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“Waiting for breast reconstruction”: An interpretative phenomenological analysis of heterosexual couples’ experiences of mastectomy for breast cancer

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ABSTRACT

Purpose: Treatment decisions, such as breast reconstruction is made by the dyad patient-physician, but close others can have an influence on the process. Shared decision-making models include close others but current studies generally investigate physician-patient interactions only. Moreover, little is known about couples' interactions throughout the breast cancer journey and treatment decision-making. Thus, the aim of the present study was to explore couples’ experiences of mastectomy and breast reconstruction decision-making, the month following the mastectomy.

Method: Ten unstructured individual interviews, with five couples facing mastectomy for breast cancer, were conducted. A dyadic interpretative phenomenological analysis (IPA) was carried on the data set.

Results: Eight super-ordinate themes emerged from the data. Couples’ experiences were marked by the experience of the disease, the mastectomy and the impact they produced. The relationships with health professionals and partners were also important. Partners were not only supportive and protective, but directly (i.e., couples talk about treatments) and indirectly influenced (i.e., women make a decision taking into consideration how it will impact their couple) the women in their decision to have or not a breast reconstruction. The interpretative accounts underline how women and partners cope with the disease thinking about the aftertreatment.

Conclusions: This study explains for the first time how intimate partners influence breast reconstruction decision-making and how couples cope individually with the disease immediately after mastectomy. Health professionals need to involve partners more in the treatment decision-making process as the women consider and talks to them about the choices they have to make.

1. Introduction

The psychological impact of breast cancer treatments is well-known and described in the literature. Less is known about couples' interactions throughout the breast cancer journey (except in sexual difficulties) and treatment decision-making. Yet, Berg and Upchurch's model (2007) indicates how couples cope together and work as an interpersonal unit rather than two distinct individuals when they have to deal with a chronic illness. Several studies have confirmed these results (Bodenmann, 2005; Untas et al., 2012). A retrospective mixed study has specifically investigated couples' breast reconstruction (BR) decision-making process (Fasse et al., 2017; Lamore et al., 2016). The results of the thematic analysis showed how physicians were important in the decision-making and enlightened partners' roles in this choice (i.e., mostly consultative and supportive). However, the retrospective design and the method of data analysis does not give a clear explanation of how partners influence BR decision-making. Hence, the aim of the present study is to explore women and their male partners' experiences of mastectomy and BR decision-making the month following mastectomy using an interpretative phenomenological analysis (IPA; Smith et al., 2009). This approach could allow us to gain an in-depth understanding of couples' interactions at the time of mastectomy.

1.1. Mastectomy and breast reconstruction

Following a mastectomy, women can experience major difficulties, such as body image disturbance (e.g., feeling less feminine, feeling mutilated) (Davies et al., 2017; Kamińska et al., 2015; Piot-Ziegler et al., 2010), self-esteem issues (Heidari et al., 2015; Myungsun et al., 2016), fear, anxiety, or depressive symptoms (Chen et al., 2012;

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Myungsun et al., 2016), and social (e.g., feel isolated) (Chuang et al., 2017; Shrestha et al., 2012) or couple difficulties (more precisely, sexual difficulties) (Davies et al., 2017; Hummel et al., 2017; Rowland and Metcalfe, 2014). These difficulties are more prevalent after a mastectomy than a breast conserving surgery (Chen et al., 2012; Kamińska et al., 2015) or a mastectomy with BR (Fang et al., 2010; Zhong et al., 2016). A meta-synthesis conducted by Sun et al. (2018) also reported the negative experiences that come with losing a breast but underlined its positive impact as well. Women are able to find ways to cope with mastectomy and re-define themselves. BR is considered a surgical response to the psychological consequences experienced following a mastectomy (Markopoulos et al., 2009; Zhong et al., 2016) as it yields positive psychological effects and may contribute to women's well-being (De Ligt et al., 2019).

BR is a reconstructive surgery that can be performed at the same time as the mastectomy (i.e., an immediate BR) or several months after the mastectomy (i.e., delayed BR) due to adjuvant treatments (American Cancer Society and National Comprehensive Cancer Network [ACS-NCCN], 2006). Positive effects of a BR on psychological well-being, emotional and social functioning have been highlighted (Al-Ghazal et al., 2000; Harcourt et al., 2003; Lardi et al., 2013). However, several complications post BR were reported (e.g., pain, breast asymmetry, restricted physical mobility) (Browne et al., 2017; DellaCroce and Wolfe, 2013). Theses complications are generally linked to the technique used. Either implant or autologous reconstruction can be performed (DellaCroce and Wolfe, 2013).

1.2. Shared decision-making

Shared decision-making (SDM) is an international gold standard for treatment choice. It involves the physician and the patient and has three key elements: (1) sharing information, (2) providing support and (3) taking a shared decision (Ashraf et al., 2013; Charles et al., 1999). SDM in BR decision-making contributes to women's satisfaction in the choice made, reduces decisional conflict, and favors patient-physician interactions (Ashraf et al., 2013; De Ligt et al., 2019; Kuo et al., 2019; Potter et al., 2015). However, physicians usually lack the time or do not want to overload patients by giving them too much information (Charles et al., 2004; O'Brien et al., 2013). SDM in BR is also difficult to achieve for three main reasons: (1) medical factors play an important role in the choice (e.g. tumor size, general health condition, immunohistochemical characteristics) (ACS-NCCN, 2006), (2) physicians' lack of time to implement a SDM (Myungsun et al., 2016; Potter et al., 2015), and (3) women feel under-informed about BR options (De Ligt et al., 2019; Flitcroft et al., 2019; Myungsun et al., 2016; Potter et al., 2015). However, sharing information is the core of the SDM process (Ashraf et al., 2013; Charles et al., 1999). Thus, BR decision is generally left to physicians (Flitcroft et al., 2019; Mendick et al., 2010; Potter et al., 2015), but women feel highly involved in BR decision-making (De Ligt et al., 2019).

Moreover, models of SDM also include the family (Charles et al., 1997, 1999; Laidsaar-Powell et al., 2017; Légaré et al., 2011). Family members are thought to have an influence on the decision made pertaining to the treatment selected (e.g., through discussions with the patient or with the medical team). However, their influence on treatment decision-making is rarely investigated. Partners are the family member most involved in treatment decision-making and can have different roles (e.g., social support, translator) or influences (i.e., direct and indirect, positive and negative) (Lamore et al., 2017; Muhamad et al., 2011). For example, during medical consultations, partners can ask questions to obtain more information on treatment options and then discuss them with the woman. In BR decision-making, partners have a consultative and supportive role, respecting women's decision to have or not a BR (Fasse et al., 2017). Women believe that making the decision on their own is important but a majority of them (45%–84.2%) also believe that their significant other should be involved in it or want their opinion (Gilbar and Gilbar, 2009; Potter et al., 2015; Vargas et al., 2015). However, Duggal et al. (2013) found that 51.6% of women believe that their decision is not influenced by their relatives (friends, family, or partner) and that for 84.5% of women, their relatives' opinions have no impact on their choice to have or not a BR. Yet, compared to single women, women in relationships are more likely to undergo a BR (Agarwal et al., 2012; Sergesketter et al., 2019). These results underline the importance of better understanding partners' roles and influence in the BR decision-making process.

1.3. Couples’ interactions

After a mastectomy, women and men can experience sexual difficulties (e.g., reduced sexual desire or libido) (Davies et al., 2017; Gilbert et al., 2009; Marshall and Kiemle, 2005), communication difficulties (e.g., expressing their emotions) (Loaring et al., 2015; Marshall and Kiemle, 2005; Rowland and Metcalfe, 2014; Yu and Sherman, 2015) and men tend to express more anxious and depressive symptoms than women (Lim, 2014; Steiner et al., 2014). Thus, breast cancer has an impact on both women and their partners. They can be considered as an interpersonal unit rather than two distinct individuals (Berg and Upchurch, 2007). In Fang et al. (2010) study, women were worried that the loss of a breast would impact their relationship with their partners and wanted to have a BR to restore their previous appearance. Therefore, partners seem to have an indirect influence (i.e., women consider their relationship with her partner when thinking about BR) in the decision-making process. However, these studies were retrospective, interviewing either women or their partners but rarely couples, and only some of the impacts of the mastectomy on couples' relationship were reported. Conducting a study at the beginning of treatment care and BR decision-making could help better understand how women and their partners cope with mastectomy and the decision to perform BR. Couples' interactions, BR decision-making, and partners’ influence can be investigated in a qualitative study, as underlined in Lamore et al. (2017).

2. Methods

2.1. Participants

The study was proposed to couples in two hospitals and one cancer care center in the Paris area (France). The inclusion criteria were: heterosexual couples for whom the women received a first breast cancer diagnosis without metastasis (excluding in the sentinel lymph nodes) and who were to be treated by a unilateral mastectomy. The couples had to participate together in the study and to have been in a relationship for at least one year. Non-inclusion criteria were: the presence of a psychiatric disorder or a partner with a serious medical disease. Homosexual couples were not included due to differences in emotional and dyadic coping with cancer (Boehmer et al., 2013; Kamen et al., 2015).

2.2. Procedure

First, nurses and surgeons identified eligible patients based on the inclusion criteria and, between the time of diagnosis and the mastectomy, they suggested the current study to them. Secondly, the patients' contact information (i.e., name, phone number) was given to KL and KL called the patients to present the study to the couples. After acceptance, interviews were scheduled with the woman and her partner the month after the mastectomy. Women and their partners were interviewed individually the same day, between March 2017 and July 2017. Individual interviews were realized as they can capture both patients' and their partners' individual subjective experience (Berg and Upchurch, 2007; Smith et al., 2009). Moreover, in couples' interviews, partners of ill people talk little about their negative experiences and do not wish to express certain thoughts in front of their significant other. Individual interviews enable each participant to speak freely, to give his/her perspective of the experience (Morris, 2001). Interviews were conducted at the couples' home or at the hospital, and were audio recorded and transcribed verbatim. Finally, following the interviews, a consultation with a psychologist or a therapist was offered if one or both members of the couple presented major difficulties in coping with the disease.

Women's and their partners' interview followed an unstructured format and started with the question: “Could you tell me what you are currently living?”. If the subject did not appear spontaneous, the question “Which elements are going to determine your choice/help you decide to have a breast reconstruction or not?” was asked at the end of the interview to women. For men, the following questions were asked if necessary: “Which elements are going to determine your partner's decision in having a breast reconstruction or not?” and “Which elements influence your own preference pertaining her having or not a breast reconstruction?”.

These interviews are part of a larger study on BR decision-making. Couples who participated in individual interviews have also completed online questionnaires including dyadic coping and BR decision-making assessment before the mastectomy (Lamore et al., accepted).

2.3. Ethical approval

Ethical approval was granted by the CCTIRS (“Comité Consultatif sur le Traitement de l’Information en matière de Recherche”, Ref. Number 16.277) and the CERES (“Conseil d’Évaluation Éthique pour les Recherches en Santé”, Institutional Review Board number 20160800001072), as recommended in France. A declaration to the CNIL (National Commission on Computer Technology and Freedom) was also carried out. Furthermore, approval of each establishment was obtained before starting the study.

2.4. Analysis

The present qualitative study was collectively designed and conducted using IPA (Smith et al., 2009). IPA adopts an idiographic approach (i.e., to understand how individuals make sense of their experiences with no aim to develop general rules), has a phenomenological underpinning (i.e., the emphasis is on the experiential claims of the participants and how individuals make sense of their life experiences), and requires an interpretative process as the access to experience is partial and complex. This approach allows to explore in-depth individuals’ lived experience, the meaning of experience according to individuals, and how individuals make sense of that experience (Smith et al., 2009). IPA also relies on double hermeneutics (i.e., the researcher tries to make sense of the experience lived by the participants, who try to make sense of their own experience) (Smith et al., 2009). Furthermore, IPA is not only a way to analyze qualitative data, but also an approach of qualitative research defining the adequate methodology to conduct the research. Sample size is limited to less than 10 interviews (Reid et al., 2005; Smith et al., 2009) and unstructured interviews are recommended to allow participants to express themselves freely (Smith et al., 2009). This approach is widely used in clinical and health psychology (Rohleder, 2012). Thus, IPA is a suitable approach to study how women and their partners make sense, individually and as a couple, of mastectomy and BR decision-making.

The first author (KL) conducted the interviews, transcribed them into verbatim (as well as CE, see acknowledgments), and analyzed the interviews. He was trained and supervised by CF and LF, two researchers specialized in qualitative research and trained in IPA. KL, a psychologist and researcher, also followed three IPA training sessions beforehand.

Interviews were analyzed using an IPA, as described by Smith et al. (2009). The analysis consists of six major steps: (1) read and re-read the interviews, (2) initial coding (i.e., descriptive, linguistics and conceptual comments), (3) organizing the codes in superordinate and subordinate themes (i.e., major themes and sub-themes), (4) identify the links between the themes, (5) follow steps 1 to 4 for each interview and (6) identify patterns across cases to identify similarities and discrepancies between the cases. Furthermore, writing IPA results is divided into two main sections: (1) a detailed presentation of the superordinate themes that emerged from the data and (2) a presentation of the interpretative account. The interpretative account reflects the principle of double hermeneutics. Women's and their partners' interviews were analyzed separately to identify similarities and discrepancies between men and between women. Then, themes were analyzed for each couple as a unit. This method was followed by Antoine et al. (2016) and Loaring et al. (2015) to ensure a complete understanding of the individual and the couple's experiences. For confidentiality reasons the data were anonymized (fictive names were given to each participant) and identifying information was not reported in the present article.

Methods of bracketing (i.e., to recognize and set aside our *a priori* knowledge and assumptions during the research) used by KL were: (a) writing memos during data collection and analysis, and (b) be engaged in interviews with an outside researcher in psychology to discuss the research (Tufford and Newman, 2010). These methods allowed KL, in particular, to bring into awareness his preconceptions and to reflect on his engagement with the research.

3. Results

3.1. Participants

Five couples participated in the study (10 interviews). The interviews ranged from 24 to 93 min (mean = 61 min). Three women declined to take part in the study and one woman was excluded from the study for not meeting one of the inclusion criteria (i.e., the participation

Table 1
Participants’ characteristics.

Couple	Fictive name	Age	Duration of the relationship (in years)	Marital status	Number of children	Socio-professional category	Interval between the mastectomy and the interview	Surgery and/or treatment
1	*Amanda*	49	23	Married	2	Lower occupation	24 days	Mastectomy
	Alan	51				Lower occupation		
2	*Barbara*	50	24	Married	2	Higher occupation	26 days	BCS followed by a mastectomy with IBR
	Barney	52				Higher occupation		
3	*Carolyn*	50	9	Married	5	Higher occupation	10 days	Chemotherapy followed by mastectomy
	Carl	54				Higher occupation		
4	*Danielle*	30	9	Free union	0	Higher occupation	16 days	Mastectomy
	Damien	33				Higher occupation		
5	*Elizabeth*	51	18	Married	2	Self-employed	20 days	Mastectomy
	Eric	57				Self-employed		

Legend: BCS = breast conserving surgery; IBR = immediate breast reconstruction.

Table 2
Superordinate themes.

- Priority given to health and illness
- Physical and emotional impacts of the illness
- Breast loss: grieving and coping
- Living with the disease as a couple
- Breast reconstruction: A preoccupation about the future
- Quality of the relationship with health providers
- A social but sometimes hidden illness
- Couples' emotions

of both members of the couple). Participants' characteristics are presented in Table 1. At the time of the interview, all the participants were awaiting the results of the anatomopathological examination and whether treatment would be required (i.e., chemotherapy, radiotherapy, and/or hormone therapy). Furthermore, more than half of the participants were not native French people but had been living in France for a long time. This information emerged during the interviews and is reported here as it could influence couples' experiences. However, French legislation (relating to computer files and freedom of information, CNIL) (Legifrance, 2019) prohibits the collection and processing of such information. For this reason, specific details are not provided.

3.2. Themes

Eight superordinate themes emerged from participants' accounts (see Table 2). Considering the number of themes, verbatim are not given for the themes already described in the literature. More details are provided on superordinate themes never or less highlighted in past research ("Living with the disease as a couple", "Breast reconstruction: A preoccupation about the future"). Appendices A to H present details of each theme and indicates which participant talked about it.

3.2.1. Superordinate theme 1: priority given to health and illness

All the participants, except Barney, pointed out the importance given to the illness. They spoke about the care pathway and questioned themselves about the origin of the disease. Couples were focused on breast cancer treatments: "I think: 'the faster we start, the sooner it will be finished' and … the sooner it will be eradicated" (Amanda)/"Health first because …" (Alan). For Amanda, Barbara, Carolyn and Elizabeth, breast cancer had a major impact on their lives. Before the disease, they were in good health, carefree whereas now, they realize how fragile the human life is. "I'm aware the disease can affect anyone. Finally, life is too short. Well, I wasn't in danger of death but … and in one go it puts things … I have lost being carefree. I think when everything goes well, we feel a little invincible" (Barbara). This is linked to a social representation of breast cancer and the family history of cancer. Alan and Carl also highlighted the rapidity of the care (i.e., the medical exams, diagnosis, and beginning of the treatments).

At the time of interview, the major preoccupation for the couples were the treatments and, more specifically, chemotherapy. They feared the side effects of this treatment. Carl, whose wife Carolyn had neoadjuvant chemotherapy before the mastectomy, described the positive as well as the negative aspects of chemotherapy: "Every chemotherapy had other effects, other side effects which were not pleasant" (Carolyn)/"We realized that indeed there are negative things but there are positive things too. In this case, for her, it was positive. The treatment worked." (Carl).

3.2.2. Superordinate theme 2: physical and emotional impacts of the illness

The experience of the mastectomy was marked emotionally and by the presence or absence of lifestyle and family modifications in all participants.

Women experienced pain and fatigue. They felt disabled after the mastectomy as they were limited in their movements. They also faced body image issues, sexual difficulties, or expressed a loss of femininity. These difficulties were also mentioned by partners and were central in their accounts. Some examples of these difficulties are provided here: Interviewer: "What is particularly violent about removing a woman's breast?" Carolyn: "It's our femininity. Our … a part of our … of our … beauty. Of … our sex life too. Of our … of our existence. In other words, I am like this. It's like cutting off half of my butt or cutting off half of your butt. Well, it's, it's … we are not in balance anymore". In comparison, Barbara and Danielle experienced few physical and emotional difficulties after the mastectomy: "I don't feel pain or sadness" (Danielle)/"I think she took it well" (Damien).

3.2.3. Superordinate theme 3: breast loss: grieving and coping

Mastectomy is lived as an amputation or a mutilation for women (Carolyn: "[Surgeons] took a big part of myself. I would have preferred to have my uterus removed if I had the choice." Interviewer: "What is the difference?" Carolyn: "It's inside me […] It's something we do not see. And this, it can be seen. We see it clearly. It's also how other people look at me. That bothers me"). This amputation is something visible or not ("From the outside, nothing is visible, I am normal and not sick", Danielle). In either case, it represented a major preoccupation for them to appear normal (e.g., wearing an external prosthesis) and hiding the mastectomy outside the relationship. Thus, Danielle and Elizabeth compared themselves to other women they knew or met on the street. They looked at the other women's breasts and wondered if they had had a mastectomy and if it was noticeable: "They say there are a lot of women with the same problem and … so I look" (Elizabeth).

Partners' experience was less marked by the loss of a breast. They talked a little about the mastectomy. The mastectomy may not have been a problem for them, but the choice made by women between breast conserving surgery and mastectomy was. Women and their partners agreed when they talked about the scar. The scar left by the mastectomy was described as hideous: "But we feel like a monster. We don't feel pretty. That's it! How can we accept our body like that?" (Carolyn)/"[My wife says:] 'I feel like a monster … I am disfigured' …" (Carl). Elizabeth also questioned how a woman with a mastectomy can be desired, sexually, by a man: "A woman with one breast, does that make you fantasize?".

Some participants described how they coped with the mastectomy. Couples adapted to the mastectomy, either by being positive or by accepting the loss of a breast. For Barbara, the mastectomy with the possibility of an immediate BR (IBR), preserving the nipple, allowed her to feel like herself and less emotionally impacted by the surgery. Conversely, Carolyn and Elizabeth expressed denial about the mastectomy or about the disease: "Maybe I am in denial. I believe I have nothing wrong, I act like I have nothing wrong, and when I speak, I find that no, I am not going well" (Elizabeth).

3.2.4. Superordinate theme 4: living with the disease as a couple

All the participants pointed out the importance of the couple in coping with the disease. They often use the word "we" and "our" to describe their experience ("Today, it's our problems" Carl). For some of them, the disease had no impact on the relationship or even reinforced their relationship: "This is where we see if we are really close or if … a complicity, you see? It brings us closer! Like sometimes … someone can run away, but it brings us closer" (Barbara)/"Well, a husband supports his spouse … in adversity too" (Barney). Carl linked the difficulties experienced since the diagnosis of breast cancer to his and his wife's past (i.e., they were both married before and had marital difficulties).

Couples described the role each one could have. Most often, partners accompanied their spouses to medical consultations, reassured them about their femininity, and gave social and practical support. Women and men described themselves as protective of each other. Women tried to protect their partners from emotional difficulties: "I wanted to protect him, not to show myself …" (Carolyn)/"The only way I, I, I ⋯ I know, today, to protect her, well, it's doing this" (Carl). In partners' experiences, four roles emerged. Men (a) listened to and (b) were present for their spouses. For example, Barbara said that her husband was her main interlocutor with whom to speak about the disease. They also (c) favored the autonomy of their spouses and (d) helped to preserve their autonomy in decision-making about the treatments by asking questions to physicians.

Couples' experiences of the mastectomy were also depicted by the difficulties experienced individually and within the couple. Women expressed fears about their relationship and difficulties about cancer care. Amanda, Barbara, and Elizabeth feared a marital breakdown and Carolyn expressed difficulties in believing the nice things said by her husband: "He said to me: 'I accept you'. But I must see it". For Barbara and Elizabeth, difficulties were also linked to the consultations: a need for detailed explanations or difficulty in recalling information given by the physicians and a need to write down all the questions they had prior to the consultation. They linked these difficulties to the emotions which overwhelmed them.

Partners' difficulties were mainly reported by Alan and Carl. They experienced difficulties at home with the children and had other personal difficulties unrelated to the disease (e.g., job difficulties). Furthermore, one of the major difficulties pointed out by Carl was a feeling of being unable to reassure his spouse. He did not know what to say, which words to use. However, his wife was reassured: "He is cute, he always says: 'I did not get married to a breast'. Obviously, you don't get married to a breast or even two breasts. 'I married you.' Okay. That's something that reassures me" (Carolyn)/"Maybe I don't use the right words or do things the right way. I don't know" (Carl). These difficulties led to a reversal in the roles of each partner (e.g., women protected their partners from the disease).

In addition, couples' experiences were marked by a difficulty in communicating with each other (e.g., about their emotions). Sometimes, they felt alone or wanted to be alone to heal. Damien also described some tension in his relationship.

3.2.5. *Superordinate theme 5: breast reconstruction: a preoccupation about the future*

"For the moment, we must take care about the health issues and not think too much about this … and then, do the reconstruction to … yeah, to live normally". (Danielle)/"For the moment, there are other things that need to be fixed first. If it is not cured anyway, aesthetics will be useless […] I don't know in what, to what degree, how good or bad it will be. She [Danielle] looked at pictures on the internet, to see if it was … it was not so good, it was not necessary …" (Damien).

These quotes highlight the importance for the couples to be informed about BR and about the techniques used (e.g., prosthesis), while giving priority to women's recovery. As they lack information on BR, many of them did research on the internet. For women, the potential result of the BR was important, and they could think about bilateral mastectomy and having similar breasts reconstructed.

The subject of BR emerged spontaneously during the interviews, except for Amanda and Elizabeth for whom the interviewer (KL) had to ask questions directly on the subject. BR was perceived as a choice when it could be delayed, but not when IBR was proposed. In either case, BR was a difficult decision to make as couples were confronted with death. The decision to have a BR or not appeared to be influenced by the partner or made as a couple: "I want to do it for the right reasons, obviously, for me and then for my husband" (Carolyn)/"If I tell her it doesn't bother me [the mastectomy] and that I am not going to run away because she loses a breast … I hope she will take that into account" (Carl). These quotes highlight the importance of couples working together in BR decision-making. This experience was shared by all the couples. For women, it was important to discuss BR with their partners, even if the final decision belonged to them. Partners agreed the final decision had to be made by women, but they thought they could express their opinion. They wanted the best for their loved one and felt protective. The choice to have BR or not was also influenced by the importance given by the couples to social norms (i.e., to have two breasts), the aesthetics, and body symmetry. Finally, the decision would be made after discussing with physicians. At the time of the interviews, four of the women had to wait around one year to consider this surgery.

Moreover, couples made a list of arguments for and against BR. Couples' arguments in favor of BR were: to be normal, to be feminine, to feel well, to dress as the women wanted, to remove the disease, and to lessen the impact of body image issues. Women also perceived BR in more practical terms (i.e., to not have to put on an external prosthesis every day), as well as being important to couples' sexuality, favoring the acceptance of the mastectomy and avoiding other surgeries (in cases of IBR), or having less motor function (in cases of IBR). All the women expressed uncertainty during the interviews about their wish to have a BR in the future. Alan and Carl also expressed ambivalence about BR. Thus, three women and two men said they didn't want a BR if there were several surgeries or if it would be painful for women. Women's specific arguments against BR were: it is not pretty, it is not the original breast, it is not natural, and it is connected to a specific technique. For Barney, delayed BR was viewed negatively and, for Carl, he neither wanted to consider the complexity of some BR techniques nor wanted to think that it could handicap women.

3.2.6. *Superordinate theme 6: quality of the relationship with health providers*

Women's and their partners' experiences differed when they spoke about their relationships with health care providers (i.e., physicians, nurses, and psychologists). Women's experience was markedly positive or negative, while partners reported more positive interactions with health care providers.

A positive relationship seemed related to the level of satisfaction in the care, a relationship of trust, support given by the professionals to women, time allotted to women (i.e., physicians who took more time during the consultation or who gave them time to make a decision), but also to the quality of explanations and information given to the couple. The hospital's and surgeon's reputations were also important to the couples. Furthermore, for Carolyn, having the same physician throughout the cancer care was important, as breast cancer is an intimate subject. For Barney, it was important to have a physician who expressed an opinion and guided the couple in treatment decision-making.

In comparison, a negative relationship was perceived when couples felt a lack of empathy or support from health care providers, felt uninformed, experienced conflict, and when a health care provider had made a mistake: "[Her surgeon said:] 'Oh it's … it's good eh … excuse me. You are so sensitive' […] I was shocked!" (Carolyn)/"The nurses made a mistake by putting a transparent bandage on [my wife]. She saw her scar the day of the surgery. It unsettled her a little, made her upset I would say" (Carl). Women were also dissatisfied when the physician did not take enough time during the consultation, lacked "humanity", did not listen to them, and was not understandable (e.g., the information given being too complex). All of this could contribute to not trusting physicians. In addition, partners were not satisfied when physicians did not provide guidance (i.e., did not give advice or his/her opinion) and when they provided contradictory information.

3.2.7. ***Superordinate theme 7:*** *a social but sometimes hidden illness*

Couples shared their thoughts and emotions to close others. The disease was discussed with family members, friends, and colleagues. Sharing their experience allowed them to receive emotional support or helped in treatment decision-making. However, sometimes it resulted in the loss of friends when their reactions were not what the couples expected. Women talked to their female friends, while men found it more difficult to speak about the disease outside their relationship: "She, she talked about it with other women. But talking with men, well, it's … it's certainly not easy" (Alan). Finally, couples talked to other women with breast cancer to learn from their experience and to compare it with their own. The information given by these women had either a positive (e.g., reassurance and understanding) or a negative (e.g., fear) impact on the couples.

Furthermore, all the women and two of the men (Alan and Damien) said they hid the disease from close others at least temporarily. Participants did not want to worry their family or needed time before talking about the disease. Breast cancer was seen as personal and not something to be shared.

3.2.8. *Superordinate theme 8: couples' emotions*

Couples expressed mostly negative feelings when they talked about how they were coping. They expressed fear, anxiety, sadness, and guilt. Fear was linked to a fear of death, of recurrence, or of the consequences of the disease. Partners also felt anger, powerlessness, disappointment, and injustice. For example, Barbara feared the consequences of the surgery while her husband did not: “Because I am afraid to suffer” (Barbara)/“It never scared me” (Barney).

Couples rarely expressed positive feelings. Some partners reported joy, empathy, and relief. These emotions were related to the severity of the illness or to the care received: “In the end, it reassures me a little” (Alan).

3.3. *Interpretative account*

Separate interpretative accounts were developed for each of the three groups: one for women, one for their partners, and one for couples; and is influenced by KL's theoretical knowledge on health psychology, stress and coping theories, and shared decision-making models.

Four meaning-making profiles of women's experience of the mastectomy were developed. The first meaning-making profile is a process: women facing mastectomy can conceive their experience of the disease as a step in their life. It is a step by step strategy to cope with breast cancer and mastectomy (“It's a step in our lives that must be passed, as soon as possible, to be able to live properly again”, Amanda). After the mastectomy, women are focused on healing and on the physical and psychological impact of the surgery. The second meaning-making profile reveals a contrast between one problem, the cancer, and the solution. Women feared death at the time of diagnosis and mastectomy is perceived as the best way to heal and live (“I thought: “If I don't do it, I could die”, Carolyn). The mastectomy would allow them to live and they didn't think about the results of the anatomopathological examination. The third meaning-making profile is marked by a projection into the future. Even if they knew that BR would not be performed immediately, the women looked for information about it and had an opinion about whether to undergo a BR in the future: “I asked the surgeon if we could have a breast reconstruction. I know it's not possible right away” (Amanda); “But now, I am more like, waiting for the reconstruction” (Danielle). This future oriented-thinking may be a coping strategy to find a way to accept the mastectomy. BR can be seen as a way to forget the breast cancer as if it had never existed, to accept the mastectomy, and a way to keep their partners. However, thinking about BR does not mean it will be performed. For women, BR will be decided and performed only when the cancer is cured. Finally, it seems that IBR is associated with good health, which “erases” the disease. This perception allows women to act as if the disease was cured and to avoid the problem (i.e., the reconstructed breast is different from the one removed -with the tumor-).

Partners' experiences of breast cancer and mastectomy is more focused on breast loss and BR. It was more difficult for them to think about the disease as it didn't affect them directly. Three meaning-making profiles were built for their experiences. The first is oriented to the final goal: recovery. They feel concerned about their loved one, but their major preoccupation is recovery (“That she can heal completely … that's the hardest for me”, Eric). The second meaning-making profile reveals the role partners attributed to themselves. At the time of care, the major changes in their lives were dealing with family roles and the new dynamic as a couple and the perception of women's body modifications. Thus, they perceived themselves as a companion or a guide for women, during care and treatments or BR decision-making (“I let her feel she is the one who takes the decision, it's me who applies it […] I'm afraid that I will influence her to make a decision that suits me more than her”, Eric). The third meaning-making profile looks at the importance of BR for partners. Three partners (Barney, Damien, and Eric) used the word “reconstitution” instead of “reconstruction” to talk about BR. “Reconstitution” induces the wish to have both the breast and the relationship reconstructed as before, as well as to play again the relationship they had. BR is important for partners, as they have always known their partners with two breasts. Their manner of speaking and thinking about BR show their fear of the unknown and can be seen as a coping strategy. They face the mastectomy by denying the breast removal and wishing to reconstruct it: “It was reassuring. In the sense that the physician said to her: ‘We will do a reconstitution too, immediately’” (Barney).

Couples' experiences of breast cancer and mastectomy is conceived through the meaning they attributed to illness and treatment choice. First, the disease affects couples' relationships and makes them reconsider their relationship: couples feel closer to each other. Couples' experiences remind them of their wedding vows “In sickness and in health”. They form a unit to fight the disease and cope with it, even if each one has his/her own difficulties (“There are people who are tough and others who crack. There are others who run away from their responsibilities […] I am here”, Carl) Partners accompany their loved ones during the care, which helps the women cope better with the disease. Secondly, couples make sense of their partner's experience of the disease in order to make a treatment choice. Women and partners both have an indirect influence on the decisions made and treatments are decided as a couple. Women talk to their partner and make a treatment choice taking into consideration how it will impact their family and/or couple: “The look. The way my husband looks at me. That's the most important for me, before the … It's the first thing I have in my mind. The way my husband looks at me” (Carolyn).

4. Discussion

This qualitative study is the first to investigate couples' experiences of mastectomy and to look at how couples cope with the mastectomy a few days after surgery. Thinking of BR can help allay fears associated with the disease (e.g., death) and to focus on healing. They cope with the disease by thinking about the future. Furthermore, BR appears to be a decision made as a couple: women think about BR from the time of diagnosis of breast cancer. They consider the possible impact of their choice on their partners and discuss with them their wishes and fears of a BR in the future. Thus, partners, while offering support in BR decision-making (Fasse et al., 2017), also have a direct and indirect influence on BR decision-making.

Couples cope individually with the mastectomy by thinking about BR. It has been shown that future oriented-thinking has immediate psychological and social benefits (Aspinwall, 2005; Lang and Carstensen, 2002). Further studies are needed to better understand the psychological and relational impacts of thinking about BR since the initial breast cancer diagnosis. Furthermore, at the time of interviews, partners had more difficulties in perceiving how they influenced or supported their loved ones. The role they attributed to themselves (i.e., a companion) was seen as a problem-focused coping strategy. They also expressed difficulties in coping with the disease, as highlighted in the interpretative account. Loaring et al. (2015) found that couples' adjustment to mastectomy and IBR took time. Men needed more time than women to adjust to the disease, especially when they didn't perceive the gravity of the disease or how it could impact their family.

The results highlight how couples cope together the month following the mastectomy. They seem to use common dyadic coping and supportive coping strategies (Berg and Upchurch, 2007). Further studies are needed to confirm these results. Furthermore, BR decision-making is made within the couple. Currently, research has shown why women undergo a BR and how surgeons are important in the decision-making process (Fasse et al., 2017; Loaring et al., 2015). Less is known on why BR is important from the time of diagnosis of breast cancer for both members of the couple. Our results show for the first time how couples and specifically women think about BR as a way to heal, to erase the disease, or to feel like a woman. Women consider their partners in the decision-making process, and how their decision is going to impact their relationship. This is an indirect influence of partners on the decision-making process, as defined in the systematic review on family involvement in treatment decision-making by Lamore et al. (2017). Partners have their own views about BR, which may be positive or negative, but they keep their thoughts to themselves so as to not influence the decision made by women. However, couples discuss about BR and can share their knowledge. Thus, partners also have a direct influence in the decision-making process, albeit passive (Lamore et al., 2017). A passive attitude is not deemed negative when it has no negative impact on the couple's relationship. In addition, couples feel poorly informed about BR, as previously highlighted (Loaring et al., 2015). Information is given too early or too late by health professionals. Thus, couples look elsewhere for information. Health professionals should think about how to provide clear information to couples, when couples want to be informed.

This study has some limitations. First, couples' accounts could have been influenced by the questionnaires they completed online before the mastectomy and by the information in the notice presenting the study objective. Secondly, women's care trajectories were different. One woman had neo-adjuvant chemotherapy, another one had IBR after breast conserving surgery, and three women had a mastectomy alone. However, sociodemographic profiles are quite similar, and all the women had a mastectomy for a first breast cancer. Our sample can be considered as homogeneous (see inclusion criteria), as recommended in IPA (Smith et al., 2009). A third limitation is related to couples' relationships which ranged from 9 to 24 years. The sample is composed of couples with good marital relationships and they probably had to deal with other difficult events, which could have influenced their coping strategies with the disease. Investigating young couples' experiences would bring a more global understanding of couples' adjustment to breast cancer. Finally, couples' cultural norms might have impacted their experience as body image and social identity is viewed differently across cultures (Manderson, 1999). There is a lack of research on the effect of culture on dyadic coping (Berg and Upchurch, 2007). Furthermore, few research have been made on homosexual couples or dyads other than women - partner. Therefore, research investigating couples' or women - family (e.g., friend, parent, child) dyads experiences of BR decision-making between different cultures and sexual orientation is needed and could provide interesting results for health professionals.

5. Conclusion

This study allowed us to gain an in-depth understanding of couples' experiences of mastectomy and BR decision-making the month following the mastectomy. The disease is experienced by couples, and partners directly and indirectly influence their significant other in treatment decision-making. Health professionals need to be aware of the couples' dynamics when considering health treatments, as highlighted by Loaring et al. (2015). Regarding BR decision-making, couples want to be clearly informed about their options from the point of diagnosis. This could help the woman and her partner adjust to the disease and future treatments. It would be interesting to investigate prospectively couples’ accounts over time to explore how couples cope with the disease and the BR decision. Interviews before undergoing a delayed BR and after the surgery could provide important insights which could help physicians accompany women in BR decision-making and their partners.

Ethical conduct of the research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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Conflicts of interest

All authors declare no conflict of interest.

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Appendix A. Supplementary data

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