

# Mirroring, monitoring, modelling, belonging, and distancing: Psychosocial processes in an online support group of breast cancer patients

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## Abstract

Breast cancer patients are primary users of Internet Health Forums, virtual self-help communities where they find and share information, preoccupations, and support. Previous literature has mainly focused on analysing the contents and the outcomes of breast cancer forums' participation. In light of the Community of Practice theoretical model, our research investigated the psychosocial processes that build and shape patients' experience and participation in the forum. We conducted 16 semi-structured email interviews with breast cancer patients recruited within a well-established online community. Thematic analysis identified five processes—mirroring, monitoring, modelling, belonging, and distancing—that marked three phases of users' experience: initiation, participation, detachment. An interactive dynamic characterised the identified processes: the disease's experience was shaped by and, in turn, it crafted this virtual community. These community processes contributed to participants' empowerment at practical, informative, and emotional levels through the development of a shared repertoire of resources, stories, and ways of dealing with patients' recurring problems.

## KEYWORDS

cancer survivors, community of practice, group processes, patient participation, self-help groups

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## 1 | INTRODUCTION

Internet Health Forums (IHF) are patients' support groups hosted within virtual platforms developed with the advent of Web 2.0 (Turner et al., 2011). These forums are organised in sections that relate to different topics. Users can write new contents, read what others have posted, intervene to discuss or present new topics to the group. In this way, IHFs allow the making of proper virtual communities (Demiris, 2006) where users produce and share information regarding difficulties, preoccupations, and doubts based on their knowledge and experience of a particular health topic.

IHF use has been growing remarkably in breast cancer patients (Falisi et al., 2017; Nagler et al., 2010). This growth is due to four concomitant factors. First, the number of people diagnosed with and surviving cancer has increased; a population needing a significant amount of both information and socio-psychological support (Batenburg & Das, 2014; Beaudoin & Tao, 2007). Second, the rising phenomenon of patient activism in managing their health problems, especially among chronic patients (Wright & Bell, 2003). For instance, the possibility of elaborating and sharing the personal history of illness with other users allows patients to develop tools and resources to deal with cancer, rather than passively suffering the disease and its treatment (Høybye et al., 2005). Third, the increasing importance patients attribute to the knowledge and the experience of people who face the same health problem. In IHFs, this experiential knowledge is produced and conveyed through patients' testimonies and by the answers that users provided to other users' questions (Ziebland et al., 2004). Fourth, online forums offer the opportunity of overcoming obstacles usually related to the use of face-to-face support groups: (a) geographical distances or physical limitations that prevent personal mobility, (b) the reconciliation of participant's life commitments, (c) the fixed cadences of meetings over a limited period. Next to these, anonymity and the continuous availability of support are relevant features of IHFs (Tichon & Shapiro, 2003; Vilhauer et al., 2010).

Previous studies analysed messages that breast cancer patients posted on forums showing that the wide variety of covered topics concerns pain, disease management, sexuality, menopause, and psychological support (Sharf, 1997). IHFs are, therefore, liberation spaces in which patients can address issues that they may not discuss in their daily social contexts (Sandaunet, 2008). However, Sandaunet also observed that this liberation experience is limited. Even in these virtual contexts, the dominant offline discursive model of the patient heroine fighting the disease tends to reproduce. The most significant dimensions of suffering related to the disease (e.g., its senselessness) do not appear in patients' discourses (2008).

The literature also highlighted that online social support groups' participation has beneficial psychological effects on breast cancer women. For instance, qualitative studies showed that users share social support and build a sense of community online, thus counteracting loneliness that accompanies cancer (van Uden-Kraan et al., 2008). Moreover, quantitative text analysis evidenced that, regardless of the stage of their disease, women mainly wrote posts to disclose their feelings and concerns about their social relationships rather than other issues, such as death and their health condition (Malloch & Taylor, 2019). Commenters embraced this action of disclosure in their answers by supporting these feelings and sharing theirs. Consequently, IHFs users create a dynamic of mutual understanding, resulting in empathy and a sense of similarity. Based on both post analysis and interview with forum users, other research similarly showed that, by sharing common health-related experiences, members of breast cancer forums developed empathy and trust over time (Hargreaves et al., 2018; Lovatt et al., 2017). Some studies highlighted that participation in these groups allows for information support about the disease's characteristics, evolution, and therapies, which can help patients develop a frame of their experience and foster their interactions with treating physicians (Bender et al., 2013). Another relevant area is the benefits of expressing and sharing one's emotions (Rodgers & Chen, 2005). For instance, longitudinal research showed that improvement is particularly relevant for patients with a low level of emotional coping and frequently benefit from online support (Batenburg & Das, 2014). Moreover, by analysing forums discourses, La et al. (2019) investigated how women who had refused breast reconstruction re-negotiate their new femininities. In this context, an internet forum is a space where a

minority of women can rebuild femininity and attempt to resist the female body's hegemonic representation, assigning a central role to the breast.

All these elements together suggest that participation in IHFs increases patients' ability to manage their disease and its consequences (Hong et al., 2012). However, some studies evidenced that disempowerment processes are also possible, linked in particular to the possibility of coming into contact with negative experiences of the disease or therapies experienced by other participants (van Uden-Kraan et al., 2008).

## 1.1 | Theoretical framework and research aim

The examined literature evidenced that IHFs are characterised by the three main features that—according to Lave and Wenger (1991)—define the concept of community of practice (CoP): the domain, the community, and the practice. In IHFs, the domain is a common area of interest concerning the illness, its consequences at various levels, and the relative remedies. The community refers to the occurring, prolonged interactions between forums' members, which facilitate learning from and with one other. The practice consists of producing a shared repertoire of resources, stories, and ways of dealing with patient's recurring problems. This model articulates a theory of learning as participation, a theory of meaning as the set of negotiated conventions shaping the communicative practices of its members, and a theory of identity as “a way of talking about how learning changes who we are and creates personal histories of becoming in the context of our communities” (Wenger, 1999, p. 5). In particular, identity is a central issue in breast cancer because patients can experience biographical disruption at the point of diagnosis and along the path of the illness up to the terminal stage of the disease (Hubbard & Forbat, 2012). In this regard, the CoP's model proposes a process-based approach to identity formation, which is neither individualistic nor merely societal (Wenger, 1999). For instance, the focus is on the mutual identity constitution by negotiating the meanings relating to the experience of membership in social communities. Moreover, this model offers a dynamic perspective on community building by identifying various stages of its development (potential, coalescing, active, dispersed, and memorable) characterised by different levels of interaction among the members and different kinds of activities (Wenger, 1998).

So far, literature on IHFs has shown the main benefits and drawbacks of taking part in these communities, but it has overlooked the study of their construction processes. For this reason, the present research aims to deepen the existing literature on the use of IHFs for patients diagnosed with breast cancer, investigating the psychosocial processes that characterise the experience and participation of users in the forum. In light of the CoP's model, we will focus on how these processes contribute to crafting the community and how they impact the illness experience and the participants' identity in the different phases that mark this experience.

## 2 | METHOD

This article followed the consolidated criteria for reporting qualitative research (COREQ).

### 2.1 | Recruitment

The research was conducted according to the case study approach (Yin, 2003). Qualitative case studies have proven their effectiveness in understanding the user involvement in community groups, and they have the potential to sensitise practitioners to more complex realities of voluntary action than suggested by quantitative approaches (Lindenmeyer et al., 2007). We contacted the administrators of the online forum “Dure come muri” (“Hard-as-Walls”), agreeing on the permission to post a message on the forum board. The message presented the research

aims and invited users to an interview about their experience with the forum. Hard-as-Walls was established on August 23rd, 2007, on the initiative of a patient. She opened this virtual space “Because talking helps”, as the subtitle of the forum indicates. It has almost 4000 members and is the most popular Italian forum dedicated to women who received a breast cancer diagnosis. The platform has five main sections and many subsections: “Presentations”, where participants share their life and illness stories and initiatives they think might be of interest to other participants; “Breast cancer: types and treatments” in which users discuss topics related to the benefits and side effects of different therapies, including the alternative ones, and the topic of check-ups and prevention; “Surgery”, in which discussions explore the path and decision-making process leading to surgery, as well as the management of its consequences; “The Body and Mind”, where they discuss issues related to the impact of the disease on sexuality, family and friend relationships, and issues related to nutrition and aesthetics of the body, with a sub-section devoted to funny stories; “Patients’ rights”, where participants exchange advice on procedures for obtaining disability and exemptions as a result of their illness.

## 2.2 | Participants

We interviewed 16 Italian women (age: 32–63; mean = 48, see Table 1) who freely joined our invitation published on the forum. In this invitation, one of the interviewers introduced herself, briefly narrating her own indirect experience with this disease as the daughter of a patient. This was an expression of disclosure intended to indicate our interest in an authentic relationship with the participants. Some of the feedback we received even after the interviews—for example, the sending of photographs without hair to show patients’ appearance after chemotherapy or pictures of celebrations with their children —, were in our perspective indicators of a relationship with the

**TABLE 1** Characteristics of each participant

Code	Age	Marital status	Occupation	Children
A.	56	Single	Doctor	No
B.	59	Married	Teacher	Yes
C.	34	Engaged	Employee	No
D.	54	Married	Manager	Yes
E.	60	Married	Housewife	Yes
F.	40	Single	Employee	No
G.	63	Married	Housewife	Yes
H.	42	Engaged	Employee	No
I.	47	Married	Teacher	Yes
L.	33	Engaged	Employee	No
M.	46	Single	Manager	No
N.	40	Married	Employee	Yes
O.	51	Married	Librarian	Yes
P.	49	Single	Doctor	No
Q.	46	Married	Employee	Yes
R.	46	Engaged	Manager	No

participants characterised by openness and intimacy. Twelve participants were married or engaged; four were single; eight had one or more children. Fourteen of them had a job outside the home (employees, managers, doctors, teachers, librarians), two were housewives. All of them received a diagnosis of breast cancer: 13 had passed the treatment period and were undergoing checks, two had entered the postoperative phase of cancer management, one person was undergoing new treatment after the disease's reappearance years later.

### 2.3 | Data collection

We developed an ad hoc semi-structured interview based on previous literature and research's aims (the interview guide is available in the Supporting information area). The interview topics were articulated in five sections to explore each relevant aspect of the forum experience: (a) the expectations and the attractive elements of the forum (e.g., When you first encountered this forum, what interested you most?), (b) interest in topics' content (e.g., When you attend the forum, what kind of posts interest you most?), (c) the participants' contributions in the forum and the obstacles in the writing process (e.g., Have you ever written a message but then decided not to publish it?), (d) the representations of the other users (e.g., If you were to describe the typical participant in this forum, what would you say?), (e) the role of the platform in the management of the disease and critical issues related to its use (e.g., How important is the forum in your life?). We collected participants' socio-demographic data at the end of the interview.

The interviews were conducted by email by Author 1 and Author 4. Author 1 has a PhD in Psychology and is a university professor in social psychology; he teaches a Master course in Qualitative methodologies and has extensive research experience in the field. Author 4 was at the time attending an MSc in Psychology of social and economic processes. During her programme, she had received training in conducting and analysing qualitative interviews. They had no previous relationship with participants.

Each participant received a welcome message with a description of the research aims, as already presented on the "Hard-as-Walls" forum, and the request to sign the informed consent. After sending the consent, interviewees received the first section of questions. After submitting the answers, we sent a new email containing new questions to deepen previous answers and investigate the following section. We repeated this procedure for each of the five sections in the interview's topic guide. Emails allow the interviewees to reflect well on each issue and generate in-depth data; they also make it possible to monitor the participants' self-disclosure and develop interpretative hypotheses based on their answers, guiding the conduct (Burns, 2010). All the interviews were completed within a month since the first email.

### 2.4 | Ethics

Ethical approval was obtained from the ethical committee of our University. Written informed consent was obtained from all participants.

### 2.5 | Data analysis

The data analysis was conducted according to Braun and Clarke's Thematic Analysis framework (2006). The process was developed through six phases: (1) familiarisation with the data through repeated readings, which were carried out as the participants' email responses arrived; (2) inductive generation of the initial codes by tagging and naming selections of text with the aid of N-Vivo software; (3) incorporation into themes of all codes relevant to the research question; (4) revision of the collated extracts for each theme, to consider whether they formed a coherent pattern and if the resulting themes were characterised by heterogeneity compared to the other themes; (5) final

definition and nomination of the themes. A further rereading of all interviews allowed us to verify whether the identified themes were recognisable in the transcripts and ensure that all salient themes had been identified; (6) report production, selecting transcripts based on their representativeness and relevance to the themes. Along the overall process, the research group discussed each code and theme. All the data were analysed in their original language, Italian. The quotations reported in this article were first translated from Italian to English and then reviewed to ensure equivalence of meaning. Participant anonymity was protected by using code numbers.

### 3 | RESULTS

The analysis identified five interrelated processes that structured the active participation and experience of users with the forum and the formation of this community of practice: *mirroring*, *monitoring*, *modelling*, *belonging*, *distancing* (Table 2). As a whole, they allowed participants to learn how to face and positively manage the main issues related to their illness: the biographical destruction and the consequent development of a “new” identity in the interaction within this community of practice (Trusson et al., 2016), the disappearance of meaningful social relationships, the need to find motivations and personal resources to deal with illness and treatment. An interactive and double dynamic characterised these processes in light of the CoP model (Wenger, 1999). First, the user’s

**TABLE 2** Themes, definitions and representative quotations

Name of the theme	Definition	Quotations
Mirroring	A process of identification with the forum starting when patients discover people experiencing the same vicissitudes, needs, and destiny	“You find yourself wandering around the Internet, reading everything, you get scared and try to reassure yourself, you read others’ diagnoses, statistics of healings, of deaths... a madness. In the middle of all this, I found the forum. I was attracted by the fact that I found people like me, as scared as I am, as lonely as I am, people who ask for help and you can ask them for it”
Monitoring	A process characterised by continuous reflexivity over the consequences of patients’ behaviour in the forum and the quality of their relationships	“Several times I wrote and then deleted, a sentence can be interpreted differently by others, we are already scared, so it is good to use much tact”
Modelling	A process taking place when patients made sense of their own illness experience by drawing on the example of stories, feelings, and situations shared in the community by other users	“Above all, you understand that if other people made it, you could make it too, so you do not give up. Not even when you feel like you are in an abyss!”
Belonging	A process stemming from the contrast between the sense of inclusion that participants experienced within the platform, and the lack of sharing and communion they talked about concerning the offline world	“In the forum, I feel free to write my emotions, also because those inside the disease have a different sensibility, while certain relatives I have... I do not recommend them to you”
Distancing	A process of slowdown in the forum’s participation, or a series of in-and-out movements from the forum	“The forum is useful for those who have to fight the disease, but once the treatment is over they should first disconnect and then come back to say that they are well and give hope to those who start the path”

experience is built through and with the community. Second, the community stems from users' participation, activities, and experiences. Therefore, the forum was a source and a result of patients' empowerment, being the recipient of each participant's increased skills.

The preponderance of these processes varied at different stages of the experience within the forum. *Mirroring* and *monitoring* characterised the participant's discourse concerning their discovery and first approaches with the community; even if they were not limited to this stage, their positive development was a precondition for satisfactory participation. *Modelling* and *belonging* characterised participation in the forum when users started posting their writings and interacting with others. Finally, *distancing* characterised the forum's separation; this process was not a closing detachment but rather a gradual and reversible taking distance from the instrument.

### 3.1 | The discovery and the first experiences with the forum

#### 3.1.1 | Mirroring

The Mirroring is a process of identification with the forum's participants, which started when patients discovered people experiencing the same vicissitudes, needs, and destiny. Therefore, this process allowed patients to develop an interest and take part in the community. As previous literature showed, the identity and relational destruction following the cancer diagnosis is marked by feelings of disorientation and anxiety followed by an active search for resources to dominate these feelings, providing information and reassurance (Høybye et al., 2005). In this context, the discovery of the forum had an immediate positive valence because the patient mirrored herself in other participants:

You find yourself wandering around the Internet, reading everything, you get scared and try to reassure yourself, you read others' diagnoses, statistics of healings, of deaths... a madness. In the middle of all this, I found the forum. I was attracted by the fact that I found people like me, as scared as I am, as lonely as I am, people who ask for help and you can ask them for it (H).

The mirroring process is based on and fulfils different patients' needs. First, the information needs, to overcome uncertainties and fears related to the course of the disease:

I was interested above all in the possibility of getting practical advice from those who had already lived the experience I was living. When everything is new, and you are frightened, you always try to understand as much as possible (F).

Second, the patient's needs to elaborate on what happened and give an identity to the disease and its effects. Indeed, stories of other patients were repositories of images and words related to cancer that favoured this meaning-making process:

Through the others, I could tell myself what I could not decipher and feel on my own. This identification in the other participants helped me reduce the fearful/anxious aspects, allowing me to "stay in them" without escaping, finding a way to relieve, heal, and stabilise (D).

Third, the mirroring process allowed the development of empathic and supportive relationships so that the patients can overcome the loneliness they feel and face the disease positively:

In the forum, you can confront those who know what we are talking about and the same sentence (e.g.: "Your hair will grow back!") has an entirely different meaning if it comes from a "companion of misfortune" or from a healthy friend, even if she has the best intention. The latter is not helpful to me, while the first is an injection of confidence (Q).

The mirroring process's importance also emerged when participants discussed the possibility of doctors participating in the forum. All respondents believed that this would be a disturbing element because the forum's mission is to collect the stories of patients who share the same experience:

I would not recommend it to my doctor, and I hope he does not participate because I want to continue to feel completely free to express what I think... even on the healing path. There are 1000 other forums on the web where you can contact the expert, but our forum is a place for women affected by cancer who want to confront other women (P).

The last three extracts show that a significant consequence of this mirroring process is setting boundaries with others who do not live the same experience, like doctors and relatives.

Even if mirroring seems linked to different beneficial outcomes, some adverse effects also emerged in a minority of patients' narratives. For example, reading about the death of another participant led to think immediately about one's possible death: "Sometimes, it is hard because stories like yours ended badly. Furthermore, getting up every time a travelling companion dies is heart-breaking because you understand the grief of the relatives and imagine yourself in the same situation" (G).

### 3.1.2 | Monitoring

The monitoring process was characterised by continuous reflexivity over the consequences of patients' behaviour in the forum and the quality of their relationships. Monitoring is generated by patients' preoccupation of "being an outsider" or doing the wrong thing and involves a double gaze directed towards the self and the community. On the one hand, patients check whether they have the requirements for being part of the group. On the other, they reflect on their posts and the possible or actual reactions of the community.

Monitoring characterised even the decision to register in the forum, overcoming the disease's destructiveness and opening to a path of reconstruction:

It took me a while to subscribe to the forum even though I found it out almost immediately after the operation, in one of my endless internet searches. At first, I felt curious, but at the same time, I felt like an outsider. It takes some time to understand that the disease has "affected" you too, like many other women, and that they, like you, did not expect it (B).

Another issue the participants reflected at length concerned the publication of their presentation message to the other users. For instance, this represented a further step towards awareness of the existence of cancer, and patients felt so fragile that a rejection or negative response from the community could throw them into despair:

I remember not telling my story right away, I was afraid, then when I saw my message published I was happy because I did not feel lonely anymore, I had the support of many friends who understood me without too many explanations (A).



To reflect on one's message also meant to be worried about the potentially disempowering effects on other users of the posts that participants intended to publish: "Several times I wrote and then deleted, a sentence can be interpreted differently by others, we are already scared, so it is good to use much tact" (E).

## 3.2 | The time of interaction in the forum

### 3.2.1 | Modelling

Modelling occurred when patients made sense of their own illness experience by drawing on the example of stories, feelings, and situations shared in the community by other users. Therefore, patients anchored and crafted their experiences to fit the models offered by the community. For example, the stories of other women provided concrete examples of how social stigma and stereotypes related to the disease can be addressed:

Participation in the forum has helped me a lot, in a moral sense. I have seen many girls in my situation, even often in worse situations, who try not to lose heart and react to the fear and sense of "shame" and diversity caused by the disease (L).

These positive models, therefore, functioned as empowerment resources. Through the idea of possible recovery from illness or the desire to regain a dimension of "normality" in life, these models helped patients to restore hope: "The best thing is to read that many girls, despite cancer, wanted another chance. The hope of a normal life beyond cancer" (N).

Second, modelling motivated patients to cope with the difficulties of their treatment: "Above all, you understand that if other people made it, you could make it too, so you do not give up. Not even when you feel like you are in an abyss!!!!" (I). On the other hand, the disappearance of such positive models determined disempowerment. For instance, the respondents avoided reading the messages of those users who did not survive: "I would not have wanted to read one of the last messages of a woman who died (...) I was hurt by that direct testimony of the moment in which strength and hope are definitively lost" (F).

### 3.2.2 | Belonging

While interacting in the forum, patients developed a sense of belonging which stemmed from the contrast between the sense of inclusion that participants experienced within the platform, and the lack of sharing and communion, they talked about concerning the offline world: "In the forum, I feel free to write my emotions, also because those inside the disease have a different sensibility, while certain relatives I have... I do not recommend them to you" (R).

Belonging fulfils both relational and emotional needs. On the relational side, belonging helped to face and overcome the loneliness that followed the destruction of relationships caused by the disease. It does so by offering a new network of relationships: "The forum is for feeling less lonely, as the subtitle of the forum says, 'talking help', and those who have cancer need so much help" (B).

These positive relational experiences developed a sense of community among users; indeed, to describe the forum, the interviewees used metaphors such as a "big family", a "house", "a virtual square": "The forum is the virtual square where so many good things happened: birthdays, births, miracles..., sometimes some quarrels" (E).

On the emotional side, the sense of belonging to the community allowed the participants to find the support they need to face the challenges and difficulties of the disease: "You are so fragile at certain times that a good word or more than one, as happens in the forum, warms your heart" (O).

Since patients started writing in the forum, introducing themselves and telling their experience, they received immediate support from other participants. That way, the community expressed encouragement and solidarity to the new user, and she felt immediately welcomed: "I told them how I discovered the 'peanut' (the tumour)... and that when it happened, I was married for two months!!! I felt welcomed by all, and today I would rewrite the same things!" (C).

The impact and relevance of this process were also recognised by the users themselves, who, in turn, activated to offer emotional and motivational support to others: "I greet the new members... I try to give them some courage or at least make them find within themselves the strength that I have found thanks to this forum" (M). The empathy and support that users received were, therefore, a source of personal motivation, which made possible the development of a new identity, from "desperate women" to "hard-as-walls women", as the name of the forum itself, produced as a lived experience of participation in that community: "At first, we are desperate women because the world fell on us, then we become HAW (hard-as-walls), we give strength to each other, and we realise that we are much stronger than we thought..." (I).

Two features of the forum facilitate this belonging process. First, the anonymity of the interactions on the platform. Anonymity favours sharing as users feel freer to express themselves on embarrassing topics or on issues that they feel unable to discuss with their doctor: "The forum allows talking, sometimes even discussing, confronting each other, in a completely anonymous way, it leaves complete freedom of expression, also to address more delicate issues (sexuality, love) or more unpleasant ones (the fear of death)" (L). The second feature is that the forum is available 24/7; it can offer constant support and a sense of connection and is, therefore, closer to the patients' needs and times:

It is a space where a patient can search and find closeness to face the new loneliness caused by the illness. There is no long wait, someone answers you, someone is there, your despair does not rumble in your head, it will find a way out. In the forum, you can always find other women to tell your story to (D).

The sense of belonging did not cease when the acute phase of the illness was overcome or when treatment ended. Indeed, the forum was a space to keep sharing reflections on the disease, unlike in the offline world. Indeed, in the experience of our participants, relatives and friends were not willing to embrace their desire to keep reflecting on the disease and its consequences, or they explicitly delegitimised it: "Only on the forum, I can keep talking about the disease, without being accused by others of 'being obsessed'" (P).

### 3.3 | The time of separation

#### 3.3.1 | Distancing

Despite the importance of the forum, at some point, users felt the pressure to start distancing from this virtual community. The distancing process did not take the form of a clear cut, but it was a slowdown in the forum's participation or a series of round-trip movements characterised it. The latter depends on the evolution of disease or therapies and on the desire to rediscover normality in life: "Then, slowly, a little detachment is necessary. Otherwise, all you can think about is cancer. Furthermore, cancer becomes your life. You always think about it, too much, and you do not take your life back" (N).

Distancing did not imply a definitive abandonment of the forum; for some participants this was a tribute to its importance in their path of illness, others mentioned the importance of offering a positive model to those participants who just got a diagnosis or were facing a recurrence:

Now I would like to add one more thing: the forum is useful for those who have to fight the disease, but once the treatment is over they should first disconnect and then come back to say that they are well and give hope to those who start the path... (G).

## 4 | DISCUSSION

The research objective was to identify the psychosocial processes that characterised the experience of participating in an online breast cancer support group, theoretically framed as a community of practices involving people with a common domain of interests and problems related to their illness and its consequences (Wenger, 1999). In light of our theoretical model, these processes can be considered different forms of community participation which generate specific identity outcomes.

Our analysis identified five processes: mirroring, monitoring, modelling, belonging, and distancing, which developed along with three phases of the experience—initiation, full participation, detachment. Different stages in the users' forum experience were also identified in a study that analysed socialisation in an online community of breast cancer patients (Rubenstein, 2015). Rubenstein described three phases within what he called the cycle of identification with the community. An introductory phase, allowing newcomers and established participants to appraise each other, an acclimation phase into the community's social practices, and a phase in which participants became key members able to mentor others. This evidence also resonates with the CoP model, which highlighted the presence of a processual dynamic of different typical activities in five phases of the community development: potential, coalescing, active, dispersed and memorable (Wenger, 1998).

Mirroring and monitoring characterised the initial approach to the forum, even if they were not limited to that first phase. Mirroring was particularly relevant to the respondents' need for information, which has also emerged in other studies (Frigerio & Montali, 2015). In the forum, patients legitimated their doubts and questions as the other participants raised the same issues. At the same time, participants considered adequate the answers they got because the forum's posts were written by those who have lived the same experience (Barton, 1999). Our data confirm—even in this virtual health community—the value of experiential knowledge, widely recognised by health research on self-help communities (Mazanderani et al., 2012). To preserve this experiential knowledge shared by patients, respondents emphasised that participation in the forum should be reserved for those who live their illness experience and not, for example, physicians. When describing their posts in the forum, they explained that they only wrote about situations they knew well for having experienced them. Therefore, our data did not show a challenge to the hegemony of the medical discourse, but the affirmation of a consensual knowledge's value and specificity (Moscovici, 1988), elaborated in the interaction between peers from one's own experience. The discovery of shared repertoires within the community enabled shaping and defining the disease and its consequences, first and foremost on an emotional level. Mirroring oneself in the emotions and discomforts narrated by the other participants allowed participants to normalise their feelings, a prerequisite for the process of identity reconstruction that characterises cancer patients (van Uden-Kraan et al., 2008). These communicative dynamics were also the basis for building satisfying relationships within the forum, one of the most critical cancer patients' needs (Høybye et al., 2005). The understanding between participants was once again attributed to having the same problems and living the same experiences. Therefore, the mirroring was a process crafted by a double-sided dynamic aimed at negotiating community (Wenger, 1998). On the one hand, an identification one stemming from the common ground shared with other patients. On the other, a differentiation one, that creates boundaries and excludes outsiders, as physicians, relatives, and friends (Frigerio & Montali, 2015).

The monitoring process aimed to identify the right ways to participate in the community, a typical activity of the initial coalescing phase of the CoPs (Wenger, 1998). In this sense, the decision to introduce oneself in the forum and narrate one's own experience resulted from a laborious reflection process in which the patients' uncertainty

about their behaviour and their psychological vulnerability were visible. At first, participants were very cautious when writing on the forum to avoid hurting or creating a concern for the other participants, an attitude confirmed by previous studies that described the “kindness” of the users of these forums (Kinnane & Milne, 2010). Later, through participation in the community, they learned about the accepted conventions directing the communicative practices of the community members and how to use the power of narratives to shape the illness experience and convey it a meaning (Bird, 2007).

In the mirroring and monitoring processes, participants kept a double gaze on themselves and the community. On the one hand, after identifying themselves with a community, members were concerned with understanding whether they were in the right place or behaved in the right way. On the other, being new members, they needed to understand and learn the system of values, practices, and community norms. For this reason, the monitoring process had the function of continually checking users about their identities and behaviour. Therefore, it was the experiential/subjective dimension of a group process that concerned the initiation of new members and the negotiation of their membership. The monitoring process was the condition for positive experiences and interactions in this virtual community by attuning each participant with the community.

Modelling and belonging characterised patients' participation, particularly when they acted as full members involved in developing a practice with others. The testimonies of more experienced community participants offered paradigmatic trajectories and were perceived as “living testimonies to what is possible, expected, desirable” (Wenger, 1998, p. 156), favouring the patients' empowerment as other studies on online groups showed (Hong et al., 2012). In this regard, some authors point to the multidimensional nature of the construct by distinguishing different types of empowerments: an informational one that increases patients' subjective understanding of cancer treatment, an emotional one, that maintains hope and discover positive aspects of their situation, and a practical one that increases their self-efficacy (Kim et al., 2012; Rini et al., 2007). In our study, participation had empowering value on all these three levels. By reading other users' messages about decisions, treatments, consequences, and coping strategies, patient discovered sources of hope and concrete suggestions for behaviour (Mundell et al., 2012) and had the opportunity to deal with the disease in a more combative way (Gustafson et al., 1999). For this reason, those who participate in online resources and share the same illness or have survived it feel less stressed, tell each other freely and are more optimistic about life (Fogel et al., 2002; Høybye et al., 2005). These positive models also helped with addressing the stigma that some interviewees reported. They embody the possibility of overcoming shame and liberating patients from social conditioning (Heaton, 2011). Moreover, as other studies noted, the modelling process's function is to adopt the community's grammar to become a competent member (Mason-Schrock, 1996).

Belonging to the online community, favoured by the forum's anonymity, also offered a refuge from the loss of social ties in the physical world due to the disease (van Uden-Kraan et al., 2008). Users learned to express themselves about embarrassing topics or themes they would not talk about with their doctor in the forum. Sharing was all the more relevant, the more significant the loneliness experienced in the outside world. The work of engagement in the community favoured constructing a new collective sense of self, which took shape in the transformation from desperate women to “as Hard-as-Walls women”, from the forum's name, having a relevant motivational effect. The research also showed the forum's higher potential to favour new relationships than the groups of patients who meet live. The latter requires a lot of energy and time, a problem for patients who often face interventions and chemotherapies, which stress both body and mind. So, the forum can offer “cyber-support” (Sharf, 1997) and a constant sense of connection because there is always someone available to listen and respond. This feature helped patients manage crises because they knew that someone was online to help them in case of need (Vilhauer et al., 2010). Some studies have shown differences in how people use virtual resources to build new relationships (Gatti & Procentese, 2020). If the needs to be met are only those of maintaining and developing relationships, people will tend not to meet in person. Conversely, if users have a local focus and wish for more local acquaintances and interactions, these resources are associated with a greater frequency of face-to-face meetings. In our virtual community, some participants got in contact with associations of patients or other self-help groups

but none of them attended them for a long time. This situation was explained by referring to the problem of joining such groups living in a small town - since they tend to be in large cities-, and to the difficulty of reconciling that commitment with the work and family load in the situation of fatigue determined by the treatment of the disease. On the other hand, as emerged in relation to the monitoring process, the forum allows for writing posts with calm, rereading and correcting them before final posting. These actions are made possible by the forum's a-synchronicity, facilitating a greater reflection in participants (Lewinson, 2005). People, in fact, tend to feel more comfortable when writing, for example, about painful events rather than when talking about them. This is because writing allows them to take time to reflect and, for this reason, it also fulfils a therapeutic function (Pennebaker, 1997). The latter is also fulfilled by online patient support groups, which exhibit a greater level of expression of emotional support, empathy, and "self-disclosure" than face-to-face self-help groups (Heaton, 2011, p. 218).

Despite these positive aspects, both previous studies (Batenburg & Das, 2014) and our interviewees highlighted the risk that mirroring, modelling, and belonging could also have disempowerment effects. This consequence occurred when participants faced stories of patients who had had a relapse in the disease. When this happened, users tended to avoid such messages as they were afraid to see their future foreshadowed, an emotional challenge too demanding for their fragile new identity of "cancer survivors" (Anunziata et al., 2009).

Distancing, finally, is the process that characterised the phase in which patients reduced their participation in the forum or left it; it describes a series of round-trip movements rather than definitive abandonment. In this phase, participants can return to the forum from time to time to greet new users and offer their experience. This result confirmed that the support groups' empowerment also depends on the participants being able to provide help and not just receive it (van Uden-Kraan et al., 2008). Offering support can indeed help to reframe one's problems in a positive light or adopt positive strategies for coping, so prosocial effects of supportive interaction can flow from the provider to the recipient and vice versa among group members (Kim et al., 2012). Still, our participants showed no need to transform their personal experiences into social and political issues, differently from other studies that analysed self-help groups meeting in person (Brown et al., 2004). Instead, they explained their need to detach themselves from the forum, with the desire not to be absorbed into the sick role giving space to their other roles of woman, worker, mother or grandmother.

## 4.1 | Limitations and conclusion

We highlight the main limitations of the present research. First, all the recruited women freely joined an invitation published on the "Hard-as-Walls" forum. This recruitment method could have prevented some women from partaking in the present research (e.g., people participating with less engagement or who had a negative experience in the IHFs). Moreover, recruiting ex-members would have added insights on a possible process of conclusion. This could be prevented by using a gatekeeper to recruit people or employing a snowball sample technique in future research. A second issue concerns our data collection method. Conducting interviews by email has many advantages (e.g., less time consuming, no biases in transcription). Still, it may have limited the exploration of some sensitive topics, which may require face-to-face interaction and allowing the presence of empathy. Finally, even if the authors conducted the analysis separately, the identification of psychosocial processes could have been influenced by researchers' bias (e.g., common education background).

Despite these limitations, the present research shed light on the different stages that characterise the experience of IHFs among breast cancer patients: *initiation*, *participation*, and *detachment*. Five psychosocial processes structure these different stages and create a virtual community of practices involving people with a common domain of interests and problems related to illness and its consequences: *mirroring*, *monitoring*, *modelling*, *belonging*, and *distancing*. These results contribute to enrich the literature that has focused mainly on themes of discussion and outcomes of IHFs participation. Moreover, confirming previous studies, they show that the most significant potential of these online forum communities lies in the fact that they offer cyber support always available and easily

accessible, an essential element for patients who are often facing situations with high impact of psychological and physical stress. These results can be extended and deepened by exploring the experience of IHFs made by patients with different diagnoses.

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## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1002/jcop.22696>

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## REFERENCES

- Anunziata, M. A., Muzzati, B., Bianchet, B., Berretta, M., Chimienti, E., Lleshi, A., & Tirelli, U. (2009). Sopravvivere al cancro: una rassegna sulla qualità di vita nella cancer survivorship. *Psicologia Della Salute*, 55–71. <https://doi.org/10.3280/PDS2009-003004>
- Barton, E. (1999). Informational and interactional functions of slogans and sayings in the discourse of a support group. *Discourse & Society*, 10(4), 461–486. <https://doi.org/10.1177/0957926599010004002>
- Batenburg, A., & Das, E. (2014). Emotional coping differences among breast cancer patients from an online support group: A cross-sectional study. *Journal of Medical Internet Research*, 16(2), e28. <https://doi.org/10.2196/jmir.2831>
- Beaudoin, C. E., & Tao, C. -C. (2007). Benefiting from social capital in online support groups: An empirical study of cancer patients. *Cyberpsychology & Behavior*, 10(4), 587–590. <https://doi.org/10.1089/cpb.2007.9986>
- Bender, J. L., Jimenez-Marroquin, M. C., Ferris, L. E., Katz, J., & Jadad, A. R. (2013). Online communities for breast cancer survivors: a review and analysis of their characteristics and levels of use. *Supportive Care in Cancer*, 21(5), 1253–1263. <https://doi.org/10.1007/s00520-012-1655-9>
- Bird, S. (2007). Sensemaking and identity: The interconnection of storytelling and networking in a women's group of a large corporation. *Journal of Business Communication*, 44(4), 311–339. <https://doi.org/10.1177/0021943607306135>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of Health and Illness*, 26(1), 50–80. <https://doi.org/10.1111/j.1467-9566.2004.00378.x>
- Burns, E. (2010). Developing email interview practices in qualitative research. *Sociological Research Online*, 15(4), 24–35. <https://doi.org/10.5153/sro.2232>
- Demiris, G. (2006). The diffusion of virtual communities in health care: Concepts and challenges. *Patient Education and Counseling*, 62(2), 178–188. <https://doi.org/10.1016/j.pec.2005.10.003>
- Falisi, A. L., Wiseman, K. P., Gaysynsky, A., Scheideler, J. K., Ramin, D. A., & Chou, W. S. (2017). Social media for breast cancer survivors: a literature review. *Journal of Cancer Survivorship*, 11(6), 808–821. <https://doi.org/10.1007/s11764-017-0620-5>

- Fogel, J., Albert, S. M., Schnabel, F., Ditkoff, B. A., & Neugut, A. I. (2002). Internet use and social support in women with breast cancer. *Health Psychology, 21*(4), 398–404. <https://doi.org/10.1037/0278-6133.21.4.398>
- Frigerio, A., & Montali, L. (2015). An ethnographic-discursive approach to parental self-help groups. *Qualitative Health Research, 26*(7), 935–950. <https://doi.org/10.1177/1049732315586553>
- Gatti, F., & Procentese, F. (2020). Being involved in the neighborhood through people-nearby applications: A study deepening their social and community-related uses, face-to-face meetings among users, and local community experience. *CEUR Workshop Proceedings*, 2730.
- Gustafson, D. H., McTavish, F. M., Boberg, E., Owens, B. H., Sherbeck, C., Wise, M., Pingree, S., & Hawkins, R. P. (1999). Empowering patients using computer based health support systems. *Quality and Safety in Health Care, 8*(1), 49–56. <https://doi.org/10.1136/qshc.8.1.49>
- Hargreaves, S., Bath, P. A., Duffin, S., & Ellis, J. (2018). Sharing and empathy in digital spaces: Qualitative study of online health forums for breast cancer and motor neuron disease (Amyotrophic Lateral Sclerosis). *Journal of Medical Internet Research, 20*(6), e222. <https://doi.org/10.2196/jmir.9709>
- Heaton, L. (2011). Internet and health communication. In M. Consalvo & C. Ess (Eds.), *The handbook of internet studies* (pp. 212–231). Blackwell.
- Hong, Y., Peña-Purcell, N. C., & Ory, M. G. (2012). Outcomes of online support and resources for cancer survivors: A systematic literature review. *Patient Education and Counseling, 86*(3), 288–296. <https://doi.org/10.1016/j.pec.2011.06.014>
- Hubbard, G., & Forbat, L. (2012). Cancer as biographical disruption: Constructions of living with cancer. *Supportive Care in Cancer, 20*(9), 2033–2040. <https://doi.org/10.1007/s00520-011-1311-9>
- Høybye, M. T., Johansen, C., & Tjørnhøj-Thomsen, T. (2005). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology, 14*(3), 211–220. <https://doi.org/10.1002/pon.837>
- Kim, E., Han, J. Y., Moon, T. J., Shaw, B., Shah, D. V., McTavish, F. M., & Gustafson, D. H. (2012). The process and effect of supportive message expression and reception in online breast cancer support groups. *Psycho-Oncology, 21*(5), 531–540. <https://doi.org/10.1002/pon.1942>
- Kinnane, N. A., & Milne, D. J. (2010). The role of the internet in supporting and informing carers of people with cancer: A literature review. *Supportive Care in Cancer, 18*(9), 1123–1136. <https://doi.org/10.1007/s00520-010-0863-4>
- La, J., Jackson, S., & Shaw, R. (2019). 'Flat and fabulous': Women's breast reconstruction refusals post-mastectomy and the negotiation of normative femininity. *Journal of Gender Studies, 28*(5), 603–616. <https://doi.org/10.1080/09589236.2019.1601547>
- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge University Press.
- Lewinson, J. (2005). Asynchronous discussion forums: A closer look at the structure, focus and group dynamics that facilitate reflective thinking. *Contemporary Issues in Technology and Teacher Education, 5*(1), 93–115.
- Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R., & Aitchison, G. (2007). Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: A qualitative case study. *Health Expectations, 10*(3), 268–277. <https://doi.org/10.1111/j.1369-7625.2007.00451.x>
- Lovatt, M., Bath, P. A., & Ellis, J. (2017). Development of trust in an online breast cancer forum: A qualitative study. *Journal of Medical Internet Research, 19*(5), e175. <https://doi.org/10.2196/jmir.7471>
- Malloch, Y. Z., & Taylor, L. D. (2019). Emotional self-disclosure in online breast cancer support groups: Examining theme, reciprocity, and linguistic style matching. *Health Communication, 34*(7), 764–773. <https://doi.org/10.1080/10410236.2018.1434737>
- Mason-Schrock, D. (1996). Transsexuals' narrative construction of the "true self". *Social Psychology Quarterly, 59*(3), 176. <https://doi.org/10.2307/2787018>
- Mazanderani, F., Locock, L., & Powell, J. (2012). Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science & Medicine, 74*(4), 546–553. <https://doi.org/10.1016/j.socscimed.2011.10.036>
- Moscovici, S. (1988). Notes towards a description of social representations. *European Journal of Social Psychology, 18*(January), 211–250.
- Mundell, J. P., Visser, M. J., Makin, J. D., Forsyth, B. W., & Sikkema, K. J. (2012). Support group processes: Perspectives from HIV-infected women in South Africa. *Qualitative Research in Psychology, 9*(2), 173–187. <https://doi.org/10.1080/14780887.2010.500350>
- Nagler, R. H., Gray, S. W., Romantan, A., Kelly, B. J., DeMichele, A., Armstrong, K., Schwartz, J. S., & Hornik, R. C. (2010). Differences in information seeking among breast, prostate, and colorectal cancer patients: Results from a population-based survey. *Patient Education and Counseling, 81*, S54–S62. <https://doi.org/10.1016/j.pec.2010.09.010>
- Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science, 8*(3), 162–166. <https://doi.org/10.1111/j.1467-9280.1997.tb00403.x>

- Rini, C., Lawsins, C., Austin, J., DuHamel, K., Markarian, Y., Burkhalter, J., Labay, L., & Redd, W. H. (2007). Peer mentoring and survivors' stories for cancer patients: Positive effects and some cautionary notes. *Journal of Clinical Oncology*, 26(1), 163–166. <https://doi.org/10.1200/JCO.2006.08.8567>
- Rodgers, S., & Chen, Q. (2005). Internet community group participation: Psychosocial benefits for women with breast cancer. *Journal of Computer-Mediated Communication*, 10(4), 00–00. <https://doi.org/10.1111/j.1083-6101.2005.tb00268.x>
- Rubenstein, E. L. (2015). "They are always there for me": The convergence of social support and information in an online breast cancer community. *Journal of the Association for Information Science and Technology*, 66(7), 1418–1430. <https://doi.org/10.1002/asi.23263>
- Sandaunet, A. -G. (2008). The challenge of fitting in: Non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociology of Health & Illness*, 30(1), 131–144. <https://doi.org/10.1111/j.1467-9566.2007.01041.x>
- Sharf, B. F. (1997). Communicating breast cancer on-line: Support and empowerment on the internet. *Women & Health*, 26(1), 65–84. [https://doi.org/10.1300/J013v26n01\\_05](https://doi.org/10.1300/J013v26n01_05)
- Tichon, J. G., & Shapiro, M. (2003). The process of sharing social support in cyberspace. *Cyberpsychology & Behavior*, 6(2), 161–170. <https://doi.org/10.1089/109493103321640356>
- Trusson, D., Pilnick, A., & Roy, S. (2016). A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Social Science & Medicine*, 151, 121–129. <https://doi.org/10.1016/j.socscimed.2016.01.011>
- Turner, A., Kabashi, A., Guthrie, H., Burket, R., & Turner, P. (2011). Use and value of information sources by parents of child psychiatric patients. *Health Information & Libraries. The Journal*, 28(2), 101–109. <https://doi.org/10.1111/j.1471-1842.2011.00935.x>
- van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research*, 18(3), 405–417. <https://doi.org/10.1177/1049732307313429>
- Vilhauer, R. P., McClintock, M. K., & Matthews, A. K. (2010). Online support groups for women with metastatic breast cancer: A feasibility pilot study. *Journal of Psychosocial Oncology*, 28(5), 560–586. <https://doi.org/10.1080/07347332.2010.504504>
- Wenger, E. (1998). Communities of practice: Learning as a social system. *Systems Thinker*, 9(5), 2–3.
- Wenger, E. (1999). *Communities of practice: Learning, meaning, and identity*. Cambridge University Press. <https://doi.org/10.1017/CBO9780511803932>
- Wright, K. B., & Bell, S. B. (2003). Health-related support groups on the internet: Linking empirical findings to social support and computer-mediated communication theory. *Journal of Health Psychology*, 8(1), 39–54. <https://doi.org/10.1177/1359105303008001429>
- Yin, R. K. (2003). *Case study research: Design and methods*. Sage Publications. <https://doi.org/10.33524/cjar.v14i1.73>
- Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., & Rozmovits, L. (2004). How the internet affects patients' experience of cancer: A qualitative study. *BMJ*, 328(7439), 564. <https://doi.org/10.1136/bmj.328.7439.564>

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