



Sharing lives, sharing bodies: partners negotiating breast cancer experiences

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Abstract

By drawing on Jean-Luc Nancy's philosophy of ontological relationality, this article explores what it means to be a 'we' in breast cancer. What are the characteristics—the extent and diversity—of couples' relationally lived experiences of bodily changes in breast cancer? Through analyzing duo interviews with diagnosed women and their partners, four ways of sharing an embodied life are identified. (1) While 'being different together', partners have different, albeit connected kinds of experiences of breast cancer. (2) While 'being there for you', partners take care of each other in mutually dependent ways. (3) While 'being reconnected to you', partners (re-)relate to each other through intimacy and sexuality. (4) While 'being like you', partners synchronize their embodied daily lives to one another, sometimes up to the point that the self cannot be distinguished from the other anymore. These ways reveal that being a 'we' involves complex affective, bodily encounters in which the many fault lines that both separate partners into individual selves and join them together as a unity are continuously reshaped and negotiated. Being a 'we' may be understood as something we have to do. Therefore, in being true to the legacy of Nancy, we argue at the end of this article for a sensible praxis of sharing a life and body, particularly in breast cancer.

Keywords Breast cancer · Illness experiences · Ontological relationality · Partners · Nancy · Sensible praxis

You never have cancer alone, always together. Our body, yes; or, well, I do not really mean 'our' body, but she and I ... we have gone through a lot. (Roland)

Roland's partner, Ines, has breast cancer. After having been diagnosed with this potentially lethal disease, she has undergone various invasive medical treatments—mastectomy, lymph node removal, chemo- and radio-therapy. Roland's

above-cited words clearly show that he shares in the illness experience: he repeatedly uses the first person plural ('we have gone through a lot', 'our body') and he makes frequent references to a sense of connectedness between him and his partner ('never alone, always together'). By analyzing this and several other couples' illness accounts, we explore in this paper the meaning of breast cancer as a relational lived experience.

There is a growing recognition that cancer is a shared occurrence perceived to affect both patients and their partners (Ussher et al. 2011). Many studies emphasize that the psychological distress of patients and their significant others is closely connected (Hagedoorn et al. 2008; Hodges et al. 2005; Germino 1995). Other studies focus on couples' changed daily lives, when the patient's partner provides informal care and physical and emotional support (Ben-Zur et al. 2001; Given et al. 2001; Traa et al. 2015; Lopez et al. 2012). Furthermore, some authors argue that living with cancer changes relationship dynamics, that is, decreases sexual wellbeing (Gilbert et al. 2010; Vermeer et al. 2016), having (more) communication problems (Manne et al. 2010; Zahlis and Shandis 1991) and more conflicts (Manne et al. 2010; Badr and Carmack Taylor 2006). Several studies

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suggest that these kinds of problems may possibly lead to a termination of the relationship (Fergus and Gray 2009; Walsh 2005). Other studies report that cancer brings partners closer together through the experience of intimacy associated with this particular illness (Belcher et al. 2011; Manne et al. 2004). This body of literature considers cancer as a thoroughly relational experience and as such, it is quite appropriately described as a ‘we-disease’ (Kayser et al. 2007).

This article expands on the concept of ‘we-disease’ by focusing on the preliminary question of what this ‘we’ actually means for couples who deal with the experience of breast cancer. Indeed, Roland’s account suggests a strong connection with Ines, up to a point that it invites us to think of the possibility of a commonly lived, ill body. At the same time, his hesitant and stammering way of talking about ‘our’ body—saying that it is not really ‘our’ body and dividing ‘our’ in ‘she’ and ‘I’—reveals that a ‘we-experience’ is not univocal and involves more than just commonality and connectedness. Apparently, talking about a ‘we’ entails both sameness and difference. The work of the French philosopher Jean-Luc Nancy offers a useful framework for understanding these contrasting aspects involved in being a ‘we’. In place of the traditional divide between self and other, through Nancy’s philosophy we can begin to think about the characteristics—the extent and diversity—of couples’ relationally lived experiences of bodily changes (Blackman 2010; Blackman and Venn 2010; Slatman and Widdershoven 2010). Against this theoretical background, we offer an empirical analysis of how women diagnosed with breast cancer and their partners shape their ‘we-experiences’. Before turning to this empirical investigation, let us first elaborate on the ambiguities in the first-person plural.

Who are ‘we’?

The perspective that people’s lived, embodied experiences are shaped in relation to others has been extensively discussed (Weiss 1999; Shildrick 2008; Käll 2009; Blackman 2010; Blackman and Venn 2010; Ribbens McCarthy and Prokhovnik 2014; Zahavi 2014). These accounts elaborate on shifting the focus from the still-powerful precept in western thought concerning the individuality of experiences to the realm of relational experiences by showing how lived experiences unfold in co-constitutive processes (Blackman 2010; Slatman and Widdershoven 2010; Ribbens McCarthy and Prokhovnik 2014; Zeiler 2018). The increasing attention in cancer research to couples’ dyadic coping, communal living arrangements and communication patterns seems to reflect such shifting focus (Hodges et al. 2005; Given et al. 2001; Zahlis and Shandis 1991). Our aim in this paper, however, is not to consider this

move away from the paradigm of individuality and neither to merely outline the practical ways in which partners cope, go around and interact. We rather assume relationality as primary and explore the complexities involved in the ways in which couples shape their breast cancer experiences in a shared space.

To understand relationality as something primary, it is informative to look at the ideas of Nancy. By re-interpreting Heidegger’s notion of ‘Mitsein’ as an primordial rather than a derived notion of existence, Nancy (2000) claims that our existence essentially involves ‘being-with’ (*être-avec*). This notion implies that we are always already in the world with others, and for this reason *to be* automatically involves *to be together* and *to exist* is *to co-exist* (Nancy 2000). In thinking such ‘we-ness’, Nancy makes use of many terms, one of which is the French *partage*. Commonly translated as *sharing*, this term points to the ambiguity and multiplicity within our co-existence (DeVisch 2012).

On the one hand, sharing refers to a division, to that which is shared out among a number of different parties. We are able to share our life exactly because ‘self’ and ‘other’ are different. Otherwise, we would be the same subjective substance and we would have nothing—no shares—to share. On the other hand, sharing also refers to that which is shared, to what unites us in the sharing. According to Nancy, both connotations are operative in sharing. But if we are different from one other, we may ask: what do we still have in common? What we share, Nancy writes, is not some universal attribute or essence but rather the conditions that allow sharing: our embodied exposure through which we come into contact with each other (Nancy 1990; DeVisch 2012). By virtue of our embodied encounters with others—in touching and being touched—we are affected by one other’s touch or gaze without being fully able to know how the other is affected (Zeiler 2016). This affective relationship may therefore be understood as dialectical. The other’s response to, say, my pain helps to shape my way of experiencing, expressing and handling this pain, just as my expression of pain helps to shape the other’s response (Käll 2013; Zeiler 2018). Sharing a life thus means to be on the limit: through embodied exposure the self is opened up to the other, partakes in the other and is marked by the other’s alterity without being subsumed into that other (Slatman 2014).

Along the lines of this argument, a ‘we’ may be thought of as the lines of separation between bodies that allow the self to appear as distinct from the other but that may equally serve as points of their affective connection. Note the plurality in this notion of limit: there are always *lines* of separation. Each body relates to and divides from another along multiple borders: the self is many things—deadly tumors, healthy appearance, numb breasts and painful arms—and, as such, relates to another individual in many ways. A ‘we’, then, may be understood as the records of the many lines

of selves and others, lines that both separate and join them together (Perpich 2005).

These records are constantly subject to change as the lines of an embodied ‘we’ remain porous and malleable (Serial 2004). The lines of our separation take on different shapes with every specific encounter with another person—with every touch, glance, sound or smell. Rather than mistaking our shared existence for something static or fixed, ‘being-with’ is always a becoming in a specific affective encounter (Nancy 2000).

Whereas Nancy (2000) sometimes uses the term *partage* and sometimes uses terms such as relationality, co-existence, being exposed to one another, and being-with-others, when referring to the dynamic becoming in a shared, affective space, we will consistently draw on the notion of *embodied relationality* when referring to this becoming. In our view, this term best points to what sharing and being a ‘we’ signifies. There is no ‘self’, ‘other’, and then a third realm called ‘we’. Rather, being a ‘we’ is primary as both self and other are always already in a relationship in which one is dialectically affected by the other and vice versa. Fundamentally, being-with, according to Nancy, implies the possibility of being touched. Being a ‘we’, in terms of being-with, thus implies bodily affectivity. We therefore endorse Blackman and Venn’s idea that ‘bodies should be defined by their capacities to affect and be affected’ (2010, p. 14). Selves and bodies, in other words, are constituted within a radical form of relationality.

Finally, Nancy develops his idea of relationality within an ontology which reveals the human condition as inherently social. As such, he does not draw on empirical, contingent ways a ‘we’ manifests itself in different given contexts. His ontological take nevertheless helps us to understand what is at stake in being a ‘we’ and, therefore, it challenges us to delve into the ways ‘we’ are in the world. We will take up this challenge here and employ his theoretical reasoning as a framework for our empirical study, that is, as an instrument to open up a discussion of different ways in which partners share breast cancer experiences. In turn, this empirical study opens up a theoretical discussion about our ontological condition and deepens our understanding of what it means to be inherently social. The question leading this reciprocal fertilization is: how do these couples within their relational and affective bodily engagements draw boundaries of their sameness and difference?

Collecting we-experiences

In order to explore and examine ‘we-experiences’ in breast cancer, we recruited ten couples of whom the female partner have (had) breast cancer. Eventually, we conducted and analyzed eight qualitative in-depth duo interviews with

diagnosed women and their (male) partners and two in-depth interviews with only the (male) partner. The interviews with only the male partner were conducted when the ill partner was not able to attend the interview because of health reasons. Note, moreover, that this study only includes heterosexual couples. The recruitment of couples, however, was open to same sex couples as well. These couples, however, did not present themselves as participants in this study. As the inclusion of lesbian relationships may offer additional and different kind of empirical materials and interpretations, it is worth exploring in future research how women’s breast cancer experiences are shaped in relation to their female partners.

During the interviews in this study, the participants were initially encouraged to tell freely about their relationship and their breast cancer experiences. By asking open-ended questions, the interviewer zoomed in on issues related to relational experiences. Taking the hermeneutical idea that stories are not just a representation of experience but rather both express and shape experiences, this narrative approach seems to be especially effective when it comes to uncovering how experiences are shaped with a relationship (Ricoeur 1991; Lindseth and Norberg 2004; Charmaz and McMullen 2011). By inviting couples to tell their story simultaneously, we disclose how they shape their breast cancer experiences in relation to one another.

The interviews included in this study were carried out independently by the first author of this article and a research assistant. The first five couples were recruited upon their visit to the plastic surgery department of an academic hospital in The Netherlands. In order to obtain a more varied sample (i.e. not only couples of which the women consider opting for reconstructive surgery), additional participants were recruited through a call on a Dutch breast cancer patients’ website. All interviewees indicated that they were in a stable relationship at the time of the interview. The most recent breast cancer diagnosis was a few weeks before the interview. Other women were diagnosed from a couple of months before the interview up to 7 years before it.¹ All women either had a lumpectomy or a mastectomy and underwent other invasive treatments such as chemotherapy or radiotherapy. While some of these women opted for reconstructive surgery, others chose to wear external prostheses and yet others chose neither one (See Table 1 for an overview of data on the respondents).

All conducted interviews were digitally recorded and transcribed verbatim. Upon transcription, all interviews were

¹ The authors acknowledge that the variation within the time past between the diagnosis and the interview may have a significant effect on the experiences expressed by the respondents. Two of the authors elaborate on the factor of temporality in relation to breast cancer experiences in another article (de Boer et al. 2015).

Table 1 Overview of respondent's details

Couples' name and age		Relation details (time together, children)	Women's short medical history
Woman	Man		
Emma (60)	William (64)	36 years, 3 children	Bilateral mastectomy, reconstruction
	Stuart (69)	35 years, 2 children	Unilateral lumpectomy
Martha (61)	Bert (68)	30 years, she: 2 children	Unilateral mastectomy, reconstruction
Kim (29)	Wesley (34)	11 years, 2 children	Bilateral mastectomy, reconstruction
Patricia (67)	Luke (65)	40 years, 1 child	Bilateral mastectomy, reconstruction
Claudia (42)	Billy (53)	10 years, no children	Unilateral mastectomy, reconstruction
	Michael (60)	10 years, he: 2 children, she: 3 children	Unilateral mastectomy, external prosthesis
Eva (52)	James (55)	25 years, 2 children	Bilateral mastectomy, reconstruction
Ines (72)	Roland (71)	51 years, 4 children	Bilateral mastectomy
Elsbeth (52)	Chris (50)	21 years, no children	Unilateral mastectomy

anonymized. Only the interviewers—one of which is the first author—know the identity of the respondents. Ethical clearance was obtained for this study from the hospital's ethical review board (file number 13-4-086). Informed consent was obtained from all individual participants included in the study.

In the analysis phase, the first author interpreted the collected data by using the hermeneutical phenomenological analysis method (Cohen et al. 2000; Lindseth and Norberg 2004; Smith et al. 2009; Van Manen 1990).² This means that the first author first attributed open, descriptive codes to excerpts of the interviews that are related to sharing and co-shaping of experiences. Examples of these codes are 'partners assisting women: household', 'disagreements/conflict' and 'sexual practices'. Second, on the basis of these codes, more general themes and storylines involving embodied and relational breast cancer experiences were identified in consultation with the second and third author of the article. Finally, the analysis of the interviews involved interpretations of (notes on) the respondent's gestures and movements

during the interviews, and incorporated self-reflection as to the role of the interviewer. Our analysis also engaged in a conversation with theoretical frameworks related to the relevant storylines within the interviews—in this case, with Nancy's notion of sharing (Nancy 1990, 1993, 2000) but also with other relevant philosophical and sociological theories (Foucault 1963; Goffman 1963; Grosz 1994; Leder 1990; Shildrick 2001; Weiss 1999; Young 2005). By involving these theories, as well as other contextual elements like the respondent's gestures and notes of the interviewer into the interpretation of the interviews helped the authors to remain sensitive to nuances and ambiguities of the expressed meanings and the different contexts in which these meanings take shape (Charmaz and McMullen 2011).

Four ways of sharing

Guided by the question, based upon Nancy's (1990, 1993, 2000) work, of how couples in breast cancer draw boundaries of their sameness and difference within their relational and affective bodily engagements, we identified four different ways of couples' sharing an embodied life in the context of breast cancer. First, while the partners we interviewed may have different kinds of experiences of breast cancer, it turns out that these differences do not occur in a vacuum: partners are different together. Second, our interviewees testify that sharing a life during and after treatment means that partners have to be there for each other: taking care of each other. Third, given that breast cancer is a life-changing and a body-altering experience, all partners appear to engage at some point in practices of re-relating to each other, in particular to her new body within and through sexuality and intimacy. Apart from presenting these re-relating practices, we also extensively reflect in this section on the meaning of the senses when couples' look at and touch each other in an effort to re-relate to each other. Finally, some of the couples

² This way of analyzing empirical material, in fact, corresponds very well with various phenomenologists' views on how to do their phenomenology. In line with Husserl (1960), Merleau-Ponty (1962) (and his successors) claim that we have to break with our natural attitude and thus to perform a phenomenological reduction. However, unlike Husserl, he emphasizes that the main lesson that the reduction can teach us is that a complete reduction is never possible (Merleau-Ponty 1962). The reduction does not reveal a world without our prejudices. More likely, it shows that we can never start from a value-free perspective. We have to take seriously our prejudices and explore them, something that hermeneutics professes. Phenomenology thus goes together with hermeneutics. Hermeneutic phenomenology, then, is concerned with human experiences as these are lived; it stays attentive to that which might otherwise be taken-for-granted, with the purpose of understanding and exploring the situated meanings of the subject as being-in-the-world, and as researchers, we acknowledge the need to reflectively attend to our own assumptions or prejudices as part of the interpretive process.

in our sample who live through breast cancer together synchronize their embodied daily lives up to a point that these appear to be alike in various and far-reaching ways. Based on these four ways of sharing, we show how the principle of sameness and difference between self and other as elaborated on by Nancy (1990, 1993, 2000) may take on different ratios (i.e. proportion of sameness to difference) and different modes (i.e. identification/dissimilarity; proximity/distance etc.) in practice. In the following sections, we explore how couples shape their shared, affective bodily existence in response to breast cancer; how they continuously define the many lines that both separate and connect them.

Note that although various ways of sharing are theoretically distinguished in the results section, this does not mean that they do not change over time and that they, as we will show, do not intersect and overlap in reality. Furthermore, while the focus is on couples' sharing their lives and experiences of breast cancer, the presented results show that these intimate spacings are embedded within a larger socio-cultural context.

Being different together

Many of the couples interviewed describe that they have different kinds of the experiences of having breast cancer and getting treatment. These differences may relate not only to the fact that the disease, strictly speaking, physically affects only one of the partners (Zahlis and Shandis 1991), but also to the partners' different responses to diagnosis and treatment (Ben-Zur et al. 2001). This is the case for Luke and Patricia. While she speaks about her breast cancer-related concerns with him, he, in turn, explains that he keeps his anxieties to himself and 'take[s] it out on nails and bolt'. During her treatment, he built a roofing over their terrace. She elaborates on this: 'Of course, we all have our ways; I was fine with it. And anyway, well, what can you do? [...] But was it easy? No, not really.'

Similarly, Emma and William also have different experiences of and dealings with the cancer, especially when it comes to decision-making. As they explain:

Emma: '[I] make my own choices [about treatment options] and you [her partner, William] just hear it afterwards, right?'

William: 'Yes, I trust her. I didn't want to interfere; it's her body after all. You don't have to understand all of it. I was only there to listen and nod.'

In these narrations, both couples seem to have their territories staked out: they have their differences and do not interfere in each other's dealings. Here, the question arises whether these couples' dynamics are stretched beyond the limits of what may properly be understood as sharing in a Nancian sense. Nancy, after all, shows that in order to

share, we have to partake in each other's difference and thus become both the same as and different from the other (Nancy 2000). Both Luke and Patricia's and William's narration, however, seems to exemplify difference more than anything. William does not seem to have any voice in Emma's decisions about her body, and Luke and Patricia's do really seem to partake in each other's different dealings with breast cancer: they merely have a reluctant agreement to be different and to not understand one other entirely. In such narrations, the alterity of the other, and the role of the other for the self's subjective illness experiences is given little space, and when these couples speak in the first person plural, it seems to signify a sharing restricted to listening and nodding. It seems to signify a sum of two singular selves.

For most couples in this study, however, partaking in each other's differences and actually relating to one another proves to be a significant issue. This is the case, for instance, for Kim:

'You know, it's my breast and he [Wesley, her partner] doesn't have it. [...] You can never know what it is before you experienced it yourself [having breast cancer]. So I turned to others who have gone through the same. [...] When I meet [other breast cancer survivors], what a feast of recognition it is. But at home it's just different [...]; I would like him to understand, real bad, but well, I guess, no, it's just not possible.'

For Kim, it seems that in the midst of her and Wesley's (assumed) radical different embodied experiences that relating to each other becomes important. She wants Wesley to understand what she is going through, something that in her view only seems possible if Wesley would have similar embodied experiences, in this case, that of having breasts and breast cancer. For her, understanding each other seems to require a strong sense of identification in which there is a convergent resonance of lived experiences in each other (Dautenhahn 1997). As such, Kim's story of sharing is a wishful one. Her desire for Wesley to understand her, to identify with her and thus to partake in her experience presumes an interesting, yet unfortunate interplay of sameness and difference between her and her partner: their different embodied experiences instigate Kim's desire for Wesley to understand her, as well as underscore its impossibility. Here we see that (desiring) partaking in each other's experiences may also be up to a point that the principle of sharing is undercut: (desiring) being too similar may negate the condition of difference in sharing (Nancy 2000).

Being able to relate to each other despite mutual differences, however, does not necessarily involve such a strong demand for identification. Ines, for example, reports that Roland fears her dying and him being left behind. She, in turn, is rather preoccupied with 'daily discomforts' and 'getting through the day'. His fears keeps Ines from

communicating, at least to some extent, her experiences to him. ‘He is so afraid you know’, Ines says, ‘so this [keeping her experiences to herself] is a way of protecting him’. Despite their different experiences in the face of breast cancer, Ines seems to be capable of not only understanding Roland’s experience but also what he needs from her: not being confronted with some of her experiences. As a narrated example of embodied relationality, and of how self and other can co-emerge in shared space (Nancy 2000), Ines’s reflection exemplifies a far-reaching reflexivity when partaking in the other’s alterity. Ines’ strategy of not disclosing all her experiences to Roland—and thus of preserving their differences—seem to rest with her specific understanding of him. Affect—in this case fear—is narrated as what makes her avoid sharing some experiences with him. Here, the lived ‘we’ of her and him may be understood as truly ambiguous (Nancy 2000): Roland’s assumed alterity—i.e. Ines understanding of how his experiences are different from hers—help shape her bodily being-with him, her way of relating to him.

Being there for you: care-giving and care-taking

The women who participated in this study are all somehow emotionally or physically burdened by their diagnosis and (intrusive) treatments. In coping with their fate, they relied to a certain extent on the support and assistance of their partners. Some of the couples’ accounts elaborate on him giving her emotional support: showing interest in her well-being or encouraging her to talk with friends. This section, however, focuses on couples’ stories of physically assisting each other. These stories detail body care (replacing bandages, assisting in washing, or going to the toilet), expatiate on helping her to navigate in public life, and expound on ways in which the partner manages to take over her former—often comparably large—roles in the household or as a caregiver of their children.

At first glance, these narrations reveal assisted care routines that are directed to the female caretaker and directed by the male caregiver. ‘I stand in front of her in the lines at the supermarket’, William tells about his wife Emma, ‘to protect her so nobody bumps into her [painful] chest [and arms]. I know how to handle her’. Upon closer inspection, however, such care incidents seem to emerge from a dialectical relationship between the two partners, suggesting an mutual form of care. While typically the men enact care-giving, the women initiate and co-direct the care arrangement (see also Garland-Thomson 2015). Emma regularly instructs William (how) to help her to reach for certain things because of her painful arms due to lymph node removal. ‘In the shower’, she says, ‘he does the wound on the back. I tell him, no, not that way, and I let him know when it hurts.’ While he assists

her with particular movements, she assists him in assisting to move (for) her.

Note that the above-described scenes of assistance bring to mind Merleau-Ponty’s ‘I can’. Merleau-Ponty (1962) locates our existential possibilities—the ways we can be ‘in the world’—in our motility, and perhaps in the mode and limits of our embodied capabilities. While, as the terminology suggests, Merleau-Ponty starts with the issue of how *the embodied self* handles her movements and actions, some of this study’s couples reveal that her bodily possibilities may be managed as inherently *relational*.³ For these women, acquiring a comfortable equilibrium of going around easily is located in a mutual intimate relationship of care. Here, it becomes clear that Nancy’s notion of sharing, of being a ‘we’, is intimately connected to couples’ dealings with her embodied (in)capability (Nancy 2000). This ‘we can’ may be understood, in the words of Garland-Thomson, as ‘a choreography of reciprocal navigation’ in which each of the partners contributes to the task of getting her around (Garland-Thomson 2015, p. 304).

Moreover, while the men take care of the women by contributing to their mobility, this kind of assistance may also involve care for the men themselves. Several of the care-givers report that being there for the other was crucial for being able to live through the illness period. As Chris reports, taking care of his wife was ‘not only a distraction from all the rumination; [...] it was essential for me to get through the day!’ As such, these couples’ care choreographies can be understood as dialectical in the sense that that they are not only directed *by* both partners but also *towards* each other. In such narrations of their caring relationship, both partners are affected by the other on a bodily level—by touching and being touched or by dealing with one another. Sharing a life, in this sense, means that selves do not fully determine themselves in the encounter with other selves. Rather, couples’ lives and bodies are mutually constitutive as both men and women are assistants in moving the other (to move around), and because both of them take care of the other through (allowing) caregiving.

Such a dialectical relationship, of course, involves two poles that do not collapse into each other. Likewise, for the partners who are involved in a mutually constitutive

³ In his later work, especially in *The Visible and the Invisible* (1968), Merleau-Ponty sets out an ontology that ensures that in some sense the other is always already involved within the self, and he explicitly suggests that self and other are but the obverse and reverse of each other. In this ontology, however, relationality figures as an aspect of the selves’ lived experiences, instead of—as Nancy would argue—as the constitutive ground of lived experiences as such. Moreover, in *The Visible and the Invisible*, Merleau-Ponty predominantly refers to visuality in outlining this kind of relationality. The concept of motor-intentionality and the notion of ‘I can’ is not extensively elaborated on.

relationship of care it remains significant to also be a self-determining self apart from the other's determination—a self, for example, who acts on her/his own desires and needs. Even more, it seems to be a precondition to or part of a mutually constitutive caring relationship. Many of the care-givers comment that assisting and supporting the other can be 'quite heavy at times' (Wesley) or 'a burden [in that] you may have to sacrifice some of your own needs' (Billy). In order to be able to be there for the patient, both physically and emotionally, it is essential, they claim, to have at least some time for themselves. In this context, partners mention activities such as physical exercise (Wesley), going to work or listening to music (Billy's). In turn, some of the women also need room for their own activities, something which under the circumstances is hard to find at times. In the same vein, Martha says that she wants to be something other than merely the object of support; in other words, she wants to be acknowledged as having needs, aside from those that she shares with her partner Bert. This becomes clear in the interview with them:

Bert: At first of course the wound itself needed care, day in day out. [...] I had to do it. Yes, I was really a 'nurse' [...]. [I was] constantly busy with the wound. [...]

Martha: 'That is what I find annoying, he does that all the time; I only have to do something like this [puts on a painful face] and then he says "what is it, is there something wrong?!". Once in a while I get pissed at him, I say "stop it". We get into fights because of it all the time. [...] I think he sees me as something he constantly has to nurse. And I want my husband back, right! You know, I am also a sexual creature! [...] Once in a while, [...] you just want a man to grab you, you know...'

While both Martha and Bert feel the need for a caring relationship, Martha also has needs of her own—a sexual desire she does not seem to (fully) share with Bert. Interestingly, Martha's—but also Wesley's and Billy's—needs are in fact highly relational: for Martha it involves a sexual relationship with Bert, and for Wesley and Billy it involves activities so that they can take care of their partners. Therefore, as we see played out clearly in Martha and Bert's story, sharing a life and having a supportive relationship requires constant negotiation, sometimes even conflict, on how, where and when to maintain some kind of independence and self-determination while, even in this independence, being co-constituted by the other.

Despite both partners' best efforts and struggles, however, some caring relationships exceed the limits of what seems possible. This is the case for Wesley:

Well, when you have children that are that young, they need their mom. I cannot give them that special something that mothers have; even if you may want to so badly, you still cannot give them that.

Wesley's quote demonstrates that a supportive relationship does not only relate to couples' negotiation of how, when and where to give and receive assistance, but also relates to the normative structure in which this support may take place. It seems that, in part, Wesley's notion of motherhood and fatherhood prevents him from taking over the caring role of his ill (female) partner. Feminist theorists argue that what we do and in what way is shaped by shared gendered norms and values (Grosz 1994; Weiss 1999). Even more, socialization with and incorporation of certain gender norms may feed into men's and women's perception and experience of what they actually can and cannot do (Young 2005; Malmqvist and Zeiler 2016). Wesley's words, then, may be understood as referring to an incorporation of the apparently distinct features of what a mother role and father role should be. This, in turn, inhibits him from offering 'that special something' (whatever that may be) that only mothers supposedly have and children need. Wesley's assumption that he and his partner as care-givers for their children are/should be different prevents him from taking over her care-giving role. Sharing a life by mutually assisting the other, then, does not merely involve the preservation of a certain kind of selfhood—for example, having your own activities and needs—in a couples' relational vacuum. It also involves the fact that selfhood—as being and acting different from *and* similar to the other—is shaped against the backdrop of cultural, and often normative ideas of what a certain self is or is not.

Being re-relating to you: intimacy and sexuality

The period of treatment is regularly referred to by both partners as a rollercoaster ride in terms of temporary and permanent bodily changes, such as baldness, breast(s) amputation, breast reconstruction, or scarring. After treatment, therefore, partners attempt to re-relate and familiarize themselves with each other again, mainly through re-relating to her new body by exposing herself to her partner. Thus, while a growing body of literature on post-breast cancer sexuality predominantly focuses on the treatment's negative impact on sexual well-being (Mercadante 2012; Gilbert et al. 2010), this section discusses couples' attempts to re-relate to each other in intimacy and sex through specific bodily strategies.

For many couples, such bodily strategies involve looking at her naked body: either he looks at her, or they gaze together in the mirror to her body. This is done until both arrive (again) at some sense of normalcy of her appearance—until, as Bert says, it was 'just normal' again. Nevertheless, as Luke implies, looking at her body does not

necessarily lead to (re-)familiarization, and may even be a source of tension and the distancing between partners:

My wife says: ‘I have lost my femininity’. Next, she shows me [her reconstructed breasts] and [says]: ‘what you think of that?’ And I always respond with ‘it’s just fine [to me]’. But Patricia keeps going on about it [asking what he thinks of her breasts]. And then I say to her like ‘come on, am I married to your tits or am I married to you?’ [...] Now she doesn’t show them [her breasts] so much anymore; she does not want to. Locks the bathroom and stuff.

Michael also experiences that looking at his partner’s naked and scarred body does not lead to familiarization. While talking about his sexual relationship with Eileen, Michael elaborates on his preferences on how she put forth her body:

So she was happy with the prostheses. Me too, right. Look, before the mirror with bright lights you still saw what was going on [that she has been very sick], but in the right bra you had no idea; that’s what I liked very much. And [...] yes that [having sex] is not something you do under bright lights.

The strategies mentioned by both Michael and Luke of locking the bathroom or wearing a bra with prostheses while putting on dimmed lights, that is, of covering up, hiding, or disguising deviant, scarred bodies seem to underline Goffman’s (1963) argument that we tend to normalize appearances outside the spectrum of what is generally considered acceptable, beautiful or healthy. Goffman, however, predominantly focuses on normalization practices *in public contexts*. In line with Ucock’s findings about stigmatization of women’s appearances in breast cancer, the above quotes show that normalization practices ‘not only [pertain] to public life but also [have] a significant place in intimate contexts’ (2005, p. 314). Yet in addition to the significance of intimate normalization practices, some of the experiences mentioned above also show that intimate relationships exactly allow space to be deviant from dominant normative structures, namely when her altered appearance is eventually considered to be ‘just normal’ (Bert). In different ways, then, these intimate practices bring into view how sharing a life involves familiarization with each other’s body, and in the case of a changed body, re-relating practices which are explicitly embedded in a—sometimes restrictive, sometimes permitting—socio-cultural, normative context.

Apart from the woman’s appearance, couples’ re-acquaintance practices also apply to her changed body in a tactile and felt sense. Many women experience to some extent painfulness or numbness in the operated areas. Eva, for instance, does not like to be touched in this area because it exactly confronts her with that ‘there is no feeling’. In turn, some of the women’s partners state that touching their

partners’ breast(s) felt different than before: ‘harder’ (Stuart) and ‘like a stone’ (James). These altered experiences in tactility and feeling often figure a sense of discomfort and unease for both partners and as such, couples require different dynamics of touching: for example, a lighter touch, or refraining from touching all together.

The abovementioned experiences show that both the gaze and touch are significant in familiarizing with each other’s body, and thus, in sharing a life and being a ‘we’ (Nancy 2000). The conveyed felt/tactile experiences, as compared to the visual experiences mentioned, are interesting in the light of debates on the meaning of our senses in bodily encounters between two individuals. These debates often reflect prevailing convictions that the gaze is characterized by difference and the interval of distance and that touch as an embodied gesture sustains a reciprocal sense of receptivity and proximity. In terms of the double ontology of the body, tactile experiences are understood as enabling a focus on the lived body-subject as the corporeal here and now—i.e. ‘the body here’—more so than the gaze, which instead is assumed to bring out the body as an object, that is, ‘the body over there’ (Sobchack 2010). Foucault (1963) and Sartre (1943), for instance, attribute objectifying power to the gaze, which is made possible by the spacing between observer and observed. In turn, the tactile, as Shildrick (2001) puts it, is often seen as ‘a sensation that both frustrates detachment and compromises objectivity by reason of its reversible nature’ (Shildrick 2001, p. 393; see also Grosz 1994). Although it is acknowledged that touching each other may indeed be harmful—in the case of physical violence—many feminist and care-ethics studies prioritize touch over the gaze in social encounters, because touch is generally understood as featuring more proximity, even immediacy, and more affective engagement than the objectifying gaze (Shildrick 2001; Routasalo et al. 1999).

Although these ‘commonsense’ narratives of what gazing and touching may entail touch on some strong and even very urgent points, they fail to consider the full array of affective complexities involved in visually or tactilely encountering the embodied self and other as both a subject and an object. Akin to Merleau-Ponty’s description of vision in terms of touch and touch in terms of vision (Slatman 2005), the data in this study suggests that vision may be modeled after the meaning predominantly attributed to touch and vice versa.

On the one hand, couples’ re-relating strategies reveal that vision does not only refer to distancing differences, but also feeds into the body-subject. Much academic thought about the body, as Featherstone (2010) points out, has tended to focus on the body as similar to a mirror image, as appearing as a clear, static object for others (See Masumi 2002). Discussed practices like looking in the mirror together or including the other’s visual preferences in how to present her, however, show that the gaze—similar to

touch—fondles and molds how we feel about the (looks of the) other. Through this practice, couples attempt to—sometimes successfully—re-relate to each other. As such, the body image should not only be understood as a static object for others as it affects these couples illness experience and is central to how they experience their bodies as lived. It is, as Merleau-Ponty describes, through such a vision as a kind of palpation that we experience ‘proximity through distance’ (Merleau-Ponty 1964 in Slatman 2005, p. 315).

On the other hand, although touching another person involves a self and other to be in close contact with each other, the couples’ narrations in this study suggest that touching one’s partner does not necessarily involve a sense of closeness. Our data shows that touching the other may—quite literally—feel as objectifying the other: as touching a lifeless object (‘a stone’). Reversibly, while being touched on her breasts, Eva feels that there is nothing ‘there’. For her, the double bind between feeling (being) touched and touching is broken. What this numbing experience can mean in terms of the double bodily ontology—as both an object and a subject—becomes clear by juxtaposing it with the experience of a phantom limb discussed by Sobchack (2010). While looking at the site where a leg was before amputation, the amputee sees nothing ‘there’ but may feel something ‘here’ subjectively. Speaking with Leder (1990), we could say that for the amputee, ‘here’ is the possibility of experiencing the body as a subject, as lived—an experience of a body that retreats in the background, is ‘absent’ rather than present—without a body as an object being actually present. For Eva, it seems to be the opposite: she may see her breasts before her, but she feels nothing ‘there’. While felt experiences typically throw back a person to her body as lived—even in the case of a physically absent body—the *absence* of feeling in a touching encounter makes the (present) numb body *present* itself as an object, becoming the focal point of attention (Slatman and Widdershoven 2010). So while we are inclined to consider touching and being touched as a sense of subjectifying closeness, being in close contact may also feature—twisting Merleau-Ponty’s words—a sense of objectifying distance through physical proximity.

This kind of rethinking of the gaze/touch opposition, however, still does not do justice to the diversity and complexity of the interviewed couples’ bodily encounters in their re-acquaintance practices. While the above-described cases show that objectifying vision may integrate a sense of touch and vice versa, these senses still appear as separately operating in re-relating practices. Some partners’ re-relating strategies, however, are based upon an amalgam of the gaze and touch. In contrast to scarring bodies and absent breasts, treatment-induced felt and tactile changes are often not immediately noticeable, at least not for the other. Because of this disguised change, approaching each other’s

body differently calls for multi-sensory re-relating strategies. Michael and Eileen’s strategy is a good example of this:

Yes, and then you don’t do that [touching her numb chest] anymore. I have tried it for a long time. We really sat down for it. And then I did this [make a touching gesture] very carefully, and kept looking at her, at her face, how she responded, right. If she responded at all [to his touch] [...] I thought it would be alright eventually, if only I would develop that *finngerspitzen* sense – sometimes found among blind people – where it [the touching] can be felt and [where it] cannot be felt. But, well, it wasn’t meant to be. (Michael)

Michael’s touching strategy can be interpreted as a way to initially dissect where she does (not) feel his touch through looking at her and, eventually, through this practice, develop a touching sense of how to caress her in a pleasant way. Or, as Merleau-Ponty beautifully writes, Michael wishes his ‘fingertips to have eyes’ (1973, p. 19). Although Michael’s attempts are not successful, it does show how different senses may operate together in re-familiarization strategies. In this case, through carefully looking at her while touching Eileen, Michael aims to access and even incorporate what Eileen feels, and thus the gaze in combination with touch may potentially assume more openness and receptiveness than the touch or the gaze alone. As such, at the intersection of these senses one may well find a very intimate, bodily mode of familiarization in sharing a life and being a ‘we’.

Being like you: synchronizing life and body

After being faced with the reality of a breast cancer diagnosis, many of the interviewed couples adjust and synchronize their daily, embodied activities. As of the day of the diagnosis, partners are caught up in a shared rhythm of treatments, hospitals visits and (providing/receiving) daily medical care. These experiences of synchronization are not necessarily harmonious, as Michael’s account suggests:

It is all about Eileen and the cancer now; it dictates the course of our days. [...] She decides on the pace [of our activities] and what I do and stuff. Every now and then she gets irritated when things don’t go her way. [...] It doesn’t escalate right away, [...] but you try to make clear [...] that everybody tries to do their best, and that much work goes into making the best out of it. (Michael)

The effort of partners to share and synchronize their lives does not stop upon the completion of treatment as is suggested in the case of Chris and Elsbeth. After their last hospital visit, the couple celebrates this milestone by getting tattoos. Elsbeth chooses a colorful tattoo that symbolizes

the end of a ‘dark’ period and welcomes a ‘brighter’ one: a flower surrounded by leaves and butterflies on the scars of her chest. In this case, getting a tattoo may be understood, according to Langellier, as capturing ‘the palimpsest of breast cancer written on [a] body: the layered marking of breast cancer, the mastectomy scar, and tattoos, each inscription overwritten, imperfectly erased and still visible on the parchment/skin’ (2001, p. 145). Langellier argues that the act of getting a tattooed marking to cover a tattooing scar may transform the meaning of such a marked body: while a mastectomy or radiotherapy may *inflict* markings on Elsbeth’s body, by *getting* a layered tattoo she may reclaim embodied agency. Although Chris does not have an actual scar, he feels the need to get a similar, slightly more ‘masculine’ tattoo: a leaf on his arm. ‘It felt good’, he says, ‘it was so intense, you shared well, yes, a lot. And now we share this as well.’ As these words underscore, marking a body may be both a shared and a gendered matter. While Chris and Elsbeth’s tattoos show that feminine bodies apparently need different markings than masculine ones, their tattoos still mean to represent that he is part of and partakes in her illness experience and its aftermath of reclaiming agency over a branded body. Chris and Elsbeth now share a similar, yet explicitly different palimpsested body.

Finally, some couples take their bodily sharing to such levels that one can no longer distinguish where one body ends and the other begins. This is well demonstrated by the account of Roland and Ines, with which this article started. Like many women who suffered from breast cancer, Ines has to live with the lasting physical consequences of treatment. She and Roland elaborate how they deal with this permanent bodily change:

Roland: ‘Before the breast cancer we would easily take a walk for 2, 3 hours. We don’t do that anymore, you know. Now we walk shorter distances, like an elderly couple, that’s what I mean.’

Ines: ‘The first hill makes me already feel like pff..’

Roland: ‘Right, the first one is a pain already, while before we just walked and walked, even on steep hills. This is an example of that we’ve gotten older because of the breast cancer. [...]’

Interviewer: ‘And do both of you have that?’

Roland: ‘Mwha, my wife has it, yes.’

Ines: ‘You too!’

Roland: ‘Well yes, you simply adjust yourself; it comes naturally, you know. You never have cancer alone, always together. Our body, yes; or, well, I do not really mean ‘our’ body, but she and I... we have gone through a lot.’

Whereas Ines is the only one who—strictly speaking—is physically affected by the treatment, Roland appears to have adjusted to Ines to the extent that it also redefined what he

can and cannot do. This brings about a new kind of understanding of what capabilities in encounters with others may entail (Zeiler 2014). As Weiss argues (2009), the physical boundary between one person and another has always served as a means to distinguish one’s capabilities from those of another. This view resonates with Merleau-Ponty’s earlier discussed individualistic reasoning on embodied capabilities: his idea of ‘I can’ (1962). Although in sharing a life, as we have argued, one person’s (in)capabilities may be handled in relation to each other—resulting in locating that person’s ‘I can(not)’ in couples’ collaborative ‘we can’—such capabilities may still be understood as the originary property of one person’s body only. But the comments by Ines and Roland suggest that capabilities themselves are thoroughly relational. Ines and Roland do not just *handle* their (in)capability to walk in relation to one another; their (in)capability apparently even *arises* in a specific bodily self-other encounter. By walking together, their capabilities seem to be expressed and constituted in concert; they cannot do long hikes in the hills anymore. In speaking of ‘our body’, Roland seems to refer to this relational (in)capability, to this ‘we cannot walk’. Importantly, while Roland seems to partake in Ines’ capabilities up to a point that one is inclined to speak of relational capabilities, his somewhat resistant and hesitant way of speaking about a shared body reveals that as a couple they do not melt into each other on a bodily level. If the boundary between his and her body in terms of capabilities may be blurring, he keeps insisting on this boundary: ‘my wife has it’; ‘not really our body’; ‘she and I’. Sharing an embodied life up to this extreme, then, is a matter of inhabiting ‘our body’ while at the same time being a self distinct from the other—an effort at balancing a separation line that seems to vanish with every attuned step.

We share breast cancer

By taking the concept of ‘we-disease’ (Kayser et al. 2007) as a point of reference and by drawing on Nancy’s ontology of coexistence as a theoretical framework, we explored what is actually at stake in sharing a life in the context of breast cancer. For Nancy (2000), sharing is a matter of embodied exposure to others who are similarly exposed, an exposure in which the self is affected and co-constituted by the other and vice versa. Self and other, then, may be understood as being in a dialectical relation in which the self is both the same yet different than the other. Through interpreting the illness stories of the participating couples, it is revealed that partners are thoroughly touched and altered within and through their bodily modes of acting and interacting with each other.

By way of distinguishing four ways of sharing, we outlined a spectrum of different modes of relationships in which the lines of intimate partners’ bodily sameness and

difference are shaped. We have seen that sharing could mean having different kinds of experiences of breast cancer—even the sustainment thereof—at the heart of a couples’ protective connection, and that being a self apart—but not too apart—from the other is part and parcel of a co-constitutive relationship of care. Moreover, we have shown that obscure bodily encounters may take place in attempts to re-relate to each other: closely touching each other with indifferent distances, or objectifying gazes that facilitate intimacy. Note that this description of re-relating practices provided a rethinking of the meaning of sensuous encounters with others, one that avoids privileging one particular sense—such as the gaze or touch—over the other. Finally, we have seen that sharing may involve synchronization of life and body without merger, albeit sometimes only very provisionally.

As we have shown, this kind of sharing takes on different ratios, that is, different proportions of sameness to difference between the self and the other. Sometimes the two partners are more dissimilar than that they identify with one another; more distant than proximate. And sometimes couples are more mutually constitutive than that they are unique selves; more connected than disconnected.

More than merely disclosing ways and ratios of sharing in an intimate relationship, the interviewed couples’ narrations reveal that being touched and affected by the other is embedded within a larger socio-cultural, normative context. For these couples, the woman’s non-conforming physical appearance, for instance, calls attention to her body and how she relates to prevailing norms about healthy appearance or feminine shapes. As a consequence, these couples’ un/successful strategies of re-relating to each other involve dealing with these norms in the intimacy of their private home. Moreover, the ways and extents to which these couples share their embodied lives is also influenced by and co-dependent on concrete third parties: children, friends, fellow breast cancer survivors and, not in the least, surgeons, nurses and other professional caretakers. As such, the ‘we’ in ‘we-disease’ may be understood as not only referring to both partners, but also to close and distant others.

In these situated encounters between partners, sharing is revealed to be a constitutive dimension of what it means for couples to live with and through breast cancer, and not as an optional extra that partners may or may not engage in. Although sharing, in this sense, is an existential condition, it is not given at once and it does not come naturally. For all the couple in our study, sharing an embodied life and maintaining the balance of being the same yet different proves to be a constant effort. Although such balancing acts may exist in all encounters between individuals, it seems that within a breast cancerous situation this a particularly challenging exertion. In breast cancer, partners are more dependent on each other, and the bodies of women—and, as we have seen, also of the partners—are constantly altered and drastically

shaped anew. With every specific bodily encounter, then,—with every caring choreography, every new look, very changing touch, and re-attuned walk—couples have to (re-)define and (re-)negotiate how and where to draw the boundary between their sameness and difference. While these continuous negotiations may be done in harmony or may remain implicit and involve subcutaneous struggles, some of these debates, as we have seen, are explicitly played out and even involve conflicts fought out in the interview.

Through this conclusion, we see how Nancy’s (2000) asserted ontological structure of our existence as ‘being-with’ impacts everyday life: our social condition compels us to act. Being a ‘we’ may be understood as something we have to *do*: as a verb instead of a pronoun. Our existence always involves a constitutive embodied navigating endeavour of both self and (close and distant) other(s): our ontology, in this sense, is a praxis. So, on to what praxis does our shared existence open up to, particularly in breast cancer?

Here, the key is to take a different emphasis: just as our ontology is something we have to *do*, it is something *we* have to do. Both self and other shape our existence and as such, there is always the other in its alterity that shapes this effort of being a ‘we’. With every bodily encounter between partners, as we have seen, a new ‘we’ is drawn out. And while each partner makes this happen, it also happens to them. In this sense, our existence is a leap in that it involves a dialectical constitution of selves, and therefore, the facticity that we cannot fully appropriate nor control our ontology. We all are, as Nancy (1993) holds, ‘abandoned’ to sharing. But such existential abandonment, Nancy continues, is ‘only law’: it is ‘just’ there. Our co-existence compels us to *do* the sharing, but does not predicate us *how* to do it. As such, there are many ways to take up our abandonment: ‘there are cruel abandons and gracious abandonments, some sweet, some pitiless, some voluptuous, frenetic, happy, or disastrous, and some serene’ (Nancy 1993, p. 47). In being true to the legacy of Nancy, we argue for *sensibility*, for a *sensible* praxis of sharing a life and body, for being sensible for the fact that the *being-with* happens to *us*. That is, sensible in the sense of being aware of that we are part of the constitution of ourselves and others as much as we cannot control the unfolding of those others and ourselves. Moreover, we argue for a kind of sensibility in the sense that such uncontrollability takes place on a bodily level: we are and have to be sensible to the other with our senses, with every touch, glance or walk.

Such a sensible approach would be particularly fruitful in a breast cancerous situation, and in those of illnesses at large. In these situations, a person’s autonomy is often considered to be at stake. In conventional nursing studies, autonomy is understood as self-determination, as the ability to make choices in medical practices of one’s own and act on them accordingly (Dekkers 2001; Proot 2000). In so

far as embodied experiences are discussed in these works, it mainly considers the body in terms of ownership, thereby equating bodily autonomy with control over the body and bodily processes (Käll and Zeiler 2014; Scully 2013). Although there is a growing body of literature that draws on relational and embodied views on autonomy—considering (bodily) relations which enable or disable a person to behave as a self-determining agent—this work still starts from an individualistic understanding of human existence (MacKenzie and Stoljar 2000; McLeod 2002). While our research reveals human existence in illness as intrinsically shared on a bodily level and outlines the ways in which selves and bodies shape their co-dependence, further research should expand upon the question of how this focus on shared illness experiences can contribute to the evaluation and re-organization of medical practices which are sensible to a person's autonomy as thoroughly relational on a bodily level (See Käll and Zeiler 2014; Zeiler 2018).

Thus, while this article mainly describes the meaning of breast cancer as a thoroughly shared disease, the scope of our empirical-philosophical take is much larger. By thinking with and through Nancy's philosophy, we lay out what it means to share a life and body in illness while, at the same time, urgency to be sensible follows this presentation. Thinking through our existence as shared, therefore, is a sort of sensibility itself. Here, Roland's words, with which this article started, echo as an appeal: 'You never have cancer alone, always together'.

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