (question referred to ‘foul’ discharge). Dyspareunia was recognized as a potential symptom by 43.5% of respondents in the Myanmar survey and amenorrhagia by 34% in the Laos survey.

Given the small number of studies, and that few of these reported on predictors/correlates of awareness, it is difficult to draw any conclusions about factors associated with awareness. The Australian study found that older women generally had lower levels of awareness of ovarian cancer symptoms [50], but the US awareness study found no differences by age or ethnicity, but (consistent with the breast cancer awareness research) found an association between awareness and education level [51]. The US help-seeking intention study found that older women were more likely to seek medical care for symptoms, as were black and Hispanic women and women with greater concern about getting gynecological cancer [58]. They found no differences in intentions by income, education, employment status or marital status.

Three studies sought to explore reasons for delayed diagnosis and, of relevance to this review, associations between symptom awareness and delays in seeking treatment; these included a UK study with endometrial cancer patients in hospitals (mean age: 68 years) [54]; a Canadian study with subscribers to an ovarian cancer patient newsletter (mean age: 52 years) [49]; and a Tanzanian study with hospital patients with cervical cancer (mean age: 49 years) and/or ‘other gynecological problems’ (mean age: 46 years) [52]. (A fourth study, conducted in Hong Kong with newly diagnosed ovarian cancer patients [Chan et al. [56]] was excluded as the lack of data provided in the article prevented interpretation of the findings.) Sample sizes in these studies ranged from 123 [54] to 1725 patients [49].

The endometrial cancer study found that 41 of the 85 women who reported having experienced abnormal uterine bleeding said they had no idea it was a sign of possible cancer; half waited more than a month before seeing their general practitioner and 12% waited more than 6 months [54]. The ovarian cancer study did not specifically address awareness of symptoms; however, 22% of respondents stated that they had ‘ignored’ their symptoms, suggesting that they were not aware that these were potential symptoms of ovarian cancer [49]. The Tanzanian study reported that less than half the respondents recognized the symptoms of cervical cancer (prompted recognition): irregular vaginal bleeding (38% of respondents with cervical cancer, 50.6% of respondents with other gynecological problems); postcoital bleeding (37.1 and 41.6%); postmenopausal bleeding (42.7 and 48.9%); and abnormal vaginal discharge (39.3 and 48.9%). Correlates of late presentation included not knowing symptoms of cancer and lack of formal education (data not provided). It is noteworthy that the women diagnosed with cervical cancer reported lower levels of symptom awareness than the noncancer patients [52].

**Colorectal cancer**

Excluding skin, colorectal cancer is the third most commonly diagnosed cancer in women in the UK and the USA, accounting for approximately 12% of diagnoses in the UK [9] and 9% in the US [10], and the second most common in Australia [11]. It is, therefore, somewhat surprising that there is a limited body of research on knowledge of this cancer.

Four articles were identified that addressed women’s awareness of colorectal cancer (all four studies included male and female respondents; only the data from female respondents are reported), three were from the UK [44,57,58] and one from Australia [59]. Three of these reported on population surveys of colorectal cancer awareness (Table 5), with sample sizes ranging from 526 [58] to 799 respondents [59]. One study used a recognition measure and found that, among their random sample of women aged 16 years and over, the majority agreed that blood in stools (92%), bleeding from the back passage (89%), change in bowel habit (83%), pain in the back passage (80%) and unexplained weight loss (79%) were potential symptoms of colorectal cancer, with a smaller proportion (54%) recognizing tiredness as a potential symptom [57].

The two population-based surveys that used recall measures found that blood in bowel movements was the most commonly recalled symptom (approximately one-third of those in the UK survey), with a smaller proportion identifying abdominal pain or a persistent change in bowel habits; even fewer identified the bowel not feeling empty after bowel motion, weight loss and mucus in stools as symptoms. In the Australian survey, 17% of female respondents and 53% of those in the UK survey could not name a single symptom of colorectal cancer. In the final study, only 47% of women surveyed while attending a breast or a colorectal clinic in the UK could name a symptom of bowel cancer.
The Australian study did not report data on specific symptoms separately by gender; however, it is worthy to note that most studies found women to have higher levels of awareness than men [57–59]. Consistent with the findings for other types of cancers, knowledge of colorectal cancer symptoms was associated with higher levels of education [58,59], higher socioeconomic status, ethnicity (categorized as ‘white’ and ‘other’, with the former associated with greater symptom knowledge) and knowing someone who was diagnosed with cancer [57].

### Conclusion

The small body of literature on women’s awareness of cancer symptoms, overall, suggests that the majority of women are able to recognize the more common cancer symptoms when provided with a list, but are unable to recall symptoms when asked to name warning signs of cancer (with the exception of a lump or thickening). This gap between recognition and recall was consistent for studies of specific cancer types. For example, a breast lump was the most consistently identified symptom of breast cancer, with high levels of both recognition and recall; however, symptoms, such as a lump or swelling in the armpit, discharge from the nipple and a change in size or shape of the breast, were recognized but not recalled.

A consistent finding across cancer types was that symptom awareness was associated with higher educational attainment, higher income, and being Caucasian or a member of the dominant cultural group. The association with age was varied, with levels of awareness of general cancer symptoms appearing to be higher among older women, while awareness of breast and gynecological cancer symptoms specifically appeared to be lower among older women.

These findings have important implications for both promoting engagement in cancer screening and implementing strategies to address late presentation for diagnosis and treatment. In the former case, communication campaigns to increase women’s awareness that many cancers have symptoms that can be detected by screening programs while the cancer is in its early stages (and thus require less invasive treatment with a higher likelihood of survival) may increase women’s willingness to participate in these programs. In the latter case, increasing awareness of cancer symptoms at a population level may reduce patient delay in help-seeking by enabling women to recognize that their symptoms may represent a significant medical condition (in this case, cancer). Finally, the evident disparities in symptom awareness between those of higher and lower socioeconomic status and those who are and are not members of the dominant cultural group suggest an urgent need for the development and dissemination of information on cancer symptoms in a way that is understandable, accessible and relevant to women in lower socioeconomic groups, from culturally and linguistically diverse backgrounds and with lower levels of (health) literacy.

### Limitations

The primary limitation of this study relates to the inclusion and exclusion criteria. For practical reasons, the articles included were limited to those written in English and accessible through the university’s database. Qualitative studies were also excluded; while such studies cannot be directly compared with the 52 quantitative papers that make up this review, they would likely provide rich descriptive data to contextualize and expand on the findings. Finally, the lack of reporting of key data in a number of the articles – such as sampling methodologies, age of respondents, statistical information on findings, among others – limited our ability to make direct comparisons and draw definitive conclusions about differences between countries and samples.
Future perspective
An important consideration for researchers and clinicians is to determine which of these measures is the more important indicator in terms of seeking medical advice in response to a potential symptom. It may be that recognition of a symptom from a provided list indicates that a woman would equally recognize that symptom if she experienced it, but it is also possible that on experiencing a symptom, that same woman may not recall that it could be a symptom of cancer rather than a more benign condition. Future research could usefully address this issue in order to determine what form of awareness we should be aiming for. This is particularly important given that the body of evidence – including studies reviewed in this paper and those beyond the scope of this review [60–62] – indicates that nonrecognition of symptoms is a predictor of delay in seeking diagnosis and treatment.

Breast cancer was by far the most studied type of cancer, with 34 articles meeting the inclusion criteria for the review. These studies also suggest that awareness of breast cancer symptoms is, across the countries and samples studied in the papers included in this review, considerably higher than awareness of gynecological and colorectal cancer symptoms. This could be a function of the nonspecific nature of the symptoms of some of these cancers (e.g., ovarian cancer). This position is supported by the relatively high recognition of nonsymptoms as being symptoms of ovarian cancer in the two studies that included these as control variables [50,51]. It is also possible that the low levels of symptom awareness are associated with the more hidden nature of these cancers due to social stigma and reluctance to discuss conditions affecting bodily functions and intimate body parts [63–67]. However, given the lack of understanding of these cancers as well as a lack of awareness of the symptoms – for example, studies show that many women believe a Pap smear test is for ovarian cancer [50,68] – there is a clear need to increase women’s awareness of the symptoms of these cancers and to increase their willingness to discuss potential symptoms with their health professionals.

The topic of cancer awareness appears to have been most extensively researched in the UK (17 of the 52 papers included in the review), although we were able to identify and include studies from a range of countries. Future researchers should consider conducting repeated studies over time to track changes in awareness within, or ideally across, countries. One of the factors that limited the ability to compare across studies was the variation between researchers in the wording of symptoms and the inclusion/exclusion of symptoms. This is no doubt associated with the variations in the inclusion, and wording, of symptoms between countries and between agencies within countries – but it raises two important points for consideration. From a research perspective, this limits the ability to compare levels of awareness across samples and to assess the effectiveness of interventions. From a patient (and clinician) perspective, it makes the task of learning to recognize cancer symptoms even more difficult. In an age where

Executive summary

**Background**
- Poor awareness of cancer symptoms has been associated with patient delay in help-seeking.

**Cancer symptoms**
- Few studies have been conducted; survey findings suggest recognition of symptoms are high, but recall is low.

**Breast cancer**
- There is high recognition and recall of breast lump as a symptom, but low awareness of many other symptoms.
- Low awareness of symptoms is associated with being older, less educated, lower income and ethnic minority.

**Gynecological cancers**
- There are far fewer research studies on gynecological cancers than breast cancer.
- There is a low awareness of symptoms, compounded by varied definitions and nonspecific nature of symptoms.

**Colorectal cancer**
- Similarly low levels of awareness of symptoms; blood in bowel movements is the most commonly recognized and recalled symptom.

**Conclusion**
- Inconsistent wording and inclusion of symptoms in studies makes comparison difficult.
- There is a need to determine whether recognition or recall of symptoms is the key awareness measure.
- A low level of awareness of symptoms of some cancers could be a function of the nonspecific nature of the symptoms, as well as the more ‘hidden’ nature of these cancers due to social stigma and reluctance to discuss conditions affecting bodily functions.
the vast majority of the world’s population has ready access to the Internet, a person searching for information on cancer symptoms is likely to come across an array of confusing and conflicting lists of symptoms.

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References

Papers of special note have been highlighted as:
• of interest
•• of considerable interest

• Large stratified probability sample (including 1854 women) with a response rate of 69%, which assessed awareness of a wide range of cancer symptoms.

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Websites


