



# Patients' satisfaction with a supportive care program for young breast cancer patients in Mexico: Joven & Fuerte supports patients' needs and eases their illness process

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Received: 14 December 2019 / Accepted: 28 January 2020 / Published online: 4 February 2020  
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## Abstract

**Objective** The aim of this study was to evaluate patients' outlook and satisfaction with “Joven & Fuerte: Program for Young Women with Breast Cancer (YWBC) in Mexico” (J&F) and to determine its strengths and areas of improvement to better fulfill patients' information and supportive care needs.

**Methods** Patients enrolled in J&F for  $\geq 6$  months at three cancer referral centers were invited via a messaging application to anonymously complete an online survey exploring their perspectives of the program's information delivery, support services, and research component. Descriptive statistics,  $\chi^2$  test, Student *t*, and ANOVA were used for analysis.

**Results** Of 484 eligible patients, 28% completed the survey. The program overall was useful/very useful according to 97% and aided 82% to better cope with their illness. The timing, clarity, and usefulness of the information provided were each described as good/very good by  $\geq 83\%$  for the written format and  $\geq 98\%$  for the verbal one. Eighty-four percent of patients were very satisfied ( $\geq 9/10$ ) with psychological support and genetic assessment. The number of support services used was significantly associated with patients' perception of J&F's usefulness. Regarding fertility issues, 45% recalled being informed about preservation strategies and J&F financially supported 27/39 of interested patients. Fifty-eight percent were unaware of J&F's ongoing research component.

**Conclusions** Patients' satisfaction with J&F is very high, reflecting that the program is meeting Mexican YWBC's needs by providing useful information means and support services in a limited-resource setting. Efforts must keep up to guarantee the program's continuity and advocate for its extension to other oncologic centers.

**Keywords** Breast cancer · Young women · Supportive programs · Information · Satisfaction · Mexico

## Background

Breast cancer (BC) in young women is particularly prevalent in low- and middle-income settings such as Mexico and other Latin American countries, where it accounts for approximately 20% of all BC cases, compared with 12% in more developed countries [1]. Even though specialized programs dedicated to addressing the specific needs of this young group successfully provide comprehensive care and support services, they are mainly active in developed contexts [2–7]. Hence, young patients in limited-resource settings, including Mexico, remain with unmet information- and survivorship-related needs on issues such as psychological assistance,

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genetic and fertility assessments, physical therapy, and social support [8–10].

“Joven & Fuerte (Young & Strong): Program for Young Women with Breast Cancer in Mexico” (J&F) is the first program of its kind in Latin America and intends to meet the needs of young women with BC (YWBC) in terms of information delivery and support on young women’s specific concerns. The J&F team consists of a breast medical oncologist, one to two psycho-oncologists that serve as navigators, and a research coordinator per center. Since its initiation in 2014 and up to September 2019, J&F has assisted 599 patients and is active in three sites in Mexico, one in Mexico City and two at Monterrey.

After its first five years of implementation, we found it critical to evaluate users’ satisfaction with the services provided by J&F so that unmet objectives and expectations can be identified and pertinent actions can be taken for improvement. Guaranteeing that patients are highly satisfied with the program would be expected to translate into an improved quality of health care, positive patient behaviors, increased compliance with treatment, and better health outcomes [11–15].

Thus, the aim of this study was to determine patients’ satisfaction with J&F to have an overall assessment of the program. More specific objectives were to assess patients’ outlooks on the usefulness of the information delivered by J&F, their satisfaction with each of the support services offered by the program, and their feedback on ways in which J&F could better fulfill their needs. This information will aid to further implement strategies to enhance the provision of patient-centered care.

## Methods

### Description of the J&F program

Patients aged  $\leq 40$  years with recently diagnosed BC are identified by reviewing the daily schedule and are invited to join the program by the navigator before or after their first appointment with a medical oncologist. The navigator also addresses relevant topics for YWBC, identifies patients’ particular needs, and makes referrals to the appropriate specialty consultations in the areas of fertility preservation, genetic assessment, psycho-oncology, and contraception. She also provides the J&F specially designed educational handbook and invites patients to visit the program’s website, to join the support group and the patients’ WhatsApp group, and to attend the monthly facilitator-led workshops for patients and their families, which cover diverse topics related to general BC information, young women’s concerns, and strategies to better cope with BC. In addition, patients are invited to participate in the prospective cohort for research purposes, which involves answering electronic surveys and donating tissue samples. A more detailed description of the abovementioned features has been previously published [16].

### Data collection

A cross-sectional study was carried out to evaluate patients’ satisfaction with J&F through a survey. For the design of the questionnaire, a panel of experts in BC among young women from J&F, including two medical oncologists, two psycho-oncologists, and two patient advocates, established the goals of the desired evaluation and used the survey from the PYNK program (Young Women With Breast Cancer Program, Canada) as a model, with prior permission from the Director of PYNK [5]. The survey was translated to Spanish and adapted by selecting, removing, and adding questions according to what applied to J&F. Questions that were kept from the PYNK survey explored demographics; moment of enrollment to the program; patients’ outlooks on the timing, format, clarity, and usefulness of the written and spoken information delivered; patients’ use of each of the program’s support services; satisfaction with the fertility preservation service and the research component; impressions on the program’s most helpful resource/feature; and ways in which the program could improve. Questions that evaluated patients’ satisfaction with J&F in general and with each of the support services it offers were added. The final version of the questionnaire consisted of 10 sections, which included eight open-ended and 35 multiple-choice questions (Online Resource 1).

All participants enrolled in J&F for at least six months at either Instituto Nacional de Cancerología in Mexico City or the TecSalud hospitals at Monterrey were invited to anonymously complete the survey through a messaging application.

### Statistical analysis

Likert-scale questions were analyzed and dichotomized, establishing cut-off points according to the answers’ distribution. Open-ended answers were grouped according to the most commonly mentioned topics. Descriptive statistics were used, including frequencies and percentages for categorical variables and means and standard deviation for quantitative variables. To evaluate the association between the program’s usefulness and demographic characteristics, the  $\chi^2$  test, and the Student *t* test and ANOVA were used for qualitative and quantitative variables, respectively. The association between patients’ satisfaction and time since diagnosis was assessed by categorizing patients into two groups according to the median time between diagnosis and survey completion.

## Results

Of 484 eligible patients, 134 (28%) agreed to answer the survey. Sixty-five percent of participants received attention by J&F in Mexico City. Median age at diagnosis was 35 years.

Most patients had completed at least high school education (78%). Thirty-seven percent were single/divorced/widowed and 26% were childless. Median time between diagnosis and survey completion was 20.7 months.

Respondents' sociodemographic characteristics were compared with those of all the J&F members to determine if they were a representative sample (Table 1). Both groups had similar sociodemographic characteristics. A significant difference was found only regarding education level, given that 78% of respondents had completed at least high school, compared with 61% of all J&F members.

When asked about the moment in which they were invited to J&F, 63% of patients responded they joined after diagnosis disclosure but before receiving any type of treatment. Most patients (94%) considered the timing of contact to be appropriate (Table 2).

Overall, the program was judged useful/very useful by 97% of patients. Eighty-two percent considered it helped them to better cope with their illness, mainly by delivering psychological support and more detailed information about BC (Table 2). Patients' perceptions of J&F's usefulness and its aid in better coping with BC were not significantly associated with time since diagnosis; however, more patients whose time since diagnosis was < 20.7 months reported that J&F was very useful (80% vs. 63%,  $p = 0.078$ ).

The timing, clarity, and usefulness of the written information were rated as good/very good by 83%, 85%, and 84% of

patients, respectively. As for verbal information, the same parameters were rated as good/very good by 98%, 99%, and 99% of patients, respectively. Patients' perceptions of the information provided by J&F are depicted in Fig. 1. The provided information was reported to emotionally distress 13% of respondents, mainly due to having to assimilate the diagnosis and undergo treatment, feeling fear of the uncertain future, addressing fertility issues, and having received a great deal of information in a short period.

Most of the support services offered by J&F were used by the majority of participants: the patients' WhatsApp group, the genetic assessment consultation, and the psychological support service were used by 79%, 76%, and 69% of patients, respectively. Participants' use of the program's support services is detailed in Table 3. Of the total patients who used each service or resource provided by J&F,  $\geq 82\%$  reported being very satisfied ( $\geq 9/10$ ) with the psychological assistance, genetic cancer assessments, and support groups, and  $\geq 74\%$ , with the patients' WhatsApp group and the educational workshops. Participants' satisfaction with the program's support services is shown in Fig. 2. Patients found that the program's most useful service/resource was psychological support, followed by information tools and support groups (Table 2).

The number of support services/resources used by each patient was significantly associated with their perception of the program's usefulness ( $p = 0.008$ ) and its aid in easing their illness process ( $p = 0.009$ ). No significant association was

**Table 1** All Joven & Fuerte participants' and respondents' sociodemographic characteristics

Characteristic	All Joven & Fuerte participants (599)	Respondents (134)	<i>p</i>
Age at diagnosis: median (SD)	35 (4.7)	35 (4.1)	0.254*
Has children, <i>N</i> (%)	466 (77.8)	99 (73.9)	0.252†
Educational level, <i>N</i> (%)			
None	3 (0.5)	1 (0.7)	0.004†
Elementary school	58 (9.7)	4 (3)	
Middle school	149 (24.9)	25 (18.7)	
High school	98 (16.4)	23 (17.2)	
Technical career	55 (9.2)	21 (15.7)	
Undergraduate or college	184 (30.7)	49 (36.6)	
Postgraduate	29 (4.8)	11 (8.2)	
Missing	23 (3.8)	0 (0)	
Marital status, <i>N</i> (%)			
Single	156 (26)	36 (29.6)	0.363†
Married	297 (49.6)	59 (44)	
Domestic partnership	108 (18)	25 (18.7)	
Divorced	29 (4.8)	12 (9)	
Widow	5 (0.8)	2 (1.5)	
Missing	4 (0.7)	0 (0)	

\*Student *t*

†Chi<sup>2</sup> test

**Table 2** Participants' overall outlook of Joven & Fuerte

Question and possible answers	N = 134 (100%)
<b>Invitation to join Joven &amp; Fuerte</b>	
When were you invited to join Joven & Fuerte?	
Before the breast biopsy that detected cancer	6 (4.5)
After biopsy, but before surgery or chemotherapy	85 (63.4)
After surgery	8 (6)
After surgery, but before chemotherapy	17 (12.7)
After chemotherapy had already begun	11 (8.2)
Not sure	7 (5.2)
Do you consider the moment in which you were invited to join Joven & Fuerte to be the appropriate one?	
Yes	126 (94)
No	1 (0.8)
Not sure	7 (5.2)
<b>Overall program evaluation</b>	
How would you describe the usefulness of the support/orientation provided by Joven & Fuerte?	
Very useful	94 (70.1)
Useful	36 (26.9)
Not very useful	1 (0.7)
Not useful at all	0 (0)
I did not receive support/orientation	3 (2.2)
Do you consider that the support/orientation provided by Joven & Fuerte helped you to better cope with your illness?	
Yes	110 (82.1)
No	7 (5.2)
Not sure	14 (10.4)
I did not receive support/orientation	3 (2.2)
In what way do you consider Joven & Fuerte helped you?	
Through the psychological support	40 (36.4)
By providing information about breast cancer	32 (29)
By solving doubts	11 (10)
Other	27 (24.6)
Overall, what was the most useful aspect of Joven & Fuerte?	
Psychological support	62 (46.3)
Information tools	32 (23.9)
Support groups	19 (14.2)
Other	21 (15.7)
Would you like to have more patients' meetings with other members of Joven & Fuerte?	
Yes	100 (74.6)
No	4 (3)
Not sure	30 (22.4)

found between these perceptions and patients' age, educational level, relationship status, or the institution in which they received the J&F attention.

Regarding fertility issues, 81% of patients recalled being informed about the potential effects of cancer treatment on fertility, and 45%, about preservation strategies. Notably, 33% reported they wished to have more children at diagnosis and 39/134 (29%) wanted to preserve fertility. J&F promoted the use of preservation procedures among 27 of those interested: 15 received gonadotropin-releasing hormone

analogues, nine had an oocyte/embryo cryopreservation procedure, and three did not recall which strategy was used for preservation (Table 4). For the remaining 12 patients who desired to preserve fertility but did not receive any measure to do so, the most common reason was patients' perception of the need to start cancer treatment as quickly as possible (75%).

When asked about the J&F ongoing cohort, 27% of patients were unaware of its research nature and 31% were not sure; 29% did not recall being involved in any research projects and 23% were not sure; and 12% considered the amount of surveys applied to be either not enough or too many.

Finally, patients reported that J&F could improve by offering more educational workshops (31%) and by making its support services more widely known (21%). Likewise, three-fourths of patients stated that they would like to have more patients' meetings (Table 2), and most were very interested ( $\geq 9/10$ ) in receiving additional information through the program's written media.

## Discussion

J&F has provided support services for young BC patients since 2014. As part of its quality assessment and continuous improvement approach, an evaluation of patients' satisfaction with the program and its services has been performed for the first time.

Nearly all respondents rated J&F as useful/very useful and most believed it helped them to better cope with their illness. These rates indicate that the program is considered a valuable and helpful tool by the vast majority of participants.

Another relevant aspect in the current assessment is patients' satisfaction with the information provided through the program. Most patients gave high grades to the timing, clarity, and usefulness of written and verbal information, with 83–85% and 98–99% evaluating each format, respectively, as good/very good. Satisfaction with the timing, clarity, and usefulness of written and verbal information was also high among YWBC from the PYNK program [5]. Similarly, two other patient information programs that included BC patients independently of their age found that >90% were satisfied/very satisfied with disease-related information, regardless of its format [17, 18]. Previous studies have reported that a high level of satisfaction with information has positive effects on patients and empowers them to participate more actively during medical appointments [19] and helps them achieve a better psychological health [20]. Additionally, high satisfaction with information has been associated with patients' perception of receiving a more patient-centered care [21, 22]. This is especially valuable in the young women's group, which has been recognized to be particularly dissatisfied with counseling and information [23].

Notably, only 13% of respondents reported feeling emotionally distressed by any of the information provided by J&F.

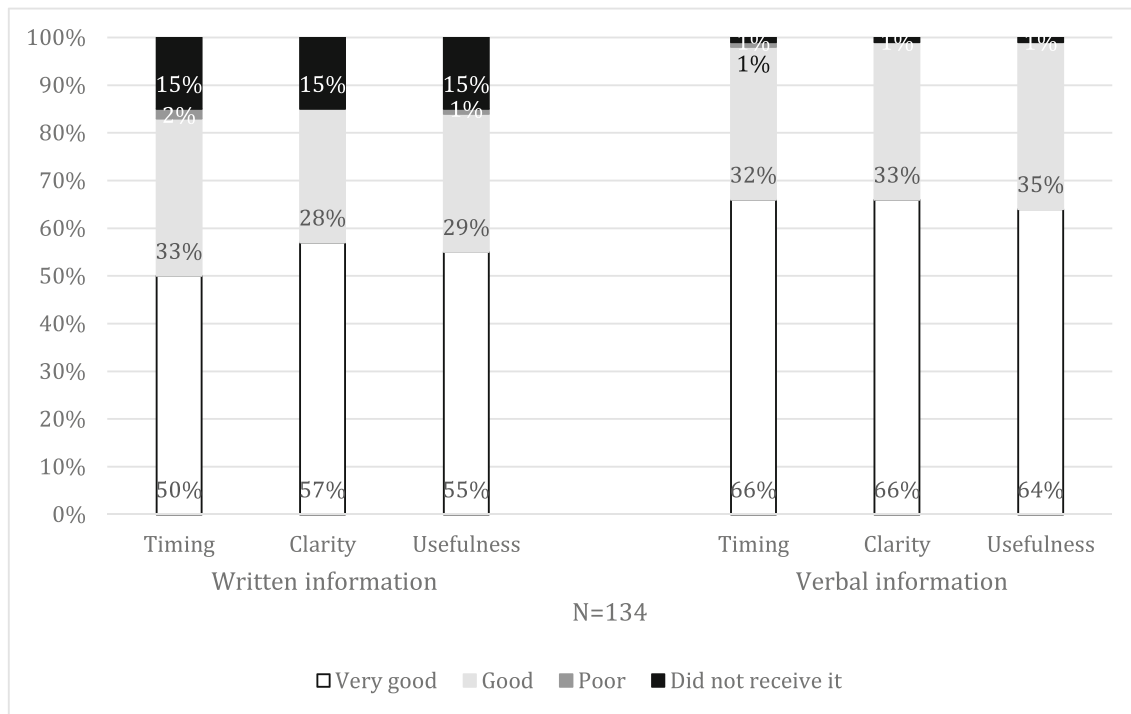


Fig. 1 Participants' perceptions of the information provided by Joven & Fuerte

This rate was lower than that reported in the PYNK study, where almost 50% of participants found the verbal information they received to be upsetting [5]. In their case, receiving and discussing cancer diagnosis at such an anguishing time were the main reasons for their distress [5].

Another positive finding in this study was that most participants reported very high satisfaction with the services offered by J&F. A possible reason for this might be the active role of the navigator in J&F, who also represents the pillar of successful programs such as PYNK and Young and Strong due to her role as the program's hostess and guide for patients throughout their cancer journey [2, 5]. Remarkably, the importance of addressing YWBC's special needs and the paramount impact of a navigator in accomplishing this objective have been acknowledged by another center, which has assigned a navigator exclusively to coordinate and facilitate fertility discussions and referrals [24]. Moreover, YWBC have greater supportive care needs than their older counterparts and may thus appreciate to a higher degree the provision of complementary resources [25, 26]. This is supported by the finding in our study

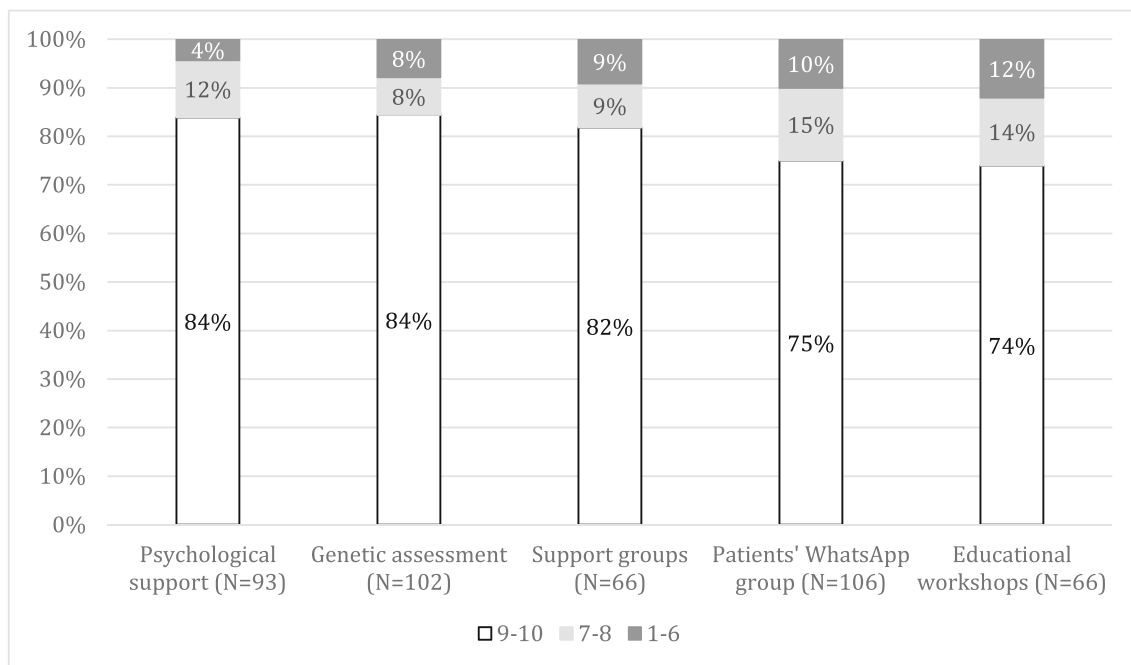
that, the higher the number of support services used by patients, the better their perception of the program's usefulness and its aid in easing their illness process.

According to participants, psychological support was the most helpful resource, followed by information tools and support groups. This is in accordance with what was reported by our group in a previous study where newly diagnosed YWBC stated that receiving psychological assistance was one of their most important needs [10], similar to what other authors have documented [17, 27]. Likewise, other studies have demonstrated that psychological support is a valuable asset of cancer care, particularly for young patients, including Hispanic women [28, 29], and it aids patients in developing coping skills that may lead to better quality of life and possibly increased survival [10, 30, 31].

Notably, our patients' satisfaction with the information received during genetic assessments was very high in > 80% of cases. This positive finding may be a result of the formal implementation of a genetic cancer risk assessment clinic, which has been possible in part through a partnership with

Table 3 Participants' use of the program's support services

Support service/ participants' responses	Patients' WhatsApp group	Genetic assessment	Psychological support	Support groups	Educational workshops
Used it	106 (79.1)	102 (76.1)	93 (69.4)	66 (49.3)	66 (49.3)
Did not use it	12 (9)	21 (15.7)	36 (26.9)	49 (36.6)	45 (33.6)
Did not know it was available	16 (11.9)	11 (8.2)	5 (3.7)	19 (14.2)	23 (17.2)



**Fig. 2** Participants' satisfaction with the program's support services. Each category's *N* is different given that not all support services were used by the same number of respondents.

an international institution and has allowed J&F to overcome barriers related to the high cost of genetic testing and to give young patients access to this service [16, 32].

As for oncofertility services, J&F provides opportune information about the possibility of premature ovarian failure related to cancer treatment and supports those patients interested in preserving fertility. This has been possible by facilitating timely referral for cryopreservation at several centralized, experienced centers, as turning to a major fertility unit could increase preservation procedures' rates and improve their cost-effectiveness [33]. Additionally, J&F has succeeded in giving access to preservation procedures by partially or totally covering their costs through collaborations with assisted-reproduction centers.

Most participants (81%) recalled being informed about the fertility-associated risks of cancer treatment. Noteworthy, 38/44 (86%) of interested patients recalled being informed about the different preservation strategies. Moreover, almost all respondents who expressed their wish to preserve fertility were timely referred and most were supported with full or partial coverage from J&F to receive a preservation strategy (oocyte/embryo cryopreservation or use of gonadotropin releasing hormone analogues). This number of fertility preservation measures is remarkably higher than what was reported by our group in previous years when J&F was not yet running, when only 31% of young patients recalled being informed about fertility issues associated with BC treatment, and just one patient underwent embryo cryopreservation [34]. This difference may be explained by what was reported in a previous study which found that dedicated programs for YWBC

promote the discussion of fertility issues during medical appointments and therefore increase fertility preservation referrals [35].

Regarding the program's research component, even though 88% of the total J&F members are part of its prospective cohort, more than half of respondents stated being unaware of participating in a research study. A probable reason for this lack of awareness may be that most respondents do not know or do not remember the purpose of the study's surveys, given that they could assume that the questionnaires are part of their routine cancer care. Verbal reminders of this component should be done during every survey application to address this issue and reinforce adherence to the research study.

The results of the present report suggest that J&F fulfills the requirements of highly effective support interventions, which attend to patients' personal preferences, remove barriers, provide information and educational material, and offer psychosocial assistance [36]. Patients' suggestions and feedback will be integrated and used to further refine the program's services and resources. For example, more workshops will be scheduled taking into account patients' topics of interest, and more diffusion of J&F's components will be made through social media and the program's website. In addition, to further improve patients' satisfaction with written sources of information, J&F will add more content on topics such as managing finances, handling changes in patients' working ability, dating issues, participating in healthy activities, and searching for additional support resources in their communities, as young groups in other studies have recommended [20, 37].

**Table 4** Participants' responses to the fertility section of the survey

Question and possible answers	N = 134 (100%)
At the time of breast cancer diagnosis, did you want to have more children?	
Yes	44 (32.8)
No	81 (60.4)
Not sure	9 (6.7)
Did anyone discuss with you the possible effects that cancer treatment might have on your fertility (possibility to have more biological offspring)?	
Yes	109 (81.3)
No	15 (11.2)
Not sure	10 (7.5)
At the time of breast cancer diagnosis, were you interested in receiving information about treatments and methods to preserve fertility?	
Yes	44 (32.8)
No	88 (65.7)
Not sure	2 (1.5)
Did you receive information about treatments and methods to preserve fertility?	
Yes	60 (44.8)
No, I was interested but did not receive information on this topic	6 (4.5)
No, I was not interested in receiving information on this topic	68 (50.7)
At the time of breast cancer diagnosis, were you interested in receiving treatments or undergoing procedures to preserve fertility?	
Yes	39 (29.1)
No	92 (68.7)
Not sure	3 (2.2)
After breast cancer diagnosis, did you receive any treatment or undergo any procedure to preserve fertility?	
Yes	27 (20.1)
No, I was interested but did not receive or undergo any fertility preservation method	15 (11.2)
No, I was not interested in preserving fertility	92 (68.7)
What treatment or procedure was used to preserve fertility?	
I did not preserve fertility	107 (79.9)
Embryo/oocyte cryopreservation	9 (6.7)
GnRH agonists	15 (11.2)
I do not know/remember	3 (2.2)

Moreover, the J&F team considered that patient care could also be improved by identifying patients' most relevant needs and by addressing them in a more systematic manner. The design of a methodical action plan in which the program's multidisciplinary team objectively evaluates each patient's needs according to the navigator's interview and the surveys' results would enable the implementation of directed and timely actions. The efficacy of these interventions would have to be subsequently evaluated to determine optimal resource allocation.

This study has some limitations that must be considered when interpreting the findings. Its cross-sectional design

restricts the possibility of establishing causal associations between patients' satisfaction and clinical and quality of life outcomes, which could be overcome in the future with our longitudinal study. Furthermore, continual assessments will be necessary to evaluate patients' satisfaction levels over time, as well as changes in their information and support needs depending on time since diagnosis or treatment stage. There is also the possibility of recall bias from participants in relation to their use of J&F's support services, especially among patients whose diagnosis was made several years before this survey. In addition, the quality of our results depends on patients' self-report and is subject to a potential respondent bias,

where patients could have responded in a socially desirable way due to fear of losing services or benefits if they stated low levels of satisfaction with the program in spite of its anonymous nature. It should also be highlighted that respondents had a higher level of education than all J&F members. This might be explained by the fact that this was an online survey, and more educated patients could have felt more comfortable handling electronic devices and hence had a higher rate of participation. Likewise, there could be a self-selection bias in which respondents might be more satisfied with J&F and thus had more interest in answering this survey than less satisfied patients. Finally, there was a moderate response rate (28%), but this was comparable to the average response rates of other studies (11–34%) [38–40], and respondents' characteristics were similar to those of all J&F members.

In order for the program to continue running and improving, crucial factors that need to be considered are financial constraints and long-term sustainability. J&F must continuously seek governmental funds, non-governmental organizations' donations, and limited grants to keep offering its support resources to meet the needs of YWBC and to expand its services to other cities. To guarantee the provision of an integral care for young patients, institutions should formally commit to cover, at least partially, supportive care services and foster interinstitutional collaborations to make the most of available resources [4].

## Conclusion

Patient satisfaction with J&F is very high, reflecting that the program is achieving its main goal of meeting the needs of Mexican YWBC by providing timely, clear, and useful means of information and valuable supportive care services in a limited-resource setting.

Several collaborations have been established to strengthen and accomplish the program's objectives of delivering specialized care through services such as fertility preservation assessment and genetic counseling. These partnerships have enabled J&F to provide YWBC with access to resources that would otherwise be prohibitive due to their high costs. It is crucial to promote these services among patients and their families and to highlight the program's research component to enhance its reach. Likewise, it is essential that J&F continues offering an emotional support service not only due to the high satisfaction of patients with this resource but also because it aids in developing coping skills that may lead to relevant outcomes such as better quality of life and increased survival. Finally, it is imperative to keep efforts to guarantee the program's continuity and advocate for the extension of its benefits to other cancer centers.

Overall, J&F will serve as a model especially to other Latin American countries that aim to meet the needs of YWBC and

to increase the availability and enhance the utility of targeted supportive care services, which will ultimately improve these women's quality of life and long-term outcomes.

**Acknowledgments** The authors thank Dr. Ellen Warner, Director of PYNK (PYNK: Breast Cancer Program for Young Women), for the kind provision of the questionnaire used by PYNK to assess patients' satisfaction with the program.

**Author contributions** Cynthia Villarreal-Garza, Alejandra Platas, Melina Miaja, Enrique Bargallo-Rocha, and Alejandro Mohar contributed to the study conception and design. Material preparation and data collection and analysis were performed by Fernanda Mesa-Chavez, Marisol Garcia-Garcia, Alan Fonseca, Claudia Pineda, Sylvia de la Rosa-Pacheco, Carmen L. Galvez-Hernandez, Janeth Castro, David Rodriguez-Gomez, and Marlid Cruz-Ramos. The first draft of the manuscript was written by Cynthia Villarreal-Garza, Fernanda Mesa-Chavez, and Marisol Garcia-Garcia, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

## Compliance with ethical standards

Patients' participation in this study was in accordance with the ethical standards of the institutional research committee of "Escuela de Medicina del Instituto Tecnológico y de Estudios Superiores de Monterrey" (reference number: P000100) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent was obtained from all individual participants included in the study.

**Conflict of interest** The authors declare that they have no conflict of interest.

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