# Gaps in Knowledge and Understanding of Patients With Metastatic Breast Cancer in Mexico

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#### **Abstract**

There is paucity of data regarding the knowledge and understanding of patients with metastatic breast cancer (MBC) about their disease stage and treatment goals. This study assessed these patients' awareness of MBC incurability, topics reviewed with their oncologist, perceptions of having enough knowledge to participate in treatment decision-making, most helpful information source, and satisfaction with the information they received. For this purpose, 185 patients with MBC who attended follow-up medical appointments at a Mexican referral cancer center completed a survey designed by the Metastatic Breast Cancer Alliance. Clinical data were obtained from medical records. Descriptive statistics were applied, and associations between qualitative and quantitative variables were assessed with  $\chi^2$  and Mann-Whitney U tests, respectively. Half (52%) of the patients were aware that their disease was incurable, while 31% were not sure, and 17% thought it was curable. Forty percent found it difficult to talk about treatments because they did not understand the options that were available to them. The medical staff was the most helpful information source for 74% of participants, and 64% scored their satisfaction with information  $\geq 9$  of 10. A significant association was found between higher satisfaction and knowing that MBC is incurable, as well as being older than 40 years. These results illustrate the significant lack of understanding patients with MBC have regarding their cancer, even when reporting high satisfaction with the provided information, and identify a critical need for improved patient education to enhance their comprehension and promote their participation in decision-making processes, treatment adherence, and, ultimately, outcomes.

## **Keywords**

metastatic breast cancer, awareness, patient knowledge, cancer stage, patient satisfaction, information preferences, decision-making, patient-centered care, Mexico, Hispanics

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# Introduction

Patients with metastatic breast cancer (MBC) often find it difficult to receive and accept this unexpected and devastating diagnosis. To better cope with this condition, it is vital that patients have enough information about their disease and the objectives of its treatment. In Mexico, there is currently no information about these patients' awareness of their cancer stage, and the existing data on this topic regarding the Latina population in general are considerably limited. The scarce available information about knowledge of the metastatic state of the disease of Latino patients with cancer comes from a study carried out in the United States, which found that Mexican-born patients had a higher risk of being unaware of their metastatic stage when compared with patients born in the United States (odds ratio: 2.75). Moreover, up to 40% of metastatic patients do not know their cancer stage, which is worrisome given that a general understanding of disease and stage is crucial for cancer treatment decision-making and adherence.1

Particularly, the Latin American population might have distinct ethnic culture—based attitudes and beliefs concerning the disclosure of a metastatic diagnosis to patients and regarding ideas about dying. Previous studies have reported that, when compared to European Americans and African Americans, Mexican Americans are more likely to think that a patient should not be told the diagnosis of metastatic cancer<sup>2</sup> and that terminal patients have a more passive role in medical decision-making, leaving treatment choices to the health-care system.<sup>3</sup> However, to date, no studies have been conducted that evaluate disease awareness and preferences on how to receive medical information in Mexican patients with MBC.

This study aimed to assess the understanding about the noncurable nature of the disease, the perception of having enough knowledge to participate in treatment decision-making, the notion about the most helpful source of disease- and treatment-related information, and the satisfaction with the discussions with the medical team in patients with MBC. With an exploratory intention, the existence of associations between variables that could possibly influence patients' knowledge of the incurability of MBC and satisfaction with their discussions in the clinic was also evaluated.

## **Patients and Methods**

To assess the knowledge, preferences, and outlook of patients with MBC regarding the previously mentioned topics of interest, a cross-sectional study was carried out through the use of a survey for patients with MBC developed by Dr Corrine Ellsworth-Beaumont at Worldwide Breast Cancer, sponsored by the Metastatic Breast Cancer Alliance, to assess patients' knowledge and to understand what their conversations with health-care professionals (HCP) are like. The survey was initially conducted by Ellsworth-Beaumont with 487 patients with MBC who were 40 to 70 years old and mostly United States residents and had not been applied to other populations.

The survey included a free-text question exploring patients' knowledge of their breast cancer (BC) subtype; multiple-choice questions evaluating participants' awareness of MBC incurability, topics reviewed with and suggested by their oncologist, need for additional information regarding MBC and their most helpful source of information; and a numerical scale measuring satisfaction with their discussions in the clinic, where 0 stood for "not satisfied at all" and 10 represented "extremely satisfied." A question regarding age was added to the available Spanish version, which was then pretested among 10 patients, and appropriate adaptations were made according to their suggestions. The final version of the survey was applied in a printed format.

Participation was voluntary, and patients' answers were completely anonymous, with no possibility for researchers to track either who answered the survey or which were each participant's answers. Due to the anonymous and untraceable nature of the questionnaire, and no more than minimal risk to participants related to the study, an ethics committee approval was not required. Verbal informed consent was obtained from all individual participants included in this study.

The survey was applied in Mexico City at Instituto Nacional de Cancerologia (National Cancer Institute, INCan), a public institution that is the largest cancer center in the country and the main referral center for specialized, multidisciplinary cancer care to the uninsured population. Moreover, it is the leading institution and governing body for cancer policy, treatment, education, and research in Mexico. Accordingly, INCan hosts some phase II and III international clinical trials that include all the spectrum of BC stages.

Patients were screened for eligibility by reviewing the daily schedule of the BC department at INCan and by then examining their medical files to determine whether they fulfilled inclusion criteria. All consecutive patients previously diagnosed with MBC who were literate and attended their follow-up medical appointments from January to December 2018 were invited to participate, regardless of the time since their initial MBC diagnosis. A psychoeducational session was provided for 48 patients who wished to have more information after completing the survey.

Clinical variables such as time since MBC diagnosis, moment of MBC diagnosis (de novo or recurrent), number of metastases (single or multiple), site of metastasis (local, systemic, or both), use of palliative care services, and type of treatment (oral, intravenous, or both) were obtained from patients' medical records.

Descriptive statistics were used to analyze clinical data and questionnaire answers, using frequencies and percentages for qualitative variables and medians and ranges for quantitative ones. In a first analysis, age, time since MBC diagnosis, use of palliative care services, and type of treatment (oral vs intravenous) were defined as exposures and their association with patients' perceptions of the incurability of MBC was explored. In a separate analysis, the knowledge that MBC is incurable and age were treated as the exposures in relation to patients' satisfaction. For this purpose, satisfaction was dichotomized

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Table I. Patients' Clinical Characteristics.

Characteristics	N = 185 (%)
Aged >40 years	168 (90.8)
Type of metastasis	` ,
De novo	103 (55.7)
Recurrent	82 (44.3)
Number of metastasis	` ,
Single	77 (41.6)
Multiple	108 (58.4)
Site of metastasis	` ,
Local	9 (4.9)
Systemic	145 (78.4)
Both	31 (16.8)
Palliative care	84 (45.4)
Treatment	180 (97.3)
Intravenous	41 (22.2)
Oral	84 (45.4)
Both	55 (29.7)
Months since metastatic breast cancer diagnosis	` ,
Median (range)	22 (0-241)

according to its distribution into <9 and  $\geq$ 9 (median), which was deemed very high. The associations between qualitative and quantitative variables were assessed through the  $\chi^2$  test and Mann-Whitney U test, respectively.

## Results

All 186 patients who were invited accepted to answer the survey; 185 of them completed it and one was unable to do so due to high levels of emotional distress. The majority (91%) of patients were older than 40 years. Regarding treatment, 97% were receiving pharmacological therapy intravenously (22%), orally (45%), or both (30%), and 45% of patients were on palliative/supportive care. Median time since MBC diagnosis was 22 months. See Table 1 for the description of patients' clinical characteristics.

Patients' answers to the questionnaire are described in Table 2. Fifty-two percent of participants were aware that their disease was incurable, while 31% were not sure, and 17% believed it was curable. No significant association was found between age, time since MBC diagnosis, use of palliative care services, or type of treatment, and patients' perception that MBC is incurable. Moreover, 82% of patients did not know their BC subtype, and 81% reported to want more information on this topic.

Forty percent of patients stated they found it difficult to talk about treatments with their physician because they did not understand the options that were available to them. Additionally, 25% considered that their goals and priorities were taken into account during the selection of their treatment.

Regarding patients' conversations with their oncologist, the most commonly discussed topics were chemotherapy (93%), radiotherapy (68%), and symptom and pain management (65%). The most commonly recommended management options, according to patients, were chemotherapy (93%),

**Table 2.** Results of the Survey for Patients With Metastatic Breast Cancer.

Question	N =	185 (%)
Is metastatic breast cancer curable?		
Yes		(17.3)
No		(51.9)
Not sure	57	(30.8)
What is your metastatic breast cancer type?		
I do not know my cancer type/I am guessing		(81.7)
Estrogen-receptor positive		(1.1)
Progesterone-receptor positive		(5.4)
Her2 positive		(3.2)
Triple negative		(4.3)
Other type	ŏ	(4.3)
Which topics did your oncologist discuss with you?		
(check ALL that you can remember) Chemotherapy	172	(92.9)
Radiation		(92.9) (68.1)
Symptom and pain management (plan to		(65.4)
counteract side effects, preserve quality	121	(65.4)
of life)		
Surgery	115	(62.1)
My hobbies, interests, and goals		(48.6)
Treatment breaks (reasons to postpone a		(47.6)
treatment)		()
Complementary therapy (nutrition, exercise,	85	(45.9)
counseling, acupuncture, etc)		` ,
Hormone therapy	53	(28.6)
Clinical trials	39	(21.1)
Targeted therapy	20	(10.8)
Second opinions	14	(7.6)
Which topics were recommended as options for you		
by your doctor? (check ALL that you can remember)		
Chemotherapy		(92.9)
Radiation		(65.9)
Surgery		(51.8)
Symptom and pain management (plan to		(38.9)
counteract side- effects, preserve quality of life)		(27.0)
Complementary therapy (nutrition, exercise,	70	(37.8)
counseling, acupuncture, etc) Hormone therapy	44	(35.6)
Clinical trials		(17.8)
My hobbies, interests and goals		(17.3)
Treatment breaks (reasons to postpone a		(14.0)
treatment)	20	(11.0)
Targeted therapy	18	(9.7)
Second opinions		(7.0)
Which of the following statements are true for you?		( )
(check ALL that apply)		
I wish I knew more about the type of cancer I	149	(80.5)
have		` ,
I found it tough to talk about treatments because I do not understand all of the options available to me	74	(40.0)
This clinic is where I got my second opinion	50	(27.0)
My life goals and priorities were discussed as part		(24.8)
of my treatment options	10	(= 1.5)
Clinical trials were a topic discussed with my doctor	45	(24.3)
I strongly considered or got a second opinion	23	(12.4)

(continued)

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Table 2. (continued)

Question	N = 185 (%)
Do you feel you have enough knowledge now to participate fully in treatment discussions?	
Yes	77 (41.6)
No	108 (58.4)
Did you research treatment options before starting treatment?	
Yes	42 (22.7)
No	143 (77.3)
What information source has helped you the most so far? (check ALL that apply)	, ,
Conversations with my doctor, nurse, or other health professional	136 (73.5)
Printed information given to me at the clinic	44 (23.7)
Internet website	30 (16.2)
Books	9 (4.8)
Acquaintances	6 (3.2)
None	2 (I.I)
How satisfied are you with the quality of discussions so	` ,
far in the clinic? On a scale of 0-10. Zero being not at all, 10 being extremely satisfied.	
Median (range)	9 (0-10)

radiotherapy (66%), and surgery (52%). Twenty-four percent of respondents reported having discussed the existence of clinical trials with their physician, and 2% received a suggestion from their doctor to participate in one as part of their treatment.

Sixty-four percent of participants scored their satisfaction with their discussions in the clinic  $\geq 9$  of 10. The most helpful source of information was the medical staff for 74% of patients, followed by printed information provided at the clinic for 24%, and the Internet for 16%.

Participants who knew MBC is not curable were 1.26 times more likely to be very highly satisfied with their conversations in the clinic (risk ratio [RR]: 1.26, 95% confidence interval [CI]: 1.01-1.58; P=.038), as 71% of patients who answered that MBC is not curable reported satisfaction  $\geq 9$  of 10, compared to 56% of those who believed MBC is curable. Furthermore, participants who were >40 years old were 2.28 times more likely to be very highly satisfied with their conversations in the clinic (RR: 2.28, 95% CI: 1.09-4.81; P=.002), as 67% of patients aged >40 years reported satisfaction  $\geq 9$  of 10, compared to 29% of those aged  $\leq 40$ .

# **Discussion**

This is the first study to explore the knowledge of patients with MBC regarding their disease status and notion of having sufficient information to actively participate in treatment decision-making in Mexico. Remarkably, these findings show that almost half (48%) of patients were not aware of the incurable nature of MBC, with 17% believing it could be cured and 31% not being sure. This overall rate is higher than that reported by a patient, caretaker, and provider survey applied in the United

States, in which 28% of participants interpreted that one goal of the treatment for MBC was to provide a possible cure. In addition, a population survey carried out across 14 countries reported that 59% of Mexican respondents believed that MBC was curable, suggesting that the general public also lack knowledge regarding the prognosis of patients with MBC.

Another relevant finding in this study was that 40% of patients claimed they found it difficult to discuss topics about their treatment with their physician because they considered they did not have enough knowledge about their management options. Similarly, in a survey that evaluated MBC patients' knowledge and communication experience with HCP in the United States, one-third of the respondents felt they did not have sufficient information to participate in treatment decision-making processes,4 which is understandable given that uninformed patients might find it difficult to express their treatment preferences and engage in decision-making. Moreover, previous research has highlighted the importance of providing comprehensive information about disease management among patients with BC in order to deliver patient-centered care, which is known to be associated with better outcomes in terms of quality of care, coping with illness, and treatment adherence.8

One of the reasons for the lack of disease- and treatmentrelated information among women with MBC might be inadequate communication between them and their HCP. In a recent study evaluating Mexican oncologists' communication challenges, end-of-life care and treatment objectives were the issues that physicians considered the hardest to discuss with patients, while being honest without taking away hope and dealing with patients' emotions were the most difficult challenges they faced when breaking bad news.9 Additionally, in the aforementioned survey involving patients, caretakers, and providers, 27% of oncologists indicated that, at times, they do not tell patients that MBC is incurable. However, as other authors have suggested, withholding bad news and endorsing unrealistic expectations for cure as a means to protect patients can ultimately cause increased and unnecessary suffering, as well as loss of trust in the physician as the disease progresses.<sup>6</sup>

Another possible explanation for this limited knowledge could be that patients' denial to accept their advanced disease stage may lead to a misconstruction of the goals of palliative treatment and their prognosis. A previous US-based study reported that oncological patients, including patients with MBC, used denial as a means to cope with cancer, independently of their degree of knowledge about their disease. <sup>10</sup> Thus, as suggested by other authors, patients with terminal illness may never fully become aware of their disease state, despite receiving clear and understandable explanations of their situation. <sup>11</sup>

A final reason that could be related to paucity of information in patients with MBC is that most conversations with HCP are verbal, a communication method with a poor retention accuracy. Spoken medical instructions have been associated with a recall rate of 14%, which is significantly low in comparison with the 85% achieved when combining oral instructions with

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visual aids. 12 Additionally, as has been previously reported, patients with cancer often feel overwhelmed immediately after being informed of their diagnosis, 13,14 and this can interfere with their understanding and assimilation of the information provided by their physician. Thus, women in other studies, including Mexican patients, 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. 13-15

Also related to making informed health-care decisions, only one-fourth of patients in this study believed that their goals and priorities were considered by physicians when selecting their treatment. This is alarming because being attentive to patients' particular concerns and informed preferences is an essential component of patient-centered care and shared decisionmaking, which may positively impact patients' autonomy, knowledge, and affective-cognitive outcomes. 16-18 On the contrary, a lack of recognition of patients' concerns, even when sufficient information is provided, may lead to dissatisfaction with communication. 19 Unfortunately, despite the increasing advocacy for shared decision-making, it has been previously noted that it is not standard practice yet. 18,20 Therefore, it is imperative to balance the importance of evidence-based approaches and each patient's unique context through the recognition of their values, appraisals, feelings, and desire to be involved in decisions.<sup>21,22</sup>

Regarding satisfaction, 64% of participants were very highly satisfied with their discussions with their HCP. Another study predominantly evaluating patients with breast and lung metastatic cancer in England has also described satisfaction with information and reported that a lower 48% of participants gave grades  $\geq 4.5/5$ . Moreover, the proportion of satisfied patients in our study is comparable to that found by other authors evaluating women with MBC in the United Kingdom, who observed that 62% of patients were satisfied with the information and advice they had received. Also similar to our results, they reported that older patients were significantly more satisfied with the information they had been given.

The fact that more than half of our participants were very highly satisfied with their discussions in the clinic is remarkable considering that 81% wished they knew more about their type of cancer, only 40% felt they had enough knowledge to participate fully in treatment discussions, and merely 25% believed their life goals and priorities were discussed as part of their treatment options. These counterintuitive findings could be a consequence of the way in which the satisfaction question was asked given that patients could have answered it based on their general experiences in the clinic and not specifically according to their satisfaction regarding the interaction with their HCP. Moreover, their response could be influenced by the quality of the patient–physician relationship, which has been shown to be high among Latinas.<sup>24</sup>

In the present study, participants who knew MBC is incurable were more likely to be very highly satisfied with the discussions in the clinic. Other authors have found that

patients' level of satisfaction with information strongly correlates with their perception of patient-centered communications with their physicians.<sup>25,26</sup> These findings reinforce that an empathic, thorough, and clear delivery of information to patients with MBC can translate into higher patient satisfaction.

This study also found that most patients mentioned conversations with their physician, nurse, or other HCP as their most helpful information source, followed by printed information provided at the clinic and the Internet. Likewise, physicians represented the major source of information among patients with BC in two studies from Mexico and Nigeria. Moreover, it has also been reported that printed materials are the preferred information source among BC survivors in Mexico and that most Mexican women express high interest in obtaining information online, despite having a low educational background and limited Internet access. <sup>13,29</sup>

Remarkably, a minority of participants reported having discussed the existence of clinical trials with their physician, and merely 2% received a suggestion from their doctor to participate in one as part of their treatment. Others have reported that, when patients have a poor prognosis, oncologists are less likely to recommend participating in clinical trials given that they might be randomized into a placebo or standard treatment arm that would only provide a modest benefit, instead of to the experimental arm. 30-32 In contrast, when patients have nonmetastatic BC, these referral rates can reach 22% of cases. 32 Moreover, it should be noted that Mexico currently has 65 MBC clinical trials registered at Clinical Trials.gov, which is a markedly small number when compared with the 1515 listed by the United States. These mixed phenomena could explain the low rate of discussion and recommendation of clinical trials observed in this study.

To improve physicians' competences to communicate MBC disease- and treatment-related information, our group is participating in and organizing trainings on communication skills and psychoeducational interventions. Likewise, an additional consultation in which doubts, priorities, and emotional distress are addressed in a less overwhelming setting is also being modeled with the aim of improving patients' comprehension rates and making appropriate referrals, when needed, to psychology, psychiatry, supportive/palliative care, or support groups. Lastly, we have been developing different kinds of educational resources, including printed material and reliable websites, <sup>33,34</sup> in order for patients with MBC to have access to understandable information in the most commonly preferred formats.

This study has some limitations that should be noted. First, a selection bias could be present since only literate patients were included, and this may lead to an overestimation of participants' knowledge and rates of information-related behaviors, since these patients are probably more informed ones. Second, patients with MBC were invited to participate at any point in time since their diagnosis, which could introduce a recall bias that might influence their answers to some of the survey's questions. More precise results could have been obtained by

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including a more homogeneous patient population with a recent diagnosis of MBC. Moreover, responses to some items of the questionnaire were subjective, particularly the one assessing satisfaction, and might have been affected by a variety of factors external to the study.

#### Conclusion

This study showcases the significant lack of understanding that most patients with MBC have about their disease stage, which might partially be a consequence of inadequate communication with HCP, patients' resistance to accept their diagnosis, and limited or nonexistent informational resources for patients in this disease stage. Moreover, these findings emphasize a critical need for improved patient education, which could be achieved through the enhancement of physicians' communication skills and the implementation of psychoeducational interventions as well as through the provision of written and online instructive material. The fulfillment of this gap would enable patients to participate in informed decision-making in which their priorities are acknowledged and the optimal management options are selected in a personalized manner.

Further examination is needed to explore how increased knowledge and enhanced comprehension may contribute to patients' ability to actively engage in decision-making processes and, ultimately, receive patient-centered care that will improve their treatment adherence and outcomes.

# **Authors' Note**

Participation was voluntary and patients' answers were completely anonymous, with no possibility for researchers to track neither who answered the survey nor which were each participant's answers. Due to the anonymous and untraceable nature of the questionnaire and no more than minimal risk to participants related to the study, an ethics committee approval was not required. Verbal informed consent was obtained from all individual participants included in this study.

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