

SPECIAL NEEDS OF YOUNG WOMEN WITH BREAST CANCER IN LIMITED RESOURCE SETTINGS

CARMEN LIZETTE GÁLVEZ-HERNÁNDEZ^{1,2}, MARÍA CECILIA GONZÁLEZ-ROBLEDO^{3*},
REGINA BARRAGÁN-CARRILLO^{2,4} AND CYNTHIA VILLARREAL-GARZA^{2,4,5}

¹Catedrática-CONACYT, Instituto Nacional de Cancerología, Mexico City, Mexico; ²Joven y Fuerte: Programa para la Atención e Investigación de Mujeres Jóvenes con Cáncer de Mama, Mexico City, Mexico; ³Centro de Investigación en Sistemas de Salud, Instituto Nacional de Salud Pública, Cuernavaca, Mor., Mexico; ⁴Centro de Cáncer de Mama, Hospital Zambrano Hellion, Tecnológico de Monterrey, Monterrey, NL, Mexico; ⁵Department of Investigation and Breast Tumors, Instituto Nacional de Cancerología, Mexico City, Mexico

ABSTRACT

Background: Young women with breast cancer (YWBC) comprise a group of patients with unique biopsychosocial characteristics with a special perception of needs throughout their disease and survivorship. Contexts marked by restricted allocations and economic constraints might further aggravate the struggle of these patients living within limited resource settings and can demand added requirements for them and their families. **Objective:** To analytically explore the existing knowledge regarding the needs of YWBC in low- and middle- income countries (LMICs). **Methods:** We conducted a thorough literature review of scientific journal databases available in Spanish and English containing information on YWBC in LMICs. **Results:** We did not find any publications exclusively assessing this topic in resource-limited settings. We looked for data on the different types of YW need from studies in the region that assessed the needs of breast cancer (BC) patients in general and described in their findings the particularities of young patients. Young BC patients described within the literature present a variety of needs. Those reported most frequently as unmet were related to information needs and psychological counseling, practical and physical assistance, and social and spiritual support. **Conclusions:** Published literature on the subject - particularly in Latin America - is extremely scarce. This offers an area of opportunity for conducting further research in this topic that would help improve health professional training and establish health policies in favor of YWBC.

Key words: Needs assessment. Supportive care needs. Breast cancer. Young women. Low- and middle-income countries. Latin America.

BACKGROUND

Breast cancer (BC) is the leading cause of cancer-related death and disability among women in low- and middle-income countries (LMICs)^{1,2}, where the proportion of incident and fatal cases among women aged ≤ 45 years is substantial: 20% versus 12% in high-income countries (HICs) for incidence and 14% versus 7% for mortality, respectively². In Mexico, for example, BC is the second-leading cause of death among women aged 30-54 years³. Hence, understanding

and assisting young women (YW) who are facing this disease in resource-limited contexts acquires great relevance.

YWBC is regarded as a special population with distinctive requirements based on at least three considerations: (1) Cancer presenting at a young age is often diagnosed at advanced stages, with a higher frequency of more aggressive subtypes; therefore, it has been associated with a poor prognosis^{2,4-7}. (2) Young BC patients often receive aggressive and prolonged

Corresponding author:

*María Cecilia González-Robledo
Centro de Investigación en Sistemas de Salud
Instituto Nacional de Salud Pública
Av. Universidad, 655
Santamaría Ahuacatlán
C.P. 62100, Cuernavaca, Mor., México
E-mail: cecilia.gonzalez@insp.mx

Received for publication: 10-05-2017
Approved for publication: 16-06-2017
doi: 10.24875/RIC.17002285

treatments that can be associated with important long-term morbidity^{8,9}. (3) Finally, YWBC is subject to significant psychosocial vulnerability resulting from high levels of emotional distress and depression associated with oncological interventions^{2,6,10}. The preceding factors pose complex issues for YWBC, particularly in regard to their family, social, and professional lives^{8,11}, thereby substantially undermining their quality of life^{2,10,12}.

Context: Countries with limited resources

Countries with limited health resources fall under the category of LMICs and are characterized by insufficient funds to cover the individual and public healthcare needs, which include limited access to medicine and health-related equipment, rudimentary infrastructure, and deficient or inadequately trained clinical personnel¹³. These conditions differentiate health outcomes from patients in HICs compared to those in LMICs. For instance, the rate of 5-year BC survival in HICs ranges between 80% and 90%, but falls to 40–60% in LMICs and even to a staggering 12% in parts of Africa^{13,14}.

Furthermore, the epidemiology of BC differs greatly between regions. Compared with BC patients in HICs, those in LMICs are diagnosed at younger ages^{7,13,15}. For instance, a study in Kenya reported that the mean age of BC diagnosis was 44 years¹⁶, in contrast to 61 years in the USA. In Latin America, one of every 5 cases is diagnosed in women aged <45 years, almost twice as many as in HICs¹⁵. The contrasting ages of onset among HICs and LMICs have been attributed to the younger age distribution of LMICs populations compared with developed countries. However, biological and genetic differences have also been adduced¹³.

In addition, BC in LMICs is usually detected at more advanced stages than in HICs, owing largely to protracted diagnosis and treatment¹⁷. This has been explained by various factors, including lack of awareness, limited access to diagnostic evaluations and treatment initiation, cultural attitudes among women such as fatalist outlooks (beliefs and/or taboos), stigma surrounding cancer, and gender discrimination^{17,18}.

Other significant burdens that BC diagnosis confers young patients in poor countries are profound and long-lasting repercussions on the economy of the families and community, owing largely to the role of women as labor and sustenance providers, a situation

which has increased appreciably in recent years¹⁷. This acquires particular relevance in the case of YW, where the number of lost years of potential productivity is critical².

Given the paucity of research into the requirements of this young population group^{19,20}, studies are greatly needed to characterize this vulnerable population, particularly those living in socioeconomic disadvantage marked by little access to health care. In this manuscript, we aim to analytically explore existing knowledge regarding the needs of YWBC in LMICs to provide a better understanding of their specific requirements and to guide the future targeted strategies for healthcare providers in limited resource settings.

METHODS

A systematic search was conducted in English and Spanish publications. YW was operationally defined as ≤ 40 years old at the time of diagnosis. Limited resource settings included all the countries classified in low-income (GNI per capita \$1,025 or less), lower middle-income (\$1,026 and \$4,035), and upper middle-income (GNI per capita \$4,036 and \$12,475) economies according to the World Bank Group report. To assess the supportive care needs of young BC patients in LMIC, the following key words were searched for in both English and Spanish: BC or breast neoplasm, young or younger, supportive care needs or supportive care or psychosocial care or need or unmet need or needs assessment, limited resource settings, low income economies, developing countries, emerging economies, poor countries, as well as with the particular names of countries belonging to the groups of the low-income economies, lower-middle income, and upper-middle income economies. Studies that have assessed unmet needs of women with BC, including young patients, and have been conducted in limited resource settings were considered for review. To determine perceived needs, we used two conceptual frameworks of supportive care needs and quality of life, adapted for cancer survivors^{21,22}. Epidemiological studies carried out in HICs, and data from mixed cancer types were excluded.

Since there are no publications that exclusively assessed this topic among young BC population in LMICs, we pursued data on the different types of needs of YW from studies conducted in the region which assessed the needs of BC patients in general

and in their findings described the particularities of young patients. Fig. 1 shows a flowchart of the selection process for including manuscripts to be discussed in this review. Tables 1 and 2 provide further details on studies' findings.

Supportive care needs of YWBC

For the purpose of presentation in this manuscript, we classified supportive care needs into six main clusters according to the two conceptual frameworks of needs and quality of life adapted to cancer survivors: (1) Physical, (2) psychological, (3) information and health system, (4) social, (5) spiritual, and (6) practical needs. Furthermore, the different stages of survivorship were also taken into account: Acute or short-term (immediately after diagnosis), extended or medium-term (end of the initial cancer treatment), and permanent or long-term (when cancer treatment ends and patients must readapt to their daily lives)^{21,22}.

Physical needs

It is well known that YWBC experience treatment-derived side effects, consisting mainly of induced ovarian failure, premature menopause, infertility, osteoporosis, and weight gain²³. Regarding sexual activity, most studies report the presence of sexual dysfunction, impaired sexual desire, and low frequency of sexual activity^{24,25}. As for cognitive function, the most frequently affected domains include speed of processing, attention, and memory, that is, a number of women have been found to experience difficulty in remembering things, reading the newspaper, and watching television²⁶⁻²⁹. The rest of the treatment-related morbidity associated with systemic and local therapy is similar to that of the general BC patients, mainly including headaches, xerostomia, nausea, dysgeusia, alopecia, lymphedema, alterations in skin integrity (erythema and desquamation), and radiated area pain, among others^{25,30-32}.

Figure 1. Flowchart of literature review process.

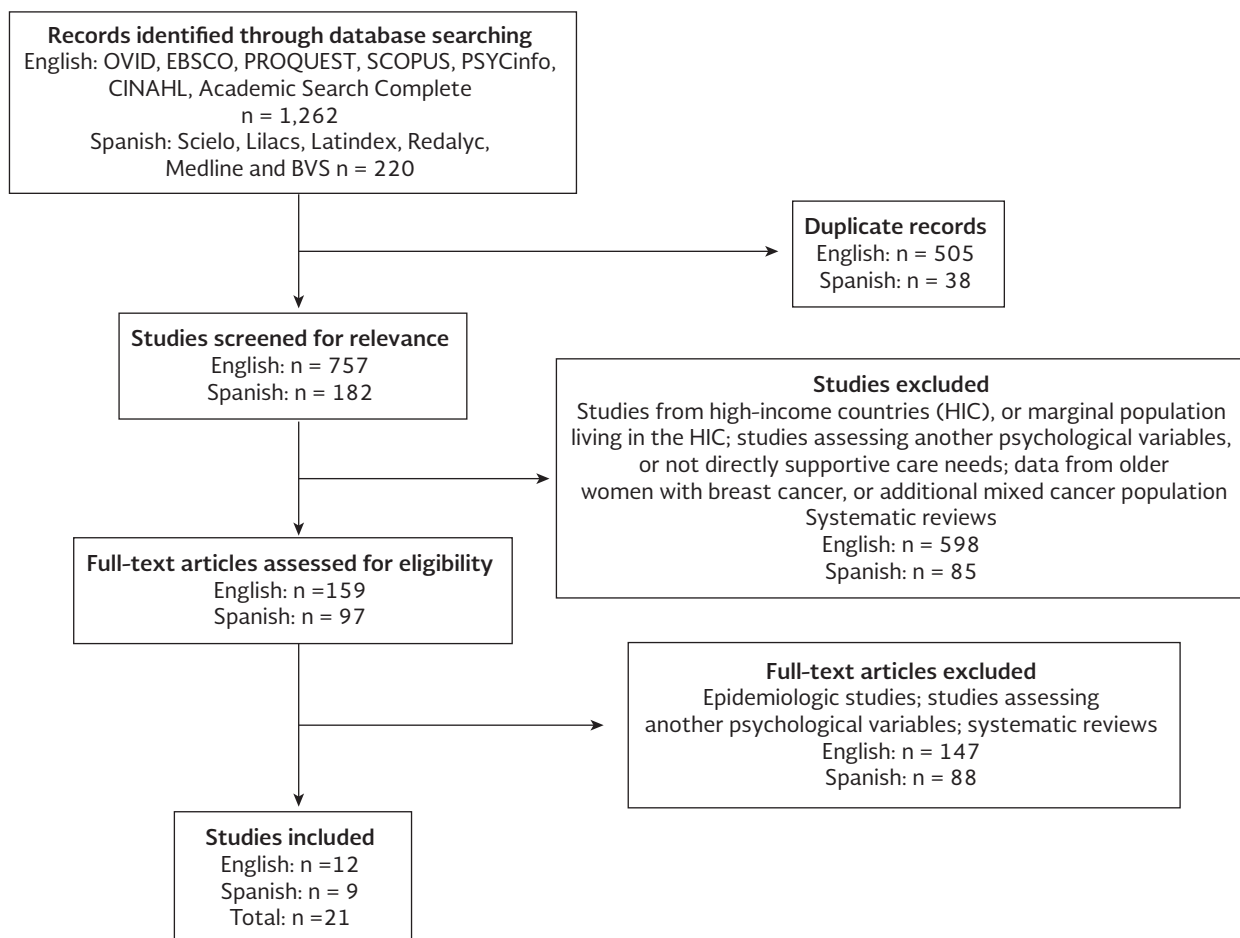


Table 1. Variables of interest, population, and design of studies addressing special needs of YWBC in LMICs

| References | Variables of interest | Population | Design |
|---|---|---|--|
| Can et al. 2004 (Turkey) ³⁵ | Fatigue level experienced during adjuvant chemotherapy and influencing factors | 90 women, aged 30 to > 60 years, 27 YWBC aged 30-39 years (30%) | Descriptive study instruments: Rotterdam Symptom Checklist; Piper Fatigue Scale |
| Cho et al., 2011 (Korea) ⁴² | Communication needs with physicians on the internet | 1355 women, aged 22-65 years, mean 38 years | Qualitative content analytic approach Instruments: Online Q and A board |
| Da Silva and Dos Santos, 2010 (Brasil) ³⁷ | Stressors in BC post-treatment | 16 women, aged 35-75 years, mean 61 years | Qualitative, descriptive, cross-sectional study instruments: Semi-structured interviews |
| Edib et al., 2016 (Malaysia) ³³ | Prevalence of unmet supportive care needs and QoL | 133 women, 16 YWBC aged < 40 years (14%) | Cross-sectional instruments: Supportive Care Needs Survey-SF34; EORTC QLQ-C30 |
| Erci and Karabulut, 2007 (Turkey) ⁴¹ | Range of needs grouped into seven clusters: Diagnosis, treatment, support, femininity, and body imagen, information and after care | 143 women aged 20-> 54 years, 62 YWBC aged 20-45 years (43%) | Descriptive Instruments: Self-assessed support needs of women with BC Questionnaire |
| Barboza and Forero, 2011 (Colombia) ⁵⁴ | Religiosity/spirituality related to depression and anxiety | 61 women, 19 women aged 30-39 years (31%) | Descriptive, cross-sectional study Instruments: HADS Hospital Anxiety and Depression Scale |
| Fong and Cheah, 2016 (Malaysia) ³⁴ | Prevalence of unmet needs and associated factors | 101 women, mean 57.9 years, 57 women < 60 years (56%) | Cross-sectional study Instruments: Supportive Care Needs Survey-SF34 |
| Garduño et al., 2010 (Mexico) ²⁷ | Effects of a cognitive-behavioral intervention on QoL | 60 women, aged 31-67 years | Prospective study (pre-post) Instruments: InCaViSa QoL assessment with the inventory of QoL and health |
| Hubbeling, 2015 (Mexico) ⁶⁰ | Supportive care needs of young survivors (> 5 years after diagnosis) | 25 women ≤ 40 years at diagnosis | Descriptive, cross-sectional study Instruments: Semi-structured interviews |
| Hernández-Moreno and Landero-Hernández, 2014 (Mexico) ³⁹ | Stress, negative thoughts, and social support related with QoL | 50 women, aged 34-73 years, mean 48.7 years | Descriptive, cross-sectional study Instruments: PSS Perceived Stress Scale; EORTC QLQ-C30 |
| Iskandarsyah et al., 2013 (Indonesia) ⁴⁴ | Level of satisfaction regarding the received information addressing illness and treatment, associations with patients' illness perceptions, and QoL | 70 women aged 28-66 years, mean 45.6 years | Correlational-descriptive study instruments: Demographic form, satisfaction with cancer information profile, brief illness perception questionnaire, and the World Health Organization QoL-BREF |
| Karaöz et al., 2010 (Turkey) ⁴³ | Needed and received information regarding contraception, early menopause, infertility, fertility preservation, and sexuality | 20 women, mean 40 years | Qualitative exploratory methodology |
| Ornelas-Mejorada et al., 2011 (Mexico) ³¹ | Prevalence of anxiety and depression among women with BC from radiotherapy | 203 women, women aged 15-44 years (23%) | Structured interviews Instruments: HADS |
| Salas and Grisales, 2010 (Colombia) ⁵⁰ | QoL in women diagnosed with BC undergoing treatment | 220 women, aged 28-80 years, median 53.5 years | Cross-sectional study Instruments: WHOQOL BREF QoL |
| Sat-Muñoz et al., 2011 (Mexico) ⁴⁹ | Socioeconomic factors, comorbidities, and process of care associated with QoL | 314 women, mean 52.2 years | Cross-sectional study Instruments: EORTC QLQ-C30, IN-PATSAT 32 |

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Table 1. Variables of interest, population, and design of studies addressing special needs of YWBC in LMICs (*Continued*)

| References | Variables of interest | Population | Design |
|--|--|--|---|
| Hoppenstedt, 2005 (Mexico) ²⁶ | Processes of change in self-concept, emotions, and sense of life in women with BC | 12 women, 10 aged 38-48 years | Qualitative study with phenomenological analysis |
| Recalde and Samudio, 2012 (Paraguay) ²⁵ | QoL in women with BC | 125 women aged 25-90 years, mean 55 years | Descriptive, cross-sectional study instruments: EORTC QLQ-C30, EORTC QLQ-BR23 |
| Roquebert et al., 2012 (Panama) ⁴⁸ | Barriers and opportunities in the access and continuum of care | 21 women in focus groups and 14 were interviewed, overall 7 patients aged < 50 years | Qualitative study methodology: In-depth individual interviews and focus groups |
| Villarreal-Garza et al., 2016 (Mexico) ⁴⁰ | Describe the specific needs among young BC patients in Mexico through focus groups | 29 YW, aged 18-40 years | Cross-sectional, descriptive, qualitative instruments: Focus groups through semi-structured interviews |
| Villarreal-Garza et al., 2016 (Mexico) ⁴⁵ | Understand the demographic factors affecting the information-seeking practices of BC survivors in Mexico | 310 women, aged 19-87 years, 113 YW aged 18-40 years (27%) | Cross-sectional, descriptive Instruments: 10-item self-administered survey |
| Villarreal-Garza et al., 2017 (Mexico) ³⁶ | Evaluate the concerns of YW with BC toward the risk of infertility in two referral centers in Mexico with access to public health services | 134 YW, aged ≤ 40 years | Cross-sectional, descriptive Instruments: 25-item in-person paper survey |

QoL: quality of life; YW: young women; BC: breast cancer, LMICs: low- and middle- income countries; YWBC: young women breast cancer

Edib et al. studied Malayan women (38.5% under 50 years of age) who had been diagnosed with BC at least 2 years before the study. In addition to presenting a high prevalence of unmet physical needs, these women reported, “feeling unwell a lot of the time” (51.8%), “lack of energy and tiredness” (57.3%), and pain (55.6%)³³. Likewise, during a study on the Malayan population, Fong and Cheah found a high prevalence of unmet physical needs among BC patients (median of 8.2 years of follow-up). They found that, on average, those under 60 years had higher levels of unmet physical (e.g., pain, lack of energy, work around the home, feeling unwell, and not being able to do the things they used to do) and sexual needs in comparison to older patients. Interestingly, they also found that patients with higher scholarship and ≤ 5 year-survival reported greater physical needs³⁴. A study of the needs of Turkish women with BC, including mainly women aged <50 years, found that the majority of those who had undergone adjuvant chemotherapy reported gradually losing their capacity to resume their normal daily activities due to fatigue³⁵.

Villarreal-Garza et al. conducted the first-ever study aimed to identify fertility concerns among Mexican YWBC. The authors found that only 31% of patients

recalled having received information regarding infertility risk from their physicians despite that 44% of women expressed some level of concern about infertility secondary to systemic treatment. They also found that the only factor significantly correlating with fertility concern in their sample was the previous desire to have children³⁶.

In short, the main physical needs of YWBC indicate that they arise as side effects of oncologic treatment and are primarily associated to the time of exposure. The most common physical needs expressed by YWBC concern fertility and sexuality, whereas fatigue is the symptom more frequently reported by women with BC in general.

Psychological needs

Women diagnosed with BC undergo profound emotional and psychological distress, regardless of their age. The first impact is occurring at the moment they are informed about their diagnosis, at which time the majority of patients express being devastated. However, their suffering persists in the form of fear, anxiety, depression and feeling of mutilation related to surgery, chemotherapy, and radiotherapy^{26,31,37}. Reviewed studies demonstrate that, when they find

Table 2. Main findings regarding special needs classified by physical, psychological, health systems information, and social/practical clusters in YWBC in LMICs

| References | Physical | Psychological | Health systems and information | Social and practical |
|--|---|--|---|--|
| Can et al., 2004 (Turkey) ³⁵ | Post-treatment increase of fatigue, nausea, anorexia, vomiting, constipation, depression | Pre-treatment distress, depression. Post-treatment loss of hope for the future, relative risk for cognitive/mood fatigue in patients with early stage versus locally advanced stage | – | – |
| Cho et al., 2011 (Korea) ⁴² | – | Association between strong emotions and informational request. Expressed emotions tend to be negative: Anxiety/worry, fear, sadness, disgust/dislike, and confusion | Most requested information regarding special topics: Treatment, physical condition, and lifestyle/self-care Emotional requests were often embedded within informational requests | Sought some form of socioemotional exchange: Approval, reassurance, or legitimizing statements (18%) |
| Da Silva and Dos Santos, 2010 (Brasil) ³⁷ | Upper limbs movement limitations (due to surgery or radiotherapy) | Body image non-acceptance, lack of self-sufficiency feeling, fear of recurrence, and of cancer's natural history | – | Guilt around the family, work-related issues derived from the disease |
| Edib et al., 2016 (Malaysia) ³³ | Feeling unwell a lot of the time (58%), lack of energy/tiredness (57%), and pain (56%) | Supportive care needs: Uncertainty about the future (79%), fear about cancer spreading (76%), and sadness (69%) | Wanted to receive explanation of tests (30%), aspects regarding managing illness and side effects at home (27%), and benefits and side effects of treatment before initiation (23%) | – |
| Erci and Karabulut, 2007 (Turkey) ⁴¹ | – | Need to adjust for their changed appearance and to have this accepted by their partners | Needs of information regarding treatment, recurrence, chance of cure and risk in family members | Support on domestic chores, reassurance, acceptance and emotional support from partner, having an open and honest communication and their family around, support of husband and other relatives |
| Barboza and Forero, 2011 (Colombia) ⁵⁴ | A negative conception of QoL was found, where disease and pain were to be avoided, reduced or improved in the group of women aged 41–50 years | Levels of depression and anxiety were higher in women who underwent surgery and radiation therapy Women with BC refer being spiritual and religious (higher values for spirituality than religiosity) | – | – |
| Fong and Cheah, 2016 (Malaysia) ³⁴ | The most prevalent sequela was hair loss (67%) Sexual function: low desire levels (81.2%), irregular sexual activity (62%) | Younger respondents < 60 years reported higher level of unmet needs in the psychological and daily living domains (feeling down or depressed, sadness, not feeling in control of the situation, not keeping a positive outlook, worrying that the results of treatment are beyond their control) | – | Higher risk of encountering unmet needs in the patient care and support domain reported by younger patients (not having enough choices of available hospitals, hospital staff not attending promptly physical needs) |

(Continue)

Table 2. Main findings regarding special needs classified by physical, psychological, health systems information, and social/practical clusters in YWBC in LMICs (Continued)

| References | Physical | Psychological | Health systems and information | Social and practical |
|---|--|--|--|--|
| Garduño et al., 2010 (Mexico) ²⁷ | Hot flashes (60%), headaches (55%), and dry mouth (51%). Daily activities: Difficulty taking long walks (41%), difficulty performing physical efforts (58%), and trouble fatigability (58%), and trouble sleeping (54%). Cognitive function: Difficulty remembering things (68%), difficulty watching TV, or reading the newspaper (21%). Sexual function: low sexual desire (70%), lack of interest in sex (69%), and low frequency of sexual activity (64%) | – | – | – |
| Hernández-Moreno and Landero-Hernández, 2013 (Mexico) ³⁹ | – | Association between negative thoughts and stress Negative association between stress and QoL | – | – |
| Hubbeling, 2015 (Mexico) ⁶¹ | – | Alterations in body image, cognitive performance, and the constant threat of recurrence and early death | Fear/uncertainty from fertility discussions, change in body image perception Dissatisfaction with amount and content of the received information (access to patient support groups and treatment's impact on long-term QoL) and with the provided written information | Working life/ employment discrimination |
| Iskandarsyah et al., 2013 (Indonesia) ⁴⁴ | – | – | – | – |
| Karaöz et al., 2010 (Turkey) ⁴³ | – | Anxiety about the future and fear of recurrence during and after pregnancy | No disclosure from healthcare staff regarding fertility preservation, chemotherapy effects on reproductive potential and ovarian function, and sexual counseling | Financial and psychological burden related with child care |
| Ornelas-Mejorada et al., 2011 (Mexico) ³¹ | – | Major depression (28%), anxiety (27%) | – | – |
| Recalde and Samudio, 2012 (Paraguay) ²⁵ | Hot flashes (post-menopausal 53% and pre-menopausal 41%) | Concern about health in the future (84%), worried (73%), anxious (64%), depressed (46%), and irritable (43%) | – | Physical state or medical treatment did interfere with family life (31%), significant impediment to perform their jobs (15%) |
| Roquebert et al., 2012 (Panama) ⁴⁸ | Sequelae of BC treatment (loss of breast, movement limitations) | – | Lack of information was identified as a barrier | – |

(Continue)

Table 2. Main findings regarding special needs classified by physical, psychological, health systems information, and social/practical clusters in YWBC in LMICs (Continued)

| References | Physical | Psychological | Health systems and information | Social and practical |
|---|--|--|--|--|
| Salas and Grisales, 2010 (Colombia) ⁵⁰ | Hair loss disrupted women self-image and manifested themselves as feeling shame. Other effects: digestive and eating disorders, weakness and general malaise, and skin alterations | The main moral support provider was relatives (87%), friends (82%), children (78%), and partner (53%) | – | Patients did not receive social support from any institution and they did not know about the existence of institutions dedicated to providing this type of support (91%) Financial difficulties |
| Sat-Muñoz et al., 2011 (Mexico) ⁴⁹ | Anorexia, fatigue, nausea, and vomiting | – | – | Financial difficulties (more prevalent in advanced stages) |
| Hoppenstedt, 2005 (Mexico) ³⁶ | Clinical stage conditioned differences in fatigue, nausea, and vomiting (higher in advanced stages) | During diagnosis and treatment, patients went through anger, fury, and vulnerability After treatment, they referred appreciation for being alive and with the people who accompanied them | – | |
| Villarreal-Garza et al., 2016 ⁴⁰ | – | Psychological care was described as extremely important as participants reported needing emotional support at time of diagnosis and during treatment for themselves and their caregivers | Assertive communication with healthcare providers is essential during diagnosis and treatment Particular needs of written and electronic information on specific issues faced by young patients | |
| Villarreal-Garza et al., 2016 ⁴⁵ | – | – | Most important specific information to be addressed online resource: Diet and exercise, survivorship issues, treatment, prognosis, risk factors, and symptoms | – |
| Villarreal-Garza et al., 2017 ³⁶ | – | – | Patients did not receive information by their physicians regarding infertility risk before starting oncologic treatment (69%) | – |

QoL: quality of life, YWBC: young women breast cancer; BC: breast cancer, LMICs: low- and middle- income countries

themselves unable to perform their normal activities at home and at the workplace, women experience distress, anxiety, and depression. The symptoms expressed most frequently are concern, nervousness, and irritability^{24,25,29,38,39}. Various studies on the quality of life of BC patients report that women need understanding, affection, a quiet environment, time with their loved ones, and a strong family unit to face better the process of their illness and treatment. Studies also show that acceptance, a positive reinterpretation of the situation and use of social support, are the best strategies to cope with cancer in terms of health-related quality of life³². Finally, it has been observed that women with breast reconstruction obtained higher scores in the quality of life emotional component³⁸.

Villarreal et al. studied a group of 29 young Mexican women aged 18–40 years, being to date the only study specifically addressing YWBC needs in Latin America. The authors described that psychological care was extremely important for this subgroup of patients, since participants reported needing emotional support at the time of diagnosis and during treatment for themselves and their caregivers⁴⁰.

Turkish patients aged 20–45 years and who had recently undergone a mastectomy reported having unmet needs for support in managing changes in their perceived femininity and body image. Specifically, they referred a strong need to adjust to their changed appearance and to have this accepted by their husband/partners⁴¹. Another Turkish group with an average age of 40 years (standard deviation [SD] = 5.2), who had been diagnosed with early stage BC and had received various treatments, when they were asked about pregnancy, reported worry about the financial and psychological burden that came with an infant, and feeling anxious about the future and fearful that the disease could recur during and after pregnancy. In a Korean study, Cho et al. indicated that women with an average age of 38.4 years (SD = 9.6), who had been diagnosed with BC, manifested emotional requests often embedded within informational needs; 63% expressed both, concern and worry, and 75% of the requests included at least one emotional expression. The patients desired informational and psychological support, and expressed concern and restlessness (52.7%) on this subject⁴².

Likewise, in Malayan BC patients, including YW, it has been described that psychological needs were the most frequently unmet. Among the unmet supportive

care needs, the most prevalent were uncertainty over the future (78.6%), fear about the cancer spreading (76.1%), feelings of sadness (69.2%), and concerns about death and dying (68.4%)^{33,34,41}.

While no additional results were found specifically on YWBC, other studies that focus on this age group consistently address the psychological and psychosocial distress experienced by young patients. As it can be expected, one of the most intense psychological demands among young patients, who would otherwise be healthy, relates to the constant threat of recurrence and death^{2,12}.

Informational needs and the health system

In their study of young Turkish women, Erci and Karabulut reported that their sample patients showed high levels of informational needs regarding BC diagnosis and treatment. They were particularly interested in signs of recurrence, opportunities for healing, and their family's vulnerability to cancer⁴¹.

In another Turkish study, this one on pre-menopausal patients with BC, Karaöz et al. found that none of the women had been offered counseling or had received information on contraception, early menopause, infertility, fertility preservation, and sexuality, despite their willingness to receive information. However, they reported being conscious of their need for contraception and attempted to obtain related information from other sources⁴³.

In Indonesia, Iskandarsyah et al. assessed both, the extent to which patients were satisfied from the information they received and the association between satisfaction, on the one hand, and perception of the disease and quality of life on the other⁴⁴. This study comprised 77 patients with a mean age of 45.6 years (SD = 7.88), 50% of whom were at an advanced stage at diagnosis and had most undergone surgery and chemotherapy. The authors found that many of the women were dissatisfied with the information they had received. For instance, regarding the amount and content of the information, they reported not having received what they needed to access a support group, to apply for financial aid and to understand how treatment could affect their ability to work. Most of the patients were also dissatisfied with the amount of written information provided. Those who reported being satisfied with the promptness

of delivery and the types of information were characterized by having stronger beliefs in personal control, lesser concerns about their health condition, better understanding of their disease, and a positive perception of their psychological and general health.

The Malayan survivors, particularly those who were under 60 and had higher education levels as well as fewer years of survival, reported that information was the most needed item. They also indicated that the majority of their unmet needs fell within this category, namely, “having one member of the hospital staff with whom you can talk about all aspects of your condition, treatment, and follow-up” (34.7%), “receiving explanations about the tests for which you would like to get more information” (29.7%), and “having access to professional counseling if you or your family and friends need it” (27.7%)³⁴.

In exploring the demographic factors associated with the demand for information by young patients in Mexico, a qualitative study searching patients’ needs through focus groups found that YW request written and electronic information about particular issues, such as fertility preservation, genetic counseling, and handling side effects⁴⁰. In addition, another study addressing YWBC in Mexico described that this population was more interested in learning about the adverse effects of treatment, but there was no difference between YWBC and their older counterparts regarding other aspects of perceived information needs. They also considered that receiving information through the internet was useful. The most important specific information survivors would have liked to see addressed in an online resource was diet and exercise, followed by issues related to survivorship, treatment, prognosis, risk factors, and symptoms⁴⁵.

The informational needs of YWBC are related, in a large proportion, to their late stages at diagnosis. This clearly calls for targeted information strategies designed to raise awareness of the importance of timely diagnosis and treatment, and to modify the cultural habits and religious beliefs that might be hindering access of YW to healthcare services⁴⁶. Healthcare interventions are also required to improve the quality of life, and written resources and web-based decision aids should be developed and routinely provided in young patients’ native language^{2,12,47}.

As for the needs regarding the healthcare system, young Panamanian women with BC experienced cost-related

barriers and difficulties in obtaining medical appointments for their clinical assessment, obstructing the path to a timely health-service provision⁴⁸.

To sum up, informational needs are described as the most frequent and important in this type of patients with BC. However, the need for specific information is different depending on clinical stages and treatment trajectory.

Social needs

The impact of BC on intimate relationships is one of the most prevalent challenges women face while they adapt to their new body image after mastectomy²⁴. Studies also associate the following social factors with diminished quality of life (physical and psychological) in BC-diagnosed women: Those who live in disadvantaged socioeconomic contexts, have low scholarship and are unpaired, experience acute levels of fatigue, pain, anxiety, and depression⁴⁹. On the other hand, Salas and Grisales suggested that moral support from relatives and friends is fundamental to achieve a favorable quality of life perception⁵⁰.

Erci and Karabulut found significant differences in perceived quality of life in Turkish women between the age groups 20–45 years versus > 54 years, regarding a greater need of support from family and friends⁴¹. Similarly, Cho et al. explored the questions posed mainly by young patients to the physicians and observed a greater need for socioemotional support coupled with informational requests⁴².

As YW increasingly play a role for the household provision, workplace concerns are particularly relevant for these patients, as cancer diagnosis and treatment may affect their careers. In a Cuban study, Izquierdo-González et al. reported that as a consequence of BC diagnosis, some women changed their jobs to reduce their physical activity, and none encountered reinsertion difficulties subsequent to treatment²⁴.

It is noteworthy that LMICs provide little or no available information on work-related issues (e.g., resuming work and discrimination/stigma) compared to HICs, where these issues are described in greater detail. The literature on HICs indicates that some women experience economic problems as a result of having to leave their work; BC can have a negative impact on women’s decision to work; women with BC are less likely to find employment than women who have not been ill; and

survivors experience employment discrimination⁵¹⁻⁵³. This topic offers an opportunity for further research in LMICs contexts.

Spiritual needs

Many of the women interviewed had existential (religious or spiritual) beliefs that favorably supported their perception of disease and gave them strength to cope with their condition⁵⁰. At the time of diagnosis, the first thoughts of these women were that things happened by chance, destiny, or luck. Subsequently, when they reached the treatment, follow-up, and control stages (once they were tumor-free), they assured their “faith in God” had allowed them to get that far⁵⁴. A diagnosis of cancer has been observed to arouse guilt and fear in these women, which they elaborate as a sign that one of the reasons for their diagnosis is punishment from God.

In a Mexican study, Gallegos-Alvarado et al. found that faith and spiritual beliefs offered women with BC a “reason to live,” “gave meaning” to their lives, and enabled them to find well-being and inner peace. On this basis, women in their study succeeded in adapting to their condition and enduring treatments required for their health care⁵⁵. A study on the spiritual perspective of Colombian women with BC indicated that spirituality allowed women to “find forgiveness” (patients often have guilt feelings in relation to their illness) and to “make existential reflections” as they attempted to find life’s meaning and to discover what disease and pain represented for their transcendence and inner happiness. These reflections were pursued through meditation and private prayer⁵⁶. In Chile, Choumanova et al. analyzed how religion and spirituality helped women with BC deal with their illness, how the disease changed the role of religion and spirituality in their lives and how faith helped them recover⁵⁷. According to their findings, these women depended on God to guide them through their illness and received extensive social support from the members of their faith communities. Many declared that BC had increased the presence of religion and spirituality in their lives by deepening their faith in God. Almost all women endorsed the idea that faith could help patients to recover from cancer.

A study in Iran explored how women faced a cancer diagnosis and observed a combination of attitudes: Some women exhibited positive thinking in the form of hope and intentional oblivion; others held negative thoughts resulting in hopelessness and fear. The authors

concluded that faith played a major role in coping with disease and considered that their findings served to design new healthcare approaches in nursing⁵⁸.

In short, spirituality occupies a fundamental place on the lives of these women as they attempt to resume their former lifestyle and daily routines, and strive to make sense of this experience. There are no studies from the region that explore the needs on spirituality and religion among YW.

Practical needs

The most important finding reported in the literature referred to the dramatic changes in lifestyle that women, and those around them, must endure. As mentioned previously, women with BC are often hindered from performing their normal activities, particularly those related to their family dynamics. As a consequence, roles within the household must be redistributed (e.g., childcare for small and adolescent children and caregiving for family members who are ill or disabled). BC survivors, therefore, lose their autonomy and become dependent on the decisions of others.

Erci and Karabulut observed that patients perceived a need for physical and practical support to perform a number of activities after leaving the hospital and during treatment⁴¹. Furthermore, according to Karaöz et al., women worried that having a child would pose an unsustainable financial and psychological burden should they choose to become pregnant after BC treatment⁴³. As YW might face employment difficulties during diagnosis, treatment, and survivorship, the deriving economic problems that affect their family finances could force them and their families to engage in new activities^{29,49}.

To conclude the former, practical needs in YWBC focus mainly on lifestyle disturbances and their consequences on the household, financial instability as well as unemployment issues.

DISCUSSION

In summary, patients with BC described throughout the literature exhibited diverse and frequent needs in all the analytical categories⁵⁹. The most common unmet needs in the literature were related to information (e.g., demands from the healthcare system) and psychological support, followed by practical and physical needs. Social needs were the ones least reported and spiritual needs the ones least studied.

Informational needs were related mainly to treatment side effects (i.e. signs and symptoms and management recommendations), the possibility of recurrence, susceptibility of family members to cancer, and adaptation strategies subsequent to treatment.

Psychological needs referred to the support required in handling the emotional impact produced by both, treatment side effects and threat of recurrence and death (fear and uncertainty).

Physical needs were related mostly to assistance after surgery and during chemotherapy, as well as survivorship-related issues, mainly secondary to oncologic treatment such as induced ovarian failure, premature menopause, sexual dysfunction, and cognition impairment.

As YWBC perceived a less favorable social environment, their social needs involved greater support from family and friends for coping with the associated changes that cancer treatment imposed on their social roles.

Furthermore, the socioeconomic and cultural contexts of BC patients clearly permeate their entire disease process, beginning with their condition before diagnosis, continuing with treatment and survivorship, and culminating with death, particularly in young patients.

To address the physical, psychological, and informational needs of these patients, healthcare systems in LMICs must elaborate and implement integral, multi-disciplinary programs that respond opportunely to the problems arising from disease and to the side effects of oncologic treatments. It is particularly important to develop strategies that guarantee fertility preservation for those who require it; to target actions which ensure an improved and long-term quality of life for survivors through an adequate management of early menopause and sexual dysfunction; and to implement timely psychological interventions which prevent emotional symptoms that lead to depression. It is also essential for physicians, nurses, psychologists, and social workers to make efforts in sustaining interpersonal communication with patients, and to identify the most effective mechanisms, whether verbal or written, for meeting the information needs of women with BC and their families.

Specifically, regarding YWBC in LMICs, it is striking that the existing information on the subject is scarce, particularly in Latin America. Numerous opportunities, therefore, exist for promoting research, training of health personnel, and establishing health policies in

support of these women to, in the end, improve health outcomes.

The key limitation of our literature review encompasses the difficulties encountered in identifying studies on women, especially YWBC in LMICs. Since it was virtually impossible to find references using the key words which we initially established, we broadened the terms of our search to encompass studies on the psychosocial effects of diagnosis and treatment in women with BC in general, and included documents addressing the needs of women under 50. While other, unidentified, literature may have been omitted, our study provides a unique collection of research studies of this type.

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