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ORIGINAL ARTICLE

Medical and information needs among young women with breast cancer in Mexico

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Abstract

Objective: To describe clinical and information needs, identify unmet support services and guide interventions for young breast cancer (BC) patients in Mexico.

Methods: Cross-sectional, qualitative study, using interpretive description methodology. Patients with initial BC diagnosis within 6–12 months prior to enrolment, ≤40 years old and literate were included in focus groups.

Results: Twenty-nine patients were included. Expressed needs were classified into the following categories: (a) understanding diagnosis and treatment; (b) treatment side effects; and (c) time, source and communication means. Patients felt their medical team did not provide enough information regarding diagnosis, treatment and relevant side effects related to fertility, menopause and sexuality. Lack of information fuelled uncertainty, distress, anxiety and fear, and could negatively influence treatment decisions. Patients wished that news be communicated considering their own attitude regarding the disease and providing psychological support when necessary, including partners, relatives and friends. They recommended that information should be delivered with an empathic and personalised approach, with take-home educational material to help them recall, comprehend and/or expand verbal information received during medical appointments.

Conclusions: This study provides valuable insight to increase attention on unmet needs of young BC patients and to improve doctor–patient communication to ensure better care.

KEYWORDS
breast cancer, information needs, low-resource settings, unmet needs, young

1 | INTRODUCTION

Breast cancer (BC) is the leading cause of cancer-related death and disability among young women in low- and middle-income countries (LMICs) (Shulman, Willett, Sievers, & Knaul, 2010). In this age group, BC is often diagnosed at advanced stages and has a more aggressive behaviour when compared to older women (Anders et al., 2008; Villarreal-Garza, Mohar, et al., 2017). Consequently, these patients often receive aggressive and prolonged systemic treatment that can be associated with significant long-term adverse effects. Additionally, burden of disease derives not only from the high morbidity and mortality rates seen in young women with BC (YWBC) but also on the

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profound and long-lasting impact on self-development, family dynamics, social interactions and professional lives (Villarreal-Garza & Castro-Sanchez, 2017).

Particularly, challenging age-related issues associated with short- and long-term morbidity include chemotherapy-induced premature ovarian failure, infertility, body-image disturbances, altered sexual function and anxiety/depression, which greatly undermine YWBC's quality of life (QoL) (Adams et al., 2011; Champion et al., 2014; Howard-Anderson, Ganz, Bower, & Stanton, 2012; Morrow et al., 2014). Moreover, young BC patients are more likely to be carriers of genetic mutations, which involves additional difficult decisions and adds emotional burden to these women (Villarreal-Garza, Castro-Sanchez, & Ulloa-Aguirre, 2017).

Furthermore, YWBC's information needs are not routinely met, as patients have expressed being dissatisfied with the advice provided by their physicians (Ben Charif et al., 2015), request that information and care be tailored to their age and life stage (Gould, Grassau, Manthorne, Gray, & Fitch, 2006), and are particularly interested in treatments' side effects (Recio-Saucedo, Gerty, Foster, Eccles, & Cutress, 2016). However, they often report receiving insufficient counselling on contraception, early menopause, infertility and fertility preservation (Karaoz, Aksu, & Kucuk, 2010).

Despite these unmet needs, cancer-control efforts in LMICs have been predominantly aimed at improving medical care and access to oncological treatment, bypassing survivorship issues and supportive care. In these settings, only a limited number of initiatives have embarked on addressing the particular issues of YWBC (Villarreal-Garza, Martinez-Cannon, Platas, & Ramos-Elias, 2015). Furthermore, most of the research studies regarding YWBC have predominantly been conducted in developed countries, with limited representation of the Hispanic population and its unique socioeconomic, cultural and religious context (Galvez-Hernandez, Gonzalez-Robledo, Barragan-Carrillo, & Villarreal-Garza, 2017).

Therefore, promoting research focused on the unmet needs of YWBC in Latin America is key for developing targeted strategies to enhance BC comprehension and improve QoL. This study aims to describe clinical and information needs, to identify unmet support services and to guide the further development of educational and supportive interventions for young BC patients in Mexico.

2 | METHODS

An exploratory, cross-sectional, qualitative study was conducted using a focus group technique. Patients with initial BC diagnosis within 6–12 months prior to study participation, who were 40 years or younger at diagnosis and literate were included. Patients with concurrent severe physical disease, stage IV BC, recurrence or severe psychopathological disorders were not eligible.

2.1 | Study design

The interpretive descriptive analysis was chosen as an appropriate methodological design for this study. It consists of a qualitative investigation of a clinical phenomenon of interest for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 6). Accordingly, based on the theoretical knowledge of the interpretive approach, clinical pattern observations and illness phenomena can be generated (Thorne et al., 2004).

An interview outline was created based on a Spanish adaptation of a previously published study that evaluated young patients' needs in the United States (Ruddy et al., 2013). Subsequently, concepts proposed by Fitch's supportive care framework for cancer care were integrated (Fitch, 2008). Afterwards, the interview outline was revised by a BC expert panel (two oncologists, two psychologists and one sociologist) and adapted to match the current psychosocial and health system scenario in Mexico.

The interview outline was piloted on five patients with the purpose of assessing each question's clarity, relevance, acceptability and comprehension, as suggested by Cull et al. (2002). Upon completion, a revised version of the interview outline based on the pilot's results was prepared.

2.2 | Patients

Patients that met inclusion criteria were prospectively identified and approached by phone. Those who accepted were accrued and scheduled for the focus groups. A total of 94 patients that met inclusion criteria were identified from the "Joven & Fuerte" prospective cohort information was outdated for 33 women and 21 did not accept to participate. A total of 40 patients were enrolled, 32 confirmed attendance, and 29 showed up to the focus groups appointments. Informed consent was obtained from all participants included in the study.

2.3 | Focus groups

This study was carried out in two oncologic centres in Mexico. Approval from the respective institutional ethical and research review boards was obtained. Relevant sociodemographic and clinicopathological variables were extracted from medical records. Five focus groups with 5–6 participants were assembled. Interviews were led by a female sociologist, expert in qualitative research, from a private institution specialised in designing and carrying out qualitative research studies. Patients met with the interviewer for the first time at the focus group. Each session lasted approximately 120 min, and audio was recorded for future analysis. Along with the moderator, two authors were present at each session as observers and field note-takers. Each patient was assigned a code name to preserve anonymity. No repeat interviews were conducted.

2.4 | Data analysis and interpretation

Audio recordings transcribed, and information was organised and coded using Atlas TI, version 8.3. The analysis was performed

TABLE 1 Sociodemographic and clinical characteristics

Characteristics	Patients ($N = 28^a$)
Age (years)	
Median (range)	39 (29–44)
Level of education, *n* (%)	
< High school degree	11 (39)
≥ High school degree	17 (61)
Employment status, *n* (%)	
Unemployed	20 (71)
Employed	8 (29)
Relationship status, *n* (%)	
Non-partnered	10 (36)
Partnered	18 (64)
Number of children, *n* (%)	
None	9 (32)
1–2	9 (32)
≥3	10 (36)
Stage, *n* (%)	
0	1 (4)
I	4 (14)
II	11 (39)
III	12 (43)
Surgery, *n* (%)	
None	4 (14)
Lumpectomy	4 (14)
Mastectomy	20 (71)
Chemotherapy, *n* (%)	
No	5 (18)
Yes	23 (82)
Radiotherapy, *n* (%)	
No	16 (57)
Yes	12 (43)
Endocrine, *n* (%)	
No	15 (54)
Yes	13 (46)
Status, *n* (%)	
Undergoing treatment	15 (54)
Survivor	13 (46)

[a] Information not available for one patient due to lack of access to medical records.

utilising an inductive approach with interpretative description methodology, as recommended by Thorne et al. (2004). The first data categorisation was done through two analytic techniques: (a) deductive coding framework derived from Fitch (2008) and Mullan (1985) and (b) researchers' discussion. Afterwards, inductive analysis was done, and the information was classified into categories and subcategories of patterns of medical and information needs as reported by the patients and according to the analysis' findings. Results were not disclosed to patients. However, free educational material derived from this research was made available to them after its completion.

3 | RESULTS

The qualitative analysis of data contains a set of perceptions, visions and conceptions of YWBC regarding the medical needs they considered should be met as well as the communication means and sources that are appropriate to meet their information needs. A summary of the patients' sociodemographic and clinicopathological characteristics is outlined in Table 1. The clinical information of one patient was not available, as she decided to seek medical treatment elsewhere.

Needs were classified into three major categories: (a) BC diagnosis and treatment; (b) treatment side effects, including relevant issues in YWBC and (c) time, source and communication means. Patient narratives related to each category are presented in Table 2. Appendix 1 lists additional patients' narratives.

3.1 | Needs related to understanding BC diagnosis and treatment

This category includes the experience of YWBC facing the information given at the time of diagnosis.

3.1.1 | Description of aetiology and BC diagnosis

The set of interviewed YWBC agreed that once the diagnosis is confirmed, medical doubts arise immediately. These include knowing the factors that may have caused the disease, explanation of diagnosis and stage, ideal treatment and prognosis.

Although most patients received information about their diagnosis, they stated that the medical team often lacked sensitivity and empathy. They perceived the information as given drastically, sometimes even cruelly, especially when they had more advanced disease. Sometimes, women were informed about the situation in such a discouraging manner that it made them consider that receiving treatment was pointless.

Patients perceived that when the medical team provided information in a non-empathic, technical and deficient manner, it increased uncertainty and fostered negative feelings. These young women thought that clinical information should be provided by a cancer specialist and not by other healthcare professionals who are not experts on this matter.

Thus, patients recommended that news should be communicated with a compassionate and personalised approach, taking into account the emotional dimension, and providing psychological support when necessary, including their partner, relatives and

TABLE 2 Patients' narratives on relevant topics in young women with BC

1. NEEDS RELATED TO UNDERSTANDING BC DIAGNOSIS AND TREATMENT
1.1. Description of aetiology and BC diagnosis
G: […] I wasn't told the name of my cancer, how big it was […], I didn't know anything. I asked my oncologist once […], he told me the name, but it was too long, and I didn't understand.
M: […] When I asked the physician in what stage I was and what we had to do, he answered in a very pejorative way "cancer is cancer" […] he got me even more anxious because he gave me no information […] I felt totally frustrated, until I saw my psychologist.
1.2. Description of local and systemic treatment of BC
T: […] I wasn't told what chemotherapy was, how many or how long. Nobody explained […].
L: […] after the surgery, should I be in bed a long time? […] I thought I was going to be in bed for one month, unable to move […].
O: […] Doctors told me "you can continue with your activities," but I was worried […] I didn't want to hurt my breast […] how could I exercise at home? What about food and other care?
G: […] People need to know what they're going to need during a chemotherapy session […] Some people come to the chemotherapy with nothing at all, and inside they are cold, hungry and thirsty […].
2. NEEDS RELATED TO TREATMENT EFFECTS
2.1. Physical effects related to BC treatment toxicity
2.2.1. Consequences of local treatment
Pu: […] they need to explain the physical changes on the body […] I didn't know that they would remove nodes from my armpit and now I have a hole […].
Pa: […] I thought that I might need someone to look after me after surgery, and I had no one […] I thought I wouldn't move later, wouldn't drive, go downstairs […] I think having information on how to prepare is important […].
2.1.2. Consequences of systemic treatment
Pa: […] The doctor told me "you should have your hair cut/shaved" but he never told me why. I had my first chemotherapy and then I started to lose hair […] it really hurt! […].
Pal: With red chemotherapies I suffered very much […], I had nausea, I didn't want to come back to the hospital […] I wanted to cry […].
Pa: […] It's called chemo brain. Some things have been harder for me, mainly my memory […].
2.2. Significant physical effects in young women
2.2.1. Consequences of treatment on fertility
Pu: […] I did not know that chemotherapy might cause infertility.
G: […] I was very sad when I started the chemotherapy; I wanted to be a mom […].
Pu: […] the doctor told me, "you're very young, do you want to have children? […] Now we don't have time to offer other options such as preservation of ovules because you have to start chemotherapy as soon as possible" […].
T: […] after the mastectomy, a nurse told me "think well if you want to have children, why do you want to have children when you have this disease?" […].
2.2.2. Menopause
Pu: […] I was told "your menstrual cycle is likely to stop during chemotherapies and you're going to have symptoms similar to menopause" […].
T: What we are not told is, once the chemotherapy or treatment ends, when will the menstrual cycle return? Will it be normal? Will it be painful?
2.2.3. Changes in sexual life
Pa: After the surgery, will I be able to have sexual intercourse and how long should I wait? […] no one has told us […].
3. NEEDS RELATED TO TIME, SOURCE AND COMMUNICATION MEANS
Pu: […] I was given information but I can't even remember […] I was thinking "my hair is going to fall, I'll be operated on." I am 28 years old, so I was thinking about my life, what was going to change […].
L: I just had my exams and the biopsy taken. I was referred to the doctor, the doctor referred me to surgery, that's all I know […], the doctor told me that chemotherapies would start after the surgery […] that's all the information I had […].
T: […] I had the fortune of having a psychologist […] She was with the doctor when I was told I had cancer. […] I received a lot of information from her […] She helped me keep calm.
Pa: There's a lack of written information to share with my children and husband […] several times I requested some material they could give me because I didn't know how to talk about it with other people […] but here I wasn't given any material.
G: I think it is important that, during consult with the doctor, he provides a pamphlet with information about effects on sexuality […].
Pa: I think it is important to detail on a manual whether after the surgery I might have sexual intercourse and how long I should wait, and also if there may be any physical problems.

friends. Additionally, patients suggested that the medical team should be accompanied by a psychologist when informing the diagnosis, as this could promote calmness and trust and may also aid in the assimilation of the cancer diagnosis. Finally, patients wished they had received adequate information regarding genetic aspects of the disease and available genetic tests, as these subjects were not thoroughly discussed during their medical visits.

3.1.2 | Description of local and systemic treatment of BC

Young patients considered it indispensable to receive information about the different available treatments, their purpose and administration as well as the reasons a particular management was most suitable for them.

Regarding surgery, patients perceived that they had no information on the type of procedure, recovery duration, rehabilitation techniques and pain management. Not having information in this regard made patients feel fearful about surgery-associated complications and the possibility of death. Patients believed that receiving emotional support during their hospital stay might have helped them endure this process.

Concerning chemotherapy, patients wished to know which medication they would receive and what adverse effects they might experience. They also believed it is important to receive information about nutrition, permitted daily activities and alternative therapies.

In relation to radiotherapy, patients stated they were not familiarised with the process and its duration, which made them think that radiation was harmful. On the other hand, patients who had already undergone this treatment considered that it was very simple and did not cause serious adverse events and wished they had known this before undergoing treatment.

Finally, knowing the waiting times, the duration of procedures and what personal articles they should bring would have helped them feel less anxious. With respect to hospital stays, being informed about the approximate number of hospitalisation days, personal belongings needed and the discharge process would have allowed them to be prepared.

3.2 | Needs related to treatment effects

This analysis category retrieves perceptions of YWBC about the need for information on implications and physical consequences of treatment.

3.2.1 | Physical adverse effects related to BC treatment toxicity

Consequences of local treatment

Patients believed that one of the most important consequences of mastectomy was losing their breast and were often overwhelmed by this thought. They considered they required to know what the implications of a mastectomy were and, if applicable, why it was necessary to remove the whole breast when tumours only covered a portion of it. In addition, it was unclear for them how the breast and axila would look after the surgery as well as the available options for breast reconstruction. The psychological and social impact on patients when they saw themselves without a breast was significant and having previous information would have allowed them to be emotionally prepared for it, they stated.

Moreover, participants believed it was necessary to obtain information about the medical care they should have after the surgery as well as receiving information on how to identify potential complications from the surgery or knowing whether the signs and symptoms they experienced were expected. As patients declared, this would have benefited them in their emotional dimensions, as anxiety and anguish after the surgical procedure might have decreased.

Consequences of systemic treatment

Hair loss and changes in nails Patients believed the physician should inform them at the beginning of treatment about the loss of hair in various parts of their bodies as well as the duration of this side effect and its reversibility. They also wished to be told about nail changes.

Nausea and vomiting Patients were interested in knowing how to manage these symptoms, which drugs they should take and when to seek medical attention.

“Chemo brain” Interviewed women reported a mild decrease in their cognitive functions, such as concentration and memory.

3.2.2 | Relevant physical effects in young women

Consequences of treatment on fertility

Interviewed patients agreed that the information provided by the medical team about treatment consequences on fertility was insufficient. Furthermore, patients stated they did not know about the available options for fertility preservation and believed that some physicians did not consider fertility preservation a priority to discuss. Patients felt that when they disclosed to their physicians that they had children or that they were not currently interested in having more children, clinicians automatically omitted talking about the treatment impact on fertility.

With respect to becoming pregnant during treatment, some patients agreed that they were informed about the risks of pregnancy, but not all of them were recommended appropriate contraception methods.

Menopause

Regarding chemotherapy-induced menopause, patients stated that physicians informed them their menstrual cycle could cease, but they did not mention they might experience other symptoms such as hot flashes and decreased sexual drive.

Changes in sexual life

Patients reported that sexuality is not a topic that is discussed in depth with the medical team. They also expressed the need to receive information on when to resume sexual life after mastectomy, if it was possible to have sexual intercourse during treatment and what kind of lubricants they could use in case of vaginal dryness.

3.3 | Needs related to time, source and communication means

Participants stated that they could not identify an ideal time to provide the information regarding the medical explanation of BC and treatments, as these were news they would never have wanted to receive. However, they agreed that it should not be done on the same day the diagnosis is confirmed, mainly because at this time patients were overwhelmed thinking about how their lives would change, and fear and anxiety did not allow them to pay attention to the information given by physicians.

The recommendation given by patients was that the medical information should be communicated after emotional preparation, or that psychology staff should be present in this disclosure appointment to provide support. They also stated that they believed it was indispensable that their families were present in this consultation.

Regarding additional sources/means of communication, patients preferred written and audio–visual sources. They also advised not to use technical language, as this information should be understandable for the public. Patients also requested the creation of special material targeted to children and partners, which might aid in diminishing fear and anguish.

4 | DISCUSSION

In this study, we aimed to identify unmet supportive care services among YWBC in Mexico. Overall, we found that patients felt their physicians did not provide enough information about their diagnosis and potential treatment side effects. Additionally, we found that some patients who did receive information felt it was insufficient, delivered in a non-empathic way and hard to understand. These results align with previously reported findings from Mexican BC survivors (Hubbeling et al., 2018).

Several patients mentioned not being informed in detail about the treatment they would receive. Some even believed it would harm them, which fuelled anxiety and fear. Patients' perceptions of inadequate information can lead to uncertainty, distress and dissatisfaction, and can negatively influence patients' treatment decisions, as previously reported (Fallowfield, Ford, & Lewis, 1995). Moreover, it has been reported that uninformed patients cannot express their treatment preferences and participate in the decision-making process (Goss et al., 2015). Thus, meeting patients' information needs is key in achieving appropriate medical care with a patient-centred approach, which is known to be associated with better quality of care, coping with illness and treatment adherence (Joosten et al., 2008).

Another issue that deeply concerned our patients was the lack of information regarding treatment side effects on fertility and sexual function as well as fertility preservation options. Other authors have also confirmed dissatisfaction with the information provided regarding these topics (Ben Charif et al., 2015). Our patients felt their physicians did not consider these a priority and deliberately chose to ignore these topics to focus on BC treatment.

Reasons for the unmet information needs among YWBC might include physicians' time limitations, non-identification of particular concerns and lack of training in communication skills. Younger patients require sufficient time to address all of their concerns, and low physician availability correlates with higher information needs in these patients (Bredart, Kop, Fiszer, Sigal-Zafrani, & Dolbeault, 2015). Lack of time during medical appointments limits the exchange of information between patients and physicians, especially at the first medical visit. Also, clinicians tend to underestimate the amount of information that patients would like to receive (Degner et al., 1997; Fallowfield et al., 1995). Furthermore, it is not uncommon that the first medical contact is made with physicians in training who have less experience in giving bad news (Lown, Roy, Gorman, & Sasson, 2009).

As previously mentioned, our patients perceived that healthcare providers lack empathy when communicating bad news. In these settings, physicians face the challenge of communicating information in a way that is responsive to the patients' emotional status, aligns with the comprehension level of each patient and is sufficiently informative to allow decision-making to take place (Goss et al., 2015). Efforts must be made to encourage clinicians to address their patients' information and supportive needs, along with delivering adequate oncological care. Improved communication between cancer patients and their physicians could be achieved by developing training programmes focused on communication skills and, thus, achieve a better doctor–patient relationship (Gorniewicz et al., 2017; Kuzari, Biderman, & Cwikel, 2013; Thewes, Meiser, Rickard, & Friedlander, 2003).

Another possible reason for these unmet needs might be related to the patients' mindset at the time of diagnosis. In our study, we found that patients were very preoccupied during the first medical consultation and had difficulty paying attention to and understanding what their physician was saying, as they were thinking mainly in how their life was going to change after BC diagnosis. Previously, other studies have shown that patients feel overwhelmed immediately after being informed of their diagnosis, a time when their key priorities are survival and treatment options (Thewes et al., 2003). Therefore, we suggest delivering information in two phases: at the first medical appointment, details regarding diagnosis and staging should be provided; in a second visit, specifics about different treatments and adverse effects can then be addressed. Also, delivering information at two different medical consults might allow patients with high levels of distress to receive psychological support between visits, as severe anxiety has been shown to relate with greater dissatisfaction on information (Ben Charif et al., 2015).

Our patients also emphasised the importance of being accompanied by a family member during their first medical visit. Previous studies have shown an adequate social support system is effective in reducing the negative impact of diagnosis and treatment and promoting psychological well-being in cancer patients (Cohen & Wills, 1985; Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992). Additionally, both patients and caregivers requested information addressed to the family, partner and/or children (Recio-Saucedo et al., 2016). Thus, medical professionals should also aim to meet family members' information needs and encourage their involvement in comprehensive cancer care.

Furthermore, patients in our study found that talking with a psychologist before or after their first medical appointment aided in further comprehending the disease process and managing their emotions. Hence, psychological support should be provided in a case-by-case basis to promote adequate coping, social support utilisation, communication, sexual health and adherence to medical and supportive care recommendations, as other studies have suggested (Gudenkauf & Ehlers, 2018; Matthews, Grunfeld, & Turner, 2017).

Finally, patients in this study agreed upon the importance of having additional information in electronic or print format, detailing specific topics such as possible adverse effects of treatment, tips on how to communicate with their spouses and children, checklists with questions to ask their physicians in further consultations and hospital logistics. Furthermore, it has been reported that among BC survivors in Mexico, printed materials are the preferred information source and that most women express high interest in obtaining information online, despite having a low educational background and limited Internet access (Soto-Perez-de-Celis, Perez-Montessoro, Rojo-Castillo, & Chavarri-Guerra, 2018; Villarreal-Garza, Platas, et al., 2017). Similarly, women in other studies have mentioned that some form of take-home information, such as handouts or pamphlets, would have helped them recall, comprehend and/or expand upon the verbal information received during their medical appointments (Hubbeling et al., 2018; Thewes et al., 2003).

The creation of educational materials for patients, as part of a supportive care programme, has been demonstrated to be an effective strategy to address many of the patients' information needs and improve the patient–doctor relationship, as previously reported in a pilot study that designed, implemented and evaluated web-based and paper-based materials tailored to the BC patients' needs (Haq et al., 2013). As a matter of fact, the information obtained during this project guided the development of the first dedicated educational material for Mexican BC patients, which is available online at www.jovenyfuerte.com.mx. This resource includes general information, relevant topics for young women, fact sheets and checklists, in a user-friendly format.

It is worth mentioning that participants included in this study were treated in comprehensive cancer centres with dedicated BC programmes. However, psychological support and genetic services are not routinely available in less specialised institutions. Thus, patients receiving care in more limited-resource settings might face additional challenges and have significantly more unmet needs. Additionally, it is necessary to characterise the specific needs of patients living with recurrent or metastatic disease, as they may experience more isolation and unmet necessities related to disease-coping mechanisms.

5 | CONCLUSION

Overall, results from this study revealed that patients felt their medical team did not provide enough information about diagnosis, treatment and relevant side effects for young women, such as fertility, menopause and sexuality. Furthermore, patients agreed that this lack of information fuelled uncertainty, distress, anxiety and fear, and could negatively influence their treatment decisions.

We consider this study provides three main contributions to its field. First, results show that the two factors that might influence the presence of unmet information needs in Mexican women with BC are physicians' lack of training on communicating bad news and patients' emotional distress generated during the medical appointment. Second, important recommendations aimed at satisfying the medical needs of young Mexican patients with BC were identified, such as the delivery of information with an empathic and personalised approach, involving family members, and educational take-home materials to help them recall, comprehend and/or expand upon the verbal information received during their medical appointments. Finally, our results highlight the relevance of psychological intervention before or after the first medical appointment as well as during the diagnosis disclosure to provide support for patients and family members.

To conclude, this study provides valuable insight on how to increase attention to specific unmet needs of Mexican YWBC and how to improve doctor–patient communication around those issues, which may ultimately promote better care for this population. Targeted strategies on how to approach this vulnerable group of women must be designed and implemented as soon as possible, in order to reduce emotional distress, increase treatment adherence and improve QoL. Still, further research and actions are needed to completely characterise and address the issues faced by YWBC in Mexico in a comprehensive manner.

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CONFLICT OF INTEREST

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APPENDIX 1

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1. NEEDS RELATED TO BC DIAGNOSIS AND TREATMENT

1.1. Description of aetiology and BC diagnosis

G: […] I wasn't told the name of my cancer, how big it was […], I didn't know anything. I asked my oncologist once […], he told me the name, but it was too long that I didn't understand. […] Tell them you are healing and done.

G: […] I wasn't told that my breast was going to be removed, but only that they would put an implant on me.

M: I think one should be told in what stage the disease is and present an overview of what is about to come.

C: Well, I think that in addition to diagnosis, […] one should be told whether it can be cured and if there is a treatment […]

PR: […] when you are given a diagnosis, obviously you are given the results […] give us an interpretation so that one can read it and understand it […]

R: […] when I came, the doctor – very drastically – told me […] you can't be cured now […] I felt it was very cruel […] I said "why would I take a treatment if I won't be cured?" She told me "I'll refer you to the psychologist because you took this news too badly" […] No news can be good if they're said like this […]

Pu: Oncologists are not empathic at all with what you're experiencing in that moment.

G: […] be treated as a human being, a unique person. To consider more the emotional dimension […] and that they talk about the physical dimension lastly […] being told that you have cancer and that currently people don't die from cancer […] this is not the end, it's not over, you are not going to die from this […] you're in the best place and we have the best drugs, medical equipment, staff and infrastructure […] you're going to be alright.

M: […] a resident informs me that I have cancer. Then, in the next visit, I see the associate physician; when I ask him in what stage I am and what we have to do, he answered in a very pejorative way "cancer is cancer" – He told me I was getting ahead and that I was very anxious […] he got me even more anxious because he gave me no information […] he didn't clarify what to do, to expect and the steps to follow […] I felt totally frustrated and choked, so I saw my psychologist.

M: […] I approached a nurse and she made me the favor of accessing the system; then I found out that I have early cancer. The doctor then told me only that I was candidate to conserve my skin and possibly my nipple, but for a person who is fully unknowledgeable about this matter, it doesn't mean anything. That's why I was so sad, so anxious, so nervous… I left feeling very bad […]

Pa: Genetic counseling is important for our families and for risks of other cancers.

O: To know if it is inherited […]

M: […] in my case, for my daughter […] and my sister.

Pal: […] to know if it could harm my children.

G: My family was very aggressive, especially my sister […] I was requested to bring her here but she didn't want to come and told me that I wanted her to have her breast removed like me.

Os: […] I had the fortune of having a psychologist […] She was with the doctor when I was told I had cancer. Then, when I got out of there, she took me with her […] I received much information from her […] She helped me keep calm.

Pal: […] It should be treated with the family as well […] Some family members have experienced situations in the past where there was no chance to save the relatives they lost, and then someone in the family gets sick again […] family members get depressed. […] the psychologist, along with the doctor, […] should treat both parties (patient and family).

Pr: Sometimes it is important that you are accompanied by your relatives, husband, partner, child […]

R: […] to inform this kind of diagnosis or treat patients for the first time if they are not tactful, they should be supported by psychologists or someone qualified […]

1.2. Description of local and systemic treatment of BC

Pa: I think it is important to describe the general treatments [...] a synthesized description of procedures [...] generates many doubts [...]
R: [...] I wasn't told what chemotherapy is, how many or how long. Then, when I was about to enter, I was scared because I didn't know what was going to happen, nobody explained [...]
Pa: Explain how chemotherapy can be given, either intravenously, by a catheter [...]
G: [...] to know if you're a candidate for surgery, the types of surgeries, [...] how long should one wait after the chemotherapy?
L: [...] after the surgery, should I be in bed a long time? [...] I thought I was going to be in bed for one month, unable to move [...]
L: I thought I'd be very very sore after the surgery [...]
G: [...] in the end, regardless of the extent of a surgery, you are fearful [...] you don't know whether you'll be alright or not [...] when I hear the word "cancer" I think about death, that's what I figure out [...]
T: [...] They do not explain what can be considered as a normal symptom [...] or what warning signs require attention at the hospital.
G: [...] They should tell us [...] during your process, at some point you might have foot pain, muscle cramps [...]
O: [...] Doctors told me "you can continue with your activities," but I'm worried about [...] I like to dance very much and I didn't want to hurt my breast [...] how could I exercise at home? What about food and other care?
M: [...] I continued inquiring the doctor, I told him I wanted to know which alternative therapies he recommended to help me go through this process as best as possible, but he said that he didn't know [...] I asked him about biomagnetism, acupuncture, homeopathy and scorpion venom capsules [...] he said, "You don't need to know that," so he didn't clarify anything and I was so doubtful and insecure.
L: [...] I thought I was going to be burnt.
Pal: It's very quiet compared to chemotherapy [...] 'till now my skin has reacted very well, it has not been dry or anything [...] you feel nothing, it is very quick, it takes longer to wait in the room than the treatment administration [...] you are told that you might feel tired, sleepier, but that's it.
G: [...] that you can't use deodorant or talc or creams, and you should wear light clothing because you have to take the clothes from the waist up. It lasts five minutes, you leave, and all is OK, you feel nothing [...]
M: I know I might be waiting for hours [...] to be attended [...] I'd be very nervous, and my anxiety would increase as I spend more time in the waiting room.
L: [...] I don't know what time I'll be operated on [...] I also heard out there comments that some women are operated and discharged in the afternoon, I don't know if I'll be discharged too.
Pa: [...] I think there's a lack of information; I'd add [...] that you should bring a change of clean clothes [...] the approximate estimated surgery time. If you are discharged on the next day, which seems to be the standard, [...] then you could plan everything and check who's going to stay with you. I had a doubt as well, can my relative stay too? [...]
G: It is very important that they arrange the schedule at radiotherapy so that there's not too many people waiting [...] I'm tired of coming and waiting for hours and hours; once it was my turn, but they told me that the equipment was damaged or there was an emergency [...] same as in chemotherapies, the room schedules, to open more room, because sometimes I have the chemotherapy at 10 AM, I arrive at 8 AM, and sometimes it's already 8 PM and I haven't left the chemotherapy area [...] one misses many things to do [...]
G: [...] The people need to know what they're going to do in chemotherapy, because you are told to have breakfast, or if it's in the afternoon, to have lunch. But, in my case, as I have my mother's experience, I bring my backpack, blanket, water, Coca-Cola, cookies and an apple. Some people come to the chemotherapy with nothing at all, and inside they are cold, hungry and thirsty [...]
G: [...] you can bring a magazine or Internet game with you. I want to promote that we should have free Wi-Fi for patients to access the Internet and be entertained [...] there are things that might make the chemotherapy and radiotherapy more bearable for patients [...]

2. NEEDS RELATED TO TREATMENT EFFECTS

2.1. Physical adverse effects related to BC treatment toxicity

2.1.1. Consequences of local treatment

G: [...] One does not understand why they not only remove what I have here but the entire breast, if I had nothing there [...] I wanted to know how advanced and big it was, whether it was necessary to have my breast removed, and if it was malignant or benignant.
G: [...] It is not superficial [...] to be crying for a breast when your life is being saved [...] I will not prepare for mourning.
Pu: [...] they need to explain the physical changes on the body [...] be told "we will remove one breast, maybe you'll have a hole in here" [...] I didn't know that they would remove nodes from my armpit and I have a hole now [...]
Os: [...] he told me [...] you'll receive an antibiotic, [...] general anesthesia, you won't feel anything [...] thanks to this, at the next day [...] I was ready for all this.
Pa: [...] How do I know if there are complications? [...] I wasn't told too much, and I wanted to know more [...] they could make it more explicit, how to be more careful, and what they would do [...] a liquid was coming out and I didn't know if it was pus or something normal [...]
Pa: [...] but this is very distressing at that moment, not knowing if what you have, that symptom, may be part of a major complication [...]
Pa: [...] I thought that I might need someone to look after me, and I had no one [...] I thought "I couldn't move later, I couldn't drive, go downstairs [...]" I think that all this information about how to prepare is important [...]

2.1.2. Consequences of systemic treatment

Pa: [...] The doctor told me "you should have your hair cut/shaved" but he never told me why. I had my first chemotherapy, and then I started to lose hair [...] it really hurt! [...]
R: [...] This is what scared me most, my hair [...] how long will I be bald?
Pr: So, I wanted to see the positive side [...] "you won't have body hair anymore" [...] I mean, you touch your skin and it feels so nice.
P: [...] He told me [...] "your nails will get darker."
P: [...] "But don't worry, [...] it will return to normal later [...], that is, your skin and nail color."
O: The first one went very well, [...] but in the second one [...] I started to have symptoms (nausea and vomiting) [...]
Pal: With red chemotherapies I suffered very much [...], I had nausea, I didn't want to come back to the hospital [...] I wanted to cry [...]
Pa: [...] I had more difficulty in certain areas, for example, remembering names [...]
Pa: [...] It's called chemo brain [...] some things have been harder for me, mainly my memory [...]

2.2. Significant physical effects in young women

2.2.1. Consequences of treatment on fertility

Pal: [...] I think that a single woman who has not yet married is impacted, so she should be told that chemotherapy has consequences on fertility [...]

Pu: [...] I did not know that chemotherapy may cause infertility.

G: [...] I am afraid that I could not get pregnant [...] I was very sad when I started the chemotherapy; I wanted to be a mom [...]

Pu: [...] the doctor told me, "you're very young, do you want to have children? [...] Now we don't have time to offer other options such as preservation of ovules because you have to start chemotherapy as soon as possible, but you can use an injection [...]" I said, "but why don't we have time? I'd like to be a mother [...] how's that there's no time? I want to be a mother and I cannot."

T: [...] I want to have a child, feel that joy [...] don't want to live with that fear [...] thinking that I am on treatment, that I'm going to be healed, and that I'm going to have a near-normal life.

T: [...] in my case, for him (the physician) cancer is a priority, and afterwards we'll see if I can have children. [...] I do want to have children. [...]

T: [...] he told me, you can do ovule preservation [...] if there are possibilities and the Institute is open to help us with infertility issues [...]

T: [...] after the mastectomy, a nurse told me "think well if you want to have children, why do you want to have children with this disease?" [...]

Os: [...] to receive information (about impact on fertility) from the oncologist.

P: [...] The doctor told me to be very careful, that I shouldn't get pregnant right now.

2.2.2. Menopause

Pa: [...] I was told there was nothing to do about hot flashes [...]

Pu: [...] I was told "your menstrual cycle is likely to cease during chemotherapies and you're going to have symptoms similar to menopause" [...] I was told I'd have hot flashes, and I did have many.

G: I was never told that the menstruation would cease with the chemotherapies, I knew this from the psychologists through WhatsApp [...] nor was I told that I'd have hot flashes like in menopause [...]

T: What we are not told either is, [...] once the chemotherapy or treatment ends, when will the menstrual cycle return? Will it be normal? Will it be painful?

2.2.3. Changes in sexual life

Pa: After the surgery, will I be able to have sexual intercourse and how long should I wait? [...] no one has told us [...]

L: [...] I thought that if you have a wound you cannot have sexual intercourse because it can get infected [...] our doubts have not been clarified or we didn't ask because of embarrassment.

Pa: I think it's important to know whether you can use lubricant [...] because menopause symptoms begin, and you present dryness [...]

3. NEEDS RELATED TO TIME, SOURCE AND COMMUNICATION MEANS

Pu: When you're told that you have cancer, you get shocked; it's like you can't hear what you're being told. The doctor starts to give a series of instructions [...] I could only see that she was speaking but actually I wasn't understanding anything of what she was telling me.

Pu: [...] I was given information but I can't even remember it [...] in fact, at that time, I couldn't even ask questions [...] I was thinking "my hair is going to fall, I'll be operated on." I am 28 years old, so I was thinking about my life, what was going to change [...] rather than in the chemotherapy or surgery.

Os: I think we should be prepared first [...] now we have the fortune of having a psychologist [...] that before seeing the doctor, women could talk with the psychologist.

T: When we are told the diagnosis [...] they don't know how we feel emotionally [...] I believe this is very important because maybe you're not in the best time in your life and then you're told this [...] when my diagnosis was confirmed [...] the psychologist [...] told me [...] "look, you're going to be OK, you have our support, we'll provide psychological support, for whatever you need, you family can be supported too."

Pa: There's a lack of written information to share with my children, either by a tale or some way that helps open a communication channel. It should be something that helps talk about it, and also for my husband [...] several times I requested some material they could give me because I didn't know how to talk about it with other people [...] but I never found it [...] here I wasn't given any material. They told me they'd send me something, but what they sent wasn't what I expected [...] I found information on other websites and it helped me a lot [...]

Pa: Something targeted to the caregivers [...] in my husband's case, I understood him [...] I knew he was afraid of losing me, he was afraid about that I could get very ill [...] the pamphlets I found on websites were about cancer, but they are usually from Spain, because here we don't have that kind of materials.

Pa: [...] In the websites I searched there was something I liked about the information contained in the pamphlets on how to talk to other people [...] they proposed that you had to build a support network [...] that sometimes not telling it was like shutting yourself away with your problem and carry all the weight alone [...]

Pal: The medical terminology is important for them (physicians) but unfortunately patients cannot understand it [...]

R: [...] My husband told me "why are you crying if you never cry? you're strong, you don't bow down before anything [...]" the most important is to know the changes, that you're going to be alright, that it's not a diagnosis of death and give you hope.

Pa: I think we need more experience [...] I mean, we need to know experiences of people [...] in my family many persons had cancer [...] I saw the changes and I didn't want to be like that. I was too afraid of looking like my mom or aunts.

Pa: [...] It's encouraging to know that someone experienced this too, that they overcame it and they're OK now [...]

R: I think that there should be a talk for husbands, so that they're asked how they feel, because obviously my husband is not going to tell me what he's feeling [...] my husband told me "I wish you were not ill" [...] but actually I don't know what he's feeling or if he's telling me that so that I feel OK. So, no support might be better than [...] a psychologist to consult with and to encourage him or teach him how to tell things [...]

L: I just had my exams and the biopsy taken. I was referred to the doctor, the doctor referred me to surgery, that's all I know [...], the doctor told me that chemotherapies [...] would start after the surgery [...] that's all the information I had [...]

G: I think it is important that, during consult with the doctor, he provides a pamphlet with information about effects on sexuality [...]

Pa: I think it is important to detail on a manual whether after the surgery I might have sexual intercourse and how long I should wait, and also if there may be any physical problems.