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## ANALYSIS OF ILLNESS NARRATIVES OF BREAST CANCER, AN INVITATION FOR A CHANGE IN PATTERNS.

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# ANALYSIS OF ILLNESS NARRATIVES OF BREAST CANCER, AN INVITATION FOR A CHANGE IN PATTERNS.

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## ABSTRACT:

**Objective:** To explore the lived experience of women diagnosed with breast cancer through the analysis of illness narratives, as an example of a Narrative Based Medicine approach.

**Setting:** Spain.

**Participants:** Nine narratives originating in non-fiction books, and seven in interviews through online platforms. All the women interviewed were born and currently living in Spain, between 40 and 60 years of age. The only inclusion criterion was having been diagnosed with breast cancer.

**Results:** The main topics that appeared on the analysis were: secondary effects of treatment, breast loss and scars, breast reconstruction, long term effect of treatment, positive attitude, illness as learning and use of language. The results of this research are preliminary, but from them the authors suggest that there is not a common pattern of behaviour for patients, and that societal preconceptions become a burden for them. Hiding their baldness or not, going through reconstructive surgery, and fulfilling the 'patient role', are choices they want to make on their own priorities, and not because of impositions. Even though women agree with the benefits of having a good attitude, they also ask for space to feel rage and sadness, not to be compared with others, and to be heard with no haste, as well as to be accompanied beyond the treatment, and for their long-term effects of medications to be validated. The importance of the type of comments and language used is emphasized.

**Conclusion:** The thematic analysis of illness narratives, within the framework of a Narrative Medicine approach, enables us to incorporate the patient experience into the understanding of

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3 breast cancer. We encourage clinicians to be aware of the concepts of normality held by women,  
4 and to welcome different choices and different ways to experience illness, breaking with  
5 established societal patterns and the paternalistic medical discourse.  
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## 11 STRENGTHS AND LIMITATION OF THIS RESEARCH:

- 12 • There are no similar analyses that investigate the illness experiences of breast cancer  
13 in Spanish women and its application to medical education.
- 14 • The incorporation of the teaching of Medical Humanities has not permeated Spanish  
15 Medical School, thus the importance of highlighting their relevance through a specific  
16 example of its model of achieving knowledge.
- 17 • All the books reviewed are first-person narratives, as none were found written by carers  
18 or family, and all of them are stories of survival.
- 19 • To the date of its writing, only 7 women had been interviewed, which does not allow for  
20 a thorough qualitative analysis. Nevertheless, there are themes and comments that  
21 have appeared in most of the interviews and books and have been used as examples for  
22 this article.

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35 **KEY WORDS:** Medical Humanities. Illness narratives. Breast cancer. Narrative Based  
36 Medicine.  
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## 38 TAKE-AWAY POINTS

- 39 • There is a felt need, from education, clinical practice, and patients, for a model of  
40 medicine that includes different views of illnesses, away from the biomedical model. A  
41 Narrative Based Medicine approach is proposed as an option.
- 42 • The analysis of Illness narratives, in this case, from women who were diagnosed with  
43 breast cancer, can contribute to a more person-centred approach, by offering illness  
44 experiences from an individual point of view.
- 45 • The findings of this research suggest that there are situations, like coping with the  
46 secondary effects of treatment, or the decision to have a reconstructive surgery, where  
47 the medical point of view and society's fixed standards prevail beyond women's choices.
- 48 • Women who have suffered from breast cancer want their voices to be heard, their own  
49 priorities to be considered, and for their fear, rage, and sadness to be unstigmatized.

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57 **INTRODUCTION:** \*(re-written, comments on the values of illness narratives added)  
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3 Throughout the history of Medicine, the questioning of paradigms have changed the way  
4 Medicine is practised and taught (1); the turn of the 20<sup>th</sup> century called for a rethinking of the  
5 biomedical model as it didn't provide a satisfactory explanation for illness. This, along with the  
6 raising of the advocacy for patient's autonomy (and in the case of breast cancer, feminism),  
7 turned into an interest in the incorporation of humanities and communication skills within  
8 teaching in Medical Schools (2,3). A model based on facts and findings, centred on a search for  
9 the explanation of illnesses, but not in the understanding of processes, was no longer  
10 acceptable. Narrative Based Medicine, which prioritises active listening, subjective symptoms,  
11 and the importance of life experiences, surfaced as an approach to illness in which contradictory  
12 and complex experiences were valued and contributed to a patient-centred care. (4,5) Within  
13 this model, medical narratives shift from the physician's perspectives to the patient's stories,  
14 becoming a useful resource to understand "the patient-specific meaning of illness" (4).

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18 Specifically in the case of breast cancer, where breasts are regarded as the cornerstone of  
19 femininity, where the "pink ribbon" approach which encourages a positive attitude, and the  
20 quest for an "acceptable social appearance" (4) prevail, illness narratives enrich us with diverse  
21 and non-conventional stories. They expose us "to personal accounts of the journey through  
22 illness and treatment, offering us details, emotions, phrasing and imagery from an individual  
23 perspective", complementing the medical knowledge and improving the complexity of breast  
24 cancer.(6,7).

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28 By using a thematic analysis of illness narratives, this article seeks to exemplify the different  
29 lived experiences of women with a diagnosis of breast cancer, to provide a space for their voices  
30 to be heard and be an invitation to the construction of a more critical look at medical advice and  
31 societal standards and demands.

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33 **METHODS: \*(unnecessary information suppressed, internet search better explained, snowball**  
34 **method referenced, information about books authors included in table 1, and about the women**  
35 **that participated, in Table 2, interviews better explained)**  
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41 This paper uses qualitative research, through a thematic analysis approach. An initial Internet  
42 search using google search engine for the terms "Illness narratives" and "Pathographies" was  
43 conducted, but there were no findings for this search, as these two words are not yet part of the  
44 academic or day to day vocabulary in Spain. Following this, a search was done on book sellers  
45 web pages (Amazon, Casa del Libro) and book reviews on Spanish newspapers, which included:  
46 breast cancer in women, nonfiction, illness as main topic, written originally in Spanish, and by  
47 women living in Spain. Self-help books were excluded. After this search, eight books were found,  
48 all written in first person. Table 1 shows the information for these books. A thematic analysis of  
49 these books was conducted, and using it as framework, a semi-structured interview was  
50 constructed, following Rubin and Rubin's sequence(8), which was used as a guide for important  
51 topics, but was not meant to be followed strictly. Participants were recruited by word of mouth  
52 and using the snowball method (9); the only inclusion criteria being having a diagnosis of breast  
53 cancer. Table 2 shows the information of the participants. Interviews were done through virtual  
54 platforms (Zoom, Teams), recorded, and transcribed for analysis. The participants were invited  
55 to relate freely their experiences of living with breast cancer, making special emphasis on the  
56 descriptions of their interactions with health professionals, the information they received, how  
57 the diagnosis was communicated to them, and the process of decision-making. Following this,  
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the emphasis was placed on the effects of cancer and its treatments, how they had affected their life and how they had coped with them.

In the first stage of the field work, interviews with seven women were conducted and analysed. The main themes found were secondary effects of treatment (hair loss, scars, mastectomy), reconstructive mammoplasty, long-term effects, positive attitude, illness as learning and use of language.

The appropriate Ethical Committee approval was obtained for the interviews, and consent forms were signed by the participants. (Universidad Rey Juan Carlos, Madrid, Spain. Internal registry number: 0803202106921)

Patient and Public Involvement: Not applicable

**TABLE 1**

REFERENCE NUMBER	TITTLE	AUTHOR	INITIALS	AGE AT DIAGNOSIS	PUBLISHER	YEAR	MARITAL STATUS
22	<i>Diario de batalla: Mi lucha contra el cáncer.</i>	Durán, María Ángeles	MAD	54	Santillana	2003	MARRIED
23	<i>Cáncer, Contigo puedo.</i>	Arcos, Ruiz Anabel	AA	34	La esfera de los libros	2018	NO PARTNER
24	<i>Mi vida con el bicho: Superar el cáncer de mama</i>	Mallebrin, Steffi	SM	45	Oberon	2021	MARRIED
25	<i>Tópico de cáncer: Manual de supervivencia</i>	Koska, Susana	SK	53	Ediciones B, S.A.	2014	MARRIED
26	<i>Vivir y superar el cáncer de mama.</i>	Bianchi, Ilaria	IB	39	Arcopress	2018	NO PARTNER
27	<i>Una travesía por el cáncer de mama</i>	Lizasoáin Rumeu, Olga	OL		Eunate	2020	MARRIED

28	<i>Te invito a un Mojito</i>	Mabel Lozano	ML	53	Catedra Editorial	2021	MARRIED
		Paka Diaz	PD				PARTNER
29	<i>La rubia que se quedó calva. El cáncer en tiempos de pandemia</i>	Porto Alarcón, Natalia	NP		Natàlia Porto Alarcón	2021	NO PARTNER

TABLE 1

TABLE 2

## WOMEN INTERVIEWED

PSEUDONYM	INITIAL	AGE AT DIAGNOSIS	TIME SINCE DIAGNOSIS (years)
Iris	I	48	6
Rose	R	37	11
Ana	A	56	2
Clara	C	51	2
Julia	J	42	6
Susana	S	36/39*	5/2

\*Two diagnosis of breast cancer.

## FINDINGS

\*(section re-written for better understanding)

When extracts from the books are used for examples, they are identified with the initials of the author. The examples from the interviews are identified with the initial of the pseudonym chosen for each woman, in lieu of anonymization.

**SECONDARY EFFECTS:** Under this heading we describe the comments on common side effects of chemotherapy drugs, being hair loss the one that appeared as prevalent.

A concern most women had was about the information they received on hair loss: health practitioners gave them a great amount of information about losing the hair of the scalp, including pamphlets and advice on where to have a wig made, but the fact that they would lose all body hair, as well as the uncomfortable side effects that come with this, was not often mentioned, and came as a surprise for most of them. For instance, C says: "I lost the hair in my nostrils, which was very uncomfortable, as I had a runny nose all the time." Similarly, SK remarked that her facial expression, which was part of her identity, drastically changed with the loss of her eyebrows, and chose to get new ones tattooed on.



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Contrary to popular belief, most of the women didn't give scalp hair loss much meaning. I says: "Opposed to everybody's concern about me losing my hair, I didn't care. This would pass. Hair doesn't hurt. Hair grows back." Most of them chose to cut their hair short before it started to fall. NP and AA invited their young daughters to shave their heads as a gesture to open-up to them and normalize being bald. AA invites us to sing the song *Respect* "for all women that shave their heads. That have the ovaries to show it. Because I spent 1000 quid on a wig. But I wanted to show you my picture. My bald head. My face. Show it to you in case you decide to shave your hair." (23)

MAD, on the other hand, writes a lot about the wig and uses it most of the time, because "it is more important to me than I thought." "The wig is important because if it shows, it proclaims the risk and the threat. If it doesn't, the threat is not visible, and in a way, it is mitigated and delayed. If it shows, it introduces a special kind of unrest. It communicates the news without permission, spreads it the wrong way and against the will of her owner, it reveals the truth of the fiction between what you want to be and what you are." (22)

R's father was very concerned because she didn't want to use a wig; his father had died of cancer and seeing his daughter ill had a strong emotional effect on him. R says: "Some people identify your health state with the way you look. If you use a wig, it seems nothing is happening." However, R preferred using a headscarf, and even more so, not wearing anything. Like I, and MAD, she would only cover her hair in front of her children. "To avoid him the embarrassment in front of his friends" (22) (MAD, talking of her teenage son) or, in the case of R and I, because they have children with a diagnosis of a condition that would not allow them to thoroughly understand what was happening.

**EFFECTS OF BREAST LOSS AND SCARS:** Our findings on these themes show that most of the women cherish their scars as tokens that will always remind them of the ordeal they went through and make them feel grateful for being alive. Furthermore, the feeling of a lack of femininity or loss of identity, were not feelings expressed by any of them.

When taking into account partners and sexual relationships, there was a clear difference between those women who had a partner or a long-lasting relationship and those who didn't have one at the moment of their diagnosis: B, L, A, P, M, S and R were married; none of their partners had problems handling the situation of them having only one breast or a scar, except for the initial fear of hurting them. S and J told us how their doctor advised them to have a reconstruction "for the sake of your husband," whilst their husband showed no concern. The case for AA (34 years old), without a partner, exemplifies the different stages women can go through. She doesn't relate any conflict with having her breast removed, so much so that she throws a farewell party for her breast the day before her surgery and even dedicates a whole chapter of her book to say thank you. However, later she does write about going through a phase of rage, tears, and depression a week before the mastectomy. After the surgery, she clearly states: "Nothing has changed, I am the same woman who entered the operating suite." (23) She recounts difficult situations associated with the prosthetic breast, like the fear of it falling when she is on a date, or at the queue to pick-up her daughter. Just as for NP and MAD, the inconvenience lies in revealing the illness in moments when they want to conceal it, not in having one breast. In AA's case, a man she was dating told her "He was not able to cope with her cancer", when she was about to have her mastectomy.

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4 **BREAST RECONSTRUCTION:** Seven out of the sixteen women chose to have a  
5 reconstruction. For R and SM, a major factor influencing the decision to have a reconstructive  
6 surgery was their doctor's insistence, because "they were very young." NP and AA, chose to have  
7 the surgery mainly for aesthetic reasons, but both write that it wouldn't have made a difference  
8 if they had kept just one breast. AA saw reconstruction as an opportunity to "close the circle."  
9 During her interview, R says: "Recovery from reconstruction was more difficult than from  
10 mastectomy. There is more emotional burden; the recovery is more emotional than physical. It  
11 is very complicated.... If I had to do it again, maybe I wouldn't."  
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14 The importance ascribed to aesthetic results by some health professionals is clearly exemplified  
15 in the case of IB, (26) where her surgeon suggests he will also intervene the healthy breast, so  
16 they both have symmetrical scars. IB, being a gynaecologist, refused this operation, but this  
17 makes us wonder how many women, without enough knowledge of the subject have been  
18 submitted to this kind of procedure. J told us how, even though her breasts look symmetrical  
19 and 'beautiful', they don't feel as they used to, and there is no sensitivity in her nipples,  
20 something she is still not used to.  
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23 As mentioned before, the arguments of "do it for your husband" or "do it for your children"  
24 appear in the medical discourse frequently. The husbands and children of the women  
25 interviewed were not concerned by them having scars or just one breast, even more so, many  
26 of them preferred for them not to have a reconstruction, because of the fear of something going  
27 wrong during a surgery solely for aesthetic reasons. (J, S, R)  
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30 In her interview, S talked about the decision of having the reconstruction being the hardest she  
31 had to take during her process. At first, "out of fear", she wanted to have a double mastectomy,  
32 but she was advised against this by her doctor. She sought for different medical opinions, some  
33 of which were contradictory. Her initial decision was not to have a reconstruction, because she  
34 prioritised "risk before aesthetics." She calls our attention to the fact that most people, she puts  
35 her surgeon as an example, take for granted that you are going to have a reconstruction and  
36 encourage you to do it by saying "you will look so much better." S feels that these "unfortunate  
37 messages", "with an optimism that does not go well with the person's situation", instead of  
38 helping her, made her feel "mutilated" and unacceptable. Finally, after listening to other  
39 women's testimonies and having time to set her own priorities, S decided to have a  
40 reconstruction which took eleven hours. The aesthetic results were not as perfect as expected:  
41 "You can clearly tell I have an operated breast, but I am not going to do anything about it."  
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46 **LONG TERM EFFECTS TREATMENT:** This was a theme that surfaced in many of  
47 the narratives and includes effects of medications and surgery. Even though the women  
48 understand the importance of being treated, they were left with secondary effects that will last  
49 a lifetime: loss of memory and cognitive impairment (A y R), limitation of mobility and  
50 lymphedema of arms (R an SK), chronic fatigue (all). What they most regret is that these  
51 symptoms were not validated by their oncologists.  
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54 In their book, ML and PK (28) advocate for giving the patient more information about the  
55 treatment they are going to receive and challenge the concept of "personalised chemotherapy  
56 treatment"; they cite Anne Boyer, author of the book *Undying* (14) as an example of someone  
57 who, after acquiring enough information, requested and got a change in her treatment. They  
58 also note how Boyer references recently published articles that show that the side effects  
59 related by many women are in fact secondary to the chemotherapy treatment.  
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4 **POSITIVE ATTITUDE AND ILLNESS AS LEARNING:** Except for *Tópico de*  
5 *Cáncer*, (25) and *Te invito a un mojito*, (28) all books concur with the prevailing idea of illness as  
6 learning. The importance of a positive attitude is a clear message on all published illness  
7 narratives. Even though self-help books were excluded from the search, all of them contain  
8 advice on diets, explanations of medical terms, exams, and procedures. *Tópico de cáncer* is the  
9 only one that crudely describes the author's ordeal through her treatment.

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12 Even though the women interviewed do mention the fact that going through breast cancer has  
13 made them set their priorities more clearly, their call is for a space for all kinds of feelings and  
14 attitudes, not only the positive attitude that society in general, and most cancer associations in  
15 particular, ask from them. As MAD states, there should not be "publicly acceptable feelings a  
16 cancer patient can express" (22) and there should not be standardized ways of behaviour.  
17 Women recalled being uncomfortable with people who minimized their symptoms ("but this is  
18 just like a bad cold"), told them stories about women who "went to and back from  
19 chemotherapy on their bicycles" and those who insisted on the power of a good attitude  
20 towards healing. S says, "the diagnosis of breast cancer comes with rage, anger and fear, and  
21 words like 'do not worry', far from helping me, make me angry; feeling unwell must be  
22 destigmatised." ML states that "an illness like this is not inspiring or beautiful, it is \*\*\*, but we  
23 have to accept it."

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27 SK's favourite place is the bathtub: "where I don't have to speak or look courageous. Where I do  
28 not have to have a plan for the future, for when we have defeated the bug. Where I don't have  
29 to keep a stiff upper lip."

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31 ML and PD join the quest against metaphors of war; it is not because you are a "warrior or a she-  
32 hero" that cancer is cured; using this type of language is very unfair to the women who do not  
33 experience successful treatment and puts the blame on them. "You would never ask a person  
34 with a diagnosis of syphilis or diabetes to have a positive attitude." (PK, 28) ML highlights the  
35 importance of the word chosen: "Don't tell me I have a 'good cancer', no cancer is good, and  
36 you don't 'tiptoe through cancer', as a friend told me." She and PD made their diagnosis public  
37 on social networks in an effort to normalise illness and as part of their campaign to stop the  
38 victimisation of cancer patients. Not all agree with this concept, as others (A and C) feel they will  
39 always be oncologic patients and will live forever with the fear of a new diagnosis of cancer. SK  
40 writes: "I feel Damocles' sword hanging over me all the time."

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44 MAD writes: I don't want to call it, as I once heard a millionaire doctor say, 'a mutilated breast,'  
45 This word connotes war, martyrs, complexes, and depression, which do not solve the problem.  
46 Mine is just a diminished breast, without tragedies surrounding it." (22)

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49 The words preferred in these stories to refer to their illness trajectory were journey, a hurricane,  
50 a chain, baggage, or the ascent of a mountain. On the other hand, the euphemisms used when  
51 referring to their tumours, had mainly a negative connotation: "the rat", "the dragon", "bug",  
52 "the bug with the poisonous mouth", or " \*\*\*pea." SK describes feeling like "Anne Boleyn on  
53 her way to the gallows" before her oncology consultations.

## DISCUSSION:

\* (The comments on FINDINGS sections were be incorporated here. Some of the references with literal words were shortened or suppressed.)

Writing or talking about illness is not well looked upon within Spanish society, here lies the difficulty in finding illness narratives of breast cancer; this was seen by us as an opportunity to use our findings to make illness experiences more visible, within the cultural and lifestyle context of Spain. Health professionals see patients at a given point of their life, but as MAD writes, “there is a bigger part of our lives that they don’t see.” (22) The dominant medical narrative is in line with Goffman’s concept of the ill person being responsible for how they present themselves and display the signs of their illness, and with Pearson’s idea of the “patient role”, where ill people are expected to get better to go back to their assigned place in society (15). Our findings show that women with breast cancer would prefer to build their own more welcoming spaces, but unfortunately, until patients’ narratives are regarded as an important part of medical practice, this will not be possible. This is best explained by Rosenblatt’s comment that “when patients are faced with the need to reconfigure themselves during and after illness, there is a difficulty, because medical categories and corresponding guidelines direct treatments conceived for a group, not for an individual,”(21)

When looking for advice on the internet or from friends and family, women are told to mask the changes chemotherapy can produce on their skin and to use wigs or headscarves to cover their baldness, but these are not necessarily the choices shown in the illness narratives analysed. Most women felt the wig was uncomfortable and some of them felt that baldness didn’t have to be hidden and normalised it by letting their kids shave their heads. On the other hand, others used their wigs to comply with family and society’s rules not to look ill.

Medical literature often uses words like “disfigurement,” “mutilation,” and “loop-sided” to describe the post-mastectomy patient, reinforcing women’s own sense of their bodily imperfections (10) but these are not the words used in the illness narratives analysed. Denford states that when women try to adjust to life after cancer, they “commonly strive to be ‘normal’ after mastectomy and reconstructive surgery, [but] research surrounding individual perceptions of normality is lacking.”(10) Our findings from the lived experiences of women with breast cancer show that even though half of them chose to have a reconstructive surgery, none of them felt that having only one breast made them less a woman and all of them cherished their scars as remembrance of the journey they had gone through. In Spain each year around 16.000 mastectomies are performed, but only 4.800 women opt for a reconstruction. (28) One of the main concerns through a feminist theory analysis, is that the breast is considered an “iconic representation” of a woman’s femininity and identity (11) and that “the experience of breast cancer is clearly influenced by the cultural emphasis on breasts as objects of male sexual interest and male sexual pleasure.”(10). There is still a medical discourse coming from different health care scenarios that encourages women to “look better for their husbands” and believes that “you will feel better if you look better” and were the decision for reconstructive surgery is based mainly on aesthetic reasons (13); the women interviewed would like to be able to make their choices based on their own priorities, and not to comply with fixed standards of beauty, which resonates with Sun’s meta-analysis of the impact of losing a breast in women who survived breast cancer (12).

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3 Recent studies are looking at the effects of chemotherapy on cognitive function (18, 19) and of  
4 the appearance of chronic fatigue (20) We hope that health carers take this information into  
5 account when choosing treatments, and that they validate these women's symptoms.  
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7 As evidenced in our findings, there is still a trend towards the belief that a positive attitude is an  
8 important ingredient for healing. We are aware of the risk postulated by Solbrække (7) of  
9 perpetuating the 'gold standard' of cancer survivorship, and agree with Nielsen's (17) comment  
10 to "resist calls for hope and courage". After this preliminary analysis, new stages for the research  
11 are going to be developed among which interviewing more women, from different cultural and  
12 social backgrounds, focusing the interviews on more specific themes of research, and including  
13 third person illness narratives will be considered. We expect to learn about the experience of  
14 carers, but also to give voice to breast cancer journeys that concluded in death, and those of  
15 women suffering from metastatic breast cancer. The analysis of other type of narratives, that  
16 move to a more systematic consideration of the place of illness narratives in promoting cultural  
17 change and a shift in medical discourse could broaden the findings of this research.  
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21 Even though the metaphors of war prevail, the illness narratives analysed showed that there is  
22 a trend towards language that does not blame the person. On the other hand, the negative  
23 connotation attributed to illness, and specifically cancer, is exemplified in the euphemisms used  
24 to describe the tumours.  
25

26  
27 It is important to mention that the women interviewed were thankful for having an opportunity  
28 to speak out about their cancer and share feelings or thoughts they had never shared with other  
29 people. This falls in line with the Narrative approach to Medicine, which suggests that telling  
30 their story is a way for patients to regain control and thus "diminish the sense of helplessness,  
31 marginalisation an isolation that are inevitable aspects of serious disease." (21) These women  
32 were also happy to contribute with advice for a better person-centered approach to Medicine,  
33 with the hope that uncomfortable situations that they had to face, will not happen to other  
34 women again.  
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37 CONCLUSIONS: \*(re-written)  
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42 Denford et al (11) state that clinicians should be aware of the concepts of normality that  
43 everyone has, and how these shape their expectations and standards for results. One way to  
44 achieve this is through a Narrative Based Medicine approach, in which the lived experience of  
45 illness becomes an important piece of information in the model of explanation and management  
46 of illnesses. As M tells us: "I don't want to be compared to anybody." Some of these women feel  
47 healthy, want to put the cancer behind; others are in a liminal space, where on medical terms  
48 they are cured, but in their lived experiences they still need support. R (10 years after diagnosis)  
49 told us: "I have cancer, but I don't feel sick. I am cured, but I don't feel healthy." As shown in this  
50 article, the analysis of illness narratives, both from published books and from interviews to  
51 women who have been diagnosed with breast cancer, can give us clues on the diverse ways  
52 people cope with side effects of chemotherapy and surgery and the different needs and  
53 priorities that are considered in decision making; they give a space for their voices to be heard,  
54 and for their advice to be incorporated into healthcare interactions.  
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# BMJ Open

## THEMATIC ANALYSIS OF ILLNESS NARRATIVES AS AN EXAMPLE OF AN APPROACH TO BETTER UNDERSTAND THE LIVED EXPERIENCE OF WOMEN DIAGNOSED WITH BREAST CANCER IN SPAIN

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# THEMATIC ANALYSIS OF ILLNESS NARRATIVES AS AN EXAMPLE OF AN APPROACH TO BETTER UNDERSTAND THE LIVED EXPERIENCE OF WOMEN DIAGNOSED WITH BREAST CANCER IN SPAIN

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## ABSTRACT:

**Objective:** To explore the lived experience of women diagnosed with breast cancer through the analysis of illness narratives, as an example of a Narrative Based Medicine approach.

**Setting:** Spain.

**Participants:** Nine narratives originating in non-fiction books, and six in interviews through online platforms. All participants were currently living in Spain, and between 34 and 60 years of age. The inclusion criteria were being a woman and having been diagnosed with, and treated for breast cancer in Spain.

**Results:** The main topics that appeared on the analysis were: secondary effects of treatment, breast loss and scars, breast reconstruction, long term effect of treatment, positive attitude, illness as learning and use of language. The results of this research are preliminary, but they suggest that there is not a common pattern of behaviour for patients, and that societal preconceptions become a burden for them. Hiding their baldness or not, going through reconstructive surgery, and fulfilling the 'patient role', are choices they want to make on their own priorities, and not because of impositions. Even though women agree with the benefits of having a good attitude, they also ask for space to feel rage and sadness, not to be compared

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3 with others, and to be heard with no haste, as well as to be accompanied beyond the treatment,  
4 and for their long-term effects secondary to medications to be validated. The importance of the  
5 type of comments and language used is emphasized.  
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7 **Conclusion:** The thematic analysis of Illness narratives, within the framework of a Narrative  
8 Medicine approach, enables us to incorporate the patient experience into the understanding of  
9 breast cancer. We encourage clinicians to be aware of the concepts of normality held by women,  
10 and to welcome different choices and different ways to experience illness, breaking with  
11 established societal patterns and the paternalistic medical discourse.  
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## 18 STRENGTHS AND LIMITATION OF THIS RESEARCH: 19

- 20 • The use of open interviews and a qualitative research approach allowed women to talk  
21 freely about their lived experience of illness.
- 22 • Not limiting the interviews to a specific health facility allowed us to hear testimonies  
23 from different settings.
- 24 • To our knowledge, this is the first study of its kind designed in Spain.
- 25 • All the books reviewed are first-person narratives, as none were found written by carers  
26 or family, and all of them are stories of survival.
- 27 • To the date of the writing of this paper, only 7 women had been interviewed, which  
28 does not allow for a thorough qualitative analysis.
- 29 • The design of the study leaves out lived experiences of breast cancer of men and trans  
30 people.  
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**KEY WORDS:** Medical Humanities. Illness narratives. Breast cancer. Narrative Based Medicine.

## INTRODUCTION:

Throughout the history of Medicine, the questioning of paradigms have changed the way Medicine is practised and taught (1); the turn of the 20<sup>th</sup> century called for a rethinking of the biomedical model as it didn't provide a satisfactory explanation for illness. This, along with the raising of the advocacy for patient's autonomy (and in the case of breast cancer, feminism), turned into an interest in the incorporation of humanities and communication skills within teaching in Medical Schools (2,3). A model based on facts and findings, centred on a search for the explanation of illnesses, but not in the understanding of processes, was no longer acceptable. Narrative Based Medicine, which prioritises active listening, subjective symptoms, and the importance of life experiences, surfaced as an approach to illness in which contradictory and complex experiences were valued and contributed to a patient-centred care. (4,5) Within this model, medical narratives shift from the physician's perspectives to the patient's stories, becoming a useful resource to understand "the patient-specific meaning of illness" (4,6) and thus incorporate focused interventions aimed at improving their health and wellbeing.(6)

Specifically in the case of breast cancer, where breasts are regarded as the cornerstone of femininity, where the "pink ribbon" approach which encourages a positive attitude, and the quest for an "acceptable social appearance" (4,7) prevail, illness narratives enrich us with diverse and non-conventional stories. They expose us "to personal accounts of the journey through illness and treatment, offering us details, emotions, phrasing and imagery from an individual perspective" (8), complementing the medical knowledge and improving the complexity of breast cancer.(6,9).

This paper reflects the preliminary findings of the field work for a PhD thesis that aims to present a proposal for the introduction of the teaching of the Medical Humanities in Schools of Medicine in Spain. The original research question hinges on how women with breast cancer envision the ideal health consultation. By using a thematic analysis of illness narratives, this article focuses on the accounts of the lived experiences of the women interviewed, to provide a space for their voices to be heard and be an invitation to the construction of a more critical look at medical advice and societal standards and demands.

## METHODS

This article uses observational qualitative research, through a thematic analysis approach. An initial Internet search using google search engine for the terms "Illness narratives" and "Pathographies"(10) was conducted, however there were no findings for this search, as these two words are not yet part of the academic or day to day vocabulary in Spain. Following this, a search was done on book sellers web pages (Amazon, Casa del Libro) and book reviews on Spanish newspapers, which included breast cancer in women, nonfiction, illness as main topic, written originally in Spanish, and by women living in Spain. Self-help books were excluded. After this search, eight books were found, all written in first person. Table 1 shows this information. A thematic analysis of these books was conducted, and using it as framework, a semi-structured interview was constructed, following Rubin and Rubin's sequence(11) (appendix 1), which was used as a guide for important topics, but was not meant to be followed strictly. Participants were

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3 recruited by word of mouth and using the snowball method (12) ; the inclusion criteria were  
4 being a woman and having been diagnosed and treated for breast cancer in Spain. Table 2 shows  
5 the information of the participants. Pseudonyms were used to preserve anonymity and were  
6 preferred over numbers or codes in line with a person-centred approach. Interviews were done  
7 through virtual platforms (Zoom, Teams), recorded, and transcribed for analysis. They were all  
8 conducted in Spanish and excerpts translated by one of the authors (NMF). The participants  
9 were invited to relate freely their experiences of living with breast cancer, making special  
10 emphasis on the descriptions of their interactions with health professionals, the information  
11 they received, how the diagnosis was communicated to them, and the process of decision-  
12 making. Following this, the emphasis was placed on the effects of cancer and its treatments,  
13 how they had affected their life and how they had coped with them.  
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17 In the first stage of the field work, interviews with six women were conducted and manually  
18 analysed. At this point, the interviews were revised, and the objectives of the thesis  
19 reformulated, reaching the decision to focus mainly on the health interactions. There was very  
20 rich information that we didn't want to lose, and thus was used for this article. (At this stage of  
21 the research saturation point had not yet been achieved)  
22

23 The main themes found were secondary effects of treatment (hair loss, scars, mastectomy),  
24 reconstructive mammoplasty, long-term effects, positive attitude, illness as learning and use of  
25 language. The main topics were extracted by NMF and then discussed with AM and JS. The  
26 original research design has been audited by an outside researcher from URJC. (DM)  
27  
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29 By limiting the interviews to women, we are aware we are leaving out the lived experience of  
30 men and trans people (5). We thought this was pertinent, to exclude other cultural and  
31 behavioural factors that may influence the way an illness is experienced, which, even though we  
32 find very important, are not the aim of this specific research.  
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34 On the other hand, we would have liked to include narratives from carers and family. We were  
35 not able to find published narratives on this kind, but we are considering interviewing other  
36 participants in further stages of the study.  
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39 By choosing a qualitative research approach we were able to gather an extensive amount of  
40 powerful information that was examined in detail. Nevertheless, we acknowledge that with his  
41 approach reproducibility and generalization to a larger population cannot be achieved.  
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#### 45 **ETHICAL APPROVAL:**

46 Ethical Committee approval was obtained for the interviews, and consent forms were signed by  
47 the participants. (Universidad Rey Juan Carlos, Madrid, Spain. Internal registry number:  
48 0803202106921)  
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#### 51 **Patient and Public Involvement:**

52 Not applicable. Even though patients were not directly involved in the research design, their  
53 comments will be part of a proposal for the introduction of the teaching of Medical Humanities  
54 in schools of Medicine in Spain.  
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TABLE 1

REFERENCE NUMBER	TITTLE	AUTHOR	INITIALS	AGE AT DIAGNOSIS	PUBLISHER	YEAR	MARITAL STATUS
(13)	<i>Diario de batalla: Mi lucha contra el cáncer.</i>	Durán, María Ángeles	MAD	54	Santillana	2003	MARRIED
(14)	<i>Cáncer, Contigo puedo.</i>	Arcos, Ruiz Anabel	AA	34	La esfera de los libros	2018	NO PARTNER
(15)	<i>Mi vida con el bicho: Superar el cáncer de mama</i>	Mallebrin, Steffi	SM	45	Oberon	2021	MARRIED
(16)	<i>Tópico de cáncer: Manual de supervivencia</i>	Koska, Susana	SK	53	Ediciones B, S.A.	2014	MARRIED
(17)	<i>Vivir y superar el cáncer de mama.</i>	Bianchi, Ilaria	IB	39	Arcopress	2018	NO PARTNER
(18)	<i>Una travesía por el cáncer de mama</i>	Lizasoáin Rumeu, Olga	OL		Eunate	2020	MARRIED
(19)	<i>Te invito a un Mojito</i>	Mabel Lozano	ML	53	Catedra Editorial	2021	MARRIED
		Paka Diaz	PD				PARTNER
(20)	<i>La rubia que se quedó calva. El cáncer en tiempos de pandemia</i>	Porto Alarcón, Natalia	NP		Natàlia Porto Alarcón	2021	NO PARTNER

TABLE 2

## WOMEN INTERVIEWED

PSEUDONYM	INITIAL	AGE AT DIAGNOSIS	TIME SINCE DIAGNOSIS (years)
Iris	I	48	6
Rose	R	37	11
Ana	A	56	2
Clara	C	51	2
Julia	J	42	6
Susana	S	36/39*	5/2

\*Two diagnosis of breast cancer.

For the protection of anonymity, information such as married status, educational background, or type of job are only mentioned when relevant.

## FINDINGS

When extracts from the books are used, they are identified with the initials of the author. The examples from the interviews are identified with the initial of the pseudonym chosen for each participating woman.

**SECONDARY EFFECTS:** Under this heading we describe the comments on common side effects of chemotherapy drugs, being hair loss the one that appeared as prevalent.

A concern most women had was about the information they received on hair loss: health practitioners gave them a great amount of information about losing the hair of the scalp, including pamphlets and advice on where to have a wig made, but the fact that they would lose all body hair, as well as the uncomfortable side effects that come with this, was not often mentioned, and came as a surprise for most of them. For instance, C says: "I lost the hair in my nostrils, which was very uncomfortable, as I had a runny nose all the time." Similarly, SK remarked that her facial expression, which was part of her identity, drastically changed with the loss of her eyebrows, and chose to get new ones tattooed on.

Contrary to popular belief, most of the women didn't give scalp hair loss much meaning. I says: "Opposed to everybody's concern about me losing my hair, I didn't care. This would pass. Hair doesn't hurt. Hair grows back." Most of them chose to cut their hair short before it started to fall. NP and AA invited their young daughters to shave their heads as a gesture to open-up to them and normalize being bald. AA invites us to sing the song *Respect* "for all women that shave their heads. That have the ovaries to show it. Because I spent 1000 quid on a wig. But I wanted to show you my picture. My bald head. My face. Show it to you in case you decide to shave your hair." (14)

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3 MAD, on the other hand, writes a lot about the wig and uses it most of the time, because “it is  
4 more important to me than I thought.” “The wig is important because if it shows, it proclaims  
5 the risk and the threat. If it doesn’t, the threat is not visible, and in a way, it is mitigated and  
6 delayed. If it shows, it introduces a special kind of unrest. It communicates the news without  
7 permission, spreads it the wrong way and against the will of her owner, it reveals the truth of  
8 the fiction between what you want to be and what you are.” (13)  
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11 R's father was very concerned because she didn't want to use a wig; his father had died of cancer  
12 and seeing his daughter ill had a strong emotional effect on him. R says: “Some people identify  
13 your health state with the way you look. If you use a wig, it seems nothing is happening.”  
14 However, R preferred using a headscarf, and even more so, not wearing anything. Like I, she  
15 would only cover her hair in front of her children: they both have kids with a diagnosis of a  
16 condition that would not allow them to thoroughly understand what was happening. MAD says  
17 the wig “avoids him the embarrassment in front of his friends” (12) (referring to her teenage  
18 son).  
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21 **EFFECTS OF BREAST LOSS AND SCARS:** Our findings on these themes show that most of  
22 the women cherish their scars as tokens that will always remind them of the ordeal they went  
23 through and make them feel grateful for being alive. Furthermore, the feeling of a lack of  
24 femininity or loss of identity, were not feelings expressed by any of them.  
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27 When considering partners and sexual relationships, there was a clear difference between those  
28 women who had a partner or a long-lasting relationship and those who didn't have one at the  
29 moment of their diagnosis: B, L, A, P, M, S, J and R were married; none of their partners had  
30 problems handling the situation of them having only one breast or a scar, except for the initial  
31 fear of hurting them. S and J told us how their doctor advised them to have a reconstruction “for  
32 the sake of your husband,” whilst their husband showed no concern. The case for AA (34 years  
33 old), without a partner, exemplifies the different stages women can go through: She doesn't  
34 relate any conflict with having her breast removed, so much so that she throws a farewell party  
35 for her breast the day before her surgery and even dedicates a whole chapter of her book to  
36 thank her breast. However, later she does write about going through a phase of rage, tears, and  
37 depression a week before the mastectomy. After the surgery, she clearly states: “Nothing has  
38 changed, I am the same woman who entered the operating suite.” (14) She recounts difficult  
39 situations associated with the prosthetic breast, like the fear of it falling when she is on a date,  
40 or at the queue to pick-up her daughter. Just as for NP and MAD, the inconvenience lies in  
41 revealing the illness in moments when they want to conceal it, not in having one breast. In AA's  
42 case, a man she was dating told her “He was not able to cope with her cancer”, when she was  
43 about to have her mastectomy.  
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48 **BREAST RECONSTRUCTION:** Seven out of the thirteen women interviewed who had a  
49 mastectomy, chose to have a reconstruction. For R and SM, a major factor influencing the  
50 decision to have a reconstructive surgery was their doctor's insistence, because “they were very  
51 young.” NP and AA, chose to have the surgery mainly for aesthetic reasons, but both write that  
52 it wouldn't have made a difference if they had kept just one breast. AA saw reconstruction as an  
53 opportunity to “close the circle.” During her interview, R says: “Recovery from reconstruction  
54 was more difficult than from mastectomy. There is more emotional burden; the recovery is more  
55 emotional than physical. It is very complicated.... If I had to do it again, maybe I wouldn't.”  
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59 The importance ascribed to aesthetic results by some health professionals is clearly exemplified  
60 in the case of IB,(17) where her surgeon suggests he will also intervene the healthy breast, so



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3 they both have symmetrical scars. IB, being a gynaecologist, refused this operation, but this  
4 makes us wonder how many women, without enough knowledge of the subject have been  
5 submitted to this kind of procedure. J told us how, even though her breasts look symmetrical  
6 and 'beautiful', they don't feel as they used to, and there is no sensitivity in her nipples. Her  
7 surgeon did not tell her about this possible side effect.  
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10 As mentioned before, the arguments of "do it for your husband" or "do it for your children"  
11 appear in the medical discourse frequently. The husbands and children of the women  
12 interviewed were not concerned by them having scars or just one breast, even more so, many  
13 of them preferred for them not to have a reconstruction, because of the fear of something going  
14 wrong during a surgery solely for aesthetic reasons. (J, S, R)  
15

16 In her interview, S talked about the decision of having the reconstruction being the hardest she  
17 had to take during her process. At first, "out of fear", she wanted to have a double mastectomy,  
18 but she was advised against this by her doctor. She sought for different medical opinions, some  
19 of which were contradictory. Her initial decision was not to have a reconstruction, because she  
20 prioritised "risk before aesthetics." She calls our attention to the fact that most people, she puts  
21 her surgeon as an example, take for granted that you are going to have a reconstruction and  
22 encourage you to do it by saying "you will look so much better." S feels that these "unfortunate  
23 messages", "with an optimism that does not go well with the person's situation", instead of  
24 helping her, made her feel "mutilated" and unacceptable. Finally, after listening to other  
25 women's testimonies and having time to set her own priorities, S decided to have a  
26 reconstruction which took eleven hours. The aesthetic results were not as perfect as expected:  
27 "You can clearly tell I have an operated breast, but I am not going to do anything about it."  
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32 **LONG TERM EFFECTS TREATMENT:** This was a theme that surfaced in many of the  
33 narratives and includes effects of medications and surgery. Even though the women understand  
34 the importance of being treated, they were left with secondary effects that will last a lifetime:  
35 loss of memory and cognitive impairment (A y R), limitation of mobility and lymphedema of arms  
36 (R an SK), chronic fatigue (all). What they most regret is that these symptoms were not validated  
37 by their oncologists.  
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40 In their book, ML and PK (19) advocate for giving the patient more information about the  
41 treatment they are going to receive and challenge the concept of "personalised chemotherapy  
42 treatment"; they cite Anne Boyer, author of the book *The Undying* (21) as an example of  
43 someone who, after acquiring enough information, requested and got a change in her  
44 treatment. They also note how Boyer references recently published articles that show that the  
45 side effects related by many women are in fact secondary to the chemotherapy treatment.  
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### 48 **POSITIVE ATTITUDE, LANGUAGE, AND ILLNESS AS LEARNING**

49 Except for *Tópico de Cáncer*, (16) and *Te invito a un mojito*, (19) all books concur with the  
50 prevailing idea of illness as learning. The importance of a positive attitude is a clear message on  
51 all published illness narratives. Even though self-help books were excluded from the search, all  
52 the books analysed contain advice on diets, explanations of medical terms, exams, and  
53 procedures. *Tópico de cáncer* is the only one that crudely describes the author's ordeal through  
54 her treatment.  
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58 Even though the women interviewed do mention the fact that going through breast cancer has  
59 made them set their priorities more clearly, their call is for a space for all kinds of feelings and  
60 attitudes, not only the positive attitude that society in general, and most cancer associations in

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3 particular, ask from them. As MAD states, there should not be “publicly acceptable feelings a  
4 cancer patient can express” (13) and there should not be standardized ways of behaviour.  
5 Women recalled being uncomfortable with people who minimized their symptoms (“but this is  
6 just like a bad cold”), told them stories about women who “went to and back from  
7 chemotherapy on their bicycles” and those who insisted on the power of a good attitude  
8 towards healing. S says, “the diagnosis of breast cancer comes with rage, anger and fear, and  
9 words like ‘do not worry’, far from helping me, make me angry; feeling unwell must be  
10 destigmatised.” ML states that “an illness like this is not inspiring or beautiful, it is \*\*\*, but we  
11 have to accept it.” (19)

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14 SK’s favourite place is the bathtub: “where I don’t have to speak or look courageous. Where I do  
15 not have to have a plan for the future, for when we have defeated the bug. Where I don’t have  
16 to keep a stiff upper lip.” (16)

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19 ML and PD (19), as well as S, join the quest against metaphors of war; it is not because you are  
20 a “warrior or a she-hero” that cancer is cured; using this type of language is very unfair to the  
21 women who do not experience successful treatment and puts the blame on them. “You would  
22 never ask a person with a diagnosis of syphilis or diabetes to have a positive attitude.” (PD) ML  
23 highlights the importance of the word chosen: “Don’t tell me I have a ‘good cancer’, no cancer  
24 is good, and you don’t ‘tiptoe through cancer’, as a friend told me.” She and PD made their  
25 diagnosis public on social networks in an effort to normalise illness and as part of their campaign  
26 to stop the victimisation of cancer patients. Not all agree with this concept, as others (A and C)  
27 feel they will always be oncologic patients and will live forever with the fear of a new diagnosis  
28 of cancer. SK writes: “I feel Damocles’ sword hanging over me all the time.” (16)

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31 MAD writes: I don’t want to call it, as I once heard a millionaire doctor say, ‘a mutilated breast,’  
32 This word connotes war, martyrs, complexes, and depression, which do not solve the problem.  
33 Mine is just a diminished breast, without tragedies surrounding it.” (13)

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36 The words preferred in these stories to refer to their illness trajectory were journey, a hurricane,  
37 a chain, baggage, or the ascent of a mountain. On the other hand, the euphemisms used when  
38 referring to their tumours, had mainly a negative connotation: “the rat”, “the dragon”, “bug”,  
39 “the bug with the poisonous mouth”, or “\*\*\*pea.” SK describes feeling like “Anne Boleyn on  
40 her way to the gallows” before her oncology consultations. (16)

## 41 42 43 44 45 DISCUSSION:

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48 Novels and autopathographies contain valuable information on the ways people with cancer  
49 make sense of their illness and treatments.(22) Nevertheless, writing or talking about illness is  
50 not well looked upon within Spanish society, and here lies the difficulty in finding illness  
51 narratives of breast cancer; this was seen by us as an opportunity to use our findings to make  
52 illness experiences more visible, within the cultural and lifestyle context of Spain. Health  
53 professionals see patients at a given point of their life, but as MAD writes, “there is a bigger part  
54 of our lives that they don’t see.” (13) The dominant medical narrative is in line with Goffman’s  
55 concept of the ill person being responsible for how they present themselves and display the  
56 signs of their illness, and with Pearson’s idea of the “patient role”, where ill people are expected  
57 to get better to go back to their assigned place in society (23). Our findings show that women  
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3 with breast cancer would prefer to build their own more welcoming spaces, but unfortunately,  
4 until patients' narratives are regarded as an important part of medical practice, this will not be  
5 possible. This is best explained by Rosenblatt's comment that "when patients are faced with the  
6 need to reconfigure themselves during and after illness, there is a difficulty, because medical  
7 categories and corresponding guidelines direct treatments conceived for a group, not for an  
8 individual,"(24)  
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11 When looking for advice on the internet or from friends and family, women are told to mask the  
12 changes chemotherapy can produce on their skin and to use wigs or headscarves to cover their  
13 baldness, but these are not necessarily the choices shown in the illness narratives analysed.  
14 Most women felt the wig was uncomfortable and some of them felt that baldness didn't have  
15 to be hidden and normalised it by letting their kids shave their heads. On the other hand, others  
16 used their wigs to comply with family and society's rules not to look ill.  
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19 Medical literature often uses words like "disfigurement," "mutilation," and "lopsided" to  
20 describe the post-mastectomy patient, reinforcing women's own sense of their bodily  
21 imperfections (25) but these are not the words used in the illness narratives analysed. Denford  
22 states that when women try to adjust to life after cancer , they "commonly strive to be 'normal'  
23 after mastectomy and reconstructive surgery, [but] research surrounding individual perceptions  
24 of normality is lacking."(26) Our findings from the lived experiences of women with breast  
25 cancer show that even though half of them chose to have a reconstructive surgery, none of them  
26 felt that having only one breast made them less a woman and all of them cherished their scars  
27 as remembrance of the journey they had gone through. In Spain each year around 16.000  
28 mastectomies are performed, but only 4.800 women opt for a reconstruction. (19) One of the  
29 main concerns through a feminist theory analysis, is that the breast is considered an "iconic  
30 representation" of a woman's femininity and identity and that "the experience of breast cancer  
31 is clearly influenced by the cultural emphasis on breasts as objects of male sexual interest and  
32 male sexual pleasure."(26) There is still a medical discourse coming from different health care  
33 scenarios that encourages women to "look better for their husbands" and believes that "you  
34 will feel better if you look better" and were the decision for reconstructive surgery is based  
35 mainly on aesthetic reasons (27); the women interviewed would like to be able to make their  
36 choices based on their own priorities, and not to comply with fixed standards of beauty, which  
37 resonates with Sun's meta-analysis of the impact of losing a breast in women who survived  
38 breast cancer (28).  
39

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41 Recent studies are looking at the effects of chemotherapy on cognitive function and of the  
42 appearance of chronic fatigue (29–32). We hope that health carers take this information into  
43 account when choosing treatments, and that they validate these women's symptoms.  
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46 As evidenced in our findings, there is still a trend towards the belief that a positive attitude is an  
47 important ingredient for healing. We are aware of the risk postulated by Solbrække (9) of  
48 perpetuating the 'gold standard' of cancer survivorship, and agree with Nielsen's (33) comment  
49 to "resist calls for hope and courage". Even though positive thinking can be helpful, "mandating  
50 it often silences and induces shame." (32) After this preliminary analysis, new stages for the  
51 research are going to be developed among which interviewing more women, from different  
52 cultural and social backgrounds, focusing the interviews on more specific themes of research,  
53 and including third person illness narratives will be considered. We expect to learn about the  
54 experience of carers, but also to give voice to breast cancer journeys that concluded in death,  
55 and those of women suffering from metastatic breast cancer. The analysis of other type of  
56 narratives, that move to a more systematic consideration of the place of illness narratives in  
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3 promoting cultural change and a shift in medical discourse could broaden the findings of this  
4 research.  
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6 Even though the metaphors of war prevail, the illness narratives analysed showed that there is  
7 a trend towards language that does not blame the person. On the other hand, the negative  
8 connotation attributed to illness, and specifically cancer, is exemplified in the euphemisms used  
9 to describe the tumours.  
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11 To our knowledge, this is the first study of its kind in Spain. Kaptein's article (22) analysed 29  
12 books on cancer in general. Kugbey's a study on illness perceptions of breast cancer in Ghana  
13 (6) showed that the majority of women interviewed relied predominantly in religious faith and  
14 spirituality as key coping mechanisms, and mentioned illness being a test from God. The theme  
15 of spirituality however did not appear in any of the narratives analysed for this paper. This is an  
16 example and a strong argument of the importance of developing culture-specific narrative  
17 research, to best understand and incorporate specific lived experiences of illness, as the  
18 proposed intervention for Ghana are not applicable for other setting, as in this case, Spain.  
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22 It is important to mention that the women interviewed were thankful for having an opportunity  
23 to speak out about their cancer and share feelings or thoughts they had never shared with other  
24 people. This falls in line with the Narrative approach to Medicine, which suggests that telling  
25 their story is a way for patients to regain control and thus "diminish the sense of helplessness,  
26 marginalisation an isolation that are inevitable aspects of serious disease."(24) These women  
27 were also happy to contribute with advice for a better person-centered approach to Medicine,  
28 with the hope that uncomfortable situations that they had to face, will not happen to other  
29 women again.  
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## 32 33 CONCLUSIONS: 34 35 36 37

38 As shown in this article, a Narrative Medicine approach using the analysis of illness narratives,  
39 both from published books and from interviews can be utilized in clinical practice, research, and  
40 education to promote healing. When used with women who have been diagnosed with breast  
41 cancer, it can give us clues on the diverse ways people cope with side effects of chemotherapy  
42 and surgery and the different needs and priorities that are considered in decision making; they  
43 give a space for their voices to be heard, and for their advice to be incorporated into healthcare  
44 interactions.  
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For peer review only

**SCRIPT. INTERVIEWS ON HEALTH CONSULTATIONS TO PACIENTES WITH DIAGNOSIS OF BREAST CANCER**

Start interview on a cordial tone, do not go directly to the diagnosis

RUBIN Y RUBIN	TOPIC	QUESTION
CREATION OF AN EASY (natural) INVOLVEMENT	<ul style="list-style-type: none"> <li>• Age</li> <li>• Family group</li> <li>• Occupation</li> <li>• MOTIVATION TO PARTICIPATE</li> </ul>	<p>Can you please tell me a little about yourself?</p> <p>What has motivated you to participate in this interview?</p>
HONE CONVERSATIONAL COMPETENCE	<ul style="list-style-type: none"> <li>• Aim of the research</li> </ul>	<p>Overall, how would you describe the health consultations you had during your illness process?</p> <p>Did you notice any difference in the attention received by?</p> <ul style="list-style-type: none"> <li>• Physicians</li> <li>• Nurses</li> <li>• Technicians</li> </ul>
SHOW UNDERSTANDING AND EMOTIONAL INVOLVEMENT		<p>Regarding the health consultations:</p> <ul style="list-style-type: none"> <li>• What was good?</li> <li>• What was bad?</li> <li>• What was missing?</li> </ul>



<p>GATHERING OF BASIC FACTS</p>	<p>ILLNESS TRAJECTORY</p>	<p>Do you know which type of breast cancer you had? Which treatment did you receive? Can you please tell me about the diagnosis process?</p>
	<p>ABOUT SPECIFIC HEALTH INTERACTIONS</p> <ul style="list-style-type: none"> <li>• Family doctor</li> <li>• Gynaecologist</li> <li>• Oncologist</li> <li>• Surgeons</li> <li>• Chemotherapy nurses</li> <li>• Radiotherapy technicians</li> <li>• Administrative staff</li> <li>• Other</li> </ul>	<p>Is there a specific health consultation you would like to talk about? Did you feel your opinion was considered in the process of decision-making? Where you allowed/invited to actively participate?</p>
	<p>INFORMATION</p>	<p>How would you rate the information you received?</p> <ul style="list-style-type: none"> <li>• Quantity</li> <li>• Quality</li> <li>• The way it was delivered</li> <li>• The timing</li> <li>• The place</li> </ul> <p>Did you feel you were “in good hands? Do you trust the staff treating you?</p>

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		<p>Where else did you look for information?</p> <ul style="list-style-type: none"> <li>• Social networks</li> <li>• Internet</li> <li>• Cancer associations</li> <li>• Support groups / friends</li> </ul>
<p>DIFFICULT QUESTIONS</p>	<p>LIVING WITH THE DIAGNOSIS OF CANCER / SECONDARY EFFECTS / SUURVIVING</p>	<p>How did the diagnosis of cancer impact your life?</p> <ul style="list-style-type: none"> <li>• On a personal level</li> <li>• At work</li> <li>• Within your family circle.</li> </ul> <p>Did you receive any kind of support from the health staff to get through these changes?</p> <p>Can we talk about the secondary effects of the treatments and how they impacted on your life?</p> <ul style="list-style-type: none"> <li>• Hair loss</li> <li>• Scars</li> <li>• Loss of breast(s)</li> <li>• Sexuality</li> <li>• Fertility</li> <li>• Self-esteem</li> <li>• Digestive symptoms, fatigue, etc</li> <li>• Effects of radiotherapy: tattoos, skin lesions</li> </ul>

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		<p>Currently, what does having had cancer means to you? Are you still being followed-up? Do you think the timing between follow-ups is good?</p> <p><b>COULD YOU PLEASE TELL ME HOW DO YOU ENVISION THE IDEAL HEALTH CONSULTATION?</b> (What advice would you give students)</p>
CALMING DOWN THE EMOTIONAL TONE	CONCILIATION METHODS	<p>Brief summary of the last answer</p> <ul style="list-style-type: none"> <li>• Do you think you have changed after the diagnosis?</li> <li>• Do you think there has been a learning?</li> <li>• Did you carry out any therapeutic activity (Writing, reading, dancing, theatre, singing)</li> <li>• Have you considered writing a book about your illness?</li> <li>• Do you have an explanation for your illness?</li> </ul>
CONCLUDE, WITHOUT LOOSING CONTACT		<p>Is there something else you would like to share with me? Something I did not ask but you would like to tell me?</p> <p>Acknowledgements.</p>

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## THEMATIC ANALYSIS OF ILLNESS NARRATIVES AS AN EXAMPLE OF AN APPROACH TO BETTER UNDERSTAND THE LIVED EXPERIENCE OF WOMEN DIAGNOSED WITH BREAST CANCER IN SPAIN

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# THEMATIC ANALYSIS OF ILLNESS NARRATIVES AS AN EXAMPLE OF AN APPROACH TO BETTER UNDERSTAND THE LIVED EXPERIENCE OF WOMEN DIAGNOSED WITH BREAST CANCER IN SPAIN

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## ABSTRACT:

**Objective:** To explore the lived experience of women diagnosed with breast cancer through the analysis of illness narratives, as an example of a Narrative Based Medicine approach.

**Setting:** Spain.

**Participants:** Nine narratives stemming from non-fiction books, and six from interviews through online platforms. All participants were cis women and their ages ranged between 34 and 60 years. The inclusion criteria were being a woman and having been diagnosed with and treated for breast cancer in Spain.

**Results:** The main topics that appeared on the analysis were: secondary effects of treatment, breast loss and scars, breast reconstruction, long term effect of treatment, positive attitude, illness as learning and use of language. Although the results of this research are preliminary, it can be said that societal expectations quickly became a burden for the patients. Moreover, there was no common behavioural pattern among the participants and how they chose to manage their cancer journey. Choosing whether or not to hide their baldness, go through reconstructive

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3 surgery, or fulfil the 'patient role', were options they wanted to review based on their own  
4 priorities, and not because of external impositions. Even though the women agreed with the  
5 benefits of having a positive attitude, they also asked for space to feel rage and sadness, not to  
6 be compared with others, and to be heard with no haste, as well as to be accompanied beyond  
7 the treatment, and for their long-term effects of medications to be validated. The importance  
8 of the type of comments and language used is emphasised.  
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10  
11 **Conclusion:** A Narrative Medicine Based approach enables us to incorporate the patient  
12 experience into the understanding of breast cancer. We encourage clinicians to be aware of the  
13 concepts of normality held by women, and to welcome different choices and different ways to  
14 experience illness.  
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## 16 17 18 19 STRENGTHS AND LIMITATION OF THIS RESEARCH: 20

- 21
- 22 • The use of open interviews and a qualitative research approach allowed women to talk
- 23 freely about their lived experience of illness.
- 24 • Not limiting the interviews to a specific health facility allowed us to hear testimonies
- 25 from different settings.
- 26 • All the books reviewed are first-person narratives, as none were found written by carers
- 27 or family, and all of them are stories of survival.
- 28 • To the date of the writing of this paper, only six women had been interviewed, which
- 29 does not allow for a thorough qualitative analysis.
- 30 • The design of the study leaves out lived experiences of breast cancer of men and trans
- 31 sexual people.  
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35 **KEY WORDS:** Medical Humanities. Illness narratives. Breast cancer. Narrative Based  
36 Medicine.  
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## 39 40 41 INTRODUCTION: 42

43 Throughout the history of Medicine, questioning paradigms has changed the way medicine is  
44 practised and taught (1); the last decades of the 20th century called for a rethinking of the  
45 biomedical model as it didn't provide a satisfactory explanation for illness. This, along with the  
46 raising of the advocacy for patient's autonomy (and in the case of breast cancer, feminism),  
47 turned into an interest in the incorporation of humanities and communication skills within  
48 teaching in Medical Schools (2,3). A model based on facts and findings, centred on a search for  
49 the explanation of illnesses, but not in the understanding of processes, was no longer  
50 acceptable. Narrative Based Medicine, which prioritises active listening, subjective symptoms,  
51 and the importance of life experiences, a emerged as an approach to illness in which  
52 contradictory and complex experiences were valued and contributed to a patient-centred care.  
53 (4,5) Within this model, medical narratives shift from the physician's perspectives to the  
54 patient's stories, becoming a useful resource to understand "the patient-specific meaning of  
55 illness" (4,6) and thus incorporate focused interventions aimed at improving their health and  
56 wellbeing.(6)  
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3 Specifically in the case of breast cancer, where breasts are regarded as one of the cornerstones  
4 of femininity, where the “pink ribbon” approach which encourages a positive attitude, and the  
5 quest for an “acceptable social appearance” (4,7) prevail, illness narratives enrich us with diverse  
6 and non-conventional stories. They expose us “to personal accounts of the journey through  
7 illness and treatment, offering us details, emotions, phrasing and imagery from an individual  
8 perspective” (8), complementing the medical knowledge and improving the complexity of breast  
9 cancer. (6,9).  
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12 This paper reflects the preliminary findings of the field work for a PhD thesis that aims to present  
13 a proposal for the introduction of the teaching of the Medical Humanities in Schools of Medicine  
14 in Spain. The original research question hinges on how women with breast cancer envision the  
15 ideal health consultation. By using a thematic analysis of illness narratives, this article focuses  
16 on the accounts of the lived experiences of the women interviewed, to provide a space for their  
17 voices to be heard and be an invitation to the construction of a more critical look at medical  
18 advice and societal standards and demands.  
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## 23 METHODS

24 This article uses qualitative research, through a thematic analysis approach. An initial Internet  
25 search using the google search engine for the terms “narrativas de enfermedad” (Illness  
26 narratives) and “patografias” (patographies) (10) was conducted, however there were no  
27 findings for this search, as these two words are not yet part of the academic or day to day  
28 vocabulary in Spain. Following this, a search was done on book sellers web pages (Amazon, Casa  
29 del Libro) and book reviews on Spanish newspapers, which included breast cancer in women,  
30 nonfiction, illness as main topic, written originally in Spanish, and by women living in Spain. Self-  
31 help books were excluded. After this search, eight books were found, all written in first person.  
32 Table 1 shows this information. Findings were collected on an Excel matrix. A semi-structured  
33 interview guideline was constructed following Rubin and Rubin’s sequence(11) (appendix 1) and  
34 using the eight books selected as a framework. The interview script was used as a guide for key  
35 subjects but was not meant to be followed strictly. Participants were recruited by word of mouth  
36 using the snowball method (12) ; inclusion criteria were being a woman and having been  
37 diagnosed and treated for breast cancer in Spain. Table 2 shows the information of the  
38 participants. Pseudonyms were used to preserve anonymity and were preferred over numbers  
39 or codes in line with a person-centred approach. Interviews were carried out through virtual  
40 platforms like Zoom and Teams, recorded, and transcribed for analysis. They were all conducted  
41 in Spanish and excerpts translated by one of the authors (NMF). The participants were invited  
42 to relate their experiences of living with breast cancer freely, placing special emphasis on the  
43 descriptions of their interactions with health professionals, the information they received, how  
44 the diagnosis was communicated to them, and the process of decision-making. Following this,  
45 the emphasis was placed on the effects of cancer and its treatments, how the illness and care  
46 had affected their life and how each woman had coped with them.  
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54 In the first stage of the field work, interviews with six women were conducted and manually  
55 analysed. At this point, the interviews were revised, and the objectives of the thesis  
56 reformulated, resulting in a decision to focus mainly on health interactions. There was very rich  
57 information that we didn’t want to lose, and thus was used for this article. (At this stage of the  
58 research saturation point had not yet been achieved)  
59  
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The main themes found were secondary effects of treatment, for example hair loss, scars, and mastectomy; reconstructive mammoplasty, long-term effects, positive attitude, illness as learning and use of language. The main topics were extracted by NMF and then discussed with AM and JS. The original research design has been audited by an outside researcher from URJC. (DM)

TABLE 1

REFERENCE NUMBER	TITTLE	AUTHOR	INITIALS	AGE AT DIAGNOSIS	PUBLISHER	YEAR	MARITAL STATUS
(13)	<i>Diario de batalla: Mi lucha contra el cáncer.</i>	Durán, María Ángeles	MAD	54	Santillana	2003	MARRIED
(14)	<i>Cáncer, Contigo puedo.</i>	Arcos, Ruiz Anabel	AA	34	La esfera de los libros	2018	NO PARTNER
(15)	<i>Mi vida con el bicho: Superar el cáncer de mama</i>	Mallebrin, Steffi	SM	45	Oberon	2021	MARRIED
(16)	<i>Tópico de cáncer: Manual de supervivencia</i>	Koska, Susana	SK	53	Ediciones B, S.A.	2014	MARRIED
(17)	<i>Vivir y superar el cáncer de mama.</i>	Bianchi, Ilaria	IB	39	Arcopress	2018	NO PARTNER
(18)	<i>Una travesía por el cáncer de mama</i>	Lizasoáin Rumeu, Olga	OL		Eunate	2020	MARRIED
(19)	<i>Te invito a un Mojito</i>	Mabel Lozano	ML	53	Catedra Editorial	2021	MARRIED
		Paka Diaz	PD				PARTNER

(20)	<i>La rubia que se quedó calva. El cáncer en tiempos de pandemia</i>	Porto Alarcón, Natalia	NP		Natàlia Porto Alarcón	2021	NO PARTNER
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TABLE 2

## WOMEN INTERVIEWED

PSEUDONYM	INITIAL	AGE AT DIAGNOSIS	TIME SINCE DIAGNOSIS (years)
Iris	I	48	6
Rose	R	37	11
Ana	A	56	2
Clara	C	51	2
Julia	J	42	6
Susana	S	36/39*	5/2

\*Two diagnoses of breast cancer.

For the protection of anonymity, information such as married status, educational background, or type of job are only mentioned when relevant.

## FINDINGS

When extracts from the books are used, they are identified with the initials of the author. The examples from the interviews are identified with the initial of the pseudonym chosen for each participating woman.

**SECONDARY EFFECTS:** Under this heading we describe the comments on common side effects of chemotherapy drugs, hair loss being the most prevalent.

A concern most women had was about the information they received on hair loss as a side effect of chemotherapy: health practitioners gave them a great amount of information about losing the hair of the scalp, including pamphlets and advice on where to have a wig made, but the fact that they would lose all their body hair, as well as the uncomfortable side effects associated with this, was not often mentioned, and came as a surprise for most of them. For instance, C says: "I lost the hair in my nostrils, which was very uncomfortable, as I had a runny nose all the time." Similarly, SK remarked that her facial expression, which was part of her identity, drastically changed with the loss of her eyebrows, and chose to get new ones tattooed on.

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3 Contrary to widespread belief, most of the women didn't give scalp hair loss much meaning. I  
4 says: "While everybody expressed concern about my hair loss, it did not bother me. This would  
5 pass. Hair does not hurt. Hair grows back." Most of the women chose to cut their hair short  
6 before it started to fall. NP and AA invited their young daughters to shave their heads as a  
7 gesture to open-up to them and normalise being bald. AA invites us to sing the song *Respect* "for  
8 all women who shave their heads. That have the *ovaries* to show it. Because I spent one  
9 thousand quid on a wig. But I wanted to show you my picture. My bald head. My face. Show it  
10 to you in case you decide to shave your hair." (14)  
11  
12

13 By contrast MAD writes in abundance about the wig and uses it most of the time, because "it is  
14 more important to me than I thought." "The wig is important because if the baldness is shown,  
15 it proclaims the risk and the threat. If it does not, the threat is not visible, and in a way, it is  
16 mitigated and delayed. If it shows, it introduces a special kind of unrest. It communicates the  
17 news without permission, spreads it the wrong way and against the will of her owner, it reveals  
18 the truth of the fiction between what you want to be and what you are." (13)  
19  
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21 R's father was genuinely concerned because she did not want to use a wig; his father had died  
22 of cancer and seeing his daughter ill had a strong emotional effect on him. R says: "Some people  
23 connect your physical appearance to your health. If you use a wig, it seems nothing is  
24 happening." However, R preferred using a headscarf, and even more so, not wearing anything.  
25 Like I, she would only cover her hair in front of her children: they both have kids with a diagnosis  
26 of a condition that would not allow them to thoroughly understand what was happening. MAD  
27 says the wig "avoids him the embarrassment in front of his friends" (12) (referring to her teenage  
28 son).  
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31 **EFFECTS OF BREAST LOSS AND SCARS:** Our findings on these themes show that most of  
32 the women cherish their scars as tokens that will always remind them of the ordeal they went  
33 through and make them feel grateful for being alive. Furthermore, the feeling of a lack of  
34 femininity or loss of identity, was not expressed by any of the women.  
35  
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37 When considering partners and sexual relations, there was a clear difference between those  
38 women who had a partner or a long-lasting relationship and those who didn't have one at the  
39 moment of their diagnosis: B, L, A, P, M, S, J and R were married; none of their partners had  
40 problems handling the situation of them having only one breast or a scar, except for the initial  
41 fear of hurting them. S and J told us how their doctor advised them to have a reconstruction "for  
42 the sake of your husband," whilst their husband showed no concern. The case for AA (34 years  
43 old), without a partner, exemplifies the different stages women can go through when faced with  
44 the indication of a mastectomy: She doesn't relate any conflict with having her breast removed,  
45 so much so that she throws a farewell party for her breast the day before her surgery and even  
46 dedicates a whole chapter of her book to thank her breast. However, later she does write about  
47 going through a phase of rage, tears, and depression a week before the mastectomy. After the  
48 surgery, she clearly states: "Nothing has changed, I am the same woman who entered the  
49 operating suite." (14) She recounts challenging situations associated with the prosthetic breast,  
50 like the fear of it falling when she is on a date or waiting in line to pick-up her daughter. Just as  
51 for NP and MAD, the inconvenience lies in revealing the illness in moments when they want to  
52 conceal it, not in having one breast. In AA's case, a man she was dating told her "He was not  
53 able to cope with her cancer", when she was about to have her mastectomy.  
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58 **BREAST RECONSTRUCTION:** Seven out of the fourteen women interviewed who had a  
59 mastectomy, chose to have a reconstruction. For R and SM, a major factor influencing the  
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3 decision to have a reconstructive surgery was their doctor's insistence, because "they were very  
4 young." NP and AA, chose to have the surgery mainly for aesthetic reasons, but both write that  
5 it wouldn't have made a difference if they had kept just one breast. AA saw reconstruction as an  
6 opportunity to "close the circle." During her interview, R says: "Recovery from reconstruction  
7 was more difficult than from mastectomy. There is more emotional burden; the recovery is more  
8 emotional than physical. It is extremely complicated.... If I had to do it again, maybe I would not."  
9

10  
11 The importance assigned to aesthetic results by some health professionals is clearly exemplified  
12 in the case of IB,(17) where her surgeon suggests he will also intervene in the healthy breast, so  
13 they both have symmetrical scars. IB, being a gynaecologist, refused this operation, but this  
14 makes us wonder how many women, without enough knowledge of the subject have been  
15 submitted to this kind of procedure. J told us how, even though her breasts look symmetrical  
16 and 'beautiful,' they don't feel as they used to, and there is no sensitivity in her nipples. Her  
17 surgeon did not tell her about this possible side effect.  
18

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20 As mentioned before, the arguments of "do it for your husband" or "do it for your children"  
21 appear in the medical discourse frequently. The husbands and children of the women  
22 interviewed were not concerned by them having scars or just one breast, even more so, many  
23 of them preferred for them not to have a reconstruction, because of the fear of something going  
24 wrong during a surgery solely for aesthetic reasons. (J, S, R)  
25

26  
27 In her interview, S talked about the decision of having the reconstruction being the hardest she  
28 had to take during her process. At first, "out of fear," she wanted to have a double mastectomy,  
29 but she was advised against this by her doctor. She sought out different medical opinions, some  
30 of which were contradictory. Her initial decision was not to have a reconstruction, because she  
31 prioritised "risk before aesthetics." She calls our attention to the fact that most people, she puts  
32 her surgeon as an example, take for granted that you are going to have a reconstruction and  
33 encourage you to do it by saying "you will look so much better." S feels that these are  
34 "unfortunate messages", "with an optimism that does not go well with the person's situation."  
35 Instead of helping her, they made her feel "mutilated" and unacceptable. Finally, after listening  
36 to other women's testimonies and having time to set her own priorities, S decided to have a  
37 reconstruction which took eleven hours. The aesthetic results were not as perfect as expected:  
38 "You can clearly tell I have an operated breast, but I am not going to do anything about it."  
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42 **LONG TERM EFFECTS OF TREATMENT:** This was a theme that surfaced in many of the  
43 narratives and includes effects of medications and surgery. Even though the women understand  
44 the importance of being treated, they were left with secondary effects that will last a lifetime:  
45 loss of memory and cognitive impairment (A and R), limitation of mobility and lymphedema of  
46 arms (R and SK), chronic fatigue (all). What they most regret is that these symptoms were not  
47 validated by their oncologists.  
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50  
51 In their book, ML and PK (19) advocate giving the patient more information about the treatment  
52 they are going to receive and challenge the concept of "personalised chemotherapy treatment";  
53 they cite Anne Boyer, author of the book *The Undying* (21) as an example of someone who,  
54 after acquiring enough information, requested and got a change in her treatment. They also  
55 note how Boyer references recently published articles that show that the side effects related by  
56 many women are in fact secondary to the chemotherapy treatment.  
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## 58 POSITIVE ATTITUDE, LANGUAGE, AND ILLNESS AS LEARNING

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3 Except for *Tópico de Cáncer*, (16) and *Te invito a un mojito*, (19) all books concur with the  
4 prevailing idea of illness as learning. The importance of a positive attitude is a clear message on  
5 all published illness narratives. Even though self-help books were excluded from the search, all  
6 the books analysed contain advice on diets, explanations of medical terms, exams, and  
7 procedures. *Tópico de cáncer* is the only one that crudely describes the author's ordeal through  
8 her treatment.  
9

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11 Even though the women interviewed do mention the fact that going through breast cancer has  
12 made them set their priorities more clearly, their call is for a space for all kinds of feelings and  
13 attitudes, not only the positive attitude that society in general, and most cancer associations in  
14 particular, ask from them. As MAD states, there should not be "publicly acceptable feelings a  
15 cancer patient can express" (13) and there should not be standardised ways of behaving.  
16 Women recalled being uncomfortable with people who minimised their symptoms ("but this is  
17 just like a bad cold"), told them stories about women who "went to and back from  
18 chemotherapy on their bicycles" and those who insisted on the power of a good attitude  
19 towards healing. S says, "the diagnosis of breast cancer comes with rage, anger and fear, and  
20 words like 'do not worry', far from helping me, make me angry; feeling unwell must be  
21 destigmatised." ML states that "an illness like this is not inspiring or beautiful, it is \*\*\*, but we  
22 have to accept it." (19)  
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26 SK's favourite place is the bathtub: "where I do not have to speak or look courageous. Where I  
27 do not have to have a plan for the future, for when we have defeated the bug. Where I don't  
28 have to keep a stiff upper lip." (16)  
29

30 ML and PD (19), as well as S, join the quest against metaphors of war; it is not because you are  
31 a "warrior or a she-hero" that cancer is cured; using this type of language is very unfair to the  
32 women who do not experience successful treatment and puts the blame on them. "You would  
33 never ask a person with a diagnosis of syphilis or diabetes to have a positive attitude." (PD) ML  
34 highlights the importance of the word chosen: "Don't tell me I have a 'good cancer', no cancer  
35 is good, and you don't 'tiptoe through cancer', as a friend told me." She and PD made their  
36 diagnosis public on social networks in an effort to normalise illness and as part of their campaign  
37 to stop the victimisation of cancer patients. Not all agree with this concept, as others (A and C)  
38 feel they will always be oncologic patients and will live forever with the fear of a new diagnosis  
39 of cancer. SK writes: "I feel the sword of Damocles hanging over me all the time." (16)  
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43 MAD writes: I do not want to call it, as I once heard a millionaire doctor say, 'a mutilated breast,'  
44 This word connotes war, martyrs, complexes, and depression, which do not solve the problem.  
45 Mine is just a diminished breast, without tragedies surrounding it." (13)  
46

47 The words preferred in these stories to refer to their illness trajectory were journey, a hurricane,  
48 a chain, baggage, or the ascent of a mountain. On the other hand, the euphemisms used when  
49 referring to their tumours, had mainly a negative connotation: "the rat", "the dragon", "bug",  
50 "the bug with the poisonous mouth", or "f\*\*\*pea." SK describes feeling like "Anne Boleyn on  
51 her way to the gallows" before her oncology consultations. (16)  
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## DISCUSSION:

Novels and autopathographies contain valuable information about the ways people with cancer make sense of their illness and treatments.<sup>(22)</sup> Nevertheless, writing or talking about illness is not viewed favourably within Spanish society, and herein lies the difficulty in finding illness narratives of breast cancer; this was seen by us as an opportunity to use our findings to make illness experiences more visible, within the cultural and lifestyle context of Spain.

Nevertheless, the study design does have some limitations: by restricting the interviews to women, we are aware we are leaving out the lived experience of men and trans sexual people affected by breast cancer. (5). We thought this was pertinent, to exclude other cultural and behavioural factors that may influence the way an illness is experienced, which, even though we find important, are not the aim of this specific research.

While we would have also liked to include narratives from carers and family members, we were unable to find published narratives of this kind. Having said this, we are considering interviewing other participants for further stages of the study.

By choosing a qualitative research approach we were able to gather an extensive amount of powerful information that was examined in detail. However, we acknowledge that with this approach reproducibility and generalisation to a larger population cannot be achieved.

Health professionals see patients at a given point of their life, but as MAD writes, “there is a bigger part of our lives that they don’t see.” (13) The dominant medical narrative is in line with Goffman’s concept of the ill person being responsible for how they present themselves and display the signs of their illness, and with Pearson’s idea of the “sick role”, where ill people are expected to get better to go back to their assigned place in society (23). Our findings show that women with breast cancer would prefer to build their own more welcoming spaces, but unfortunately, until patients’ narratives are regarded as an important part of medical practice, this will not be possible. This is best explained by Rosenblatt’s comment that “when patients are faced with the need to reconfigure themselves during and after illness, there is a difficulty, because medical categories and corresponding guidelines direct treatments conceived for a group, not for an individual,”<sup>(24)</sup>

When looking for advice on the internet or from friends and family, women are told to mask the changes chemotherapy can produce on their skin and to use wigs or headscarves to cover their baldness, but these are not necessarily the choices shown in the illness narratives analysed. On the one hand, most women felt the wig was uncomfortable and some of them felt that baldness did not have to be hidden and normalised it by letting their kids shave their heads. On the other hand, some women used their wigs to comply with family and society’s rules not to look ill.

Medical literature often uses words like “disfigurement,” “mutilation,” and “lop-sided” to describe the post-mastectomy patient, reinforcing women’s own sense of their bodily imperfections (25) but these are not the words used in the illness narratives analysed. Denford states that when women try to adjust to life after cancer, they “commonly strive to be ‘normal’ after mastectomy and reconstructive surgery, [but] research surrounding individual perceptions of normality is lacking.”<sup>(26)</sup> Our findings from the lived experiences of women with breast cancer show that even though half of them chose to have a reconstructive surgery, none of them felt that having only one breast made them less of a woman and all of them cherished their scars

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3 as remembrance of the journey they had gone through. In Spain each year around 16.000  
4 mastectomies are performed, but only 4.800 women opt for a reconstruction. (19) One of the  
5 main concerns through a feminist theory analysis, is that the breast is considered an “iconic  
6 representation” of a woman’s femininity and identity and that “the experience of breast cancer  
7 is clearly influenced by the cultural emphasis on breasts as objects of male sexual interest and  
8 male sexual pleasure.”(26) There is still a medical discourse coming from different health care  
9 scenarios that encourages women to “look better for their husbands” and believes that “you  
10 will feel better if you look better” and where the decision for reconstructive surgery is based  
11 mainly on aesthetic reasons (27); the women interviewed would like to be able to make their  
12 choices based on their own priorities, and not to comply with fixed standards of beauty, which  
13 resonates with Sun’s meta-analysis of the impact of losing a breast in women who survived  
14 breast cancer (28).  
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18 Recent studies are looking at the effects of chemotherapy on cognitive function and of the  
19 appearance of chronic fatigue (29–32). We hope that health care professionals take this  
20 information into account when choosing treatments, and that they validate these women’s  
21 symptoms.  
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24 As evidenced by our findings, there is still a trend towards the belief that a positive attitude is  
25 an important ingredient for healing. We are aware of the risk postulated by Solbrække (9) of  
26 perpetuating the ‘gold standard’ of cancer survivorship, and agree with Nielsen’s (33) comment  
27 to “resist calls for hope and courage”. Even though positive thinking can be helpful, “mandating  
28 it often silences and induces shame.” (32) After this preliminary analysis, new stages for the  
29 research will be developed, including interviewing more women, from diverse cultural and social  
30 backgrounds, focusing the interviews on more specific themes of research, and including third  
31 person illness narratives. We expect to learn about the experience of carers, but also to give  
32 voice to breast cancer journeys that concluded in death, and those of women suffering from  
33 metastatic breast cancer. The analysis of other type of narratives, which move to a more  
34 systematic consideration of the place of illness narratives in promoting cultural change and a  
35 shift in medical discourse could broaden the findings of this research.  
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39 In a study on illness perceptions of breast cancer in Ghana (6) the majority of women  
40 interviewed relied predominantly on religious faith and spirituality as key coping mechanisms  
41 and as mentioned illness being a test from God. The theme of spirituality was not present in any  
42 of the narratives analysed for this paper. This is an example and a strong argument for the  
43 importance of developing culture-specific narrative research and implementing the Medical  
44 Humanities in medical practice (34), as the proposed interventions for Ghana are not applicable  
45 for other setting, as in this case, Spain.  
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48 Even though metaphors of war prevail, the illness narratives analysed showed that there is a  
49 trend towards language that does not blame the person. That being said, the negative  
50 connotation attributed to illness, and specifically cancer, is still present in the euphemisms used  
51 to describe the tumours.  
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54 It is important to mention that the women interviewed were thankful for having an opportunity  
55 to speak out about their cancer and share feelings or thoughts they had never shared with other  
56 people. This falls in line with the Narrative approach to Medicine, which suggests that telling  
57 their story is a way for patients to regain control and thus “diminish the sense of helplessness,  
58 marginalisation an isolation that are inevitable aspects of serious disease.”(24) These women  
59 were also happy to contribute with advice for a better person-centered approach to Medicine,  
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3 with the hope that uncomfortable situations that they had to face, will not happen to other  
4 women again.  
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## 8 9 CONCLUSIONS:

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12 As shown in this article, a Narrative Medicine approach using the analysis of illness narratives,  
13 both from published books and from interviews could be utilised in clinical practice, research,  
14 and education to promote healing.<sup>(35)</sup> When used with women who have been diagnosed with  
15 breast cancer, it can give us clues on the diverse ways people cope with side effects of  
16 chemotherapy and surgery and the different needs and priorities that are considered in decision  
17 making; they give a space for their voices to be heard, and for their advice to be incorporated  
18 into healthcare interactions.  
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23  
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25 the interviews. MMF, for her editing advise. Professor Neil Vickers, for his revision and  
26 comments on the final draft of the manuscript.  
27

28  
29 **Ethical approval:** Ethical Committee approval was obtained for the interviews, and consent  
30 forms were signed by the participants. (Universidad Rey Juan Carlos, Madrid, Spain. Internal  
31 registry number: 0803202106921)  
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33  
34 **Patient and Public Involvement:** Not applicable. Even though patients were not directly involved  
35 in the research design, their comments will be part of a proposal for the introduction of the  
36 teaching of Medical Humanities in schools of Medicine in Spain  
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38  
39 **Funding:** None  
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51 with comments and improvements.  
52

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**SCRIPT. INTERVIEWS ON HEALTH CONSULTATIONS TO PACIENTES WITH DIAGNOSIS OF BREAST CANCER**

Start interview on a cordial tone, do not go directly to the diagnosis

RUBIN Y RUBIN	TOPIC	QUESTION
CREATION OF AN EASY (natural) INVOLVEMENT	<ul style="list-style-type: none"> <li>• Age</li> <li>• Family group</li> <li>• Occupation</li> <li>• MOTIVATION TO PARTICIPATE</li> </ul>	Can you please tell me a little about yourself? What has motivated you to participate in this interview?
HONE CONVERSATIONAL COMPETENCE	<ul style="list-style-type: none"> <li>• Aim of the research</li> </ul>	Overall, how would you describe the health consultations you had during your illness process? Did you notice any difference in the attention received by? <ul style="list-style-type: none"> <li>• Physicians</li> <li>• Nurses</li> <li>• Technicians</li> </ul>
SHOW UNDERSTANDING AND EMOTIONAL INVOLVEMENT		Regarding the health consultations: <ul style="list-style-type: none"> <li>• What was good?</li> <li>• What was bad?</li> <li>• What was missing?</li> </ul>

<p>GATHERING OF BASIC FACTS</p>	<p>ILLNESS TRAJECTORY</p>	<p>Do you know which type of breast cancer you had? Which treatment did you receive? Can you please tell me about the diagnosis process?</p>
	<p>ABOUT SPECIFIC HEALTH INTERACTIONS</p> <ul style="list-style-type: none"> <li>• Family doctor</li> <li>• Gynaecologist</li> <li>• Oncologist</li> <li>• Surgeons</li> <li>• Chemotherapy nurses</li> <li>• Radiotherapy technicians</li> <li>• Administrative staff</li> <li>• Other</li> </ul>	<p>Is there a specific health consultation you would like to talk about? Did you feel your opinion was considered in the process of decision-making? Where you allowed/invited to actively participate?</p>
	<p>INFORMATION</p>	<p>How would you rate the information you received?</p> <ul style="list-style-type: none"> <li>• Quantity</li> <li>• Quality</li> <li>• The way it was delivered</li> <li>• The timing</li> <li>• The place</li> </ul> <p>Did you feel you were “in good hands? Do you trust the staff treating you?</p>

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		<p>Where else did you look for information?</p> <ul style="list-style-type: none"> <li>• Social networks</li> <li>• Internet</li> <li>• Cancer associations</li> <li>• Support groups / friends</li> </ul>
<p>DIFFICULT QUESTIONS</p>	<p>LIVING WITH THE DIAGNOSIS OF CANCER / SECONDARY EFFECTS / SUURVIVING</p>	<p>How did the diagnosis of cancer impact your life?</p> <ul style="list-style-type: none"> <li>• On a personal level</li> <li>• At work</li> <li>• Within your family circle.</li> </ul> <p>Did you receive any kind of support from the health staff to get through these changes?</p> <p>Can we talk about the secondary effects of the treatments and how they impacted on your life?</p> <ul style="list-style-type: none"> <li>• Hair loss</li> <li>• Scars</li> <li>• Loss of breast(s)</li> <li>• Sexuality</li> <li>• Fertility</li> <li>• Self-esteem</li> <li>• Digestive symptoms, fatigue, etc</li> <li>• Effects of radiotherapy: tattoos, skin lesions</li> </ul>

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		<p>Currently, what does having had cancer means to you? Are you still being followed-up? Do you think the timing between follow-ups is good?</p> <p><b>COULD YOU PLEASE TELL ME HOW DO YOU ENVISION THE IDEAL HEALTH CONSULTATION?</b> (What advice would you give students)</p>
CALMING DOWN THE EMOTIONAL TONE	CONCILIATION METHODS	<p>Brief summary of the last answer</p> <ul style="list-style-type: none"> <li>• Do you think you have changed after the diagnosis?</li> <li>• Do you think there has been a learning?</li> <li>• Did you carry out any therapeutic activity (Writing, reading, dancing, theatre, singing)</li> <li>• Have you considered writing a book about your illness?</li> <li>• Do you have an explanation for your illness?</li> </ul>
CONCLUDE, WITHOUT LOOSING CONTACT		<p>Is there something else you would like to share with me? Something I did not ask but you would like to tell me?</p> <p>Acknowledgements.</p>

For peer review only

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<b>TITTLE</b>	<i>Thematic Analysis of Illness Narratives as an Example of an Approach to Better Understand the Lived Experience of Women with Breast Cancer in Spain.</i>	
<b>ABSTRACT</b>	Page 1	
<b>(KEY WORDS)</b>	Page 1	
<b>INTRODUCTION</b>		
Problem formulation	Paragraph 1	Proposal of a Narrative Based Medicine model as a complement to the current Evidence Based Medicine model. Specifically, the use of illness narratives to introduce patient experience into medical practice.
RESEARCH QUESTION	Paragraph 3.	How do women diagnosed with breast cancer in Spain describe their lived experience.
<b>METHODS</b> Qualitative approach and research paradigm	Paragraph 1	This paper uses qualitative research, through a thematic analysis approach. Narrative research.  Research paradigm: Person centred approach.
Researcher characteristics and reflexivity	Affiliations Methods Paragraph 3	NMF is a gynaecologist and holds a Master's degree in Medical Humanities. AM is an anthropologist and sociologist with experience in qualitative research. JS is a gynaecologist who has worked extensively in breast cancer. AM and JS have published multiple academic articles on their fields. To analyse the way thoughts and ideas evolve during the research process, the IP keeps a reflective journal and there have been permanent consultations with the thesis directors, as well as audits by third-party researchers.
Context	Paragraph 1	Women diagnosed and treated for cancer in Spain
Sampling strategy	Paragraphs 2 and 3	Inclusion criteria: Books: Non-fiction. written by women diagnosed and treated in Spain. Exclusion: Self-help books Participants: Women. Having been diagnosed and treated for cancer in Spain. Sampling saturation had not been reached by this step of the study.

Why breast cancer? Why illness narratives?	Introduction, paragraph 2	Specifically in the case of breast cancer, where breasts are regarded as the cornerstone of femininity, where the “pink ribbon” approach which encourages a positive attitude, and the quest for an “acceptable social appearance” (4) prevail, illness narratives enrich us with diverse and non-conventional stories. They expose us “to personal accounts of the journey through illness and treatment, offering us details, emotions, phrasing and imagery from an individual perspective”, complementing the medical knowledge and improving the complexity of breast cancer.
Ethical issues pertaining to human subjects	“Ethical approval”	Approved by Ethics Committee Universidad Rey Juan Carlos. Internal registry number: 0803202106921)
Data collection methods	Paragraph 1	Semi-structured interviews
Data collection instruments and technology		Interviews were recorded, transcribed, and manually analysed.
Units of study	Table 1 and 2	
Data processing	Paragraph 1	Manual. Excel matrix.
Data analysis	Paragraph 1	Manual
Techniques of enhance trustworthiness	Paragraph 2	The main topics were extracted by NMF and then discussed with AM and JS. The original research design has been audited by an outside researcher from URJC. (DM)  All interview recordings are safely kept in a hard disk to which only NMF has access. They are available for further analysis if needed.
Reporting back to participants	“Patient and public involvement.”	The data gathered from the analysis of these interviews will be used to design a communications skills module for health practitioners. Interview transcripts were not sent back to participants.
<b>RESULTS/FINDINGS</b>		
Synthesis and interpretation	Results	
Link to empirical data	Discussion	



<b>DISCUSSION</b>		
Integration with prior work, implications, transferability, and contribution to the field	Paragraph 1 and 7	
Limitations	Discussion	
<b>OTHER</b>		
Conflicts of interest	None	
Funding	No funding	