

# 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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**To cite:** Mesa Freydell N, Martínez Pérez A, Schneider Fontán J. 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. *BMJ Open* 2022;**12**:e060935. doi:10.1136/bmjopen-2022-060935

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-060935>).

Received 01 February 2022  
Accepted 25 August 2022



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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 surgery or fulfil the 'patient role' were options they wanted to review based on their own priorities, and not because of external impositions. Even though the women agreed with the benefits of having a positive attitude, they also asked 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 emphasised.

**Conclusion** A narrative-based medicine approach enables us to incorporate the patient experience into the understanding of breast cancer. We encourage clinicians to be aware of the concepts of normality held by women, and to welcome different choices and different ways to experience illness.

## INTRODUCTION

Throughout the history of medicine, questioning paradigms has changed the way medicine is practised and taught<sup>1</sup>; the last decades of the 20th century called for a rethinking of

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The use of open interviews and a qualitative research approach allowed women to talk freely about their lived experience of illness.
- ⇒ Not limiting the interviews to a specific health facility allowed us to hear testimonies from different settings.
- ⇒ All the books reviewed are first-person narratives, as none were found written by carers or family, and all of them are stories of survival.
- ⇒ To the date of the writing of this paper, only six women had been interviewed, which does not allow for a thorough qualitative analysis.
- ⇒ The design of the study leaves out lived experiences of breast cancer of men and transsexual people.

the biomedical model as it did not 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.<sup>2,3</sup> 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, has emerged as an approach to illness in which contradictory and complex experiences are valued and contribute to a patient-centred care.<sup>4,5</sup> 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'<sup>4,6</sup> and thus incorporate focused interventions aimed at improving their health and well-being.<sup>6</sup>

Specifically in the case of breast cancer, where breasts are regarded as one of the cornerstones of femininity, where the 'pink ribbon' approach which encourages a positive attitude, and the quest for an 'acceptable social appearance'<sup>4,7</sup> 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",<sup>8</sup> complementing the medical knowledge and improving the complexity of breast cancer.<sup>6,9</sup>

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 qualitative research through a thematic analysis approach. An initial internet search using the google search engine for the terms "narrativas de enfermedad" (illness narratives) and "patografías" (patographies)<sup>10</sup> 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, non-fiction, 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. Findings were collected on an Excel matrix. A semi-structured interview guideline was constructed following the sequence by Rubin and Rubin<sup>11</sup> (online supplemental appendix 1) and using the books selected as framework. The interview script was used as a guide for key subjects but was not meant to be followed strictly. Participants were recruited by word of mouth using the snowball method<sup>12</sup>; inclusion criteria were being a woman and having been diagnosed and treated for breast cancer in Spain. Table 2 shows the information of the participants. Pseudonyms were used to preserve anonymity and were preferred over numbers or codes in line with a person-centred approach. Interviews were carried out through virtual platforms like Zoom and Teams, recorded and transcribed for analysis. They were all conducted in Spanish and excerpts translated by one of the authors (NMF). The participants were invited to relate their experiences of living with breast cancer freely, placing special emphasis on the descriptions of their interactions with health professionals, the information they received, how the diagnosis was communicated to them and the process of decision-making. Following this, the emphasis was placed on the effects of cancer and its treatments, how the illness and care had affected their life and how each woman had coped with them.

In the first stage of the field work, interviews with six women were conducted and manually analysed. At this point, the interviews were revised, and the objectives of

**Table 1** Published narratives

Reference number	Title	Author	Initials	Age at diagnosis (years)	Publisher	Marital status
14	<i>Diario de batalla: Mi lucha contra el cáncer</i>	Durán, María Ángeles	MAD	54	Santillana	Married
13	<i>Cáncer: contigo puedo : la lucha emocional de una mujer que pedalea la vida para superar su cáncer de mama</i>	Arcos Ruiz, Anabel	ARA	34	La esfera de los libros	No partner
33	<i>Mi vida con el bicho: Superar el cáncer de mama</i>	Mallebrin, Steffi	SM	45	Oberon	Married
18	<i>Tópico de cáncer: Manual de supervivencia</i>	Koska, Susana	SK	53	Ediciones B.S.A.	Married
15	<i>Vivir y superar el cáncer de mama</i>	Bianchi, Ilaria	IB	39	Arcopress	No partner
34	<i>Una travesía por el cáncer de mama</i>	Lizasoáin Rumeu, Olga	OLR		Eunate	Married
16	<i>Te invito a un Mojito</i>	Lozano, Mabel	ML	53	Catedra Editorial	Married
		Díaz, Paka	PD			Partner
35	<i>La rubia que se quedó calva. El cáncer de mama en tiempos de pandemia</i>	Porto Alarcón, Natalia	NPA		Natàlia Porto Alarcón	No partner

**Table 2** Women interviewed

Pseudonym	Initial	Age at diagnosis (years)	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.

the thesis reformulated, resulting in a decision to focus mainly on health interactions. There was very rich information that we did not want to lose, and thus was used for this article. (At this stage of the research, saturation point had not yet been achieved.)

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 AMP and JSF. The original research design has been audited by an outside researcher from Universidad Rey Juan Carlos (DM).

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

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.

Contrary to widespread belief, most of the women did not give scalp hair loss much meaning. I says: “While

everybody expressed concern about my hair loss, it did not bother me. This would pass. Hair does not hurt. Hair grows back”. Most of the women 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 normalise being bald. AA invites us to sing the song *Respect* “for all women who shave their heads. That have the ovaries to show it. Because I spent one thousand 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”<sup>13</sup>.

By contrast, MAD writes in abundance 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 the baldness is shown, it proclaims the risk and the threat. If it does not, 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”<sup>14</sup>.

R’s father was genuinely concerned because she did not 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 connect your physical appearance to your health. 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, she would only cover her hair in front of her children: they both have kids with a diagnosis of a condition that would not allow them to thoroughly understand what was happening. MAD says the wig “avoids him the embarrassment in front of his friends”<sup>12</sup> (referring to her teenage son).

### 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 was not expressed by any of the women.

When considering partners and sexual relations, there was a clear difference between those women who had a partner or a long-lasting relationship and those who did not have one at the moment of their diagnosis: B, L, A, P, M, S, J 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”, while their husband showed no concern. The case for AA (34 years old), without a partner, exemplifies the different stages women can go through when faced with the indication of a mastectomy: She does not 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 thank her breast. 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".<sup>13</sup> She recounts challenging situations associated with the prosthetic breast, like the fear of it falling when she is on a date or waiting in line 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.

### Breast reconstruction

Seven out of the 14 women who had a mastectomy, chose to have a reconstruction. For R and SM, a major factor influencing the decision to have a reconstructive surgery was their doctor's insistence, because 'they were very young'. NP and AA chose to have the surgery mainly for aesthetic reasons, but both write that it would not have made a difference if they had kept just one breast. AA saw reconstruction as an opportunity to "close the circle" During her interview, R says: "Recovery from reconstruction was more difficult than from mastectomy. There is more emotional burden; the recovery is more emotional than physical. It is extremely complicated... If I had to do it again, maybe I would not'.

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

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

In her interview, S talked about the decision of having the reconstruction being the hardest she had to take during her process. At first, "out of fear", she wanted to have a double mastectomy, but she was advised against this by her doctor. She sought out different medical opinions, some of which were contradictory. Her initial decision was not to have a reconstruction, because she prioritised "risk before aesthetics". She calls our attention to the fact that most people, she puts her surgeon as an example, take for granted that you are going to have a reconstruction and encourage you to do it by saying "you

will look so much better". S feels that these are "unfortunate messages", "with an optimism that does not go well with the person's situation". Instead of helping her, they made her feel "mutilated" and unacceptable. Finally, after listening to other women's testimonies and having time to set her own priorities, S decided to have a reconstruction which took 11 hours. The aesthetic results were not as perfect as expected: "You can clearly tell I have an operated breast, but I am not going to do anything about it".

### Long-term effects of treatment

This was a theme that surfaced in many of the narratives and includes effects of medications and surgery. Even though the women understand the importance of being treated, they were left with secondary effects that will last a lifetime: loss of memory and cognitive impairment (A and R), limitation of mobility and lymphoedema of arms (R and SK), chronic fatigue (all). What they most regret is that these symptoms were not validated by their oncologists.

In their book, ML and PK<sup>16</sup> advocate giving the patient more information about the treatment they are going to receive and challenge the concept of 'personalised chemotherapy treatment'; they cite Anne Boyer, author of the book *The Undying*<sup>17</sup> as an example of someone who, after acquiring enough information, requested and got a change in her treatment. They also note how Boyer references recently published articles which show that the side effects related to many women are in fact secondary to the chemotherapy treatment.

### Positive attitude, language and illness as learning

Except for *Tópico de câncer*<sup>18</sup> and *Te invito a un mojito*,<sup>16</sup> all books concur with the prevailing idea of illness as learning. The importance of a positive attitude is a clear message on all published illness narratives. Even though self-help books were excluded from the search, all the books analysed contain advice on diets, explanations of medical terms, exams and procedures. *Tópico de câncer* is the only one that crudely describes the author's ordeal through her treatment.

Even though the women interviewed do mention the fact that going through breast cancer has made them set their priorities more clearly, their call is for a space for all kinds of feelings and attitudes, not only the positive attitude that society in general, and most cancer associations in particular, ask from them. As MAD states, there should not be "publicly acceptable feelings a cancer patient can express"<sup>14</sup> and there should not be standardised ways of behaving. Women recalled being uncomfortable with people who minimised their symptoms ('but this is just like a bad cold'), told them stories about women who "went to and back from chemotherapy on their bicycles" and those who insisted on the power of a good attitude towards healing. S says, "the diagnosis of breast cancer comes with rage, anger and fear, and words like 'do not worry', far from helping me, make me angry; feeling unwell must be destigmatised". ML states that "an

illness like this is not inspiring or beautiful, it is s\*\*\*, but we have to accept it".<sup>16</sup>

SK's favourite place is the bathtub: "where I do not have to speak or look courageous. Where I do not have to have a plan for the future, for when we have defeated the bug. Where I don't have to keep a stiff upper lip".<sup>18</sup>

ML and PD,<sup>16</sup> as well as S, join the quest against metaphors of war; it is not because you are a 'warrior or a she-hero' that cancer is cured; using this type of language is very unfair to the women who do not experience successful treatment and puts the blame on them. "You would never ask a person with a diagnosis of syphilis or diabetes to have a positive attitude" (PD). ML highlights the importance of the word chosen: "Don't tell me I have a 'good cancer', no cancer is good, and you don't 'tiptoe through cancer', as a friend told me". She and PD made their diagnosis public on social networks in an effort to normalise illness and as part of their campaign to stop the victimisation of patients with cancer. Not all agree with this concept, as others (A and C) feel they will always be oncological patients and will live forever with the fear of a new diagnosis of cancer. SK writes: "I feel the sword of Damocles hanging over me all the time".<sup>18</sup>

MAD writes: "I do not want to call it, as I once heard a millionaire doctor say, 'a mutilated breast'. This word connotes war, martyrs, complexes, and depression, which do not solve the problem. Mine is just a diminished breast, without tragedies surrounding it".<sup>14</sup>

The words preferred in these stories to refer to their illness trajectory were journey, a hurricane, a chain, baggage or the ascent of a mountain. However, the euphemisms used when referring to their tumours had mainly a negative connotation: 'the rat', 'the dragon', 'bug', 'the bug with the poisonous mouth' or 'f\*\*\*pea'. SK describes feeling like "Anne Boleyn on her way to the gallows" before her oncology consultations.<sup>18</sup>

## DISCUSSION

Novels and autobiographies contain valuable information about the ways people with cancer make sense of their illness and treatments.<sup>19</sup> Nevertheless, writing or talking about illness is not viewed favourably within Spanish society, and 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.

Nonetheless, 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 transsexual people affected by breast cancer.<sup>5</sup> 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".<sup>14</sup> 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.<sup>20</sup> 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>21</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,<sup>22</sup> 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>23</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 as remembrance of the journey they had gone through. In Spain, each year around 16 000 mastectomies are performed, but only 4800 women opt for a reconstruction.<sup>16</sup> 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 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".<sup>23</sup> There is still a medical discourse coming from different healthcare scenarios that encourages women to "look better for their husbands" and believes that "you will feel better if you look better", and where the decision for reconstructive surgery is based mainly on aesthetic reasons<sup>24</sup>; 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; this resonates with the findings of a meta-analysis by Sun *et al* regarding the impact of losing a breast in women who survived breast cancer.<sup>25</sup>

Recent studies are looking at the effects of chemotherapy on cognitive function and of the appearance of chronic fatigue.<sup>26–29</sup> We hope that healthcare professionals take this information into account when choosing treatments, and that they validate these women's symptoms.

As evidenced by our findings, there is still a trend towards the belief that a positive attitude is an important ingredient for healing. We are aware of the risk postulated by Solbraekke and Lorem<sup>9</sup> of perpetuating the 'gold standard' of cancer survivorship, and agree with Nielsen's<sup>30</sup> comment to 'resist calls for hope and courage'. Even though positive thinking can be helpful, "mandating it often silences and induces shame".<sup>29</sup> After this preliminary analysis, new stages for the research will be developed, including interviewing more women, from diverse cultural and social backgrounds, focusing the interviews on more specific themes of research, and including third person illness narratives. We expect to learn about the experience of carers, but also to give voice to breast cancer journeys that concluded in death, and those of women suffering from metastatic breast cancer. The analysis of other type of narratives, which move to a more systematic consideration of the place of illness narratives in promoting cultural change and a shift in medical discourse could broaden the findings of this research.

In a study on illness perceptions of breast cancer in Ghana,<sup>6</sup> the majority of women interviewed relied predominantly on religious faith and spirituality as key coping mechanisms and mentioned illness being a test from God. The theme of spirituality was not present in any of the narratives analysed for this paper. This is an example and a strong argument for the importance of developing culture-specific narrative research and implementing the Medical Humanities in medical practice,<sup>31</sup> as the proposed interventions for Ghana are not applicable for other settings, as in this case, Spain.

Even though metaphors of war prevail, the illness narratives analysed showed that there is a trend towards language that does not blame the person. That being said, the negative connotation attributed to illness, and specifically cancer, is still present in the euphemisms used to describe the tumours.

It is important to mention that the women interviewed were thankful for having an opportunity to

speak out about their cancer and share feelings or thoughts they had never shared with other people. This falls in line with the narrative-based approach to medicine, which suggests that telling their story is a way for patients to regain control and thus "diminish the sense of helplessness, marginalisation and isolation that are inevitable aspects of serious disease".<sup>21</sup> These women were also happy to contribute with advice for a better person-centred approach to medicine, with the hope that uncomfortable situations that they had to face, will not happen to other women again.

## CONCLUSIONS

As shown in this article, a narrative-based medicine approach using the analysis of illness narratives, both from published books and from interviews could be used in clinical practice, research and education to promote healing.<sup>32</sup> When used with women who have been diagnosed with breast cancer, it can give us clues on the diverse ways people cope with side effects of chemotherapy and surgery and the different needs and priorities that are considered in decision making; they give a space for their voices to be heard, and for their advice to be incorporated into healthcare interactions.

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**Acknowledgements** The authors would like to thank all the women who have participated in the interviews. Maria Forero, for her editing advice. Professor Neil Vickers, for his revision and comments on the final draft of the manuscript.

**Contributors** NMF is responsible for the overall content of this article.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Consent obtained directly from patient(s).

**Ethics approval** This study was approved by Ethics Committee of Universidad Rey Juan Carlos, Spain (internal number 0803202106921). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information.

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