

# **The operations of the familial body: genes, family and hereditary cancer**

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I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

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## Abstract

This thesis examines the experiences of 47 Australian and American women who have been tested for BRCA1- and BRCA2-associated hereditary breast and ovarian cancer syndrome. Existing anthropological approaches to hereditary breast and ovarian cancer syndrome assert a stern analytic division between biomedical and genetic, and familial relatedness. By asserting the primacy of the individual, these approaches attempt to rescue the socially connected at-risk woman who chooses her relations with others affectively, from the genetic sequence that dictates her relations with others medically. This figure of the 'individual' is anthropologically considered to organise socially significant others according to either selfish or selfless motives: she may selfishly have children despite the risk of cancer she confers, or selflessly hold back her reproductive desires. These difficult emotional decisions, it is anthropologically asserted, are obscured by a medical world that dictates genetic relatedness. But, as I show in this thesis, analyses that sharply contrast genetic and social forms of relatedness prevent us from seeing their shared basis in, simultaneously, partiality and collectivity.

Rather than taking up the familiar combative anthropological stance in which the biomedical and the social are sharply contrasted, I take my cue from a basic principle of genetic inheritance. Genes challenge the discrete boundedness of the body: each person makes partial genetic contributions which, in concert with the partial contributions of others, yield the genetic collective that is 'me.' Just as persons are the collective product of partial contributions of others, so too is the social institution of the family. The family is a sociality made and maintained in fleshy relations between parts of bodies that together create a familial collective. Taking the notions of partiality and collectivity that are found in both genetic and social worlds of cancer as key motifs, I offer up a new analysis of precancerous lives. Instead of seeing at-risk women who act as bounded individuals – either selfishly or selflessly – I focus on the precancerous parts of women's bodies that threaten to disrupt familial collectivities. Such an analysis tells us much about the importance of particular body parts to the intercorporeal sociality of the family, how critical it is that those parts remain reliably there, however unreflexively

considered they might usually be, and how wrenching it is to have to remove parts critical to the making and maintenance of the family to remain in it as a living presence.

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# Introduction

How do anthropologists understand and analyse experiences of hereditary breast and ovarian cancer? The paradigmatic approach in the discipline to date is overwhelmingly biosocial. In these analyses, emphasis is placed on the presence of a genetic mutation as organising the at-risk woman's experience of (pre) cancer and her social relationships that are threatened by cancer risk. The figure of the individual is foundational to dominant anthropological accounts of the woman bearing hereditary illness and its associated risks. It is the individual who harbors, passes on and suffers disease or its spectre. This emphasis on the individual, located at the heart of a biosocial network generated by the conditions of her genes, obscures the propensity of the body to exist as an intercorporeal sociality. These approaches precede and make abstract a clearly identifiable individual who arrays a genetically given social world. This predominant figuring of precancerous women certainly sees individual bodies as *linked* to one another, in a *network* of cancerous connectivity. In doing so, these accounts that focus on the biosocial world presuppose the body's integrity, but do not attend to the ways in which the body is always, already, indistinguishable as a discrete entity. Not only is the body thought of as bounded in such approaches, it is also considered in terms of its wholeness. In the dominant anthropological literature on hereditary breast and ovarian cancer, the body is a whole fleshy entity called 'the individual.' This discrete body produces, resists, expands and constrains the social relations available to her, resultant of the genetic mutation that forms part of her medico-social identity.

In this thesis, I take a different approach to ethnographic material on hereditary breast and ovarian cancer that looks very similar to that found in existing anthropological studies, in the sense that I interviewed women making choices about how to handle their risk of developing hereditary breast or ovarian cancer. These women had a strong family history of cancer and had tested positive or were awaiting testing for a gene mutation linked to hereditary breast and ovarian cancer syndrome. As outlined below, women carrying a Breast Cancer 1 (BRCA1) mutation have between a 46-87% lifetime chance of developing breast cancer and a 39-63% lifetime chance of developing ovarian

cancer while a woman carrying a Breast Cancer 2 (BRCA2) mutation has between a 38-84% chance of developing breast cancer and a 16.5-27% chance of ovarian cancer. Although the presence of a mutation in either of these genes does *not* necessarily result in cancer, the prevalence of cancer amongst women with mutated BRCA genes is up to five times higher than those women who do not carry these mutations.

In my analysis, I move beyond the paradigmatic parameters of hereditary cancer research in anthropology to date. I do so by taking a view of a bodily being that does not presuppose a discrete wholeness of the body congruous with the classifier 'individual.' I begin rather with the notion of fleshy relationality. Instead of taking precancerous or at-risk bodies as discrete individual entities that circulate and relate in networks with other discrete individual bodies, I offer up a partial and porous body that is always relational. If we closely attend to fleshy life, the fleshy life of at-risk women and families, we see that it is hardly ever the whole body that acts, expresses and relates. It is, rather, elements or parts writ more or less significant to the occasion that come to act accordingly. An attendance to partial deployments, and not the wholeness or boundedness of flesh, reveals that it is partial relations between bodies that are responsible for creating and maintaining the institution we know as the 'family.'

Attending to partial relations is crucial to a thesis that examines the lives of people dealing with the prospect of having *parts* of their bodies removed. For women at-risk of hereditary breast and ovarian cancer, particular body parts – namely breasts and ovaries – are drawn into the foreground by precancerous means. The cancerous potential of these body parts brings to attention their more usual backgroundness in the habitual actions and rhythms of everyday life. Significantly, the cancerous potential of these body parts also serves to emphasise their role in creating institutions such as the family. As I will detail in Chapters One and Two, the recognition that body parts act together to collectively create institutions such as the factory floor or the army has been reflected upon by scholars such as Foucault (1977). Likewise, Lyon and Barbalet (1994), in considering the role of emotion in sociality, demonstrate how parts of bodies act together to create the institution of the family. Not only is the family constructed from these interconnecting parts, it is, as Merleau-Ponty (1968) suggests, the work of others

that together form the very thing that we call the person. It is in these partial relations between bodies that the body of the person and the body of the family is created. My refusal to recognise the bounds of the conceptual individual as corresponding with the boundaries of the flesh is particularly significant to my understanding of the experience of women who removed what they considered to be crucial body parts.

For at-risk women, parts of precancerous bodies are removed in the service of continued participation in the body familial, a practice that I think underscores the importance of partial relations. In the experience of my informants, some parts were more critical to maintaining familial and other social relations than were others. Relating to others with and through the presence of these parts generated something I have termed 'breasted sociality,' and 'ovarian sociality.' When those parts had to be removed, people replaced them, or found new ways to participate in the body familial and social life. In this sense, my analysis of fleshy relationality is congruous with the experience of my participants, as practitioners of partial relations. It is these partial relations that are overlooked in anthropological analyses that insist upon the individual as the key analytic unit for understanding the at-risk woman.

Another fundamental part of the approach anthropologists have tended to take towards hereditary breast and ovarian cancer has been to emphasise the capacity of the gene, or gene mutation, to relate whole individual bodies to one another. Medical anthropologists have claimed that the individual who arranges her own kinship relations, based on affectivity and choice against the backdrop of a mutated cancer gene, comes to be subsumed by the biomedical domain and must be rescued. We can see such thinking in the work of Kaja Finkler (2000), a dominant figure in the field of anthropological analyses of hereditary breast and ovarian cancer. Finkler (2000, p. 3) characterises the current age as one marked by the 'hegemony of the gene' that has ushered in the 'medicalization of kinship.' She argues that:

family and kin relationships are being drawn into the biomedical domain through current comprehension that diseases are genetically transmitted from generation to generation. The medicalization of any human condition dramatically affects people's deepest level of experience, understanding, and actions, transforming the

person from an active being [read 'individual'] into a passive patient... the medicalization of kinship is relatively recent because it is being especially promoted by the new genetics... In fact, the sharing of DNA is becoming the hallmark of people's relationships with those designated as family and kin... The ideology of genetic inheritance unites, often unwillingly, the individual with his or her family and kin, over and above the nuclear family. Whereas individuals may choose kin on the basis of affective ties, as is the case in modern society, the new genetics prescribes one's kin relations on the basis of birth rather than on choice (Finkler, 2000, p. 16)

In Finkler's (2000) analysis of genetic medicine, we see the emergence of a struggle to deliver the individual agent from the powerful force of gene hegemony as her familial relations come to be arrayed according to gene relatedness and hereditary. In Finkler's work, the individual is the key analytic unit used to distinguish the decision-taking, world-arraying woman from the genetic network of relationality which she belongs, according to medicine. It is this agential, autonomous individual, Finkler (2000) purports, who risks being subsumed by the burdens and obligations of her genetic kin, with whom she may not share affective ties. Such concern over the individual's rights and autonomy in the face of other's demands, Nedelsky (1990) argues, is well established in Western society and scholarship. The bounded individual and individuated body, she writes, is ensconced in Western ideals of personal freedom and autonomy, such concern for spatial boundaries derived from early property laws. Consequently, Nedelsky (1990) posits, the bounded individual is, often unconsciously, seen as in need of defence against others in order to ensure one's own autonomy.

Concurrent with the view of the individual struggling under the weight of genetic knowledge and responsibility we see in Finkler's (2000) work is the notion that medical views of the person are *wholly incongruent* with anthropological ones. In this thesis, I argue that they are not necessarily incongruous. I take this stance on the basis of the partial relationality that bodies-in-action and genes-in-process each share. They each make problematic the notion of the discrete and bounded whole individual body.

I have indicated my analytic interest in the partiality of the familial body and how it is foundational to the collectivity of familial relationality above, and in what follows I briefly sketch out the same with respect to genetic relations. The body, in genetic

medicine, is fundamentally partial. The ‘individual’ body is, by necessity, the yield of the genetic contributions of others. ‘It is an anthropological axiom,’ Strathern (1992a, p. 12) reminds us, ‘that however discrete they appear to be, entities are the product of relations.’ From an Anglo-American viewpoint, children, she argues, are ‘genetic hybrids by nature... regarded as constellations of elements [genes] derived from each parent but mixed in such a way as to make them into unique entities’ (Strathern, 1995, p. 429). In this regard, the concept of the discrete ‘individual’ body is inherently problematic. In a genetic sense, bodies are always produced in and through other bodies and are always relational. Indeed, genetics is *all about* the relatedness of bodies. Persons are ‘natural hybrids’ of other persons (Strathern, 1992a, p. 111).

I am not suggesting that the way in which genetics and genetic medicine view the body and the experiences of the body discussed by my informants are entirely congruous or synonymous. To insist upon such direct comparison or correlation would overlook some of the problematic ways in which particular genetic knowledge and genetic understandings of the body, for example, genetic essentialism, have strengthened essentialist thinking about identity and social connections, rendering ‘personal esteem and self-worth, group cohesion [and] access to resources’ at stake (Brodwin, 2002, p. 325). Considering the hybrid composition of bodies however, as Strathern (1992a) suggests, provides fertile grounds for reimagining the body in this space and for thinking anew about bodily experience. Throughout this thesis, I am drawing on this imagining of the body as a hybrid of partial contributions of genes, as does Strathern (1995) to think about other ways in which the body is partially constructed.

This fundamental relatedness of genes, for Finkler (2001, p. 248), is the key issue of genetic medicine as the ‘individual [who carries a cancer gene mutation] is united... by asocial and amoral DNA’ with others to whom she may have no social or affective relation. Finkler (2000) is concerned about this genetic relationality, and its capacity to dictate who is related to whom. She worries that this form of relationality may diminish how people affectively conduct kinship relations with their nearest and dearest. Consequently, Finkler (2000) and other medical anthropologists of hereditary breast and ovarian cancer (see Hallowell, 1999; d’Agincourt-Canning, 2006), seek to disrupt

this genetically 'given' relationality by vigorously reinserting the figure of the individual, one that is capable of choosing her relations on the basis of their affective qualities. Finkler's (2000) concern for the autonomous, bounded individual who becomes linked to unchosen genetic kin stands in contrast to the version of person described above by Strathern (1992a). In her examination of genetic relatedness, Strathern (1992a) identifies *persons* as always, already entwined with others. Persons are the 'natural hybrids of other *persons*,' that is, entities that produced in and through relations.

These different modes of categorising the at-risk woman, as individual or person, are consequential for understandings of the illness experience. As Harris (1989, p. 559) and La Fontaine (1985, p. 124) have argued, concepts of the person and the individual are often conflated or utilised interchangeably in anthropology. Such conflation, however, can have consequences for resulting analyses. As I will detail in the first chapter of this thesis, the 'individual' has been adopted by and large by medical anthropologists as the core analytic unit to describe the autonomous and agential at-risk woman. This individuated at-risk woman must be rescued from the pull of genetic relatedness so as to protect her ability to be a 'free agent, striving to actualize [herself] in terms of self-achievement, in a field of extrinsic social institutions, such as the family, and other associations' (Hollos & Leis, 2001, p. 371). The assertion of the individual within paradigmatic anthropological approaches to genetic medicine also has important implications for how social relations, such as affective and genetic relatedness, can be understood.

According to Conklin and Morgan (1996, p. 664), the model of the individual and its attendant ideologies of 'self-containment, self-reliance, and social autonomy' produce a mode of sociality analogous to 'bumper cars.' Individuals and their bodies in this sense, are

bounded units [that] seek rapid acceleration, watch out for one another cautiously or hit each other mercilessly, attempt to protect their space, yet inevitably bump into and rebound off one another (Conklin & Morgan, 1996, p. 664).

This framing of the individual and her relationality reflects the biosocial approach favoured by medical anthropologists of hereditary cancer. These approaches, as mentioned above, envisage relatedness as individuals linked together in a network with other discrete and bounded entities. Such views of networked and yet fundamentally detached and inviolable 'individuals,' however, obscures alternative understandings of the illness experience that preface 'openness, connectedness, and permeability to others' (Kirmayer, 2007, p. 243).

It is certainly the case that, as Finkler (2000, 2001) asserts, genetic and affective relations with kin can be substantively different. This situation was reiterated by a number of my informants. Genetic relations organise people in and on different foundational terms than affectively made choices. Different people are included and excluded in each register of acknowledging kin. Indeed, many of my informants came to know of people to whom they were genetically related, and recognised that it was important to know them in the context of a shared genetic mutation and a family history of disease. Again, these relations were often of a different affective quality than the relations they had with the kin they chose. However, there appears to be a significant limitation in the approach taken by Finkler (2000) and others in regards to the veracity with which they contrast genetic and affective kin relations. The assertion that the *individual* agent is the necessary corrective to genetic views of relatedness is somewhat problematic. Finkler (2000) notes that a relationality is insisted on and asserted by genetic views on kinship. This relationality, she submits, subsumes and obscures the individual and her ability to choose her own kin (Finkler, 2000). In her view, we must resurrect this individual from such demands forced upon her by biomedicine and its inherent 'hegemony of the gene' (Finkler, 2000, p.3).

As I have stated above, I recognise (as did my informants) that affectively and genetically arrayed kinship is qualitatively different in experience. However, the insistence on the individual as *the* figure who experiences illness, *the* figure who relates, and is related to the significant others in her familial world, obscures the ways in which the 'individual' body may not be the basis upon which the risk of hereditary breast and ovarian cancer is experienced. In focusing so directly and ferociously on the ways in

which the individual is engulfed by genetics and genetic medicine, anthropologists generally proceeded twofold; they have insisted on the dominance of the individual body as the corrective to an old enemy (the primarily biological body) and they have taken it to be the theoretical basis for analysing the body as it experiences the risk of hereditary breast and ovarian cancer. This view precludes more phenomenological and experiential insights into the partial and embodied ways in which the at-risk person is always and already enfolded into and by others. These others are, likewise, only ostensibly whole, individual, bodies. By insisting upon a critique of genetics such approaches also elide insight into the possible congruencies between medical and experiential knowledges of hereditary illness. It may be the case that the experiencing at-risk body and the genetically configured body share more in common than the current paradigmatic anthropological split permits. They are both, in essence, partial and relational bodies rather than wholly individual ones.

These new insights that I intend to make about partiality, collectivity, the relationality of the family and the at-risk body, are necessary to push past current anthropological knowledge of hereditary cancer syndromes and what I will call its 'moral impasse.' Seen as discrete individuals by the bulk of anthropologists working in this field, women (especially) are prone to being characterised as either selfish or selfless. They are selfish if they choose to pass on their genes by having children or resist undergoing the regimes of risk reduction currently recommended by medical professionals. They are selfless if they sacrifice their body parts and reproductive desires to halt the ticking time-bomb of a gene mutation in its tracks.<sup>1</sup> This selfish/selfless dyad and the notion of genetic responsibility as necessarily a part of positive testing for a genetic mutation has been examined by many such as Mozersky (2012). As Mozersky notes in an article entitled,

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<sup>1</sup> Although both women and men can carry and pass on a mutated BRCA gene, the majority of anthropological research into hereditary breast and ovarian cancer focuses on the illness experiences of women. This may be a result of the differing risk calculations for women and men carrying a mutated BRCA gene. As outlined later in the introduction, men carrying a BRCA mutation have a considerably lower risk of developing hereditary cancer of the breast (or prostate) and thus are more likely to be offered a less intensive or invasive program of surveillance or screening as risk-management rather than surgical or chemo-preventative intervention (Liede, et al., 2004).

‘Who's to blame? Accounts of genetic responsibility and blame among Ashkenazi Jewish women at risk of BRCA breast cancer:’

genetic knowledge of disease risk may induce a sense of genetic responsibility whereby those who are at risk feel an obligation to take certain actions not only in relation to their own *personal* health but also to their family, their children and many other aspects of their life... blame help[s] to mitigate or allocate genetic responsibility... Women locate responsibility or blame for genetic disease in the collective reproductive history of Ashkenazi Jews..., and this knowledge can have potential future reproductive consequences. A contradiction may arise between a pre-existing sense of responsibility to produce future generations of Jews with that of producing future breast cancer free children (2012, pp. 776-777).

We can see in Mozersky's (2012) analysis that ways in which blame, obligation and genetic responsibility to others, often genetic kin, are seen to result from a positive BRCA mutation status. Likewise, in her work on hereditary cancer in Britain, Brazil and Cuba, Gibbon (2006) notes that the genetic arraying of information also impacts the individual and whether or not she will be selfish or selfless, that is, a figure who either enacts her right to bear children and sufficiently care for them or who foregoes her desire to ultimately ‘ensure the health of others:’

women are being recruited and enrolled into this arena of health care practice and in the requirements of knowledge and for care, in the clinic, there is at least some degree of enabling slippage between the morality of health awareness for oneself and desire or perceived need to take care of and ensure the well-being of related others. That is the articulation of rights, and obligations become linked to and gain much of their force from the way that an ideology of female gender is represented and reproduced in terms of both socially configured gendered rights, and an often naturally perceived female desire and/or need to ensure the health of related others (Gibbon, 2006, p. 163).

For Gibbon (2006) at the heart of genetic medicine there is a slippage of genetic relatedness and female nurturance, in which women come to feel obligated to both genetic and affective kin. In their study of BRCA1 and BRCA2 mutation carriers in Austria, Felt and Muller remark similarly:

How individuals come to terms with these responsibilities seems highly gendered, prominently featuring the image of the nurturing woman taking care of and

protecting her family's physical and emotional health... sacrificing individual preferences for the well-being of others (for example, the option not to know her own risk) (2011, p. 346).

In Felt and Muller's (2011) account, the at-risk woman is a self-sacrificing, selfless individual who puts the needs of others before her own by dint of her gender. In these examples, the individual (woman) is a rational actor, making decisions about the fates of others that will be secured by her careful calculations and selfless decisions. Or she may be figured as the irrational actor, who, like her Ashkenazi predecessors, indulges her own selfish desires for children despite the illness burden they may have to bear. This is a very narrow, albeit very common, analytic frame, in which individuals are either/or, selfish or selfless.

In this thesis, I take issue with the thinking that underpins the use of the prefix 'self' to analyse at-risk women's decision making. I argue that this convention only makes sense if the analyst takes the bounded individual as the primary experiential basis upon which illness or the threat of illness is based. Drawing on Mauss ([1935] 1985), Kirmayer (2007, p. 239) identifies the self as the 'locus of attribution of conscious experience... voluntary action... introspection, and imagination,' what Harris (1989, p. 601) has elsewhere described as a 'human's own someoneness.' My attendance in this thesis to relational and social forms of embodiment is not intended to deny or erase the self, or to suggest that it has no role in understanding hereditary breast and ovarian cancer. After all, it is distinct and discernible women whose names and stories appear throughout this thesis. It is her body that will lie on the operating table to have her breasts removed. It is her body that will be cremated or buried should that procedure prove insufficient.

A problem arises however when the self is aligned with an inherently individualistic ethos. The categorization of at-risk women's behaviour as either selfish or selfless is symptomatic of such individualistic understandings of the self and her attending social relations (see Harris, 1989; Hollos & Leis, 2001; Mageo, 1995). As Kirmayer (2007, p. 259) explains: 'in a social world made up exclusively of willful individuals, someone is always to blame for whatever happens. There is no room for impersonal accident since this would challenge the hegemony of the individual.' When the at-risk woman is

figured by anthropologists of hereditary breast and ovarian cancer as inherently autonomous, bounded and individualistic, so too is her behavior and decision making. She bounces back and forth between concern for herself and concern for her family, analogous to Conklin and Morgan's (1996) bumper cars. This view of the at-risk woman and her decision making also presupposes a bodily and social integrity in her relating with others. Consequently, we risk overlooking complex and messy modes of world-making experienced by women at-risk of hereditary breast and ovarian cancer that refuse confinement to the neat analytic parameters of concepts such as the bounded 'individual.'

It is the case that some theoreticians have critically responded to the dominance of the individual as the core analytic basis upon which experience, particularly the experience of genetic medicine, should be examined. Indeed, as early as 2000, Novas and Rose argued that the new medical genetics offered an opportunity for scholars to explore networks and relationality. They noted how, in regards to the practice of genetic counselling, 'the genetic identity of the counselled individual is established by locating him or her within a network of relations – mapping a set of remembered relations of lineage onto a remembered web of illnesses – at the same time as those social and familial relations were reworked in genetic terms (Armstrong, et al., 1998; Novas & Rose, 2000, p. 490).

Despite recognising the inherent sociality of genetic illness and the genetic counselling encounter, Novas and Rose (2000) yet retain the individual as the key analytic basis upon which such relations should be understood. They note, for example, that while 'the "cause" of the patient's problem might be a family member in a previous generation; the diagnosis in one person now has all kinds of implications not only for themselves but also for the relatives' (Novas & Rose, 2000, p. 490). New linkages come to be traced through genetic connections, in this case, mutations, that bind one person with another. Genetic identity as a mutation 'carrier,' is thereby revealed and creates 'a web of genetic connectedness, which is *overlaid* upon a web of family bonds and family members, with their burden of mutual obligations and caring commitments, and with all the ethical dilemmas they entail' [my emphasis] (Novas & Rose, 2000, p. 490). Once

inculcated into this genetic ‘network,’ *individuals* at-risk may come to reconsider or re-evaluate their relationships through the lens of risk and inheritance. Such re-evaluation may concern their genetic *and* perhaps more significantly their affective kin; ‘lovers, potential and actual spouses, children, grandchildren and so forth’ as Novas and Rose (2000, p. 490) suggest. They may choose or feel compelled to amend aspects of their life according to medical recommendations; ‘lifestyle, diet, leisure activities, alcohol, smoking,’ in these terms, which also reshapes their relations with those with whom they interact (Novas & Rose, 2000, p. 490). Novas and Rose also recognised the ability of and modes through which these genetic relations bring forth other ‘novel networks of interaction,’ a biosociality if you will, which they describe as:

those not of ‘society,’ but of ‘community’ – groups, associations, communities of those similarly at-risk; groups of patients at particular hospitals or clinics; participants in trials of new therapies; subjects of documentaries and dramas on radio, television and movies (Novas & Rose, 2000, p. 490).

These biosocial communities are made up of what Rose (2007) has elsewhere described as the ‘somatic individual.’ Somatic individuals are, according to Rose (2007, p. 4), those ‘whose individuality is, in part at least, grounded within our fleshly, corporeal existence, and who experience, articulate, judge and act upon ourselves in part in the language of biomedicine.’ Although it may be ‘somatic’ and relational, this body is still whole. This body is still seen to enclose a bounded individual, one who operates in a discrete network to the family from this position:

the somatic individual, incorporating their genetic status, is also a subject of self-actualization, responsibility, choice and prudence – ethics that can only be operative in the light of a knowledge of one’s bodily truth. Individuals themselves are faced with questions as to whether to take genetic tests in order to predict their own future and act prudently within it, in relation, say, to their obligation to their family, the need to make provisions by way of insurance in the event of their death or incapacity, their wish to conduct their affairs in the world in the light of a knowledge of their genetic status. Genetic identity, that is to say, induces ‘genetic responsibility’ (Rose, 2007, p. 4).

While Novas and Rose (2000) recognise the relationality necessary to the procedures of genetic disease and medical knowledge, they retain the whole, bounded individual as

the key unit for analysing illness experience. I am not suggesting that the 'individual' be replaced with the corrective of 'dividual,' egocentrism with sociocentrism, in anthropological examinations of hereditary breast and ovarian cancer. To do so would reaffirm the unhelpful binary between individualism and collectivism that, as Mageo (1995, p. 282) purports, is better conceptualised as a matter of 'degree,' a continuum that is dynamic and hybrid. Everyday life, Conklin and Morgan (1996, p. 659) remind us, resists being reduced to essentialist categories of 'individualism' and 'sociocentrism.' What I am taking issue with is anthropologists proclivity to preface the individual and her 'internal' processes to the degree that other, more partial, socio-relational explanations and dimensions are overlooked to the detriment of our understanding of illness experience.

In attempting to rescue the individual from the weight of her genetic burden to other non-affective kin, existing approaches to hereditary breast and ovarian cancer have presupposed the body's integrity. The body of Novas and Rose's 'somatic individual,' for example, still reflects the social values inherent in individualism. While it may be related in a network, the body is remains 'separate from other bodies and bounded by the skin... it is disciplined, controlled, restrained, and autonomous – a private property' (Conklin & Morgan, 1996, pp. 664-665). Returning to the broader but more useful concept of the person, allows me in this thesis to offer new insights into the body of the at-risk woman and the family. Consequently, the body of the at-risk woman emerges as partial, permeable and outbound. Likewise, the body familial is not so much a network of discrete interacting individual bodies but a collective made in and through partial relations of flesh. The approach I am taking assembles as its core data that which has remained largely unexamined by the paradigmatic approaches to hereditary breast and ovarian cancer thus far and something that my informants spoke about at great length. Time and again, what came to the fore during the time I spent with these women in their homes, accompanying them on their daily routines, in local cafes and playgrounds was the ways in which time, care and their bodies were always, already enfolded into particular kinds of collectivities in the most mundane and everyday, yet vital, of ways.

Paradigmatic approaches prevent us from seeing congruencies between possible anthropological understandings of the person and genetic, medical knowledge of how such person is formed. I take as a leitmotif throughout this thesis the notion of the social body proposed by Lyon and Barbalet in 1994. Differing from the idea of the social body proposed by Lock and Scheper-Hughes (1987), Lyon and Barbalet (1994, p. 56) conceive of a social body that is fundamentally partial; it as an ‘intercommunicative and active’ form of embodiment, an ‘ordered aggregation of particular and specific types of relations between... the relevant aspects of bodies.’ In this reading the body and the familial body are not discrete units that correspond with the boundaries of the flesh but rather are created in and through the fleshy relations of body parts.

Building on this idea, I use the notion of ‘partiality’ in two senses throughout this thesis. Firstly, I recognise that the body is inherently partial; an insight I take from genetic ways of knowing the body. The body, in genetic terms, is necessarily made up from the parts of other bodies (called genes) that recombine to make up the person. This recognition in genetic medicine of the partial construction of the body in and through others, is, as I will demonstrate, congruent with anthropological understandings of the person. Tenets of genetics that recognise body parts as creating other bodies align with the insights made by Merleau-Ponty (1968) into the ways in which the person comes to be completed by their significant others; a theme that arose a number of times amongst my informants.

Secondly, I use the notion of partiality to address the ways in which the family as an institution is created in and through fleshy relationality. The family emerges as a result of syncopated and habitual deployments of body parts in close proximity. These habitual and partial deployments, acting in concert, bring together a collectivity of people that is recognised as the family. It this twofold notion of partiality – of both body and family – that is overlooked when we insisted upon the bounded individual as the unit of analysis. In this thesis, I deploy the notion of collectivity to describe the product of the partial, fleshy relations between bodies that I described above. This notion of collectivity (used here to describe both body and family) stands in contrast to the metaphor of bounded individuals relating in a network that is offered by

anthropologists such as Novas and Rose (2000). ‘No embodied form,’ Turner (2011, p. 103) argues, ‘can be understood solely as the product of its own activity, but always owes its formation in part to its relations with other bodies.’ In focusing so squarely on the individual, Turner (1994, p. 28) observes, anthropologists often unconsciously ‘ignore or misrecognize the social nature of the body, and the multifold ways it is constituted by relations with other bodies.’ Significantly, my attention to the collectivities – of person and family – produced by the multiplicity of partial relations, is important to understanding at-risk women’s decision to remove risky body parts. Assuming the body’s integrity and discreteness, as a whole that relates to other whole bodies, has consequences for how we can understand the at-risk woman’s decision to remove significant body parts and reduce cancer risk. Rather than starting with the notion that these body parts belong to an individual who makes decisions about them that will come to bear on her familial relations, I begin with the idea that these parts are constitutive of family as a collective and thus, are collective decisions.

In my thesis, I pose the question, how can we understand experiences of living with the risk of hereditary breast and ovarian cancer anthropologically? In it I respond with quite a different answer to those delivered in the space dominated by biosocial interpretations. I argue that a fundamental reimagining of the individual body is needed in order to come to fresh grips with hereditary breast and ovarian cancer, and to incorporate the relational and partial experiences of the body of which my informants spoke. I take a critical approach to the notion that we must rescue the individual from the grip of a relationality that is imposed by genetic kinship – what I take to be a well-rehearsed response to the medicalising of the body and its relations. As Novas and Rose pointed out in 2000, the genetic arraying of kinship did not necessarily ‘lead to a focus on the individual as isolate’ instead, the reverse occurred (Novas & Rose, 2000, p. 490). Genetic notions of kinship came to underscore the ‘network of relations’ in which an individual was entailed (Novas & Rose, 2000, p. 490). Somewhat ironically, this *individual* is taken to be under threat of being subsumed by genetic configurations of kinship and thus has emerged as ‘isolate’ in current anthropological understandings of the at-risk person. I conclude that refiguring the sanctity of the individual body, and relinquishing the old fight with medicine produces new insights into hereditary breast

and ovarian cancer not currently available to us within the existing paradigm. This has consequences for both understanding the ethnographic circumstances with which this thesis is concerned, and for the discipline at large. By protecting the bounds of affective sociality enacted by the discrete individual, current anthropological approaches to illness may forego knowledge issuing from other ways of envisaging relatedness.

## Chapter Outlines

I advance my argument in this thesis through four substantive chapters. In Chapter One, I present a detailed examination of the alleged ‘geneticization’ of the family and the individual that dominates anthropological approaches to hereditary ovarian and breast cancer. I track the ways in which fears about the hegemony of genetic medicine and the power of the gene initially threatened to isolate the individual, and then proceeded to diminish it, in the view of anthropologists specialising in hereditary cancer syndromes. Cutting through the polarising elements of affective versus genetic relatedness promulgated by Finkler (2000) and others, I closely examine what, exactly, is being rescued from the ‘power of the gene,’ and at what cost to our knowledge of experience of hereditary cancer. Implied here is the idea that anthropology’s oppositionary relationship with medicine has fundamentally crafted the space in which such knowledge can be produced. In this first chapter, I seek to unsettle the primacy and solidity of the discrete and bounded individual which is at the heart of such views. As I have suggested in this introduction, this view has been highly consequential in that it has narrowed our understanding of at-risk women’s decision making to a selfish/selfless binary.

I then detail my alternative re-envisaging of the body, and propose one that expands beyond the conventions of physical individuality. Drawing on concepts of a co-constructed and partial body such as those advanced by Ribbens McCarthy and Prokhovnik (2014, p. 22), I offer a reading of the body that is characterised by the ‘felt persistence of an en fleshed and material relational connection with a loved one.’ Unlike Novas and Rose’s (2000) somatic body that is fleshily connected with the bodies of

significant others as an individual body, my concept of the body is one comprised in, of and through the co-presence of others. Just as the genetically figured body is one that is composed of the contributions of others, my analytic body is not a whole, bounded, entity in, of, to or for itself. Extending this further, I draw on Lyon and Barbalet (1994) to similarly cast the family as an institution crafted of and maintained in the fleshy relations between *parts of bodies*. Some parts of bodies are more significant than others in the creation and maintenance of the family; something very pertinent to the experience of, say, considering the ongoing existence of one's breasts and ovaries in the face of cancer risk. Here, I put forth the notion of breasted and ovarian sociality to posit the ways in which these significant parts, or their approximations, work to create and maintain familial relations. I also consider how these forms of socialities are altered and transformed as such parts come to be excised from the body in the process of risk reduction. Taking this concept of the partial body and family as the analytic centrepiece of my thesis, I turn to examine how particular temporal politics and regimes of time come to bear on women at-risk of hereditary cancer.

Temporal matters are the subject of the second chapter. I explain how the disruption I have made to presuppositions of discrete intersubjective relations permit a reconsideration of illness time. I draw on my informants' reports to explore bodily co-presence, that is, their experiences of significant and socially valued parts of the bodies of their mothers, sisters and children coming to inhabit their own. I use these accounts to challenge both linear conceptions of temporality and the notion of 'patients-in-waiting' (Timmermans & Buchbinder, 2010). By challenging this notion of patients-in-waiting as those who merely wait their turn in genetic line, I reveal how illness time, like bodies, gene and caregiving refuses neat containment (Timmermans & Buchbinder, 2010). In focusing on the minutia of everyday life, I consider how the rhythms of one's life; patterns of eating, sleeping, waking, are considered by women at-risk as patterns that require syncopation. These patterns are a family matter and necessitate continued familial participation. From fast-tracking menopause to ensuring regularity in the rhythms of the family; from routines around sleeping, eating, schooling, to milestone planning; around graduations, weddings, grandchildren, the temporal experience of illness is a syncopated one, inextricably intertwined with the flesh of others. Likewise,

looking backwards, the expectation of how an illness will unfurl is inseparably enmeshed with others. It is conjointly involved with the experience of others, mothers, aunts, sisters, who are only ostensibly 'individuals' in our analytic imaginaries of them as discrete bodily entities.

Having proposed alternative ways of thinking about the body (as a constructed in fleshy relationality rather than a bounded individual entity) and time (as a community property) I turn in Chapter Three to consider how acts of caregiving operate. I dispute the notion, prominent in existing work, that caregiving pivots on notions of selfish and selfless acts on the part of the at-risk woman. Repudiating the claims made for and of the individual in paradigmatic anthropological works regarding illness experience, I take issue with prefix 'self' in the terms 'selfish' and 'selfless' in favour of a view of caregiving conducted in collectivity, in flows. Extending on Mauss' ([1950] 2010) classical theory of the gift, I consider how the reciprocity of care challenges the individualising forces ascribed to the ill body by most anthropologists. Taking this notion of reciprocity into the meshwork of the familial body, I argue that 'care' flows as a resource that is not sited in any particular body. I offer a version of care attentive to its participatory qualities, its inherent messiness, rather than understanding it as being directed from one individual to the other and reciprocated back, to ensure any debts are repaid.

Chapter Four synthesises the claims I have made for the collectivities of body, time and caregiving around a consideration of risk management. Drawing on these claims, I argue that risk management is not so much of an individual concern as it is one arrayed around ensuring a particular type of presence within the family. Drawing on Leder's (1990) work on 'dys-appearing' bodies, I put forth the notion of an 'absent presence' as one that is yearned for by at-risk women. This 'absent presence' is one that is free from the spectre of cancer; that dwells in and with the fleshy relations of familial others and enables care to flow across time. I will argue that it is this recognition of the importance of achieving an absent presence within the familialy constructed body, that allows at-risk women to ultimately remove significant parts from the body. In this sense, body parts or the replacements of body parts come into the service of the body whole. This

whole is not the buffered, autonomous bodily whole of an individual but the relational body of the familial unit.

In the conclusion, I provide a sense of what it is that my informants wanted to stave off at all costs; death and its antecedent, suffering. This conclusion aims to show not only the thanatophobic quality of action taken on the part of my informants, but also reiterate the theoretical approach of this thesis. In it, I demonstrate my issues with analyses that preface the bounded individual who alone staves off death, who acts within her remaining means to make selfless decisions in relation to those to whom she is affectively related. I use the conclusion to illustrate the concepts that I have advanced in the previous chapters; shared flesh, family, time, care, pain, and the partial relations of body parts that sustain those same collectivities of mutually constructed flesh. These concepts are the bases from which only ostensibly individual women act to stave off the potential of death handed to them by their genes.

### **Orienting notes: what is hereditary breast and ovarian cancer?**

With the development of biotechnologies to isolate and detect potentially damaging genetic mutations, people can now be tested for an ever-growing range of biomarkers linked to hereditary cancer syndromes such as hereditary breast and ovarian cancer (Bell, 2013). In 1994 the Breast Cancer 1 (BRCA1) gene was discovered by a team of researchers led by Doctor Mary Claire King, followed quickly by the detection of the BRCA2 (Breast Cancer 2) gene in 1995. The BRCA1 and BRCA2 genes are tumour suppressors, meaning that they are responsible for regulating cell growth and death. When mutated, these genes can malfunction, causing the proliferation of cancer cells. Mutations in the BRCA1 and BRCA2 genes are autosomal dominant and, as such, can be passed down the maternal or paternal side of the family, for example; mother to son, father to daughter, mother to daughter, father to son. Although the presence of a mutation in either of these genes does *not* necessarily result in cancer, it is estimated that a woman carrying a BRCA1 mutation has between a 46-87% lifetime chance of developing breast cancer and a 39-63% lifetime chance of developing ovarian cancer. A

woman carrying a BRCA2 mutation has between a 38-84% chance of developing breast cancer and 16.5-27% chance of ovarian cancer, however the risks associated with either mutation may be lesser or greater depending on particular modifiers such as the location of the mutation on the chromosome (Couch, et al., 2014, p. 1465, see also King, et al., 2003). Both mutations also confer an increased risk of other cancers. BRCA1 mutations are associated with a risk of fallopian tube and peritoneal cancer and both BRCA mutations may increase the risk of pancreatic cancer (Finch, et al., 2006). Men can also be affected by hereditary breast and ovarian cancer syndrome if they carry a mutated BRCA1 or BRCA2 gene. Men carrying BRCA mutations may be at an increased risk of breast cancer, prostate cancer and pancreatic cancer (Levy-Lahad & Friedman, 2007). While BRCA mutations can be carried by both women and men, the risk for a man carrying a mutated gene to develop cancer is considerably less than women carrying a BRCA mutation (Weitzel, et al., 2011; Liede, et al., 2004).

Table 1: Risk of Malignancy in Individuals with a Germline *BRCA1* or *BRCA2*-Pathogenic Variant.

Cancer Type	General Population Risk	Risk for Malignancy	
		<i>BRCA1</i>	<i>BRCA2</i>
Breast	12%	46%-87%	38%-84%
Second primary breast	2% within 5 years	21.1% within 10 yrs 83% by age 70	10.8% within 10 yrs 62% by age 70
Ovarian	1%-2%	39%-63%	16.5%-27%
Male breast	0.1%	1.2%	Up to 8.9%
Prostate	6% through age 69	8.6% by age 65	15% by age 65 20% lifetime
Pancreatic	0.50%	1%-3%	2%-7%
Melanoma (cutaneous & ocular)	1.6%		Elevated Risk

Source: Petrucelli et al, 2016.

An estimated 5 to 10% of all breast cancers are caused by germline mutations in these BRCA genes, with more than one million people estimated to have been tested for BRCA1 and BRCA2 mutations since they were discovered (Couch, et al., 2014, p. 145). The prevalence of cancer amongst women with mutated BRCA genes is up to five times higher than those women who do not carry these mutations, with an even high prevalence of mutations and hereditary cancer syndromes within particular populations such as women and men of Ashkenazi Jewish descent (Weitzel, et al., 2011). In America

about 12% of women in the general population will develop breast cancer within their lifetime, compared to 60% of women who have inherited a mutation in the BRCA1 or BRCA2 genes (National Cancer Institution, 2013). This being said, women may also be identified as at-risk of hereditary or familial cancer syndromes given a sufficiently strong family history or a positive test for one of the many more recently discovered cancer-linked gene mutations such as PALB2, ATM, CHEK2, PTEN, although the degree of risk conferred by these mutations remains uncertain.<sup>2</sup>

There are a number of different guidelines that exist for determining whether a person qualifies for genetic counselling and testing, depending on the country of testing and the company that is used. These criteria however, are generally similar and may be adapted during clinical encounters, as I witnessed during my observations of genetic counselling sessions in Boston, Massachusetts. The United States National Comprehensive Cancer Center Network (Daly, et al., 2016) for example, outlines the following criteria for identifying appropriate candidates for genetic testing for hereditary breast and ovarian cancer:

1. A family member positive for a known deleterious BRCA mutation
2. A personal history of breast cancer who was: diagnosed 45 years or younger, diagnosed 50 years or younger with either an additional primary, a positive family history, or an unknown or limited family structure, diagnosed 60 years or younger with a triple-negative breast cancer, OR diagnosed at any age with a relative family history (e.g. two close blood relatives, male breast cancer, or an ethnicity associated with a founder mutation)
3. A personal history of epithelial ovarian cancer (including fallopian tube or peritoneal cancer)
4. A personal history of male breast cancer

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<sup>2</sup> Recent research conducted at the University of Melbourne has confirmed that mutations in the PALB2 and ATM genes increase the risk of breast cancer. They also concluded that mutations in the CHEK2 gene can cause a moderate risk of breast cancer (Southey, et al., 2016).

5. A personal history of pancreatic, or aggressive prostate if a similar history of either, breast, or ovarian cancer is also present in the family
6. A family history of any of the above mentioned criterion in a first or second-degree family member

The United States and Australia, where my fieldwork was carried out, like many countries around the world, offer clinical recommendations or guidelines on risk reduction.

In the tradition of non-directive genetic counselling, these aim to give the patient the information required to make choices regarding regimes of risk reduction.<sup>3</sup> In the United States, the current recommendations released by the NCCN for managing the risks conferred by a BRCA1/2 gene mutation involves; breast awareness starting at 18 years of age, clinical breast exams every six to 12 months starting at 25 years, annual breast MRI screening from ages 25 to 29 (or based on earliest age of onset in family) and annual mammograms and breast MRI screenings for women over 30. There is also the option of a risk-reducing mastectomy, with or without reconstruction, alongside counselling to outline effectiveness, potential risks and options for reconstruction

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<sup>3</sup> There exist a number of surgical options for the removal of breast tissue. Performed under general anaesthetic, a total mastectomy involves the removal of the breast tissue, areola, nipple and skin, while skin sparing or subcutaneous (skin and nipple sparing) surgeries remove breast tissue whilst leaving as much skin and nipple intact. The success of the surgery in reducing the risk of developing cancer varies depending on the amount of breast tissue remaining (with more risk associated with nipple and skin sparing surgeries). Due to the nature of breast tissue blending with and extending beyond the primary site, there still remains a small chance that cancer could develop despite risk-reducing surgery (Friedman, et al., 2012). This being said, studies by Hartmann et al (Hartmann, et al., 1999, Hartmann, et al., 2001) show that risk-reducing mastectomies reduce a patient's risk of developing cancer by 85% to 90%, making it lower than that of the general public. In the case of reducing the risk of ovarian cancer, surgical options range from the removal of the ovaries and fallopian tubes (known as salpingo-oophorectomy), to the removal of these parts as well as the uterus and cervix (a complete hysterectomy). The removal of the ovaries can also reduce the risk of breast cancer. Recovery after breast surgery takes weeks to months and involves the prolonged use of surgical drains to prevent fluid build-up and infection during healing. Following a mastectomy, women may choose to undergo breast reconstruction. There currently exists a wide range of procedures for breast reconstruction including implants filled with saline or silicone gel, the reshaping of breast from tissue taken from the stomach or back often in combination with implants, tissue matrices, fat grafts and nipple tattooing or reconstruction through tucking. While such procedures aim to restore the cosmetic appearance of the breast, they do not re-establish sensation to the area and can require replacement and further surgery in the future to maintain shape and appearance (Friedman, et al., 2012).

(Daly, et al., 2016). A recent meta-analysis study suggested that between 18-40% of BRCA gene mutation carriers undergo risk-reducing mastectomies, with this number varying between countries (Euhus, 2015, p. 2808).<sup>4</sup> A bilateral risk-reducing mastectomy is a major surgery that involves a considerable amount of time spent under general anaesthetic. According to Euhus' (2015, p. 2808) meta-analysis study, in 8-64% of cases, women experienced one or more complications after their risk-reducing surgery with 52-71% having to undergo reoperations, a rate that was attested to by a number of my interlocutors. A risk-reducing salpingo-oophorectomy (the removal of the ovaries and fallopian tubes) is recommended for women with a BRCA1/2 mutation, ideally between the age 35 and 40 or on the completion of childbearing. For women not electing to undergo this procedure, concurrent transvaginal ultrasounds and a CA-125 test are recommended every six months although the effectiveness of these technologies remains subject to debate (Daly, et al., 2016). By removing the ovaries, women enter into surgically induced menopause. Women may choose to have these menopausal symptoms mitigated by hormone replacement therapy depending on their family history and the possible risks of these drugs.<sup>5</sup>

Current research suggests that a risk-reducing mastectomy decreases a woman's risk of developing breast cancer to less than that of the general population (Tong, et al., 2015, p. 33). A risk-reducing oophorectomy has been shown to reduce the risk of ovarian cancer by 80% and when completed before menopause, also reduces the risk of breast cancer by 50% (Tong, et al., 2015, p. 33).<sup>6</sup> Additionally risk-reducing oophorectomies are associated with the reduction of all-cause mortality in BRCA1/2 mutation carriers (Tong, et al., 2015, p. 33). It is recommended that these surgical procedures are

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<sup>4</sup> Daly and Forman (2015, p. 153) outline four broad categories of risk-reducing recommendations; 'increased screening, pharmacologic interventions (chemoprevention), surgical prophylaxis and lifestyle changes.'

<sup>5</sup> Although the symptoms of surgically induced menopause can be mitigated with hormone replacement therapy, side-effects of the procedure can include 'vasomotor symptoms, damage to the skeletal system and sexual dysfunction as well as the more obvious loss of any reproduction capability' (Weitzel, et al., 2011).

<sup>6</sup> As mentioned above, breast cancer risk cannot be completely reduced with a mastectomy because 'short of removing all the skin of the breast envelope, it is not possible to remove all the breast epithelium in every woman' (Euhus, 2015, p. 2807).

discussed as risk-reducing options alongside chemoprevention drugs and investigational imaging and screening studies. Cancer Australia, by and large, follow similar recommendations as those set out by the National Comprehensive Cancer Network. Nevertheless, Collins et al (2013) study of risk reduction in Australia showed that the uptake of management strategies remained lower than anticipated across the country, suggesting the need to improve follow-up, multidisciplinary care and support for those facing hereditary breast and ovarian cancer. Importantly, this study noted that the lack of specialised, multidisciplinary reviews for at-risk women left few opportunities for women to discuss the options available to them after testing and how these may change over their lifetime (Collins, et al., 2013, p. 683).

Significantly, the number of people identified as being at-risk of hereditary breast and ovarian cancer is likely to grow over the coming years. This increase may be linked to higher incidences of cancer associated with an ageing and expanding global population and the advancement of early surveillance medicine and genetic testing for hereditary cancers. These technologies enable the pre-diagnosis of women and men at an early age, some as young as 18 years old (Daly, et al., 2016). The 'Angelina Jolie' effect has also been shown to have increased the demand for genetic testing for hereditary cancer syndromes (James, et al., 2013). In the week following the announcement of Jolie's bilateral risk-reducing mastectomy in 2013, familial cancer clinics in Australia reported a doubling in the number of referrals for genetic counselling (James, et al., 2013). Additionally, the decision by the US Supreme Court to dissolve the Myriad Genetic Company's patent over the BRCA1 and BRCA2 gene mutations in 2012 paved the way for more competitive and cheaper testing methods for hereditary cancer genes across the globe. As a result of this Supreme Court decision, competing companies such as AMBRY and Colour have been able to, for the first time, offer tests, some costing as little as \$200. In October 2015, the High Court of Australia also ruled that BRCA genes were not patentable subject matter in Australia, thus overturning Myriad Genetics patents in the country. Consequently, genetic testing companies are now expanding their product lines, offering tests not only for single site mutations on the BRCA gene, but also panel tests that screen for the BRCA mutations and an additional 25 mutations that may increase the risk of cancer and other diseases.

The practice of identifying and reducing the risks of hereditary cancer in the clinical setting has become common in most advanced capitalist societies. More recently, research and testing has focused on gathering information on the different variations that can occur within the breast cancer genes. This has resulted in the creation of extensive databases of genetic results, family histories and phenotypes of affected families to compare and ascertain which mutations are pathogenic and those which are of uncertain significance. As more family disease information has been catalogued and examined, these databases have helped to improve the accuracy of risk statistics and narrow the parameters of risk-reducing recommendations.<sup>7</sup> This process of cataloguing known mutations is still in its early stages especially in regards to the other associated genes for hereditary cancer syndromes included those on next-generation sequencing multi-gene panel tests.

Despite these developments in technology, accessing genetic testing services and undertaking risk-reducing strategies remains laborious and financially demanding, often precluding the uninsured, underinsured and those from socioeconomically disadvantaged backgrounds (Burke & Korngiebel, 2015). Extensive research has

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<sup>7</sup> Over the past year, the practice of testing genes for variations that may increase the risk of cancer has been transformed both scientifically and economically with the development of Next-Generation Sequencing (NGS) in the form of multi-gene panels for testing hereditary cancer syndromes. NGS, write Fecteau and Pal (2015, p. 82), has revolutionised the genetic testing paradigm and is predicted 'to become a central piece of routine healthcare management which can be practiced regularly by physicians from their offices.' Prior to NGS, suspect genes were examined by single tests for a mutation followed by further single gene tests if a variance was not identified. NGS, in contrast, allows for multiple genes to be tested simultaneously using massive parallel sequencing (Mauer, et al., 2013). This technique reduces both the time and the cost of the test itself. Costs for NGS multi-gene or multiplex tests, in contrast to the \$1000-\$2000 for a single gene Sanger sequencing, are expected to drop below \$1000 with an increasingly competitive market of laboratories releasing commercial NGS panels for hereditary cancer syndromes. NGS multi-gene panels for hereditary breast and ovarian cancer analyse not just BRCA1 and BRCA2 genes for clinically significant or 'known' mutations, but other gene variants that may be used to make clinical recommendations for preventative action. The major issue with these techniques is that, while multiple genes are tested for variants, there remains a lack of working knowledge about what these genes and variants do, producing a large number of variants of uncertain significance. As Phimister (2015, p. 2227) surmises 'a major challenge of interpreting genetic sequence is... how to determine which variants are pathogenic and which are benign' especially in the clinical setting.

identified possible barriers to genetic testing and counselling including; lack of knowledge of genetics amongst primary physicians, lack of clinical genetics support, varying genetic resources in different locations, different assignment of responsibility in different health care systems, concern for costs of testing and follow-up amongst patients and difficulty in understanding complicated testing procedures (Burke & Korngiebel, 2015). Antill (2013) identified public hospital waiting times and the expense associated with private health insurance as potential barriers to the uptake of genetic testing, counselling, and risk reduction in Australia. Similarly, Collins et al (2013, p. 683) have identified the lack of 'regular ongoing multidisciplinary specialist' support for decision making after genetic testing as contributing to the low uptake of risk-reducing strategies in Australia. These studies illustrate just some of the many ways in which BRCA research and clinical practices remain unevenly distributed and taken up across the globe (Antill, 2013; Collins, et al., 2013; Gibbon, et al., 2014, p. 4). Subsequently, the population of those recognised clinically as at-risk of hereditary breast and ovarian cancer is predominately Caucasian, urban women and men from middle to higher socio-economic backgrounds. This demographic is more likely to have access to the required resources and finances for undertaking risk reduction. I have found this to be true within my own ethnographic fieldwork in Australia and America.

## **A note on terminology**

'Previvors' or 'previvorship' as a label used to identify those living with the risk of hereditary cancer was coined by the support group Facing Our Risk of Cancer Empowered, or FORCE, in the early 2000s. Previvors are 'the portion of our community which has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer' (Friedman, 2011). This term was specifically chosen to contrast the medical terminology of 'unaffected carrier' used to identify those at-risk of hereditary cancer syndromes. This medical nomenclature, FORCE suggested, did not adequately capture the 'experience of those who face an increased risk for cancer and need to make medical management decisions' (Friedman, 2011). Throughout the thesis, the terms at-risk women and previvor will be used

synonymously to reflect the most common terms my informants used to describe themselves. Notably, the preference for a particular label tends to fall along geographic lines. *Previvor* was the more common term used by informants to describe their experience of being at-risk of hereditary cancer in the United States whilst my Australian informants generally referred to themselves as 'at-risk' or 'high-risk.'

Throughout this thesis, I use feminine pronouns as the majority of my informants (excluding five male informants) were femme-presenting and identified with the use of feminine pronouns. I also use *she* as the generic or gender-neutral singular pronoun throughout this thesis to reflect the trend in the anthropological literature on hereditary breast and ovarian cancer to focus on the experiences of women.

## **The study**

Over a period of two and a half years spanning from 2013 to 2016, I conducted multi-sited ethnographic fieldwork amongst women and men at-risk of hereditary breast and ovarian cancer and their families in Australia and the United States. The nature of the hereditary breast and ovarian cancer community is disparate. Those clinically recognised as being at-risk of hereditary breast and ovarian cancer are located across the world in predominantly advanced Western societies. As such, rather than focusing on a single, fixed location, my fieldwork took the form of multi-sited ethnography and followed 'people, connections, associations, and relationships across space' (Falzon, 2016, p. 2). This focus on what Falzon (2016, p. 2) describes as the 'substantially continuous but spatially non-contiguous' fieldwork site mirrors the formation of the at-risk community within and across countries. As a result, much of the interaction taking place within the at-risk community relied on popular media platforms such as Facebook and Twitter and local outreach events (Falzon, 2016, p. 2; see also Coleman & Collins, 2006).

The United States and Australia proved fruitful locations for fieldwork as they are home to world-class facilities dedicated to the study of hereditary cancer and, as such,

communities dedicated to supporting and advocating for those at-risk. These locales enabled me to gauge the developments in genetic and genomic medicine and interact with the people involved in these spheres. In Australia, I volunteered with a national support group for at-risk women and men to conduct participant observation and to recruit participants into the study from across the country. During this time, I interviewed 35 Australian women and two Australian men who carried a BRCA mutation or were identified as at-risk about their experiences of living with hereditary cancer. These semi-structured interviews, conducted in local cafés and public spaces, as well as over the phone, generally lasted between one to three hours. Participants were also recruited outside of the national support group through the method of snowballing as, being a hereditary condition, informants would often recommend their extended family members for the project. In this sense, my fieldwork could at times be considered informal ethnography. I was invited to participate in familial discussions and family gatherings such as birthday parties. Recruitment was further facilitated by two surveys distributed throughout the national support group's online forum. Over 200 responses were gathered, identifying key thematic concerns for analysis as well as further possible informants for interviewing. During this fieldwork period, I also undertook participant observation within the wider hereditary breast and ovarian cancer community, attending fundraisers, public outreach events and ambassador weekends organised by the national group, as well as medical research conferences and information days held across the country. I also conducted two focus groups with at-risk women and men in Canberra.

The primary fieldwork undertaken during my time in America was participant observation within a cancer prevention and genetics clinic in Boston. Over a period of six months, I observed over 50 genetic counselling appointments, spanning between 30 minutes to an hour. These observations gave me the opportunity to engage with at-risk women and men in the community who presented at the clinic for counselling, testing and surveillance as well as the workings of the clinicians, genetic counsellors, nurses and genetic testing company representatives. This time spent in the clinic allowed me to observe the procedures and protocols through which a person becomes recognised, clinically, as 'at-risk' and those who fall outside of such criteria. While in Boston, I also

immersed myself in the HBOC community and genetic scientific and research network. Home to more than 20 hospitals, including the top five recipients of National Institute of Health research dollars, Boston was an ideal location in which to witness the cutting-edge of genetic medicine coming out of these centres. I attended conferences, symposiums and seminar days, engaging with health-care professionals to make sense of these and future developments in 'precision' medicine around hereditary cancer syndromes. I also attended conferences and fundraisers organised by the leading US support group for previvors, FORCE. During these events I engaged in more informal and unstructured conversations with women and men at-risk of hereditary breast and ovarian cancer. While based in the US I conducted a further 16 one-on-one interviews (12 women, four men) with previvors. These interviews often arose from interactions with attendees at the cancer genetics and prevention clinic where I was based and from my interactions with the FORCE community.

Informants opted in for an interview based on their interest in the project and willingness to be involved. In terms of the selection process, I purposely kept the selection criteria broad; potential informants only needed to have reason to believe they were at high-risk of hereditary breast and ovarian cancer. This included people who had a family history of breast and ovarian cancer but had not yet undergone genetic testing, those who had been tested, including those who received inclusive results and those who had not undergone genetic testing but had, under the advice of their doctor, undergone risk reducing surgery. It also included people who had been diagnosed with cancer and, as a result, been tested for a hereditary cancer mutation.

My informants in Australian and America ranged in age, BRCA mutation status and the stage of risk reduction they had or were considering undertaking. Interviewees ranged in age from 18 to 69 years. While the majority of my informants were women (47), I also interviewed six men. While both women and men can carry BRCA mutations, the chance of men developing the associated cancers is considerably less. Although I conducted interviews with at-risk women and men, my study focuses on women's experiences of being at-risk of hereditary breast and ovarian cancer. This focus arose from my interest in how female participants discussed the ways in which particular body

parts, namely their breasts and ovaries, related to others within the family. This sociality based on these significant body parts – breasts and ovaries – was not as applicable to men’s experience of hereditary cancer risk. Further anthropological research is required to investigate men’s particular experiences of hereditary cancer risk and how it may, too, impact on their modes of sociality and means of relating with familial others.

The majority of my informants had tested positive for a mutation in either the BRCA1 or BRCA2 gene. A small portion of informants (two in total) had a VUS result, that is, a variance of uncertain significance, however, on the basis of their family history, were considered at-risk of a hereditary cancer syndrome. As mentioned above, the population of previvors in Australia and America are predominately educated Caucasian, urban women from middle to higher socio-economic backgrounds. This being said, I endeavoured to broaden my sample to include a range of ages, genders, education levels and ethnicities. Information about each informants’ circumstances, for example, age, BRCA mutation status, gender, ethnicity and regime of risk-reduction is located in Appendix A.

I have located the information concerning my informant’s social context in an appendix rather than in text to emphasis the voices of my informants and *their* descriptions of their experiences. Rather than converting these women’s voices and experiences into the perhaps more conventional, narrative form, I have purposely chosen to rely on excerpts from my interview data, as supported by some instances of participant observation, to support my investigation. This aligns with my theoretical interests across this thesis, namely, women’s own descriptions and reflections of their experiences of cancer risk, family life, temporality and care-giving. My reliance on interview data likewise reflects my interest in countering existing anthropological approaches to hereditary breast and ovarian cancer that focus primarily on the biosocial as a unit of analysis, for example, the collective experiences of at-risk women within a support group and as a social corrective to the individualising forces of genetic medicine. My rationale for this approach is discussed in further detail in Chapter One.

I conducted interviews until a clear pattern of responses had emerged, as described throughout this thesis. I reach a point of data saturation in late 2016. This interview data was then transcribed and, with the notes collected from participant observation, coded thematically. My research was provided human ethics clearance by the Australian National University Research Ethics office, protocol number 2013/537 and Harvard University Committee on the Use of Human Subjects Institutional Review Board.

## **Cast of characters**

Although the voices and experiences of a number of women appear in this thesis, they are not represented equally. This uneven representation is not because these women did not talk about, speculate on or agree with the issues discussed in this thesis. Rather, over the course of my research, certain informants emerged whose expressions and insights helped me to talk about these experiences in the clearest of terms. One of these informants was Lily.

It seems like some kind of fate that I was to meet Lily, one of my key informants, on my very first day of fieldwork. Nervous and running late as usual I stumbled into the crowded seminar room of a Sydney hotel for the 2013 Annual Information Day for those living with BRCA1/2 gene faults, held by the Association of Genetic Support of Australasia (now known as Genetic Alliance Australia). Making my way to the back of the room, I noticed a spare seat next to a young woman holding a small squirming child. After sitting through the first presentation, an overview of the different methods of screening; mammogram, 3D ultrasound and MRI, I had a chance to speak with the other people at my table. Lily introduced herself and her mother, Beth. Like me, they had travelled up from our home city that morning to attend the information day. Beth explained why they had come along. After a diagnosis of aggressive ovarian cancer in her early 60s, Beth had tested positive for a BRCA2 mutation. Her daughter Lily was tested for a BRCA mutation earlier in the year, at the age of 34 and also tested positive. Like the other 150 or so women and men in the room, Lily and Beth were looking to gather information about living with a BRCA mutation. They wanted to know how to

make sense of and minimise their risk of developing hereditary breast and ovarian cancer, or in Beth's case, a reoccurrence.

Over the course of the day we sat through seemingly endless PowerPoint presentations given by genetic counsellors, geneticists, clinical oncologists, clinical psychologists, breast surgeons and other at-risk woman. The presentations covered the different forms of surveillance and surgical risk reduction regimens available; how these may impact on one's family planning and physical wellbeing and the ways in which such health information could be communicated among relatives. There were numerous slides bearing the statistical calculations of lifetime risks of cancer, of surgical complications, of false positive CA-125 tests, of IVF success and failure. There were many tears and consoling hugs as one woman recounted her experience of losing her mother to aggressive breast cancer while she was pregnant. She spoke of how she decided to undergo a risk-reducing bilateral mastectomy not long after. By the end of the day, I overheard many of the attendees talking of 'information overload' and emotional fatigue, including Beth and Lily.

During one of the afternoon tea breaks, I began talking to Lily. At the time, Lily was on maternity leave from her job as a public servant in the Australian government. It so happened that she was organising an upcoming fundraiser for the main HBOC support group, Pink Hope, in Australia and it would be held in our neighbourhood in a few months, November of 2013. Sensing a good opportunity to familiarise myself with the HBOC community, I offered to help Lily by volunteering to deliver pamphlets around the city. In the weeks leading up to the fun run, I met with Lily to deliver flyers and to help set up the information tent at her event. After the fun run and Christmas break, Lily and Beth, now familiar with my research project, kindly offered to meet with me for an interview. In February of 2014, we started what would be the first and most formal of our many discussions concerning their family history of cancer and our many interactions over the coming years. Cups of tea in hand, we began by talking through the Brooks family's various cancer diagnoses. Beth's mother (Lily's grandmother) had been diagnosed with breast cancer at the age of 51 and in the following year, she underwent a radical mastectomy, radiation and chemotherapy. She passed away not

long after these treatments. Beth's father was diagnosed with cancer and passed away a few years after her mother. Beth's maternal grandfather died from bone cancer. Beth was shocked when she herself was diagnosed with stage 4 ovarian cancer at the age of 59. She had always been very careful to have regular check-ups after 40, every second year, and then every year at 50. Given her family history of multiple cancers, her doctor suggested that her cancer could be hereditary and advised that she and her family be tested for the BRCA1/2 gene mutations, a recommendation that was supported by her oncologist.

After undergoing surgery and chemotherapy to treat her ovarian cancer, Beth began the process of genetic testing. 'I felt like I was undergoing an interrogation,' Beth declared. Beth was asked to recount her family history of cancer to the genetic counsellor, including the types of cancers present and the ages of diagnosis and death. 'I came out drained,' she noted. Beth waited six weeks for her blood test results, after which she was contacted by the genetic counsellor and told that she carried a mutation in her BRCA2 gene (located in the eighth exon between nucleotides 658 & 659). Finding out this information close to Christmas, Beth took the opportunity to inform her close family. Beth called her brother Eric (who lived in England at the time, working as an executive in a media company) and spoke with Lily and her oldest child Dylan in person. At the time, Lily was due to give birth to her second daughter. Beth's sister Charlotte, at first, did not want to know about the gene mutation nor be tested for it. However, given time to consider the news and its implications, Charlotte decided to undergo a hysterectomy and a risk-reducing mastectomy not long after she was told of the familial risk. Charlotte's three sons each tested negative for the mutation. Beth's brother Eric also tested positive for the gene mutation in his mid-sixties, as did his daughter Chloe, now in her early thirties. While both Lily and Dylan were eligible to undergo genetic testing, given their mother's diagnosis and family history, only Lily chose to be tested. Lily tested positive for a BRCA2 mutation not long after giving birth to her second daughter. 'Mum did good!' Beth exclaimed, as she listed the number of family members carrying a mutation. Of the eight family members who had been genetically tested, five tested positive for a BRCA2 mutation (Beth, Lily, Charlotte, Eric and Chloe).

During this initial interview, Lily recounted her own experience of testing positive for a BRCA2 mutation:

I was 34 and in the sauces aisle of my local shops when I received a call from my genetic counsellor advising me that I had a 66% lifetime chance of developing breast cancer. After nearly dropping the phone and looking at my two young daughters, I thought that it was probably time for me to take this hereditary cancer stuff seriously.

Lily spoke to me about the difficulty she experienced in making decisions about a course of action when it seemed like there were so many different recommendations and studies constantly changing and emerging. One of her main frustrations with her situation, and one that we often spoke about, was the difficulty she experienced in making sense of *her* risk against the broader predictions, statistics and population-based risk calculations:

I was talking to my friendly genetic counsellor last week and was asking about all the 'lifestyle' factors that the BOADECIA risk calculator takes into account when it gives a percentage risk for developing breast and ovarian cancer. It turns out that it only takes into consideration family history. So I asked if there was another risk calculator that would give a more accurate percentage risk calculation based on lifestyle factors as well as family history and Tanya said the 'Tyrer Cusick' calculator takes into account: age of having babies, height, weight, age of first period. So I gave her my details for that and now my risk has gone up from 66% to 74% lifetime risk for breast cancer! She then went on to say that she and Dr Hamilton felt in their 'gut' that this percentage was a bit too high for me so they said it should be slightly lower... So essentially I've been given two risk calculation figures, one based on four factors plus a gut feeling, and the other on family history, neither of which take into consideration my breast feeding history which is supposed to cut your cancer risk by 50%, my pill taking history which is supposed to drop your ovarian cancer risk, my smoking status, my alcohol consumption or my level of physical activity. Honestly, why isn't there another tool that takes everything into consideration.

Lily also felt this frustration and confusion in regards to risk-reducing options such as screening and surgery. She recalled being given a few general information brochures about how she could proceed with risk reduction, but she wished that there existed something more akin to a 'decision tree,' as she called it. Lily desperately wanted a resource that showed a 'path' or 'checklist' you could follow. For example, she could

select the criteria that best describes her situation; 'I am a young mum, breastfeeding my bab[ies] and juggling a part time job,' and follow it along 'branches' to find what the most suitable risk reducing strategy or option would be. Yet even then, she told me, she could still get cancer:

It's frustrating that you can do nothing about your genes. It's frustrating that you can do everything right like, have kids early, breastfeed, exercise, not drink alcohol, be a healthy weight and not smoke but STILL get ovarian cancer because you've got some ridiculous gene mutation.

Over the coming years, Lily and I would often talk about the difficulty she faced in deciding what to do about her BRCA2 mutation. When we first met, Lily had only recently found out about her mutation and was thoroughly preoccupied with nursing a newborn baby and toddler. Towards the end of my fieldwork and having completed her family with a baby boy, Lily was beginning preparations for undergoing risk-reducing surgeries. She had begun a savings fund for her operations and was hoping to take a voluntary redundancy at her job to give her the additional time and money to undergo the procedures. On one of our drives to a conference in 2014, Lily told me how she had been surprised by what she felt was the emphatic support for surgery she received from her doctors:

Within one minute of meeting you [they say], 'oh you've got the gene, so we'll take your breasts and then you should consider a hysterectomy when you've done with your family.' It's like they don't even consider the myriad of other emotional issues there are to deal with. Obviously I appreciate that doctors are gurus and to reduce your risk you should have the surgery, but sometimes doctors forget that it's a *massive* deal and that there are a lot of things to consider.

This uncertainty often played on Lily's mind, especially as she approached the age in which risk-reducing oophorectomy is recommended for BRCA mutation carriers. 'I will never know if I have made the right decision,' whether the cancer would develop or not, 'it is such a gamble.' And yet, as she astutely observed, 'if you choose not to have the surgeries and you develop cancer, you have to live with knowing you could have done something, that you were wrong, you got it wrong...You'd never want to lose the bet when cancer is the result... But on the other hand, there's a 40% chance I may be

removing perfectly healthy body parts.’ But it was not just this state of ambiguity that impacted on Lily’s everyday life. There were and still are practical matters that arise from living in the spectre of hereditary breast and ovarian cancer; issues of time, money and careers. ‘I waste a lot of time going to doctors to get little things checked out, little lumps or little abdominal pain, things I wouldn’t normally worry about.’ Lily often felt that she did not ‘have the time for this bullshit.’ Dealing with risk-reducing surveillance often ate away time from Lily’s busy everyday routine as she tried to coordinate school drop-offs, swimming lessons, work obligations and social events. While the whole process was less of a worry in terms of discovering a tumour or pre-cancerous growth, she noted how it often presented a challenge in trying to find someone to watch her children; ‘I am using up all the babysitting quota on getting ultrasounds.’ Lily’s concerns are indicative of a number of issues and worries that I heard from my informants over the course of my fieldwork.

Lily’s life and that of her family members changed in a number of ways over the period of my fieldwork. When Lily and I first met in late 2013, she was on maternity leave having recently given birth to her second daughter. Towards the end of my fieldwork period in late 2015, Lily gave birth to her third child, a son. Over this period and up to the present, Lily continued to collect information to aid her in the process of deciding if and when she will undergo risk reducing surgery in the form of a bilateral risk-reducing mastectomy and oophorectomy. Beth’s ovarian cancer also returned during this period. In early 2015, her cancer markers increased and it was confirmed that her ovarian cancer had spread throughout her lower intestines and bowels (despite having undergone a complete hysterectomy). She went on hormone therapy in the hope of avoiding another round of chemotherapy. Beth spent much of 2015 in and out of hospital and in treatment as the hormone therapy proved unsuccessful and she underwent another round of chemotherapy and surgery to try to remove the diseased tissue. In 2015 she also enrolled in a clinical trial of a PARP inhibitor designed specifically for women with recurrent BRCA ovarian cancer during which her health

stabilised and her tumours dramatically decreased in size for a short period of time.<sup>8</sup> Mid-way through 2016, Beth's cancer markers began to increase again.

Over the period of my fieldwork and in the months I worked on writing my dissertation, I spent an increasing amount of time with Lily and the extended Brooks family. Living in the same city at the beginning of my fieldwork, Lily and I would often carpool to hereditary cancer conferences and Pink Hope events which lead to a friendship that extended beyond the fieldwork setting. In 2015, as my fieldwork was coming to an end in the United States, Lily and her mother Beth travelled to America to attend the FORCE annual conference in Philadelphia. Beth's niece and Lily's cousin Chloe had moved to New York the year before to take up a legal internship. After some family consultation, Chloe decided to attend the FORCE conference along with her father Eric, who would travel over from England. For the week prior to the conference, I stayed with Lily, Beth, Eric and Chloe in New York City. This time spent with the extended Brooks family, this family of 'mutantees' as Chloe would call them in a mock David Attenborough accent, helped to crystallise my understandings of 'what really matters' to the Brooks family – what they value, cherish and strive to protect from the threat of hereditary cancer. 'Ah the elderly mutantees seems confused by the amuse-bouche,' Chloe chortled one day, playfully mocking me as I quickly scrawled down observations from the day in my fieldwork notebook over dinner. As Eric helped Beth choose the best low-fibre option for dinner, part of her post-surgery diet, Lily and Chloe chatted about risk reduction. The two laughed as Lily recounted how she was told that she left it 'too late' to have children at 31, joshing that Chloe better 'get cracking.' 'I should text Adam and let him know it's time to start popping out some kids,' Chloe responded, pretending to pull her phone out of her bag to text her boyfriend. While Lily and Chloe were able to use humour to talk about their situation both, on different occasions, felt intensely the

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<sup>8</sup> PARP or poly(ADP-ribose) polymerases are 'enzymes involved in DNA-damage repair' (Livraghi & Garber, 2015, p. 1). PARP inhibitors offer a 'promising strategy for targeting cancers with defective DNA-damage repair, including BRCA1 and BRCA2' (Livraghi & Garber, 2015, p. 1).

uncertainty of making decisions about their health, their families, and their careers in light of a BRCA2 mutation.

## **Everyday life with the Brooks**

During my two years of fieldwork and extended writing periods thereafter, Lily, Beth and I would attend BRCA-related events, fundraisers and community outreach groups together. We travelled to Sydney, Melbourne, Philadelphia and New York to learn about the developments in the field of hereditary cancer and meet with other at-risk women and men. During these times, we got to know the ins and outs of hereditary cancer risk management and, more importantly, each other. The aim of an anthropologist, writes Foster et al (1979, p. 180), 'is to be able to relate to people, not simply as informants, but as friends who share much more than an immediate concern with data.' Over these years, Lily and I developed a strong relationship of care and friendship. This relationship remained strong during our times together and apart, as I travelled away to conduct fieldwork in the United States and moved to a different city upon my return to Australia. Lily's and her family's experiences of being at-risk of hereditary breast and ovarian cancer are ones with which I feel incredibly privileged to have been able to engage. Over the course of my fieldwork, Lily not only tirelessly discussed with me the issues that pertained to her experiences of being at-risk but welcomed me into her life and family as a friend. She encouraged me to speak to her different family members and updated me on any developments in their lives. In welcoming me into her life as lived, I was able to spend time with her husband James and children, her cousins and uncles, parents-in-law, work colleagues and friends. Lily's generosity, enthusiasm and dedication encouraged me to see her beyond an understanding of what she was in relation to my project – a carrier of a genetic mutation for HBOC. I came to see, and to appreciate who she is and 'who she is struggling to be, both now and in the future' (Willen, 2014, p. 97).

Things were said and left unsaid in our relationship. Some weeks we would spend time together and not speak of hereditary cancer, some weeks we spoke about it a great deal. For periods of time I saw Lily and her family daily, we shared meals, perused the local

markets, went running and cycling around the streets, travelled together within Australia and abroad. I have held her children, comforted them when they cried, feed them and played with them for hours on end. Her daughters introduced me to strangers and friends as their 'sister.' At other times, we went for weeks, even months without seeing one another, maintaining regular contact through texting and emails. The many hours we spent engaging with the HBOC community were informative as we shared research articles, discussed the latest developments in treatments and risk-management and bemoaned the challenges of the healthcare system. Of equal if not greater value, however, were those intimate moments when Lily invited me to engage with her and her local world. Those mundane, everyday but no less important life activities; of grocery shopping, making cupcakes and eating icing, watching bad reality TV, griping about our partners and jobs, stuffing our faces with ice-cream, were critical to developing my ideas about the shared, familial body. I sat with Lily as she breastfed her baby boy, and witnessed pure adoration as she gazed down at his tiny features and coy little smile. I held and bounced her little baby, watching as he took his first steps, played hide and seek with Suzie and did some rather enthusiastic Irish dancing with Lizzy. It was this intimacy that focused my gaze on what Mattingly (2014, p. xvii) describes as the 'humbler moments of everyday life' as we try 'to make do with the... lot that has been handed' to us. It was these lasting relationships of care that also attuned my ethnographic sensibilities to the role of the body in creating and maintaining the family, as a locus of collective experiences of temporality and as a means through which to give and receive the care of familial others.

## **My position as ethnographer**

My age and gender undoubtedly assisted me in fostering and maintaining relationships with my informants as a young woman embarking on her first extended stint of fieldwork. My positionality as a woman that bore the same parts and biological capacity as the majority of my informants certainly enabled me to interact with my informants in ways that may not have been available to a male ethnographer. Indeed, on a number of occasions, I was invited by my interlocutors to see and feel their reconstructed breasts

and to accompany them to consultations with plastic surgeons as they showed them their breasts. Similarly, my age was an asset in the field. Being in my mid-twenties, I was often the same age or close in age with my informants or the age of their adult children. On other occasions, it was not so much our shared gender or age but rather mutual interests and similar personalities that creating connections. For Andy and I, for example, our mutual interest in academia, online communities and new technologies fuelled long debates and discussions. Lily and I, as mentioned above, bonded over our shared love of running, making desserts and watching trashy TV shows.

My time spent with the Brookes family enabled me to move beyond formal data gathering to talk with and witness moments that were 'significant yet often random and unexpected – moments that one is only privy to as a result of intimate contact' (Taylor, 2011, p. 11). In attempting to respond to Benson and Lewis O'Neill's (2007, p. 31) call for anthropologists to engage in critical 'self-reflection about the fundamental face-to-face dimension of fieldwork,' in this introduction, I have suggested some of the ways in which my caring relationship with the Brooks family and others like them influenced my thinking on the social body of the family, on shared temporality and care-giving. It is shocking, write Benson and Lewis O'Neill (2007, p. 31) that for a discipline that is centred on people, anthropology often lacks 'critical self-reflection on our relationships with informants.' Wilkinson (2014, p. 94) details how, upon returning from his fieldwork on poverty and homelessness, Pierre Bourdieu was compelled to question the approach of social science to experiences of suffering. He voiced concerns over the propensity of researchers to distance themselves from their subjects and silence their voices in the process of writing up. This distancing prompted Bourdieu to challenge what he saw as the morally suspect relationship between researcher and informant. Such iterations, he suggested, promoted 'cool rationality and abstract languages' but also that the researcher adopt a 'dispassionate manner' when interacting with those experiencing suffering (Wilkinson, 2014, p. 94). Following on from such critical reflections, Bourdieu called for an approach to research that requires researchers to engage on a 'more personal level in the pains and difficulties of their responders.' He envisaged social research, as Wilkinson (2014, p. 94) explained, as a form of caregiving. This is a stance that Wilkinson (2014, p. 94) himself takes, recognising Bourdieu's

insights as a critical challenge for the discipline of anthropology as it concerns itself with suffering. Wilkinson (2014, p. 94) calls for a revision of ‘pursuit of social understanding’ that holds, at its core, a ‘caring practice.’

This form of ethnography as a caring practice, is necessarily enmeshed in the ‘contingency’ and ‘risk’ inherent in any human relationship, as Benson and O’Neill (2007, p. 31) suggest. The benefits of developing caring relationships with the Brooks family, for me, far outweighed the risks that such intimacy might pose to myself and, I hope, to them. As Jackson (1983, p. 340) has argued, we must move beyond the ethnographic use of a ‘linear communicational model for understanding... bodily praxis.’ Given this thesis’ interest in bodily praxis as integral to the formation of the family, my ethnography likewise demanded an embodied research practice. It is by using one’s own body, in concert with the bodies of others, Jackson (1983) asserts, that we can come to catch a glimpse into its significance:

By using one’s own body in the same environment, one finds oneself informed by an understanding which may then be interpreted... yet which remains grounded in a field of practical activity and thereby remains constant with the experience of those among whom one has lived (Jackson, 1983, p. 340).

It was through this relationship of care and intimacy with Lily that I came to appreciate what was at stake for her and her family. It was through being a physical presence in her family life, of caring deeply for her and her family’s wellbeing as I felt she cared for my own, that I came to appreciate what really mattered for Lily and her family; her mother Beth, her husband James, her daughters and son, her uncle Eric, her cousin Chloe. It is to them that I owe this thesis.



# Chapter One

## Genes, individuals and kin

In this chapter, I expand upon the brief genealogy of anthropological approaches to hereditary breast and ovarian cancer I provided in the introduction. In doing so, I illuminate what has become the paradigmatic approach to hereditary disease within anthropology and how this approach curtails other understandings of the illness experience. The rise of genetic medicine and genomic biotechnologies has led to much consternation among social scientists regarding how the patient and her relations may come to be understood in light of these developments. An initial fear was that those enfolded into genetic medicine would emerge in the form of the ‘individual as isolate’ (Novas & Rose, 2000, p. 490). This is a long-standing concern of medical anthropologists who worried about the ways in which biomedicine isolated the sick body from the social and cultural contexts to which it belongs and is best understood. Helman (2008, p. xvi) notes that the voicing of this concern has been a strong trend in medical anthropology since the 1980s.

This concern remains in the context of predictive genetic medicine and is perhaps even sharpened within its critiques. The ‘individual isolate’ imagined in such accounts is a profoundly decontextualised entity who is defined solely by her or his genetic matter. One more sinister manifestation of this, as Konrad (1998, p. 643) suggests, could be that genes may be fetishized. She worries that genes may come to have ‘a claim to personhood and ought, as such, to enter the legal domain as nature-endowed, rights-bearing entities,’ over and above the social, ‘choosing’ individual who is constituted by them (Konrad, 1998, p. 643). Raspberry and Skinner (2007, p. 370) put this fear in even franker terms. Being diagnosed with a genetic condition, they assert, ‘involves the process of remaking one’s self-image to accord with the sense of a “genetic identity”’ (Raspberry & Skinner, 2007, p. 370; see also Armstrong, et al., 1998). In these arguments we see a theoretical concern for the ability of a gene or gene mutation to define the at-risk woman over and above other, more affective, characteristics.

Novas and Rose (2000, p. 490) declare these fears largely unfounded on the grounds that 'individuals are subjectified [in these medical technologies] through their location in a matrix of networks' including those familiar to anthropologists such as genealogy. It is those networks of familial connectivity and affective kinship that by and large overlay genetic relatedness. They assert that individuals will remain social and will incorporate genetic 'facts' into social selves and relations. This sociality of those subjected to genetic medicine, Lindee (2005, p. 1950) submits, is actually reflective of the communal project that is genetic medicine, a field that has been 'brought into being by many social actors.' Using the example of genetic counselling, Novas and Rose (2000, p. 490) situate the genetically identified 'patient' as one who nevertheless remains at the heart of mapping a set of remembered relations onto a lineage, and in this way takes some agency in arraying illness experience and genetic inheritance around existing modes of sociality.

Konrad (2003, p. 342) argues similarly, noting that, 'the promise of future curative genetic therapies makes scientific genetics the basis for cultivating another tissue of social connectivity: kin are having to negotiate, as part of a moral and social anatomy of interdependence, the degree to which they want to know about others and, by implication, their own, genetic inheritance.' Despite the pull of nascent genetic information on relatedness and heredity, Konrad (2003) asserts, the individual remains agential in how she uses this information to recognise or refute forms of relationality. Thus, she concludes, the rise of genetic medicine and its attended forms of biogenic relatedness preclude the 'individual as isolate' as these 'moral and affective anatomies' emerge as 'new relational "webs" of kinship and relatedness' (Konrad, 2003, p. 342). These relational webs, she posits, fundamentally 'rework older anthropologically inflected meanings of "genealogy," and structural-functional concepts of genealogical "proximity" and "distance," in quite different ways' (Konrad, 2003, p. 342). Indeed, Konrad (2003) goes as far as to say that, in contemporary society, genetic knowledge of health and potential illness has become a key material through which ethicised and moral relationships between individuals come to bear. Genetic knowledge in this view is thus thoroughly affective, it is 'the contemporary "material"' that transforms people

as ethicized social relations' (Konrad, 2003, p. 349). At the heart of these reassurances offered by Novas and Rose (2000) and Konrad (2003) is the notion that the genetically imagined and defined individual will not and cannot take agentic precedence over the social, affective already-networked individual so familiar to anthropologists.

## Genetics and kinship – at odds?

Despite the reassurances offered by Novas and Rose (2000) and Konrad (2003), it is possible to see how the notion that genetics might define individuals, as Finkler (2000, 2001) and others worry, extends the concerns anthropologists already held about biological modes of kinship. In particular, these worries centred on the shortcomings of forms of biological relatedness that have already and inherently organised 'other' people into patterns of relatedness generated by the 'facts' of biological inheritance. For Strathern (1992a), however, it is this very biological and genetic mode of producing bodies that underscores the inherent relationality of Euro-American kinship models. The uniqueness of persons, Strathern (1992a) asserts in her influential work *After Nature*, is one of the key facts of English kinship. This proposition does not mean, however, that one's genetic composition comes to circumscribe the person. Rather, as Strathern explains:

The child's physical origins lie in the bodies of others, a link as indissoluble as its own genetic formation is normally deemed irreversible. Yet parents only reproduce parts of themselves. Like the fortune one may or may not be born in to, the conjunction of genetic traits is assumed to be fortuitous. While the child claims its origin in its parents' make-up, it itself evinces a *unique combination of characteristics*, and the combination is regarded as a matter of chance. This lays the basis of its individuality. *Individuality is thus a significant outcome of relationships* – indeed parents are expected to assist the child to develop that independence which is one manifestation of it (hence the lesser expectation of duty). At the same time, 'individuals' must also be seen as making themselves. Although the basis for the link between parent and child lies in the child's past, what that link will mean in the future is contingent on how the individual person acts. The nature of interaction, the degree of obligation felt, and in respect of lateral connections through the parent even whether a tie is acted on at ... all depends on what the child will *make* of its past. Such Euro-American kinship constructs thus evoke ideas about change and continuity... (Strathern, 1992b, p. 165).

In this excerpt, Strathern (1992b) draws into conversation both the seemingly immutable laws of genetic inheritance and the production of the person. Significantly, Strathern's (1992b) figuring of the 'individual' is different from that offered by Finkler (2000) and the like. The individual, for Strathern (1992b) is not bounded or discrete but is necessarily partial and hybrid. It emerges from the partial inputs of others and yet remains agential in arraying its relations, both genetic and affective. Drawing on Strathern (1992b), we see the ways in which genetics and social relationality produce the person as a hybrid that is not subject to genetic determinism but makes social and affective relations from her chance inheritance. The post-Schneiderian kinship project likewise welcomed extensive analysis of these and other forms of Western social relations that are forged beyond the confines of genetics, marriage and blood. As Strathern (1992b) asserts above, this includes taking seriously the affective as well as the biological relations that connect people through processes such as adoption and the like. As Carsten remarks, the place of biology was critically reassessed in:

studies of gays and lesbian kinship in America. Weston (1991, 1995) discusses coming-out stories which reveal that 'blood ties' are described as temporary and uncertain in the light of the disruptions to, and severance of, kinships ties experienced by gays who declare their homosexuality to their families. Meanwhile 'chosen families' of friends are invested with certainty, depth, and permanence, and spoken about in an idiom of kinship by those whose experience of biological kin has been thoroughly disrupted. This implies a view of kinship which, by displacing biology, turns the conventional understandings on their head - although Strathern underscores how the critique of gay kinship actually consists of making explicit 'the fact that there was always a choice as to whether or not biology is made the foundation of relationships'... (2000, p. 12).

As we can see in the thinking of Strathern (1992b), Weston (1991, 1995) and Carsten (2000), it is no longer the case that such biological or genetic facts can be accepted as a rule of kinship. Indeed, in anthropology, we are a long way past accepting that assumption, as Strathern (1992a, p. 12) attests, 'the pre-existing character of relationships need not after all be taken for granted.' Developing upon Strathern's work on relationality and Weston's findings in America, Putnina (2011, p. 110), in her examination of homosexual families in Latvia, identifies loves and choice not merely as

oppositional to biological heredity and kinship. Affect and choice, she posits, are also significant in linking people 'when biological categories are not available' (Putnina, 2011, p. 110). Gay and lesbian families, she continues, thus do not necessarily introduce new categories but 'displace already existing ones by taking a new standpoint on what is already present' (Putnina, 2011, p. 110). People are and can be profoundly innovative in relating to others as we see in these examples.

Consequently, Marks (2013, p. 247) surmises, anthropologists see that 'genetic facts are not natural, with meanings inscribed on them, but are instead natural/cultural: the natural facts have cultural information (values, ideologies, meanings) integrated into them, not layered on them.' It is now part and parcel of anthropological analyses to regard the once natural, given facts of biology and genetics as social constructions, and to approach their assumed hierarchical dominance with a good deal of suspicion. People make relatedness, it is not in post-post Schneiderian kinship, *given*. As Franklin (1997, pp. 210-13) puts it, 'science can no longer be viewed as extra-cultural; kinship is no longer defined against 'natural,' 'biological' facts; it is no longer 'given,' an assertion supported by Taussig (2009). Birke (1999, p. 46) has gone as far as to show how science itself is recasting the given facts of biology, referring to research that demonstrates the 'active engagements of the embryo' in its development. It is not, she purports, a 'passive victim of genetic inheritance... its essence, if there is one, is not fixity, but transformability' (Birke, 1999, p. 46). Biology and genetics are, like kinship, not static nor immutable to change and flux.

It is certainly the case that anthropologists have insisted that genetic kinship is, in the lives of those living with the risk of hereditary disease, subject to the stronger pull of chosen, affective kinship. Finkler (2000, 2001) asserts, perhaps the most vehemently, that it is affectively oriented agents that resist being organised into the 'facts' of genetic relatedness. In such an imagining, the affective individual emerges to triumph over the genetically composed individual. She asserts her ability to array her kin as she so chooses despite the pull and pressure of attending to those to whom she is genetically related. However, notions of genetic relatedness also connect bodies in a way that is, somewhat ironically, *impervious* to individual boundedness. In an important respect,

genes blur the parameters of bodies, in the sense that our cells are created from combinations issuing from partial donations of other bodies (50% of our chromosomes come from our mother, 50% from our father). These partial donations create a composite form that is not entirely its own, but rather is the result of a combination of the matter, the genes, of others. Genetic material is, as Strathern (1999, p. 42) suggests, relational and composite; 'created in the combination of sequences.' DNA sequences are, she posits, like a 'sort of life-force transmitted from one person to another... the ancestral traces of connections between the generations, [are] material evidence of the fact that features exist only as the outcome of relationships...' (Strathern, 1999, p. 42). Genes not only make us unique but bespeak our inherent connectedness with others. This point is further developed in Strathern's (1992b) work on new reproductive technologies.

New reproductive technologies, writes Strathern (1992b, p. 24) make evident the fact that 'no one comes into existence without the joining of complementary substance.' Relations are thereby 'before' persons in the sense that parents 'already united in a relationship' make children (Strathern, 1992b, p. 15). The result is a child that is at once, made of the stuff of its parents, a hybrid, and yet also a unique being in the world, a result of a recombination process. A child is thus, as Strathern (1992b, pp. 107-8) asserts, 'endowed with material from both parents, *literally formed from parts of them* [my emphasis]' and yet remains unique. The child is:

equivalent to neither mother nor father, nor to the relation between them: rather, it was a hybrid product in another sense, a genetically unique individual with a life of its own. It was only a part of their life, despite the fact that genetic material was formed wholly from theirs (Strathern, 1992b, pp. 107-8).

It is, indeed, difficult to rescue the bounded genetic individual as isolate from such partial constructions of being, a point that has been made time and time again by Strathern (1992a, 1992b) in her considerations of English modes of kinship and new reproductive technologies. And yet, as Latimer (2009, p. 58) notes in her examination of composite figures in the works of Frida Kahlo, Western society often worries about the erosion of the discrete individual. When persons are seen as the plural and

composite site of the very relationships that produced them, it generates unease. Latimer (2009, p. 58) remarks upon our discomfort when we witness in plain sight the combinations of ‘all the parts that make [a person] up, the flows of substance and relations,’ that resist categorisation as the individual. This inherent relationality of humans is something that has been increasingly explored by anthropologists in the era of the posthuman, human-animal, humanimal, Anthropocene. As Haraway posits “[h]uman” requires an extraordinary congeries of partners... We are quite a crowd, at all of our temporalities and materialities’ (Gane, 2006, p. 146 in Franklin, 2013, p. 86). This relationality has not been lost on anthropologists of hereditary breast and ovarian cancer. Felt and Muller note in the specific space of genetic testing, there is a strong emphasis on:

the *relational* character of genetic knowledge. From the beginning it is performed as knowledge not only about the *person* tested, but also about her/his genetic kinship, figuring the *individual* as the ‘family patient’... As a representative of a familial collective, the ‘family patient’ actively collaborates in materializing him/herself in the risk-based, genetically grounded construction of the medical pedigree [my emphasis] (2011, p. 352).

The jump made here, however, from the individual as isolate to the individual representing the ‘family patient,’ is that the individual is thought to be subsumed under the weight of the family. When the individual comes to represent the ‘familial collective,’ they assert, her *own* needs are likely to suffer. This relationality that emerges in the clinical encounter, they posit, may in fact have iatrogenic outcomes for the woman tested.

Here then is a combination of unsettling notions, a contradiction as such. First, genetic kinship makes the ‘individual an isolate,’ an entity constructed of genetic facts possibly unrelated to the kin that the individual chooses. Equally, gene kinship reveals that the person is anything but an individual bounded entity, and is instead the yield of combinations of others (who themselves are combinations of others before them). These unsettling notions have provoked the rescue mission proposed by Finkler (2003, 2005), who argues that the affective individual must take precedence over both the individual isolate, and the set of partial relations that collectively make Felt and Muller’s

(2011, p. 352) 'family patient;' a patient who may not even be known by the members of that (genetically constructed) family. Finkler, Skrzynia and Evans note that:

the medicalization of kinship creates a tension between the stress on individualism and choice in a democratic society and an orientation to family and kin. Individualism insists on an autonomous person, standing outside any one socially defined unit and selecting his or her life course, whereas kinship relationships based on genetic inheritance call for connectedness and circumscription of choice (2003, p. 410).

In this line of argument, Finkler objects to the individual being removed from her cultural and social context, as generations of medical anthropologist have before her (Helman, 2008, p. xvi). Moreover, she takes issue with genetic versions of kinship as it produces relations, who may now ask and place demands on her. She instead envisages the emergence of an agent who is an affective individual, making social relatedness on that basis of affective choice. She notes that:

[w]hereas family and kinship relations are fluid and can be tampered with to expand or truncate a significant same group, the genetic definition of family and kinship is grounded in biologically produced ties, especially where people enter the medical stream and are asked about their medical family history. *The ideology of genetic inheritance promoted by the new genetics recognizes biological kinship as real kinship contrary to current practices that establish family relations by choice and manoeuvrability as much as by biology.* It thus challenges the cherished Western notion of individual choice because the genealogies that geneticists construct adhere to rigid rules established by genetic testing that define who is and who is not family and kin based on the sharing of DNA. While medical technologies are assumed to be in the vanguard of Western technological progress and are expected to lead a new kind of revolution, paradoxically the ideology of the new genetics acts in the service of traditional conceptualizations of biogenetic family and kinship by excluding members of a significant-same group that may be established by choice comprised of adoptees, same sex relationships and their children, or any combination of blended families of today. The medical-genetic definition tends to limit the parameters of family and kin to specific biological ties that are identified by similarities in DNA [my emphasis] (Finkler, 2005, p. 1061).

In Finkler's (2005) view, genetic medicine and by extension gene relatedness poses a threat to the individual's ability to array her kin by her own choosing, as it gives power to and renders legitimate 'biological kinship as real kinship.' This concern over the ability of genetic medicine to rewrite kinship along biological lines and over and above

affective choice is taken up by Felt and Muller (2011). As a result of genetic medicine and hereditary illness, family structures, they write, may be reconfigured in ways that are not always welcomed:

generating a new and potentially unfamiliar vision of family in which members are not necessarily connected any longer through social bonds and collective memories, but through genetic kinship and a potentially shared genetic risk... *This genetic version of family is rarely congruent with the counselee's prior vision of her/his family.* It might exclude some that are socially near (for example, step-siblings) while it includes unknown or distant relatives, with whom they share a 'risk of risk' but not much more than that. Some family branches appear affected while others seem to be spared and thus are rendered invisible within this new 'at risk' genetic family [my emphasis] (Felt & Muller, 2011, p. 352).

Felt and Muller (2011), like Finkler, worry that genetic medicine and counselling establish modes of kinship obligation on the basis of shared genetic material over and above social and affective ties. This concern is likewise voiced by Sachs (2004, p. 24) who questions the degree to which the new genetic medicine will affect 'people's perceptions of family and kinship and to what extent genetic explanations conflict with broader social developments.' These technologies, she argues, have produced what she terms 'the molecular family' comprised of geneticised individuals. This 'molecular family' and the medicalisation of kinship, she suggests, runs contra to ways in which kinship is configured in the modern world. Families, she posits, 'are constructed by *personal choice and individual decisions* rather than based on what are accepted as being "natural" biological groupings [my emphasis]' (Sachs, 2004, p. 26). Sachs (2004, p. 26) worries that, as *all* members of the family or kin group come under examination by genetic medicine, relationships organised by genes may take predominance over those arrayed by affect, producing new 'relationships that can alter people's lives and be experienced as overwhelming.' Consequently, Sachs (2004) ruminates, people may be brought into relations with others not of their own choosing, what she sees to be a state of no return. As she outlines in her ethnography of genetic counselling for hereditary illness in Sweden:

The research related to the genealogy actually means that many persons become involved without having chosen to do so... The project for communicating information draws the informed person into something from which there is no

return; he or she *can never return to a state of being uninformed* [my emphasis] (Sachs, 2004, p. 27).

In a similar vein, Svendsen (2006) observes a bifurcation in kin relations that occurs as the result of risk-stratifying practices inherent in genetic medicine. Biologically related kin, in this context, are prefaced ahead of affective kin members as real or true kin and this information once exposed, as Sachs (2004) posits, cannot be unknown. The genealogy of the genetic counsellor she writes ‘spells out the implicit idea, inherent in genealogical diagrams, that kinship is established at the moment of conception’ and thus is fundamentally biogenetic (Palsson & Haroardottir, 2002, p. 271; Svendsen, 2006, p. 148). It is this understanding of relatedness as primarily a result of shared biogenetic substance that, she argues, emerges as paramount and produces actionable patients in the field of hereditary cancer prevention. The conceptual field of the genealogy produced in cancer genetic counselling, she writes:

defines biogenetic (i.e., bodily relationships) between individual persons and presents them as belonging to a common unity—a family... Visualizing biological relations on the family tree plays a pivotal role in establishing biological relatives as the targets of prevention. With the family tree, the genetically defined family becomes an object of medical intervention... Such an intervention requires a social contact between relatives. In this way, the production of genetic risk profiles in counselling directly affects practices and experiences of kinship... What happens in counselling is that the “fixation” of biological ties (i.e., the map making) becomes a culturally creative act as implicit assumptions about the biological groundedness of social relationships are made explicit when framed by the powerful story of “the journey of the gene” and the moral imperative of prevention (Svendsen, 2006, p. 148).

Problematically, for Svendsen (2006) as is for Felt and Muller (2011) and Finkler (2003, 2005), this production of the genetic family and genealogy by medicine subsumes other forms of kin relatedness based on affective ties of the individual’s own choosing. ‘[B]iological ties’ Svendsen (2006, p. 151) asserts ‘are described and objectified in terms of genes and, thus, are literalized as biogenetic relationships... What emerges is a genetic family.’ Consequently, Svendsen (2006) asserts, the family is transformed into a configuration more akin to what Rabinow (1992) has coined a biosociality. This biosociality, an arrangement of people united by a common biological or genetic trait,

condition or abnormality, anthropologists such as Svendsen (2006) worry, will subsume affective means of relating, especially within the family.

### **A rescue mission of sorts**

As I have indicated above, medical anthropologists have objected strenuously to the given nature of medical 'facts,' including genetic facts that have, according to Finkler (2000, 2003, 2005), Felt and Muller (2011) and Svendsen (2006), arrayed both the individual and the family in ways fundamentally different from and opposed to affective choice.

It is certainly the case that people enfold what might otherwise be called genetic facts into their lives and into the affective relations through which they form family. It is likewise the case that, as it was with my own informants, 'family' is not given by genetics, but instead persists in the affective ties that people make with the most significant of their relations. In this sense, there is no set of genetic facts that is not, already, social, chooseable, just as Strathern (1992a, 1992b), Carsten (2004), Marks (2013) and Franklin (2013) remind us. The affective individual emerges triumphantly. However, a fundamental problem emerges from the strict assertion of the affective individual who triumphs over the medical arrangement made for herself and her kin. In asserting the individual at all costs, and in reacting to genetic medicine as a 'giver' of kin relations, Finkler (2000) and others overlook something very pertinent in how genetic medicine formulates the body, in the terms of *partiality*.

I return here to an important distinction I made in the introduction between what I am calling the discrete and bounded individual as a unit of analysis and what I see to be the person as a partial, relational being in the world, and especially, in the operations of the family. I am not saying that the self, defined by Desjarlais (1999, p. 480) as 'embodied, feeling, thinking, possibly suffering' consciousness does not exist. Indeed, it would be foolish of me to do so as it is this very being and their idiosyncrasies who is acutely mourned after their death from hereditary cancer. To replace the discrete, bounded

individual with 'the social' as the unit of analysis would be equally problematic. Just as the conceptual adoption of 'the individual' cannot capture the operations of the institution of family, nor can 'the social' capture that it will be one physical body that will bear pain, suffer and die. We need to look beyond a firm insistence on either. To assert the bounded, discrete body emphasises a discreteness of experiences issuing from a singular notion of 'the individual,' and to insist on a Western version of dividuality merely inverts the problem of a prefigured theoretical insistence in understanding the illness experience.

We can see in Strathern's (1992a, 1992b) exploration of genetic medicine and kinship how this tension between genetic and social relatedness may be broached. In reproduction, she submits, we can see clearly the co-existence of the individual (used in this sense to describe a unique, hybrid being) and her relationships through her inherently relational, partial and composite creation. 'The child that comes from its parents is not its parents... Tradition innovates; relationships produce.' Genetic inheritance thus creates unique, hybrid persons that are neither the same as the mother nor the father. We can see the impulse of genetic medicine and technologies to emphasise individuality in terms of genetic uniqueness in the popularity of online genomic sequencing companies such as 23andMe which allow for a person's genome to be coded for less than \$100. However, this uniqueness is only possible, can only emerge, as a result of relationality, that is, the mixing of people together. In Strathern's words, we might say that:

relationships come 'before' persons. Parents already united in a relationship produce individual children. We might further say that their unity as one person presupposes the individuality of the child. Yet, in their children, parents (persons in a relationship) also produce other than themselves (individual persons) (1992a, p. 14-15).

In light of Strathern's insights into the co-presence of the person and her genetic and affective relationships, I take issue with how, at the conceptual level, anthropologists have overlooked these connectivities in purporting the discrete individual as *the*

exclusive unit of analysis. A distinction between data and concepts for analytically exploring the data is needed in anthropological approaches of illness experience.

Looking from the perspective of a body constructed in parts, not (pre)given in wholes makes possible an appreciation of the person who is constructed in and through her partial relations with others – one who is herself relative to others. It is this congruence, between imaginaries of partial selves routinely made by my informants, and imaginaries of persons made by the partial inputs of others evident in the field of genetic medicine and biology that provokes me to suggest that anthropology's knee-jerk reaction to biomedicine might not always be appropriate. In this case, it might even obscure what can be known of the person with a predisposition or risk of hereditary cancer.

In the remaindering chapters of this thesis, I intend to think against rigid assertions of 'the body' – whether that body is asserted and insisted to be individual or social. This intention manifests in my thesis as particularly attendant to the 'individual' body, as it is this body that is prefigured in existing literature. Any polar approach is, I think, problematic. Analysing the current conditions for anthropological thinking permits me to offer new insight into this profoundly prefigured space. This does not mean I claim some objective territory in that space, it simply means I include an analysis of the current thinking as part of the data I take for consideration. I detail how the long standing anthropological reaction to medical thinking preserves a particular notion of the individual that might prevent us from seeing her partiality. It is the case that anthropologists have privileged the thinking, choosing, socially competent *patient* who is a discrete individual capable of informed, affective choosing of her kin. This assertion obscures something already well known to genetics and genetic medicine – that this entity masquerading as the bounded individual is a composite of the flesh of others. This does not mean that this composite person does not affectively choose her kin and relations. But to prefigure the individual as a wholly bounded social and affective body that is somehow very different from the one genetics imagines is, in fact, highly consequential. It is significant in the terms that this patient is imagined as a bounded *individual*. This becomes most apparent in the actions that the hereditary cancer patient

understands to have available to her, as she deals with her affectively chosen kin: she can either be selfless, or selfish.

## **The problem with the primacy of the bounded individual**

During the preliminary stages of writing this thesis, I would present sections of my work to my department, at conferences and amongst my peers. I put forth the argument that existing anthropological approaches to hereditary breast and ovarian cancer overlooked the family as a site of embodied, relational acts of care in key ways. I would often use the following quote from Valerie, one of my informants who you will meet in more detail in Chapter Two. Valerie, a 35-year-old linguist, explained to me why she chose to undergo a risk-reducing bilateral mastectomy earlier that year (autumn of 2014):

Cancer is a very selfish disease... I didn't want that for my husband and child. I had just had my first child, and I decided the impact of cancer would be enormous on my family and loved ones. It wasn't just about me anymore.

Each and every time I gave a paper that included this quotation, I could not help but notice that a particular kind of question would undoubtedly arise, albeit in slightly different iterations. One of the following questions, without fail, was asked by my professors, colleagues, fellow students and panel mediators; 'Do women think they are being selfish if they don't get tested or have surgery?,' 'Are women seen as selfish if they don't get tested or have surgery?,' 'Do women feel they are being selfish if they have children knowing they could pass on the gene mutation?,' 'Do women really want to do risk reduction or are they being self-sacrificing?,' 'Do cancer patients think at-risk women are being selfish in taking resources to undergo surgery when they might not get cancer?,' 'Does the woman's family judge her decision to undergo testing and surgery as selfish as she is unable to work or care for others during this time?' 'Does a woman's family think she is being selfish in passing on information about their genes that they might not want to know or selfish for withholding it?'

The frequency in which these questions were asked, often immediately after I have completed my presentation, became difficult to overlook. I came to wonder why it was that, as anthropologists, we were so interested in whether the decisions and actions surrounding hereditary breast and ovarian cancer risk reduction could or would be considered as selfish or selfless. It was such a frequently remarked upon prospect, that a woman would be considered either/or, that I turned to the literature in an attempt to locate these interests of my colleagues and peers within some sort of framework. What I found in the literature was that these questions on selfish and selfless behaviour were not, it turned out, limited to anthropologists attending my seminars. Rather, this dyad of selfless/selfish and the bounded, discrete individual such approaches took to be core, were at the heart of paradigmatic anthropological approaches to hereditary breast and ovarian cancer.

Concerns around the discrete individual, namely the at-risk woman, and the perception and ramifications of her actions (as selfish or selfless) in the face of such risk emerged as a dominant feature of the anthropology dealing with hereditary cancer. The analytic through which existing data is handled is one of moral obligation and responsibility. Consequently, so are the findings concerning the pressures women, predominantly, face when having to negotiate decisions about how they will handle their cancer risks relative to their significant others, that is, their affectively chosen kin. Goldmin and Gibbon (2015, p. 291) capture the dominance of this analytic perfectly, although unreflexively. As they note of their 2015 data collected in Brazil among cancer previvors:

there is a sense of moral obligation to take care of the family, as participants in the cancer genetic clinics and in research. These sentiments about gendered responsibilities, expressed by those taking part in genetic testing for breast cancer, resonate with findings outlined elsewhere, in comparatively different national contexts... However, the strength of this articulation is particularly striking in Brazil. Here, the moral obligation to take care of the family is centrally situated in the motivation to participate in research. In Brazil, to choose not to participate is considered to be 'selfish' (Goldmin & Gibbon, 2015, p. 291).

For Goldmin and Gibbon (2015), moral obligation and responsibility are key motivations for women to enrol in regimes of risk reduction. This pervading sense of

responsibility, they argue, also fuels at-risk women's participation in BRCA research (Goldim & Gibbon, 2015). Hallowell's work carried out among previvors in the UK is perhaps even more telling of the dominance of the selfish/selfless binary upon which the moral imperative to handle cancer risk pivots:

While some women described their risk management decisions as influenced by the 'selfish' desire to fulfil their destiny, all were acutely aware of the potential impact of their actions or inaction on others, and cited more altruistic motivations for managing their risks (2006, p. 20).

In Hallowell's view, selfishness or altruism are key experiential categories of living with the risk of hereditary breast and ovarian cancer. These modes of classifying facets of the illness experience are well-established in anthropological analyses of genetic and hereditary disease. In one of the earliest anthropological examinations of hereditary breast and ovarian cancer, Lock in 1998 charted the emergence of an individual who is struck down by misfortune, and resultantly, becomes the bearer of responsibility not only for oneself, but the others whom depend upon it (Lock, 1998). She identifies the dangers associated with genetic mutations and predispositions as coming to be shouldered solely by 'responsible individuals' as it is individuals who come to be 'held accountable' (Lock, 1998, p. 11). As perpetuated in Finkler's (2003, 2005) later works, Lock expresses a concern that the affective, choosing individual will be subsumed by genetic responsibility to her kin. She worries that the woman's own concerns, experiences and 'social facts' of kinship will no longer be important in her decision making:

The current politics of breast cancer, for example, appears to be moving in a direction in which individuals are increasingly being offered a chance to take responsibility for assessing and controlling the risks to which their genetic inheritance may expose both them and their potential offspring. With the hype associated with the newly discovered gene mutants BRCA1 and BRCA2 (others genes are in the pipeline), risk is internalized, medicalized and geneticized... and social factors fade into the background (Lock, 1998, p. 11).

In Lock's (1998) work, we see the fear that the individual's ability to assert their own agency in relating to kin and in making decisions about interventions into and upon

their bodies would be eroded by genetic medicine. This concern has been borne out by scholars of preventative medicine and hereditary disease over the following decades. The concern that the individual, most likely the woman, would be held responsible for decisions concerning her own and her family's health in light of hereditary illness information, is a key anxiety for anthropologists in this area. As Sachs wrote in 2004, 'genetic predisposition confronts individuals with the responsibility of, first, deciding what to do in order to avoid possible future disease and... to communicate [this risk] with significant others in the family' (2004, p. 26). A refusal to do so or a mismanagement of said responsibility, as Krupar (2012, p. 55) notes, may have severe consequences for the at-risk women. She may no longer be a 'desirable subject' of biomedicine or neo-liberal society. Consequently, the at-risk woman opens herself to criticism and judgment for to 'ignore one's responsibilities; to choose *not* to participate means that one is not a "good subject."' In failing to fulfil her responsibility to manage her own health and the health of her familial others, Krupar (2012, p. 55) asserts, the at-risk woman is seen to put 'society in jeopardy.'

Initially I found it difficult to respond to the questions concerning selfish/selflessness that were posed to me during my presentations. All of my reading, as suggested above, clearly indicated that this analytic was dominant and thereby a well-established tenet in the field of hereditary cancer study. Much of the research to date on the subject of hereditary breast and ovarian cancer syndromes has been confined to arguments about the risks to which women are put as a result of genetic medicine. Analyses in this space often focused on the notion that women's engagements with genetic medicine, such as genetic testing, are not a straightforward 'choice' and represent yet another avenue in which medicalization impedes women's autonomy, reinforces coercive gender norms and gendered hierarchies of power. Anthropologists have been necessarily critical of the potential of genetic medicine and technologies to veil social causations and determinants of illness and strengthen essentialist thinking about identity and social connectedness (Brodwin, 2002, p. 323).

Whilst recognising the validity of these critiques of genetic medicine, I seek to push discussion in a new direction, one that, as Lock (1998, p. 209) suggests 'moves beyond

black and white arguments about oppressive paternalism and vulnerable women.’ As Abel and Browner (1998, p. 322) remind us, we must be careful not to automatically assume that the expansion of biomedicine, including genetic technologies, inevitably results in women’s loss of control. Discussions of medical technologies, as Lock suggests, ‘must not only consider political and professional discourse about the construction and manipulation of *individual* female bodies but also articulate the *range of responses* of women from various walks of life to such discourse (Lock, 1998, p. 209).’ Thus, while I acknowledge the rationale behind the focus on the individual woman and her ability to assert her agency in the face of biomedical and genetic technologies, I remain uncomfortable with uncritically adopting such a paradigm in my own research, primarily because my informants did not privilege it in their descriptions of how decisions were made, and how they related to members of their family. I came to realise, also, that this analytic only makes sense if the bounded, individual is privileged. Relative to my ethnographic data, I could not analytically privilege the individual, since it was not dominant. What was dominant in my data was a sense of partiality very similar to that advanced in the medicine imaginary of genetic inheritance and hybridity, that is, a composite person composed of the parts of others.

Since sick or potentially sick body parts are critical here, what to do with breasts, ovaries, and the like appear, on the basis of my ethnographic data, to be a collective decision. Instead of beginning with the idea that the parts in question initially belong to a bounded individual who makes decisions concerning them that will subsequently impact on her familial relations, I posit that they are instead parts of the family. Consequently, it is crucial to develop an analytic framework that takes account of such composites.

### **Part/s of the family or biosocial families?**

I here want to set out an alternative analytic frame for thinking about previvorship. The concepts I use draw upon phenomenological ideas about the ways in which bodies are formed and relate to one another. One of my key influences is Merleau-Ponty (1962),

who refused to recognise the bounds of the conceptual individual as aligning with the boundaries of the flesh. I also draw on Foucauldian notions of institutions, where parts work together to produce the manufacturing plant and the shop floor of late capitalism but also give fleshy form to the corps of the army, and to the family. These are unions not of bounded, whole, impervious bodies but of their significant parts. Contributors together yield a conceptual whole, a process not dissimilar from the way in which genetic contributions, as Strathern (1992a, 1992b) asserts, produce the conceptual, unique and essentially hybrid person. A Foucauldian institution is, as Bevir (1999, p. 352) suggests, sustained in the minutiae of parts working in concert with parts 'created, sustained, and modified through the meanings and ideas of a host of micro-practices.' I contrast this composite body of the person and of the family, with the somatic body proposed by Novas and Rose (2000). This figure, despite its somatic qualities, remains a discrete and bounded individual body operating in a network with other, whole discrete bodies. I establish this contrast as a means of grappling with the ethnographic data I collected. My data was replete with ideas about the partiality of bodies, and the collectivities these partial conglomerations produce.

As I outline briefly above, Rabinow's notion of biosociality has been used extensively by anthropologists of hereditary disease and illness experience. Biosociality speaks to the myriad ways in which social relations and modes of sociality form around what Hacking describes as 'newly recognized (or, at any rate, newly asserted) biological or genetic lines' (Hacking, 2006, pp. 81-82). These genetic identities, Hacking (2006, pp. 81-82) posits, forge 'new alliances... loyalties [and] identities.' Anthropological approaches that premise biosociality grapple with the multiple and multifarious ways in which nascent genetic knowledge affects how individuals 'come to understand themselves or relate to others' (Gibbon & Novas, 2008, p. 2). Biosocial analyses are interested in how nascent genetic identities can produce groups of like individuals who work to define and shape the 'production of knowledge about their conditions' and craft 'novel self-conceptions.' (Gibbon & Novas, 2008, p. 2; see also Hacking, 2007; p. 84, Navon, 2011). This biosociality premised on a shared, genetically marked category, encourages individuals to enrol themselves into such biomedical categories that become 'central to their social lives [and] entails the construction of an imagined kindred' (Rapp, et al., 2001, p. 395).

These biosocial or ‘technoscientific’ identities not only foster a shared, collective identity with others so identified but may, as Sulik (2009, p. 1060) asserts apprehensively, motivate the individual to ‘*become* – think of oneself in terms of – the classification.’

It is undeniable that the presence of a hereditary genetic mutation can bring, or at times force, together biologically/genetically related people who would otherwise remain estranged. In the case of my own fieldwork, informants often became aware of relatives with whom they had no previous social relationship, but shared the same genetic mutation. It was certainly the case that my informants formed new modes of sociality around their hereditary cancer risk. I engaged with a number of these communities during my own fieldwork including the US-based FORCE, a hereditary cancer support organisation, Pink Hope, an Australia based hereditary cancer support network, and BRCA Sisterhood, a Facebook group with 6735 members (and counting). Biosociality is also purported to be a force or power capable of reworking kinship and refashioning existing forms of relationality, sameness and difference along the lines of genetic identity (see for example Rapp, 2000; Gibbon & Novas, 2008; Navon, 2012). As noted in the introduction, biosociality in this sense is carefully policed, lest it issue wholly from the field of medicine and thus arrange individuals into pre-given categories of relatedness, for example, by shared biogenetic substance.

In her work on the intersection of gender, race and neoliberalism in genomic medicine, Happe (2013, p. 177) offers an alternative rendering of this coercive power of genetic medicine and identities by calling for ‘biosociality without genes.’ This approach, she posits, allows us to understand how people come to act, make alliances and form politics, based on their experience with and in connection to others but with an important caveat. A biosociality without genes, she posits, resists seeing such sociality as merely ‘the outgrowth of indelible, biologicistic, bodily attributes and their implicit valorisation of atomist identity and politics’ (Happe, 2013, p. 118). In a similar vein, Sharp (2011, p. 263) has drawn attention to the danger of an overly ‘bio’ biosociality, which would obscure the social complexity that accompanies genetic configurations of kinship. As Sharp (2011, p. 263) suggests, by invoking biosociality, anthropologists run

the risk of overlooking the forms of relationality and sentimental structures inherent in other forms of kinship.

The 'sociality' of 'biosociality' however remains dominant in the concept. In the case of the biosocial grouping Pink Hope, people were flung together as a result of their shared genetic mutation and/or hereditary cancer risk, who might otherwise have never met. The quality of the social relations in which these otherwise strangers then participate is of enduring interest to anthropologists (see Rapp, et al., 2001; Rapp, 2000; Navon, 2011). These constellations of sociality emerged time and again in my fieldwork data. For example, Billie, aged 28 at the time of our interview, was only 25 years old when she underwent a risk-reducing bilateral mastectomy. She told me just how invaluable the biosocial, patient advocacy and support group FORCE was during her recovery. After undergoing her surgery, Billie attended the annual FORCE conference:

It was nice to be around people who had done the same thing and to see that they were okay... For me, going to the conference, there was one session – the young women networking group – and I didn't know anyone, even though I connected with my local group. There was no one my age at the time you know I was thinking 'am I crazy to doing this at my age?' and 'am I being completely irrational and crazy?' but I went to that and saw people who were the exact same age or younger and had already had it done and they were happy with it. That really made me feel a lot more comfortable doing it and made me feel less crazy... [you develop a] friendship almost because you have this really weird thing that you've had done, that no one else really has, so it's like an instant bond like 'you know we had surgery within a week of each other.' Just through FORCE and some of the groups on Facebook, I have made friends that I will have forever. We try to get together once a year. So it's kind of sad I lost some local friends but I made some really, really good friends.

Such examples of sociality premised on shared genetic traits are just one of the bases upon which Novas and Rose (2000) assert that new medical genetics offers opportunities to explore existing and emergent networks of relationality. They note how 'the genetic identity of the counselled individual is established by locating him or her within a network of [familial] relations,' but it is also the case that persons find themselves in social networks of affective non-kin relations, as the above example demonstrates (Novas & Rose, 2000, p. 490). It is when it is applied wholesale to the

institution of the family, however, that the limits of the biosocial concept become apparent. The limitations of such an approach became particularly evident in terms of accounting for my own ethnographic data as I tried to comprehend what was 'at stake' in the lives of my informants (Kleinman, 2006).

### **Biosociality, the somatic individual and the family: Lily**

As a means of illuminating the possible shortcomings of predominately biosocial approaches to illness experience, I include here an account of a conversation I had with Lily during my fieldwork. One afternoon midway through 2015, Lily and I met for afternoon tea at her home. Sitting at her kitchen table, surrounded by the material artefacts of everyday life; catalogues for the Scholastic Book Club, jumbles of keys and wallets and some of Lily's divine homemade caramel slice, she informed me that Beth had been recently put on a clinical trial for chemotherapy-resistant, BRCA-mutated ovarian cancer. I asked Lily how this development influenced her own plans for risk reduction. Lily furrowed her brow as she thought, pausing before she answered, 'Mum has ovarian cancer and I've been told I only have a 7% lifetime chance of getting it but because I've watched her go through it, I want a hysterectomy so I definitely don't get it, even with such low odds.' As she was speaking, Lily's eldest daughter wandered out from the lounge room where she had been building a blanket cubby house with her sister. After passing Lizzy some popcorn, Lily mused aloud on the prospect of her daughter's futures:

I have real issues with potentially not being able to donate eggs or whatever if either of the girls had fertility issues later in life. How would I feel knowing that I could not give them, nor even offer them, one of my eggs so that they could be mothers? Though it would be a hideous situation, I would feel worse knowing that I could not be of any help. It's just another thing to consider with surgery.

Lily recalled how she asked another woman at a BRCA support day about this gamble. She asked the woman how she came to make the decision to give up her body parts and their functions without knowing with certainty whether cancer would develop. She asked whether the woman had been able to achieve peace with her decision. The woman

replied that ‘you will never know [whether cancer would have developed]’ but when she looked at her children, she knew she had made the right decision. While Lily understood this sentiment, the decision to remove her body parts and their attendant functions is not as straightforward as it may seem. What if, as she argued, in 20 years, her daughters or one of her daughters was infertile? How would she feel knowing that she could not give them, nor even offer them, one of her eggs? Yet at the same time, she lives with the pressure of this ‘what if,’ as she told me, ‘I have a kid now, I can’t die.’

It is to this set of decisions that the social element of biosociality has been applied. Novas and Rose (2000) conceptualise the at-risk individual, who faces questions about whether to take genetic tests at all, and what to do with the results of those tests in relation to their family members, as the somatic individual. This individual is oriented to the needs of others as a result of their shared [genetic] identity. They are compelled to consider how their decision making might impact on their loved ones. The decisions of the somatic individual are taken, primarily, ‘in light of a knowledge of their genetic status’ (Novas & Rose, 2000, p. 494). This somatic individual bears the weight of genetic responsibility, and how it will impact others, as a result of her decisions and her future-reaching actions.

It is not difficult to unpack Lily’s remarks about egg donation, fertility and her aspirations for her daughters in and through the prism of the somatic individual. It is ostensibly Lily who struggles under the genetic burden of deciding what to do for the good of the others related to her, just as her mother Beth did before her. Lily certainly appears to be an individual ‘whose individuality is, in part at least, grounded within [her] fleshly, corporeal existence, and who experience[s], articulate[s], judge[s] and act[s] upon [her]sel[f] in part in the language of biomedicine’ (Rose, 2007, p. 13). Lily’s experience, when read in the terms of the somatic individual, is not all that fleshy, however much her genetic makeup is enfolded into her own understanding of her flesh and the flesh of her daughters. By this I mean that as a somatic individual, Lily remains a discrete and bounded fleshy entity, making decisions about her body parts and their functions that will then come to bear on the flesh of her significant others. But what if

we were to begin with the parts Lily is worried about, from the perspective of the shared flesh of the family? To do so would allow Lily's remarks to be read rather differently.

### **The fleshy body: part of the family**

In 1994, Lyon and Barbalet proposed a mode of understanding the body that was freed from the tight constraints of individuality along with the mind-body separation insisted by the Cartesian divide. Their proposal was crafted in the form of a careful, almost technical, definition of what a family might be. Rejecting heteronormative norms, economic models and various social submissions based on affective groupings, Lyon and Barbalet (1994) dealt instead directly with the machinations of bodies that appear to create, manifest and sustain the group of people known as 'the family.' Lyon and Barbalet (1994) submit that family is formed in the manner in which other institutions are also formed, that is, precisely in and through the deployment of the body parts of one, relationally, to the body parts of another. The military and the factory floor of late capitalism also work along these lines, as Foucault (1977) amongst others, have showed us. Whole, bounded buffered bodies, as units of productive work, do not make sense in context where hands work in conjunction with other hands, and legs march together in company time. Certain bodily parts come to the fore, being, in and through the relations of capitalist or military power, privileged or more important in each of their contexts. A hand, for example, is of more value in the nimble work of the factory procession line than is the foot. Lyon and Barbalet (1994) suggest that the same is true for the operations of the family. In families, emotion is the force that often organises the deployment of bodily movements in ways that meet and are met by parts of others. Emotion drives the activity of the parts in the same sense that capitalist productive values drive hands towards other hands on the factory floor. In the family, emotion might, for instance, impel a father's lips to the forehead of his daughter, or a mothers' slapping hand to the legs of her disobedient son.

Such partial deployments, of hands to legs and lips to heads, are distinguished in subtle, habitual ways from the whole, buffered body that is conceptually 'son' or 'daughter.'

‘Son’ and ‘daughter,’ as whole bodies, are not involved in the receipt of kisses and slaps to quite the same extent that their foreheads and their legs are. These parts are the parts critically involved in the relation between them and their mother or father, and it is to these relations that Lyon and Barbalet (1994) attend. They do so because it is the partial deployment of bodies as they relate to one another that yields the family, not simply however many bodies operate in proximity as a network. These relations of parts, argue Lyon and Barbalet (1994), are critical, for it is these that together create the patterns and habits that yield and maintain the social body nameable as ‘the family.’ Indeed, as Collins (1981, p. 995 in Lyon and Barbalet 1994, p. 56), suggests the maintenance of social institutions is tethered to the ‘distinct engagements of aspects of bodily disposition.’ In the case of the family, ‘[t]he most repetitive behaviours that make up family structure are the facts that... the same [people] sleep in the same beds, that the children are kissed, spanked and fed’ (Collins, 1981, p. 995 in Lyon and Barbalet 1994, p. 56). These are the relations of parts, not whole buffered, bounded bodies. The family is a relation of bodily parts, of porous bodies, impelled towards the parts of others by emotional force. Indeed, the relations of habitual interaction, of care, that make and sustain families are conducted using parts. Significantly, and as I will discuss in the following section, some parts are more fundamental to familial creation and maintenance than are others.

This analytic of family construction also allows for relating as kin outside of the strictures of heteronormativity. As Putnina (2011, p. 110) reminds us ‘it is not the category (given/chosen, natural/nurtured, biological/social) but the ability to relate, and to create and maintain relationships, however they are categorized, that lies at the core of family and kinship.’ Similarly, it is important to recognise, as do Lyon and Barbalet (1994), that not all families, constructed of parts acting in relation to other parts are necessarily impelled towards one another by emotions of love, happiness and unwavering devotion. Biehl (2012, p. 244), in his work on care and disregard in families, draws on Lacan (1938 in Biehl, 2012, pp. 244-245) to remind us that families are, in and of themselves, ‘plural and complex.’ Families are, he asserts, caught up in ‘conflicts and inertia of their own and they must be studied with care...’ (Biehl, 2012, pp. 244-245). A similar sentiment is expressed by Putnina (2011, p. 122) in her ethnography of same-sex

relationships in Latvia. In moving beyond analysis of categories such as heteronormativity, she posits, we can begin to appreciate the work required to create and maintain families, whatever their configuration. Family, she suggests, is not necessarily a stable or given set of relationships, a sentiment evident in Strathern's (1992a, 1992b) early musings on relationality within families. As I gestured to earlier, a person may work to detach themselves from partial relations, including those partial bodily relations of the family. As Strathern (1992b, p. 125) submits, 'there is no axiomatic evaluation of intimacy or closeness' in the family. The process of relationality is 'constantly recreated in people's dealing with one another' (Strathern, 1992b, p. 125). These politics of the family are fleshed out below in the case of Anne, a woman who endeavours to expel the very parts of her body once crucial to relating her to her husband.

### **Some parts are more important than other parts**

It has long been recognised within anthropology that certain body parts, within Western culture, carry particular symbolic weight. This importance is often linked with the biological function of the part or organ in question but also its role in fostering an embodied sociality between persons (see Sharp, 1995; Manderson, 2011). In her recent work on surrogate motherhood, for example, Teman (2009) theorises the interaction between bodies undertaking individualistic pursuits and as collaborative body-part-projects. Using the idea of the 'shifting body,' Teman (2009, p. 66) argues that we must move beyond the individualistic body to show the ways in which body parts become an important 'tool of joint identity-work,' as necessary for the familial unit, whatever its configuration. The social body, or shifting body, as an interactive process, thus requires 'related types of intra-bodily interactions' to which these identity constructions are involved (Teman, 2009, p. 66).

A particular sense of this body-part-project applies to breasts and ovaries, the body parts most at risk of manifesting cancer, since both are highly relational; both are highly interactive sites of the body. The breasts are involved in relations of sexuality and

sustenance, and ovarian relations are the relations of kin, making evident and manifest sexual relations and the relations of family. The cultural significance of breasts in Western culture has been charted by scholars such as Bordo (1993), Yalom (1997) and Grosz (1994) and are summarised nicely in the work of Manderson (2011, p. 173). The breast, she writes:

is the flesh that nurtures, offers reassurance and comfort; an infant's embodied memory is buried long after the last suckle. Breasts are matters of beauty and pleasure, sex and sexuality, flamboyantly exposed in fashion, represented and admired in art, omnipresent on screen, discreetly exposed with breastfeeding... (Manderson, 2011, p. 173)

As Lock (2007, p. 569) reminds us, human body parts do not carry universal value as seen in the variety of modalities described by Manderson (2011). Just as the breasts carry multivalent meanings and import, so do ovaries. In her study of women who had undergone hysterectomies and medically induced menopause, Elson (2004, p. 32) writes that 'while the uterus is most strongly identified with its childbearing function, ovaries are the primary producers of sex hormones, which are popularly considered the essential determinates of sexual difference.' Ovaries and breasts are both parts that do important work in creating and maintaining the necessarily partial and collaborative familial body.

Kim, a 61-year-old musical theatre actress and composer based in America, spoke directly about the way in which her breasts did relational work in her family, and particularly with her husband.

I was in college at the time when people were burning bras and fighting for equal rights... but I don't think it is anti-feminist to say that when you attach yourself to another person, to your husband, that parts of you become parts of them. And to think that someone is a jerk because they are mourning the loss [of those parts]... well I have certainly talked to women whose husbands have been very jerky about that subject and accusing them of not being sexy anymore and leaving them but my husband... this has been really hard on him and in some ways it has been harder for him because he is expected to be strong, expected to not care, and you know, I got a lot of attention because I was the one getting cut up and he was supposed to suck it up and go to work because it wasn't happening to him but it was happening to him. And I would love it if people were more sensitive to [him]...

when he saw my scars, he felt it as a failure, emotionally, he knew it wasn't anything he did, but there is this woman who he had sworn his life to and he thought 'I let her get cut up.'

Kim's experiences of bodily connection to her husband and his sadness over the loss of her breasts, speaks of their relational capacity, making a certain sense of why Kim's husband suffered at their loss. They were not of his 'own' body, but they were critical to the relation that tied he and Kim together. It was this loss of relating that he felt. Having her breasts removed was difficult for both Kim and her husband as she mourned the demise of a particular physicality of their relationship; of his hand touching her breast, and what that meant to both of them. Kim and her husband's bodies reach out and recognise one another as part of a social relationship of love and care. Theirs was a 'type of mutual, collaborative, dyadic, intersubjective and embodied identity work,' a work in which whole individual bodies do not make relational sense, and in which Kim's and her husband's pain make complete sense (Teman, 2009, p. 66).

Unlike Kim, Anne, an Australian woman in her early 60s, wanted to be rid of the relationality of parts that her breasts had enacted with her husband. When I met Anne in late 2013, she told me that she has been very active in exploring her family's health history, and offered to print me a copy of the extensive family tree she has been working on after testing positive for a BRCA2 mutation. When I asked about her recent bilateral mastectomy, Anne disclosed to me that she thought she had the wrong motives behind her decision to have her breasts removed. She paused for a minute, unsure whether to proceed. Her husband, she told me, had died suddenly at the end of the previous year from a heart attack when they were out hiking. After his death, Anne was cleaning out his things. He was, as she described, a 'hoarder.' Indeed, her front lawn was littered with scrap metal from his collecting. She discovered large amounts of pornography on his computer and in boxes throughout the house. Her husband, she said, had obviously taken some of these photographs. Anne recalled being 'so angry' that she immediately wanted to be 'desexualised,' to have her breasts removed. 'They belonged to him [my breasts]. Your boobs belong to your partner' and she no longer wanted that. Angered by his deception, Anne looked to have the memories of their intimacy and their past relationship that remained inscribed upon her very bodily being excised. In a way, she

said, having them removed was a way of punishing him. She felt that she was removing that ownership of him over a part of her body, as he had violated this relationship. Anne disengaged from what Mattingly (2014, p. 17) describes as a 'history of commitments and memories' forged between her breasts and her husband's partial engagements with them. By removing her breasts, Anne sought to not only reduce her hereditary cancer risk but to relieve herself of any lingering memory of the relationship her breasts had created, maintained and made manifest with her husband. As his whole person lay dead, the memory of his relationality with her, while she still had the breasts that had maintained it, had, also, to die.

When I included Anne's comments in a seminar presentation to an anthropology department in 2015, one attendee was particularly shocked and noticeably outraged as I described Anne's motivations behind her surgery. During question time, the attendee vehemently declared that Anne's actions represented a failure in the healthcare system to provide her with adequate care and vital information about her options. She suggested that, had she been provided with sufficient, professional psychological support, she would not have made such a rash and 'drastic' decision, one that was likely to impact on her emotional wellbeing for the remainder of her life. I mention this attendee's response as it is suggestive of a particular reading of the interventions into the body that are enacted by women at-risk of hereditary cancer. This particular attendee's outrage at Anne's removal of her breasts, not only as a form of risk reduction, but as a mode of eschewing the now problematic and undesirable material memories of her husband's touch in the light of his adultery, speaks of a fundamental understanding of Anne and her body. In this reading, Anne is a bounded, discrete individual, and as such, is either inherently rational or irrational. Anne, for this attendee, was a somatic individual who attended to her buffered body and genetic identity in reference to a network of other, whole discrete bodies, both alive and deceased. Consequently, she irrationally sacrificed her own health and wellbeing due to displaced emotions of betrayal and anger. I read Anne's actions through a different lens. I argue that we need to take seriously the necessarily partial creation and maintenance of the family through habitual bodily actions. These profoundly embodied and enfolded modes of sociality were felt acutely by Anne. We can thus read her decision to excise them from her very

bodily being as indicative of their import, rather than her ‘irrationality.’ I take this co-inhabitancy or co-presence of bodies and body parts across time and within the family for analysis in the following chapter.

## **Conclusion**

Several anthropologists have worried that a woman’s individual ability to assert her own agency in relating to kin and in making decisions about interventions into and upon her body would be eroded by genetic medicine (Finkler, 2000, 2001). Likewise, they have demonstrated a long-standing concern that the individual, most likely the woman, would be held responsible for decisions concerning her own and her family’s health in light of hereditary illness information (Sachs, 2004; Krupar, 2012). On the basis of my ethnographic data, I have offered an alternative analytic frame that departs from a focus on the discrete and bounded individual to consider the ways in which my informants explained how their bodies are formed and relate to one another.

Fundamentally, genetics points to the sharedness of material and the hybridity of person. Anthropologists have read this genetic body as markedly different from the ‘individual’ who makes decisions in the social world. But, the social world, too, might also be seen as dealing in the sharedness of matter. And, in this sense, medical insights into the genetic body might not be incongruous with anthropological ones into the social body. The use of the ‘individual’ may not be understood as the best corrective to what I am suggesting is a misunderstood threat of genetic medicine to both isolate and subsume the at-risk woman. In asserting the need to rescue the individual from the weight of genetic medicine and kin, we overlook how notions such as partiality are pertinent to the creation and maintenance of the family unit. Drawing on Lyon and Barbalet (1994) I have offered an alternative reading of the family, one based on the habitual deployment of body parts to receiving body parts, driven by the agentive force of emotion.

If we return briefly to Lily and the decisions she faced concerning her risk reduction and her children's future fertility, we can see how these readings flesh out in contrast to the figuring of the family as biosocial and comprised of 'somatic individuals' relating in a network. These decisions are, as she described them, at least as much informed by the flesh of others. That is, her actions regarding her own flesh are propelled by her mother's illness, her concerns for her children and her possible grandchildren. In a sense, these others are Lily's body, her flesh, cast forward into the future through her children and grandchildren, and backwards to the beginning of her own time as a body, through the body of her mother. In her thoughts on her children's future, and her considerations of her mother's past experiences, we see Lily speculate on her 'temporal arc' (Mattingly, 1998). She considers how cancer may not only eliminate her, but also her children and possible grandchildren, as a result of her decisions. Her body parts reach out to incorporate, to enfold, others now, in the future and previously, these entailments crucial to such actions. These matters partial and temporal are the subject of the next chapter.



## Chapter Two

### Partial, habitual and syncopated deployments of bodies

To understand the complexity of subjective life, writes Throop (2010, p. 13) we must be attentive to how such experiences are situated in time. The importance of temporal matters and rhythms of life is encapsulated by Brough (2001, p. 29) when he writes: '[a]ll of the tasks and objects and activities that form the stuff of our daily lives are soaked with time... We ourselves are not only beings in time but beings whose very fabric, mental and physical, is temporal.' I argue that temporality is co-constituted, like the body and, as such, is experienced as a shared in the context of illness. In this chapter, I take as a point of departure the notion of the 'patient-in-waiting,' who waits for her own body to become ill. In the existing literature, this individual patient-in-waiting makes reference to others in her family, particularly mothers, who prefigure her experience and might inform her decisions about what actions to take, or not take as the threat of cancer looms (Timmermans & Buchbinder, 2010, p. 409). In contrast, I take a much fleshier view of time and the time-course of illness. In doing so, I suggest that temporality is not primarily the experience of one, ill body, but is instead the collective experience of syncopation that draws in the most significant parts and operations of what Lyon and Barbalet (1994) imagine as the family.

In her book *Illness as Metaphor*, Susan Sontag (1990, p. 3) wrote of illness as:

the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

As with all territories arrayed around poles, here, poles of 'well' or 'sick,' there is a liminal terrain in which one might be said to be neither unwell, nor well. Cancer previvors dwell in this middle space of Sontag's kingdoms, in its twilight, rather than the bright daylight

of wellness or its night-side of illness. Temporal matters loom large for those who are the bearers of mutated genes linked to hereditary breast and ovarian cancer. Will I become ill? When? Should I have preventative surgery? When? Should I have children now, and then have surgery? Should I never have children? Time for women at-risk is, as Munn (1992, p. 93) purports, an 'inescapable dimension' of their sociality. As I pointed out in the preceding chapter, such questions have been firmly incorporated into analyses that attend to the guilt and the selfishness or selflessness of decisions that will affect others in the future. In the hereditary cancer literature, the women who are making these decisions are often described as 'patients-in-waiting.'

### **Patients-in-waiting?**

According to Timmermans and Buchbinder (2010, p. 409), 'patients-in-waiting hover for extended periods of time under medical attention between sickness and health, or more precisely, between pathology and an undistinguished state of normalcy.' This liminality is exacerbated by the fact that new screening technologies often produce uncertain results that do not necessarily 'correlate with defined disease categories' (Timmermans & Buchbinder, 2010, p. 409). Timmermans and Buchbinder (2010, p. 417) ascribe a number of core characteristics to patients-in-waiting. Patients-in-waiting they submit:

inhabit a liminal state between sickness and health, or more specifically, between pathology and a state of normalcy. Observational assessments, screening, and test results may suggest something is awry but leave ambivalent whether patients-in-waiting are already sick, are going to become sick and, if so, what their sickness will entail... In this kind of liminality, illness experience and medical diagnosis have been severed and people experience illness in spite of symptoms or a diagnosis (Timmermans & Buchbinder, 2010, p. 417).

It is not difficult to see how this description of the patient-in-waiting could be attributed to women at-risk of hereditary breast and ovarian cancer. When entering into regimes of risk reduction through genetic testing, screening and risk-reducing surgery, women at-risk are subjected to multiple occasions in which a test result or scan may suggest the presence of something more sinister. This, for example, may occur in the form of a

slightly elevated CA-125 count or a small mass or calcification identified in the breast during a routine MRI or ultrasound. On a number of occasions, my informants spoke of the liminality they experienced whilst awaiting news of their screening results. Anita, a 29-year-old American PhD student recounted one such scare she experienced after undergoing a routine screening test:

A few years ago my gynaecologist, based on a bad misreading of this test, thought that I had ovarian cancer. Cause I had these cysts on my ovaries and that caused an elevation in some test level... And I was driving from Boston to upstate New York when she called me and she said 'I have never seen test levels this high before.' And I am parked on the side of the road and there is a five-hour drive ahead of me and she said 'I think there is a high chance you have cancer.' Hearing a doctor say 'we have never seen test results like this' is not comforting. That means that you [the doctor] are convinced based on your experience that I have cancer and you are just waiting on a confirmation. That is what she was saying to me. And I am driving back for the next five hours with this in my mind. Three years before, my mother died. And now I have to be home and tell my dad, who just lost his wife of 25 years and loved her greatly, that his only child potentially has cancer. And again, in my mind, I start projecting all these futures. 'Oh I can't have kids...' I don't remember if I was with anyone at the time but I was thinking about not being able to be with them or anyone and in my mind I kept going over all these things that were going to happen and that I needed to appreciate my life and then I get home, I play it down with my father, as I would never scare him like that, and I tried to call the doctor's office and they don't have an appointment available for six weeks! And then [after six weeks] the doctor was like, 'you are 26, you are fine, you can go home.' For six weeks I thought I was going to die.

Anita experienced six excruciating weeks dwelling in the liminal space between health and illness as she waited for a doctor's appointment. In a similar vein, we can see the second and third characteristics of Timmerman's and Buchbinder's (2010) patient-in-waiting described in Anita's experience of undergoing screening. Patients-in-waiting, they continue, 'face externally imposed uncertainty about the nature of disease.' This externally-imposed uncertainty was evident in Anita's concern as to whether her test results were indicative of endometriosis or cancer (Timmermans & Buchbinder, 2010, p. 418). Additionally, patients-in-waiting often experience a 'lengthy trajectory of medical gate keeping to establish or relinquish a diagnosis.' Again we could apply this to Anita's example as she was forced to wait two months for her pathology results

(Timmermans & Buchbinder, 2010, p. 418). In summation, Timmermans and Buchbinder assert:

patients-in-waiting thus inhabit a liminal state between normalcy and pathology, imposed by medical screening and testing technologies aimed at secondary prevention, characterized by a lengthy process of medical surveillance to resolve diagnostic uncertainty, which may spill over into personal identity and other areas of life... Patients-in-waiting [is thus] an umbrella concept to highlight the iatrogenic liminality between an unremarkable state of 'normalness' and disease and to emphasize the patience required of those in waiting (2010, pp. 417-418).

In carrying a predisposition for hereditary breast and ovarian cancer, the women with whom I conducted ethnography, like Anita, would seemingly fit seamlessly into this category of patients-in-waiting or the 'pre-symptomatically ill,' as Rose (2009) and Konrad (2003) refer to them. This patient-in-waiting as envisaged in the literature is seen to wait within and to act upon her own body. It is *her* body, imagined to be in a network relative to others, especially her mother's body, that is potentially ill. It is she who will make decisions about what to do with her body's cancerous potential relative to others, especially her children, who come after her. Subsequently, there is both a linear temporality that arranges the decision-making process, and a bounded actor that takes these decisions in her turn, from mother to daughter to daughter's daughter. This linear progression underscores the sense that one bounded individual, namely the mother at the heart of the family, will be the bounded entity who will make decisions relative to other bodies that circulate in her familial network. They are, as Das (2001, p. 3) suggests, 'connected body selves.'

I read my ethnographic data with a different view of the body in mind, one that is not bounded as such that it makes decisions that then impact on others in a network. My reading looks at the ways in which one is always and already connected to others and thereby makes decisions in concert with the bodily being of others. This is a reading that takes inspiration from the way that partial genetic contributions, genes from mother, genes from father, together make the body in which such contributions are collected. As I outline in my introduction, I am not suggesting that genetic and experiential knowledge of the partial body are entirely congruous. However, as

Strathern (1992a) reminds us, notions of genetic medicine provide us with fertile grounds for rethinking the partiality and hybridity of the body. Genetic inheritance creates a unique being through hybridization and recombination. And yet genetics are also what make us composite, a production of the relationships between people. In taking such a view, a progressive and linear series of bodies that precede and come after the potentially ill person's body – a patient-in-waiting, a somatic individual – does not make as much analytic sense as does a co-constituted body that suffers in collectivity.

## **Part/ial relations**

Like Anita, Lily is, according to Timmermans and Buchbinder (2010), a classic patient-in-waiting. During our first meeting, I asked about her experience of undergoing genetic testing and counselling and how she felt when she found out that she, like with her mother Beth, carried a BRCA2 mutation. Gesturing in the direction of Beth's chest, Lily summed up her first meeting with the doctor with a flick of the wrist; 'we will take this, and that [pointing at her mother's breasts], and this [gesturing to her mother's lower abdomen] when you're done [having babies].' She spoke of how difficult she found trying to make a decision about a course of action:

All the doctors go chop, chop...it's frustrating that you can do nothing about your genes... Mum.... passed this gene onto me, not that she had any choice in the matter... [I may have] passed the gene onto my kids. I hate the thought of my kids having to consider removing their potentially perfect body parts.

When we first met, Lily was 34 years old, mother to two young daughters, one of whom she was breastfeeding, and was contemplating expanding her family with another child. The prospect of undergoing risk-reducing surgery, namely the removal of her reproductive organs; ovaries, fallopian tubes, uterus and cervix, in the near future was made more complex given the stage of life she and her family were in. Recounting a rather difficult appointment, Lily remembered asking her gynaecological surgeon what he would recommend, in terms of risk reduction, if she were his daughter. 'I would remove your ovaries before you were forty' he replied. Lily and her partner James were still hoping to have another child, shortening the timeline for completing their family

as she entered her late thirties. The risk of developing ovarian cancer during this time, however, also played on Lily's mind, given the difficulty of diagnosing the disease in its early stages and the indeterminacy of its symptoms. After having her third child, a son, in late 2015, Lily began researching the option of undergoing a risk-removing salpingectomy as a means of delaying the removal of her ovaries.<sup>9</sup> She hoped that this procedure would help to delay the side-effects of surgically induced menopause and hormone replacement therapy. Certainly, this account of Lily's experience of living with a BRCA2 mutation seems to fit a linear timeline of referencing her mother's experience, using it to inform her own, and then thinking about how her decisions might impact on the bodies of her children. This reading also seems to fit the model of the patient-in-waiting, who is, as of yet, not ill but makes rational, calculated decisions on the basis of clinical predictions. However, a close attendance to the parts of Lily's body in and through which she conducted relations with her family troubles both of these concepts.

Lily spoke to me at length about her breasts. She talked particularly about how they related her to her children. Beginning with remarks about them as a source of nourishment for her offspring in the way one might expect her to, she spoke about how they 'don't really have a purpose after breastfeeding.' However, as she talked about the prospect of implants she revealed that her breasts were fundamental to relations with her children in other ways besides nutritional. She said she would be 'furious' if implants impacted on her ability to run and play with her children. She also worried about the stories she had read on forums that warned implants could be cold, hard and would not feel the same as before. For Lily, it was not so much that they would not feel the same for her; it was more that they would not feel the same for the people who would be feeling them. 'I won't be able to perform my normal 'Mummy' duties,' she lamented.

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<sup>9</sup> Recent studies have shown that more than 80% of ovarian tumours detected in at-risk women carrying BRCA germline mutations originate in the fallopian tubes (Crum, 2016, p. 198). Consequently, the practice of risk reduction through salpingectomy with delayed oophorectomy is being considered as an option for women looking to delay the onset of surgically induced menopause and its accompanying side-effects. This being said, the efficacy of this procedure in protecting at-risk women from the forms of ovarian cancer conferred by a BRCA mutation has yet to be established through large-scale clinical trials. Outside of the trial setting, clinicians and researchers are yet to integrate this procedure into national recommendations for risk reduction (Swanson & Bakkum-Gamez, 2016).

Khloe, an American actress in her early thirties held similar concerns as Lily. She explained her reasoning for having her risk-reducing bilateral mastectomy before having children. She noted that:

there is an aspect when you have your mastectomy where you can't lift things for a really long time and if my child runs to me and I can't lift him up that would be almost more devastating to live like that. And be like 'oh don't touch mum and this and that.' And that might not be a big deal to anyone else but I am a very physical person. If a baby is crying I lift up the baby and hug the baby and I will put them on my back and I am very active in that sense. I knew that was really important that I wanted to be a mum that wasn't living the way I was living right now.

Like Khloe and Lily, Laura, aged 28, talked about breasts and their relationship to holding and cuddling children. She described how in the lead up to her risk-reducing bilateral mastectomy, she and her daughter 'practiced for a few months,' for what it would be like to cuddle with no breasts into which her daughter could snuggle:

Like I would get on the ground with her, she would have been 13 or 14 months when I had it so she had no idea, but we practiced cuddling gently with pillows beforehand. It was hard, like I know she'd sometimes would want cuddles but I couldn't do it and she became so reliant on my husband that afterwards it took a little while when I was okay for her to come to back to me. That was probably the hardest, getting her to see that she could cuddle me again.

In her 2008 memoir *Blood Matters*, Masha Gessen, a Russian journalist and writer spoke of the grief and anguish she felt as she prepared herself and her daughter for the removal of her breasts after testing positive for a BRCA1 mutation:

I weaned my daughter. I managed to convince her that big girls do not drink from the breast. It took a couple of weeks and then she took to holding my breasts – before she went to sleep, when she woke up, or for comfort when she hurt herself or felt insulted. Every time I cuddled her, I worried: How could I get rid of them when she needed them? The argument that ought to have trumped them all – that any trauma was worth it if it meant having me around – did not convince me. What worried me, gnawed at me to the point where I felt a stabbing pain in my chest – my breast – was the fear of losing the physical connection with my daughter that I never remembered having with my mother... [Yet] sometimes I lay

down with my daughter on a futon on the floor in her room and, as she nursed and drifted off to sleep, I thought that sacrificing physical parts of myself and even my youthfulness was a small price to pay for continuing this happiness (Gessen, 2008, pp. 10-11).

Monica, in her early forties, recounted how she agonised for almost a decade over whether to have a risk-reducing bilateral mastectomy after testing positive for a BRCA mutation. In front of a room full of people at a BRCA information day in Sydney in 2015, Monica recalled being rendered almost paralysed by the decision whether to go through with surgery or to continue a routine of screening. She told of how, having come home from an exhausting day of consultations with breast and plastic surgeons, she perched herself on the corner of her son's bed as he sprawled on his stomach playing a video game. Fifteen years old and having reached the stage in life where disinterested grunts and perpetual eye rolling had become his main form of communication, Monica was not expecting much of a conversation. But she began speaking to him anyway, telling him that she had finally decided to have the surgery and that she was scared. Switching off the game, he turned to her and asked 'what of?' 'I am scared,' she told him, 'that it won't feel the same when we hug because I love hugging you.' Her son sat bolt upright and immediately wrapped his arms around her. He said, 'my cheek touches your cheek and your shoulder touches mine and my hands are on your back and nothing that you do will ever change the warmth of your hug.'

As these examples suggest, significant parts of these women's bodies, the parts that are snuggled into and cushion hugs, connect with the significant parts of their children's bodies. These connections undermine the notion that individual bodies stand apart from other individual bodies to make decisions that will impact them. This is not to suggest that the patient-in-waiting or the somatic individual as analytically imagined is not an affective and somatically oriented body. Rather it is to posit that the body these women imagined and enacted was one *already made* in and through the partial relations they had with significant others. These women often chose surgical and reconstruction methods that permitted them to return with the greatest speed possible to these partial relations in and through which, as Lyon and Barbalet (1994) argue, family persists. These are not bodies that are discreet and then relate to one another in a networks of

hugs. The parts of bodies involved in hugs make the family and the body. It is always, already, persistent in its partial relations, not just with the partial deployment of others' bodies, but in and through them.

Using a series of ethnographic examples, I have disputed the idea of the whole 'individual' body, the somatic individual, the patient-in-waiting, and introduced as a counterpoint the existence of a key partial involvement between significant parts of relating bodies. But what is to be made of the fact that these very significant parts that relate to the parts of other bodies, these acts instrumental in making the family, are the very parts that are *removed*? The act of removal is, as the above examples indicate, painful even to consider.

### **Breasted and ovarian sociality**

Part of the reason why the removal of breasts and ovaries is so difficult and painful is because these parts are so pertinent to the creation and maintenance of the family, as Gessen (2008, p. 11) explains so poignantly, her breasts are key to the 'physical connection with my daughter.' The removal of parts that are instrumental in this way is gut-wrenching. But their removal increases the chances of the family's continuance in the configuration established between its (part)icipant bodies. As the above ethnographic examples suggest, the breasted part can be replaced, or the set of relations it forged and maintained may be altered (with cushions, with new techniques for hugging, with added emphasis, as Monica's son explained, on the touching of cheeks and backs). The significance of parts is in this respect malleable and open to change. Death however, precludes all prospect of adjustment or flex. Body parts, then, as significant as they are, are sacrificed to and for the continued presence of the whole family. They are removed and replaced in an effort to protect the 'continuing happiness' Gessen (2008) describes – that conglomeration of partial deployments that, even without breasted deployment, is still 'the family.'

This proposition on part/ial relations holds across a range of relational domains in the lives of women at-risk beyond affectionate relations with children. Just as approximations were made in the absence of cuddly breasts, or replacements were made that permitted cuddling to continue, breasted sexual experience was also adjustable and malleable. Sexualised breasts were often regarded by my informants as pivotal in romantic relations between partners, being a body part richly endowed with bearing sexual relations towards another and receiving them. We can think back to Anne's removal of her breasts as a means of excising the felt memories of her deceitful husband's sexual embrace as evidence of such relationality. Subsequently, breasts operated as a very significant partial deployment of familial relations. Khloe spoke most frankly of this. She said, 'I was really worried about sex because my boobs were always there during sex.' After having her breasts removed, she underwent reconstruction with implants. 'I remember the first time I had sex after my surgery, it was two weeks after [the implants were inserted] and I was obsessed. I was like "we are having sex." I will be a sexual person even though I don't have my breasts.'

Khloe's words show the taken for granted and, prior to her knowledge of her mutation status, unreflected upon role of her breasts as a key part of relations with her husband. The fact that she replaced them with implants equally indicates their importance in that role. Breasted relations are conducted in the full view of their participants, in the sense that breasts and the relations they call forth from parts of other bodies, from the faces of snuggling babies, and from the mouths and hands of lovers, are observable. Ovarian relations, on the other hand, are not. Although internal parts of the body, ovaries play an equally important role in creating and maintaining the partial relations of the family as will be discussed in Chapter Three. Indeed, they are the very seat from which new parts of the family are issued.

Now forty-three, Penelope, a Filipino-American creative writer, talked about how difficult it was to no longer be a part of the social circle in which she participated through ovarian means since she had her ovaries removed. After testing positive for a BRCA1 mutation, Penelope underwent a risk-reducing bilateral mastectomy and a risk-reducing salpingo-oophorectomy. She talked about how difficult it was to consider how

her sociality with her female friends would be affected while deciding whether to have her ovaries removed. 'My [mutation] status made me think about time, but it made it slow down, it became torturous' she told me. 'I thought I have till I am 33 to have my breasts removed or till my forties until my ovaries have to be removed.' 'With menopause,' she said, 'my friends will be going through menopause together but for me, maybe I will be going off the hormones at that time but it won't be the same it won't be [spontaneous] like "oh I am going through menopause." It will be a planned occasion where I would get off the hormones.' Penelope worried about missing out on the sociality of shared menopause with her friends now that her ovaries have been removed.

Thirty-six-year-old Ashley, who carries both BRCA1 and BRCA2 mutations, also spoke about the unhinging of ovarian sociality. She was worried that going into surgically induced menopause would make all the worst symptoms of menopause occur, and that this would fundamentally change the relations she currently enjoyed with others. She explained:

I am just trying to find the time [to have my ovaries removed]. I have gotten back into teaching and I love it. I am in a school and teaching four days... I know my health is important but I am really enjoying that so I am thinking maybe January as that way I will have time to recover before going back [to school] or in December before the holidays when they are breaking up. I did my tubes last November and that was fine and the pathology was okay. So I am hoping just a few more months would be okay. I would hate it if I waited and got ovarian cancer but I just wanted to find the right time. So we will go and have the discussion today. He [the doctor] said I will do HRT [hormone replacement therapy] straight away, he is very pro HRT and so is my oncologist, so there shouldn't be any big changes straight away. I shouldn't have crazy menopausal symptoms or anything. That is what makes me most nervous, with the breast [surgery] I coped pretty well but the ovaries have always worried me. Maybe because first they didn't have HRT as an option I was worried about the menopause and that it would make me crazy! I am not ready. I am not ready to do that.

Angela, too, worried over mood swings related to surgically induced menopause and how this would affect her relationships with her significant others. I met Angela during one of my observation days at the Cancer Prevention and Genetics Clinic in Boston. 'There is lots of cancer on both sides of my family. I am basically screwed,' Angela told her geneticist, Dr Franklin. Angela's mother had been diagnosed with breast cancer and

died at age 63. Angela's mother had two sisters and two brothers. One brother died from lung cancer and both of her maternal aunts had breast cancer in their 60s. On Angela's father's side, one cousin had ovarian cancer when she was 67 and one cousin had breast cancer, diagnosed in her late 30s. Her paternal aunts, uncles and her father died from lung cancer. Dr Franklin told Angela that, based on her family history, she would be eligible for the chemoprevention drug Tamoxifen. Angela made a face, turning her nose up at the suggestion. 'Mum had that [drug]' she said. 'I'm scared of it because my mum took it. It is the cancer drug.' Dr Franklin explained how the drug is used for many different stages of cancer, including cancer prevention. 'It is just a mental thing,' Angela continued. Dr Franklin agreed that it was, 'not an easy drug to take, it can cause mood swings.' 'Oh my poor boys and husband!' Angela exclaimed. Dr Franklin asked how old Angela's sons were, to which she replied, '14, 21, and 23.' 'Well' Dr Franklin joked, 'they deserve anything they get.' The 23-year-old, Angela told us, had moved out of home and the 21-year-old was away at school, 'but my poor 14-year-old!' she exclaimed. 'Don't worry,' Dr Franklin responded, 'I am sure he can outdo you!'

For Penelope, ovarian sociality meant being able to engage in conversations with her female friends about their shared experiences of hot flushes, dry vaginas, sexual dysfunction, weight gain, and mood swings. For Ashley, ovarian sociality was fine, as long as one had ovaries. With that part removed, she worried that crazy mood swings might put her into significantly different relations than she currently enjoyed with her students, her co-workers and her family. For Angela, mother-son relations were at stake, as the presence of out-of-control and untimely hormonal fluctuations could set asunder the hitherto homely and amicable relations between them. For each of these women, ovarian sociality was a sociality conducted in and through the presence or the absence of a critical, relational part of themselves. Despite its containment within the body, these parts reached out to others to create and maintain a fleshy sociality grounded in the experience of having, or not having, that part.

## Social, part/ial time

Considerations of partial relations, like breasted and ovarian sociality, are also concerns about time, and particularly, the timing of children and reproductive capacity. Reproductive decisions, of course, often sit in the thick of romantic relations, as they did for 33-year-old Celia. Celia was only 18 years old when she tested positive for a BRCA1 gene mutation. Her doctor recommended that she should have her children as early as possible and then undergo a risk-reducing mastectomy and salpingo-oophorectomy. She remembered being very overwhelmed by these recommendations. Celia had married young and by 23 had divorced her first husband. As her divorce was processed, she remembered thinking, 'oh my goodness I haven't had children yet.' She met her current husband and within a year and a half, they begun having children. 'I had three out by 30. In nine years, I got three children and ten houses.' She spoke of how she felt lucky to find a man who also wanted to have children early. Celia spoke of how the death of her cousin Michelle, who passed away from metastatic breast cancer, influenced her decision making. Michelle left behind three children, now aged 18, 14 and nine. She recalled how, when they buried Michelle, her daughter asked 'Where's Mummy?' Celia subsequently decided to have her breasts and ovaries removed in her early thirties not long after her cousin passed away.

After her operation Celia remembered thinking to herself, 'what if I want to have more children? It's final, I feel robbed. This ability to have a child is such a strong female sense and I was taken from that.' Celia went on hormone replacement therapy (HRT) to help with the possible side-effects of surgically induced menopause although she was still intermittently breast-feeding her youngest daughter. She recalled being worried about what she might be giving to her daughter [in terms of chemicals] through her breast milk. 'No-one prepares you' for the experience of surgically induced menopause and the conflicting feelings it brings forth, she noted. 'What if I divorced my husband and wanted another [child]?'

Surgical interventions into one's reproductive functioning through the removal of specific body parts brings forth the biological event of menopause that, as Martin (1987, p. 42) asserts, is commonly considered as a 'pathological state' in Western societies. This view of menopause, she continues, results from a particular view of the ageing woman's body as a formally productive 'hierarchical information-processing system' in breakdown (Martin, 1987, p. 42). Such concerns about premature aging and the accompanying bodily changes were voiced by a number of my informants including Celia. Being 'feminine in the right way,' writes Schwaiger (2006, p. 30), expanding on Butler's work, 'involves adjusting to age norms' and expectations. Certainly, how women experience their surgically induced menopausal bodies stands incongruously with heteronormative modes in which time is 'socially organised' with reference to gendered reproductive capabilities. Moreover, to focus solely on such socio-political understandings of biological time as governing and disciplining these women's gendered bodies overlooks the multiplicity of ways in which they conceptualise, resist and subvert such singular, routinised temporal unfoldings. My informants were often innovative in the ways they strove to reconfigure their presently risky bodies to protect their capacity to live in familial time.

Also standing congruously with such standardised modes of temporality is the patient-in-waiting. Timmermans and Buchbinder's (2010) patient-in-waiting is lost in time. The rigid markers of both diagnosis and treatment, then death or recovery, and the life course events, like childbearing and menopause, are undone from their linear temporal moorings. This patient waits, both hesitant and impatient to act upon her own body, drawing on the discrete experience of her mother, and the-as-yet-to-come-to-pass experience of her daughter. The patient-in-waiting is frustratingly unable to return her life course to its natural order without that all important diagnosis. Even her menopause will not be on time. She will have to induce it with drugs, and not at the proper or 'natural' temporal point of her life. The waiting, the uncertainty, means she has to guess at the future, and be informed by what she knows of the past to make decisions in the present. Such a formulation, although easily applicable to my own ethnographic material, keeps in place linear progressions of time. An understanding of time, however, that is co-constituted in and through the fleshy contributions of others yields rather

different insight into the experience of being at-risk of hereditary breast and ovarian cancer.

The following examples collectively demonstrate that it is crucial for the bearers of hereditary cancer gene mutations to be astute ignorers of strict lineal divisions, such as 'past,' 'present' and 'future.' Of course, people bump up against these unsettling abstractions. Often they worry over what forms their decisions 'now' will take in the 'future,' and whether their 'future' children, should they come into being, will, like them, be carriers and may be diagnosed with cancer. But in fleshy, day-to-day living past, present and future are not discrete forms or demarcated blocks of time that proceed in linear order. They are knitted together, again, in and through the partial relations between bodies. As Brough (2001, p. 33) notes, '[w]e are always aware of the now as centred within a horizon of past and future. Now, past and future are inseparable in our experience, even if they are distinct as modes of appearance; to have one is necessarily to have others.' Nevertheless, Brough (2001, p. 38) continues, these forms of temporality are also inherently flexible 'whether one's experience of life is taken to be ordinary or extraordinary. The extraordinary, however, brings home their flexibility most vividly.' Brough (2001, p. 40) also remarks upon how such flexibility of temporal experience may be inhibited by illness. He suggests the ways in which our usual 'freedom to move about the temporal landscape of ours' can be disrupted by illness, causing a 'collision between' the 'times in which we live.' Giving attention to this temporal collision can offer us key insights into the non-linear temporality.

## **Temporal collision**

The language of collision is not uncommon in phenomenological observations about how the arrangement of the world, in this case its temporal arrangement, meets the experience of the ill or potentially ill person. As Csordas (2015) noted in his work among chronic illness sufferers in the United States, a world that is temporally organised around the rushing and fast paced rhythms of capitalism upsets the body going through an illness experience. Because the ill person cannot meet its frenetic pace, they become

slower than the world. In such experience, there emerges a collision between temporal regimes and bodily capacities: the ‘vector of agency from the world towards one’s body,’ and ‘the vector of agency from one’s body towards the world’ collide. Rather than reciprocity:

there comes to be an impasse. In this impasse, the afflicted person becomes bogged down in the practice of everyday life, increasingly exhausted by the resistance of the world, and eventually incapacitated... a vector of agency from one’s body toward the world is characterized by sufferers as a lack of stamina, a feeling of being slowed down, and unpredictable fluctuations in symptoms and their severity. This impaired agency comes up against a vector of agency from the world toward one’s body, characterized by the demand for constant activity, speed, or an accelerated pace of everyday life, and tight scheduling that extends to multiple domains of practical activity (Csordas, 2015, p. 56).

This collision of vectors of agency from world to body and body to world is explored in even more detail by Toombs (2001) as she reflects upon her own experiences living with the degenerative disease multiple sclerosis. Chronic bodily disorder, she reflects, profoundly impacts on temporal and spatial experience and one’s ability to engage with and relate to others:

Not only are the body’s natural rhythms of sleeping, eating, working and resting disturbed, but the time it takes to do things – get out of a chair, put on one’s clothes – is necessarily prolonged. One is forced to give unusual attention to the present moment, to concentrate on what is required this minute. This goes against the natural tendency that we have to focus our attention on the future – on the next project, the next task... The change in temporal experience can be extremely disruptive not only in the sense that one is necessarily ‘caught’ in the present (unable to ‘get on with’ things at the usual pace) but in the sense that the person with a physical incapacity is ‘out of synch’ with the able-bodied. This difference in temporal experiencing affects one’s relations with others. ‘What’s taking so long?’ others ask impatiently. (Think for example how difficult it is to communicate with someone whose speech is unusually slow or halting. One finds oneself desperately fighting the urge to hurry things up by interrupting and putting words in their mouth) (Toombs, 2001, p. 258).

The profound disruption to temporal rhythms is something that many at-risk women have witnessed while caring for their family members during cancer treatment. It also becomes a profound concern as they consider options for risk reduction. In

phenomenological approaches to temporality, Husserl's early musings of time-consciousness and his metaphor of a melody is often called upon to demonstrate how past, present and future unfolds in concert within a person's experience. When the present note is sounding, the just-past note is remembered and the future note is anticipated and so the melody unfolds in linear progression (Toombs, 1990). In their ethnography of women living with metastatic breast cancer, Bell and Ristovski-Slijepcevic (2011) discuss how these women are forced to concentrate their energy on anticipating notes far into the future, such focus disrupting the linear unfolding of the melody as they try to establish a legacy for their children. A similar interpretation is offered by Jain (2007, p. 80), who suggests that women diagnosed with cancer live as 'already-always-ill,' this status emerging from a particular Western cancer culture in which the temporality of the sick is 'relentlessly future-orientated.' While a definitive cancer diagnosis may bring forth temporal disorder, I argue that women at-risk of hereditary breast and ovarian cancer, yet to be diagnosed with cancer, encounter a different experience of temporal awareness.

For women at-risk, the present, that is the note played in the now is not merely prefaced nor succeeded by just-past or future notes, they are sounded in unison, like a pianist pressing down multiple fingers to produce a resonating chord. At times, they may come to attend and attune to particular temporal registers over and above another, as Desjarles and Throop (2011, p. 90) explain; '[a]s we focus closely on one aspect or reality, other potentially experienciable aspects of reality are relegated to the fringe of our awareness as a now yet still potential horizon of future experience...' Continuing with the metaphor of music, they suggest:

[A]s we foreground the sound of a bass in a jazz quartet, the sounds produced by the pianist, drummer and sax player fade imperceptibly into the background horizon of our experience of music. If we then shift to listen to the chord progressions played by the pianist, however, then the sounds of the bass guitar shifts from foreground to background, all the while remaining potentially available for once again returning to the focus of our attention (Desjarlais & Throop, 2011, p. 90).

This shifting of attunement between temporal registers in the lived experience of the now is particularly pertinent to the at-risk women. The body and body parts of her relations, her mother and her daughter, come to inhabit her and she them as the threat of cancer looms large. Women at-risk, I argue, conceptualise and experience their bodies and the temporal and spatial registers of bodily experience in ways that are different to the dominant, linear understanding of time characteristic of Western society as a whole. Tactical inventions into the body through the removal of potentially dangerous body parts may be read as servicing this temporal regime of linear order and productivity. Preventative actions, in this sense, are enlisted to ward off potential bodily failing through illness in the future. Conversely, the pre-emptive removal of body parts that may develop cancer in the future could be seen as a hastening of the decay of womanhood as reproductive functioning is relinquished decades before its otherwise natural onset.

I wish however to take an alternative approach to understanding the temporal experiences of women at-risk of hereditary cancer and their decision to intervene in their risky bodies whether through surgery or surveillance technologies. A number of anthropologists and sociologists have drawn attention to the ways in which time is conceptualised in regards to genetics. Mutations are biologically inherited, harking back to the enduring germlines of ancestors whilst simultaneously projecting forth to create what Adams, Murphy and Clarke (2009) describe as anticipatory regimes of time, characterised by speculative forecasts. Enabled by biotechnology and predictive forms of biomedicine, this movement back and forth between past, present and future, Adams, Murphy and Clarke (2009, pp. 246, 253) suggest, creates anticipatory regimes in which citizens are expected to secure their 'best possible futures' through preparedness, thus 'reterritorial[ing] and expand[ing] the domains and sites' of experience to be monitored. While this approach holds much promise in evaluating the temporal politics that emerge as a result of future-orientated, preventative biotechnologies, there needs to greater attention paid to how these temporal politics are taken up or resisted in everyday life.

This sharedness of time experience in everyday life is not restricted in any especial sense to living relations. The strictly linear progression of movement from life to death is undone when the flesh or parts of others remains at the core of fleshy relations. Familial life continues on after the death of a member as Strathern (1992b, p. 107) reminds us; 'at death, what gave the individual uniqueness was left as the acts and relations exercised during the lifetime.' This continuing dialogue between the absent and the present is discussed by Ribbens McCarthy and Prokhovnik:

Rethinking the lived reality of the material, corporeal, visceral, fleshy, seeping, affective, 'enfleshed' embodiment of the person provides a basis for revaluing all that the now-dead person brought to their relationality, much of which remains... Dominant social meanings in Western societies around the death of a loved one... [lead] to the conclusion either that there is nothing left of the loved one but the morality remains, or that one can still have a strong relationship but without embodied presence. This binary thinking, and the biologisation of death and personhood underpinning it, leads directly to the underestimation of the significance of the physicality of grief and the materiality of continuing bonds. What is missing is the understanding that the embodied relationship with the dead person does not die with the person... [Thus] specific connections [exist] between an intensive form of relationality, and embodiment and materiality in the context of care after death, in a non-binary way that indicates the porous nature of the boundaries... and manifests the possibilities of relative (dis)embodiment (2014, pp. 35-6).

As I take up in the following section, the ways in which the deceased person continues to live on, inhabiting in a non-linear sense the bodies of loved ones and transforming existing forms of relationality, is particularly pertinent to the experiences of women at-risk of hereditary cancer. For women at-risk of hereditary breast and ovarian cancer, the world organized in this linear fashion is met not head on, but ovary on, breast on, as she deals with illness or its possible manifestation. Moreover, and what is clear from the foregoing examples, is that the experiences of people's 'past' are knitted tightly into the bodies of those in the now, as are the experiences of those in the future. This framing creates a fleshy body comprised of the parts and experiences of others in 'the past' and 'the future,' drawing them into a fleshy co-presence.

BRCA mutation carrier and author Sarah Gabriel details in her memoir the presence of her mother's hands in her own, noting that:

mine are not quite so long as hers, not quite so graceful. But they are of the same genus. Fine wrists, slim palms, the knuckles gracefully articulated. And it is her voice I hear telling the children to mind the cracks in the pavement, to walk round and not under a ladder, to eat up their carrots so that they can see in the dark (2009, pp. 255-56).

Gabriel's mother, who died of ovarian cancer, remains present in the body of her daughter. She is present in much the same way that women in my study called upon and called into their own fleshy bodies the experiences of their mothers that were not bracketed into the far off past, but now constituted 'my own' body.

What I mean to suggest here is that 'my mother's body,' is brought into 'my own,' despite the fact that she lived in a different and distinct time. Her ovaries become mine, and I decide what to do with them, for I am also, now, my daughter's ovaries. I decide what to do with them, now, in the same moment as I have my mother's ovaries inside of me to consider. I am not my mother, as Strathern (1992a, p. 15) reminds us, 'parents already united in a relationship produce individual children... yet, in their children, parents (persons in a relationship) also produce other than themselves (individual persons)' but I have her ovaries, and I have my daughter's ovaries. They are comprised of shared genetic matter, and it is this part, this breast, this ovary, that makes us one body, mine. As Kleinman, Brodwin, Good and DelVecchio Good (1994, p. 9) note, to regard illness or 'pain as the experience of *an individual*... is so inadequate as to virtually assure inaccurate diagnosis and unsuccessful treatment [my emphasis].' This is a most pointed remark in respect to genetic illness, for the sufferer cannot be an individual that is bounded and discrete (this is not to say that, in such a situation she, as an agent, must be rescued as Finkler [2000, 2001, 2005] and the like would suggest). Nor can she be bracketed off in time, regarding the ills of others as existing in another time or space. They must be knitted together, in the present, for, in both a genetic sense and in a social, affective, relative way, your ovaries must be mine, for what I do to mine, I do to yours. In this sense, in the case of hereditary cancer, illness can never be understood to have happened in the isolated block of time called past, nor to be set out to be experienced only in the future, it happens in the lived *now*. Once again, this is not to say that past

and future become irrelevant, engulfed by the lived now. Rather, as Brough (2001, p. 39) reminds us, the 'now, past, and future, in their mutual interdependence, is not abrogated when the now expands [but rather], the now seems to crowd out past and future *precisely because they retain such an intense presence* in [one's] field of awareness [my emphasis].' The same crowding of the now by the presence of past and future occurs in the case of those who would 'come after' oneself, one's children.

Consider the following ethnographic example, in which Leanne, aged 52, effectively inhabits the bodies of her children, to consider how laborious (or not) the results of her 'own' decision, to have a risk-reducing bilateral mastectomy, might be for them. She also considers how certain acts of resultant medical surveillance would feel in their own bodies. After her mother was diagnosed with breast cancer at age of 41, and developed secondary breast cancer 15 years later, Leanne, a nurse and mother of two young boys with her partner Helen, decided to have a prophylactic bilateral mastectomy last year after undergoing eight years of surveillance:

For me, as I said to my partner, if it wasn't for my children and her I probably would have just gone on surveillance and done the normal [screening] but because I remember what it was like going through the various different cancers that my mother had and the family had, I just didn't want to put my children through that. There is enough shit in life that they have to deal with and I don't want them to have to watch that if there is anything I can do to stop that then I will. And both my boys have the potential for hereditary bowel cancer, our donor has been tested and has come back as positive so for me it was also walking the walk not just talking the talk as I work in an area of prevention and... um so this is my way of saying, if I can take such a radical step to prevent this from happening then, to me, the fact that you guys are going to have to have an annual colonoscopy [something that Leanne will continue to have] isn't too bad.

We see this in excerpt Leanne's awareness of her bodily interventions as forming a mode, an example of intervention, that she hopes her own boys will inhabit in the future, even after she is gone. Similarly, Gabriel (2009) recognises that her hands, washing the dishes, are her mothers, the fleshy relationality hinged on the person may persist although the tangible presence of the person has expired.

## Bodily co-presence

Ribbens McCarthy and Prokhovnik's (2014) ideas on enfolded connections and material bonds of care after death are borne out in director and actress Angelina Jolie's 2013 open letter to the New York Times. In this piece, she described her decision to undergo a bilateral risk-reducing mastectomy, her response to her positive BRCA1 mutation test. Jolie's mother, actress Marcheline Bertrand was diagnosed with ovarian cancer and died aged 56. Jolie also lost an aunt to breast cancer, aged 61. Entitled 'My Medical Choice,' Jolie wrote:

My mother fought cancer for almost a decade and died at 56. She held out long enough to meet the first of her grandchildren and to hold them in her arms. But my other children will never have the chance to know her and experience how loving and gracious she was. We often speak of 'Mommy's mommy,' and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a 'faulty' gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer... Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventative double mastectomy. My chances of developing breast cancer have dropped from 87 percent to under five percent. I can tell my children that they don't need to fear they will lose me to breast cancer. It is reassuring that they see nothing that makes them uncomfortable. They can see my small scars and that's it. Everything else is just Mommy, the same as she always was. And they know that I love them and will do anything to be with them as long as I can (Jolie, 2013).

In the letter, Jolie's mother, and more particularly, her mother's breasts and cancerous ovaries, dwell in Jolie's own, as she frets that her mother's body will manifest not in, but as, her own. It is not as straightforward as the notion that Jolie uses her mother's experience of cancer and early death as merely a template for planning her own treatment. This line of thinking is evident in the theorising of Hallowell (1999, 2002) and others. It is more than this, as Jolie comes to dwell in her mother's body, to experience it as her own, and deal with it as her own. As Jolie's chances of developing breast cancer drop from 87% to less than five percent, her mother's breasts and her mother's ovaries retreat. Jolie's parts will not become her mother's parts. But Jolie had to take them to be her own for a time, to prevent a cancerous outcome like her mother's.

She also had to take them as her own breasts, eventually reconstructed, to remain present for her children. In this way she could continue to be ‘mommy,’ not ‘mommy’s mommy.’ She would not become another memory of a loving and gracious woman whose presence her grandchildren will be told of but not experience firsthand. It is only in taking up her mother’s body as her own, that she could not become her. And even as her mother’s diseased breasts are expunged from her body, Jolie’s mother yet lingers, both as the breasts and ovaries that were made manifest in Jolie’s own body, but also as the remembered presence of a loving and gracious woman who will not ever fully leave. She remains embedded, too, in a more concerning way, that is, as the remaining five percent chance Jolie still has of becoming mommy’s mommy.

Jolie further spoke of the nuanced ways in which her mother’s body came to inhabit her own as she explained her decision to have her ovaries removed in 2015. In her letter to the New York Times she recounted meeting with her mother’s doctor to plan her salpingo-oophorectomy:

I last saw her the day my mother passed away, and she teared up when she saw me: ‘You look just like her.’ I broke down. But we smiled at each other and agreed we were there to deal with a problem, so ‘let’s get on with it.’ I chose to keep my uterus because cancer in that location is not part of my family history... It is not possible to remove all risk, and the fact is I remain prone to cancer. I will look for natural ways to strengthen my immune system. I feel feminine, and grounded in the choices I am making for myself and my family. I know my children will never have to say, ‘Mom died of ovarian cancer’ (Jolie, 2015).

In an interview given shortly after her letter was published Jolie described how:

[w]e had some of the same nurses, some of the same doctors... So, the doctor that did my ovary surgery was my mother’s doctor. And apparently my mother had said to her, ‘Promise me you will take Angie’s ovaries out.’ So when we got together, we both had a big cry, and she said, ‘I promised your mother, and I’ve gotta do this’ (Jolie, 2015).

For Jolie, her experience of having her ovaries removed, like her breasts, bespeaks the ways in which her mother’s body and its parts came to inhabit her own as she too comes to inhabit the bodies of her children. Jolie meets with the same doctor, in the same

hospital. She sits on the same waiting chair and consults with the same woman who would have cared for her mother with whom she looks so much alike. But by removing her ovaries, she is ensuring that her mother's cancerous body parts will not, cannot, become her own. They will be removed as her mother made her doctor promise they would. Jolie's mother made clear that she did not want her own cancerous ovaries to become her daughters, just as Jolie makes certain that her own experiences of losing her mother to cancer will not become her children's experience. '[M]y children will never have to say, "Mom died of ovarian cancer,"' Jolie (2015) reminds us, as she herself must say. Jolie's body will not become her mother's body. But it did, for a time, have to be inhabited by it for her to make sense of what this cancerous potentiality could mean for herself and her family. Likewise, this co-presence is evident as Jolie's body is not her children's, in full, but did, for a time, come to inhabit them so that she knew for sure what she did not want for them, what was, as Kleinman (2006) reminds us, most at stake.

This fundamental part/iality of the body, as body parts coming to inhabit one another in a mode that does not conform to linear time progression and bounded confines of the individuated body, has been a source of consternation for some anthropologists. Strathern (1992b, p. 157), for example, cites the apprehension shown by Braidotti (1988) over the fragmentation of the body that is permitted by biotechnology and biomedicine. For Braidotti, by '[s]wapping the totality for the parts that comprise it, ignoring the fact that each part contains the whole, the era of "bodies without organs," is primarily the era that has pushed time out of the bodily picture' (1988:153 in Strathern, 1992b, p. 157). I, however, read this situation differently on the basis of accounts given to me by my informants, and evidenced in the statements made above by Jolie. Rather than seeing time as pushed out of the bodily picture, as Braidotti (1988) suggests, I, alongside Strathern (1992b), draw attention to the ways in which such linear conceptualisations of time were in fact never part of the at-risk body in the first place. For Braidotti (1988:157 in Strathern, 1992b, p. 157), the 'ever-receding fragmentation and traffic in organ parts' denies a generational difference between body parts: 'my uterus, my mother's uterus.' Yet, as Strathern (1992b) asserts, this view is fundamentally flawed. By taking bodily fragmentation to be an affront to the boundedness of the bodily whole

and the linear progression of time, one ignores the very composite, hybrid and co-constituted state of the body. Such an approach to fragmentation, writes Strathern (1992b, p. 157) 'evokes a counterpart idea of some prior whole.' This discrete or priorly whole body however is untenable if we are to take seriously the experiences of enfleshed and partial co-presence, of a mother's ovaries dwelling in one's own, that are described by at-risk women such as Jolie.

These points are perhaps even more sharply evident in Valerie's case. Valerie, a British 35-year-old linguist now living in Australia, has spent much of her life thinking about her potential risk of hereditary breast and ovarian cancer. Testing positive for a BRCA1 mutation after the birth of her first child, Valerie underwent a risk-reducing bilateral skin and nipple sparing mastectomy with implant reconstruction and a bilateral salpingo-oophorectomy. Her mother was diagnosed with breast cancer when Valerie was only 16.

Valerie recalled making an appointment almost a decade ago at a familial cancer clinic in London where it was advised that her mother undergo genetic testing given their family history was 'strongly suggestive' of a genetic mutation. Valerie's mother, however, did not want to be tested. 'I just assumed I had it,' Valerie recalled and for eight years she arranged her own screening and surveillance in Australia while she waited for her mother to agree to be tested. During her mother's cancer and recovery, Valerie had been one of her primary carers, an experience that prompted Valerie to think about the practical issues associated with illness from a young age:

My priority was getting life insurance, rather than things most 20-year-olds get done. The cost [of insurance] was just like [paying for] electricity: it was something that I had to do.... I always had the idea that I wouldn't live past a certain age. It was always in my mind that I would get cancer and that I wouldn't survive. I had the idea that, around forty, I wouldn't be alive. I just knew that there was a likelihood that I would die at an early age. It's hard to [think you will] live past the age that your parent's [get sick]. My relationship with my husband became serious and practical very early on, [more] than other couples had to deal with. Our financial concerns, like paying life insurance, were different from other couples.

Valerie felt that she too would come to inhabit the same temporal unfolding and follow the same illness trajectory as her mother. This concern prompted Valerie and her partner to make decisions and plans about their life *together* faster than was the case for their friends and peers. Valerie's mother decided to be tested two years ago, just after the birth of her first granddaughter, Valerie's first child, in 2012. Valerie's mother tested positive for a mutation in the BRCA1 gene. This news brought about a range of emotions for Valerie:

I spent lots of years angry at my Mum for not testing. I was also angry about when she got the test. She got the results four days after the birth of my baby and told me [in the hospital]. My emotions were already all over the place after having the baby, I had postnatal depression, my view of the future was in flux and then I had to deal with BRCA stuff at the same time. It was a perfect storm. Four months after having my baby, I was tested for BRCA. I wasn't diagnosed with postnatal depression till months after. It drove a wedge between us. It's a bit better now but she wasn't there when I needed her.

Consequently, Valerie decided to undergo a risk-reducing bilateral mastectomy while her daughter was a toddler. She and her husband hoped to have another child and so have discussed the possibility of Valerie removing her ovaries:

I just wanted to be able to look my loved ones in the face and know that I had truly done everything in my power to minimise my risk of cancer. This was not something I felt some of my close family members could say, and I remember feeling angry about that as a child... I didn't want that for my husband and child. I also have a close friend who survived ovarian cancer, and I lost another close friend to breast cancer some years ago after a long period of illness. I believe that both these friends would have grabbed the opportunity for health with both hands had they been offered the same choice I was being offered. Once I tested positive, it became clear that the risk was very high. I was also approaching the age of typical onset in my family. I had just had my first child, and I decided the impact of cancer would be enormous on my family and loved ones. It wasn't just about me anymore. It made sense to go for surgery which at least I had some degree of control over. Also, I was tired of the screening which I'd been actively pursuing for almost ten years. I wanted this new stage of my life to be about something else... So there were lots of factors, but I would probably say a big one was that it wasn't just about me anymore. *And I didn't want to be my mother, or my aunts...* certainly I feel more angry and distant from my mother by going through this. I understand even less the choices she made, and her words and actions hurt me even more now I feel I have somewhat earned the right to say, 'OK, you can't use the fact that you went through tough times with cancer as an excuse any more.' Because I'm experiencing

similar tough times now too, and I can see that you *always* have a choice in how you handle these things [my emphasis].

Somewhat eerily, Valerie had to come to, even for the briefest of time, be inhabited by the body of her mother and of her aunt to know, most profoundly, that this was not the type of body, the type of being, she wanted for herself or for her family. Inhabiting and being inhabited by the bodies of familial others as Valerie suggested is thus, not necessarily, a welcomed experience but nevertheless a significant one. By inhabiting the body of her mother, of going through the 'tough times,' Valerie came to know what she did not want to do and who she did not want to be – her mother or her aunt. Valerie, for the briefest time, came to inhabit what it would have been had her breasts become her close friends, diseased and without the option for preventative action. She envisaged what would have been if this friend could have inhabited her body parts, at-risk but not yet pathological, and how she may have acted had this been the case, if she has been 'offered the same choice... the opportunity for health.' She also came to inhabit the body of her daughter. She considered how it would feel for her baby girl to have to go through the experience of caring for a mother with cancer, of 'feeling angry' that she did not do everything in her power to reduce her risk, as Valerie felt her own mother had not. The way in which at-risk women speak to and of this porous flesh underscores the ability of the unbounded body to seep across what the paradigmatic anthropological approaches otherwise recognise as 'individuals' and be effectively shared between them. We can remember that this sharedness of bodies is underscored by genetics, as Strathern (1999, p. 42) reminds us, reproduction 'makes children part of the bodies/persons of their parents.' Genetic inheritance thus 'points to duration,' to a sharedness across and throughout time (Strathern, 1999, p. 66). In taking cues from these fundamentals of genetic medicine, we can underscore the very sharedness of the experience of suffering. This reading allows us to see suffering across bodies and times, doing away with the overreliance on notions of the individuated, discrete and bounded body as the figure who experiences the linear progression of illness or the potential for illness.

This experience of a non-linear and porous enfleshed bodies, where body parts come to inhabit one another across time has been expressed at length by Gessen (2008). In her

memoir, Gessen (2008) spoke of her experience of living with the spectre of hereditary cancer after her mother passed away from breast cancer and Gessen (2008) tested positive for a BRCA1 mutation. She writes how the risk of hereditary cancer became part of the legacy she inherited from her mother, forming an affront to her best attempts to differentiate and distance herself from her mother and their tumultuous relationship:

And even though, like all daughters of mothers who die young, I had a difficult time visualizing myself past a certain age, I had always, without really thinking about it, assumed that I would make better of what I had, and for longer, because I am not as afraid, I thought my gifts were my own, making me free from her legacy altogether. Then I found out that I got everything from her, including the flaw that killed her (Gessen, 2008, p. 6).

Despite her conviction that she was freed from her relationship with her mother, she came to realise that she was intricately and intimately entwined in her very being, even after she had her breasts removed prophylactically. While Gessen (2008) wanted her life and her body to be her own, when her mother passed away and she tested positive for a BRCA gene mutation, she became aware of how fundamentally connected she remained to her mother. She realised how she would miss the security that her mother's presence bought her despite their differences. She was inhabited by her mother's presence. She carried her physical traits, her gestures, turn of phrase and her genes, just as Gessen's own daughters carried forth hers:

My daughter will go on in the world with feet and eyebrows that are replicas of mine, a stubbornness just like mine, and the habit – my habit – of scrunching up her face when doing something that requires great concentration.... Most important, she will carry with her the memory of me, perhaps even the physical sense of me. That physical awareness is the essential element of security. Whatever trace of my mother I carried – even if it was the mere knowledge of her existence – had kept me from feeling mortal as long as she was alive. When I awoke on the morning of her death, I felt a fear that has not left me since. For months after I learned of my mutation, I would think about this in the sleepless early morning, when my daughter pressed her hot heels into the small of my back, and I know I was the only thing that protected her from the cold wind of fear and freedom that came into the room through the open balcony door. Then she would tap me on the shoulder and ask me to turn around so she could hold my breasts... (Gessen, 2008, p. 12).

At-risk women such as Angelina Jolie, Valerie and Masha Gessen spoke of the ways in which they hoped that their children would never come to have to inhabit their grandmother's, aunt's or mother's cancerous or pre-cancerous bodies, nor have to live with the absence of these key figures in their lives. My informants however often voiced a concern about the *inability* to inhabit the cancerous familial body for those who did not live to see its suffering. As Penelope explained:

I am a bit nervous for my niece's generation as it is great that nobody is going to get cancer [after having the risk-reducing surgeries] but I worry that they won't know how bad it is. And it will be more theoretical, like 'oh maybe at age 33 this might happen' but to have been next to my sister while she had breast cancer at 33... Oh I know I don't want to have to go through that, it seems horrible. So I am a little nervous about the next generation. Because it [seeing family members go through cancer] had an impact. My cousin had breast cancer and it went to her brain and, she is alive still, but she had to get a shunt, but that didn't work and then she had to get whole brain radiation, it is horrible. I don't want to go through that and that could happen. So it is instructive to see those [things]... I wonder if, I don't know, maybe it's like, there was something I read about rises in HIV and they were saying that in this new generation they didn't grow up in the 80s, they didn't see the ravages of the community so they aren't taking it seriously. My aunts died from these diseases and then my cousin and sister didn't die but they suffered through the treatment and the uncertainty of being a cancer survivor and the fear that it will come back.

Penelope's, her cousin's, her aunt's or sister's body could become her niece's body - she too may carry a mutation in her BRCA gene. This troubles Penelope but what is of even greater concern is the fact that these suffering bodies may not be sufficiently enlivened or inhabitable for her niece and thus her ability to make sense of her risk may be jeopardised. The bodies of loved ones suffering from cancer, for Penelope, have to be enlivened through words, through stories, so that they can circulate within the next generation and be taken up as potentially 'my body' and in essence, a body that you do not want to be. Penelope worries that, by undergoing risk-reducing surgery and preventing cancer from developing, the body and the person suffering from hereditary cancer will be 'too theoretical' for the next generation. She worries that she and her sisters will not do a good enough job of enlivening them for her niece so that she too can make sense of the gravity of the situation she faces.

Having breast cancer and the suffering associated with cancer enlivened by her mother impacted on Billie's decision to undergo risk-reducing surgery in her early twenties. Billie too worried for other women who may be at-risk and face the decisions surrounding risk reduction without having had cancer enlivened for them by loved ones. She told me:

I pretty much grew up with breast cancer and I'm sure that had a lot to do with it [undergoing surgery in her early twenties]. I think... I think it's always interesting to hear, you know, I've seen a lot of cancer in my family and that's the reason why we choose to do it but I hear other women who haven't seen it, maybe their dad passed it down, so they haven't seen too much cancer and I almost feel like we have an easy choice you know. Because it's been right in our face growing up and I think... I don't know it's interesting, I just think it's a more difficult choice if you haven't seen it.

Some at-risk women, Billie worried, may find it even more difficult to make decisions concerning risk reduction as cancer had not been enlivened for them by their mothers, sisters and aunts. And yet there appears a fine line between the concern that one's children and younger relatives must be able to inhabit the cancerous familial body in order to comprehend the enormity of hereditary disease and the worry that they will come to inhabit this body for too long, that they will be engulfed by it. Thirty-two-year-old Melissa, mother to four children, aged 13, 11, nine and seven, told me that she had always been open about her risk of cancer with her children from the very beginning. Melissa's mother was diagnosed with breast cancer when Melissa was six years old. In late 2013, her sister was also diagnosed with breast cancer and underwent a hysterectomy, bilateral mastectomy and genetic testing. Melissa told her own children when she underwent genetic testing and tested positive for the 'cancer gene.' She remembered her nine-year-old daughter asking 'Mummy does that mean I have the gene? Am I going to get cancer?' Melissa did not know what to say.

Laura also contemplated how much she should tell her daughter about their family history of breast cancer and her BRCA mutation:

I want her to be a child, because I never really [was]... I was 17 when my mum got cancer and I always knew that my nan died of cancer so I want her to live a bit of

a life and once she is 18 maybe talk to her about it. But I am sure she is going to know as she is going to grow up seeing my scars. I have no idea how I am going to handle it but I don't want her growing up thinking about it all the time.

Laura worries that her daughter may come to inhabit her body for too long, that it will become her entire body instead of her very own as Laura herself felt when she was growing up. In inhabiting her mother's body and her grandmother's body from a young age, Laura suggests that she missed her own childhood. In taking up her mother and grandmother's bodies as they suffered from cancer, Laura experienced another form of suffering, a shared suffering. Melissa too remains unsure of how to explain her situation to her daughter. In each of these examples, we see how children seem to be intuitively aware that their bodies are taken up and inhabited by other bodies. Across and between generations, we see the body emerge as partial to others and, at times, non-distinct. This fundamental connectivity seems to be thought about and mused upon by children. Bodies are not separated out by generations, distinct and inaccessible, but rather are taken up and inhabited by one another. Indeed, they only appear as separate in a lineal view of time and family. However, to consider the cohabitation expressed by at-risk women such as Laura and Melissa, we need to move beyond such linear views to consider how temporality is shared in and through bodies and thus produces the co-temporal body of the family. Just as genes live in multiple iterations and configurations of bodies at the same time, bodies come to inhabit bodies in a similar way through the presence of a gene mutation and the cancerous potential it confers.

### **The rhythms of life – temporality on the small scale**

Bodies may be shared across generations, spanning across time in ways that challenge discrete notions of the past, present and future. On the micro scale, bodies may also share time in our day-to-day living, that is, they may become syncopated in their habitual and partial deployments and actions. In 1997, Margot Lyon urged us to consider the usually un-reflected upon, yet wholly necessary, everyday bodily act of respiration, as profoundly social and syncopated:

Generally speaking, a phenomenon such as respiration is assumed to be ‘merely biological,’ a bodily function in the service of the intake of oxygen and the elimination of carbon dioxide. Respiration, like most basic bodily capacities such as heart rate, blood pressure, circulation, is widely considered to be irrelevant to sociological analysis per se. Further, given the conventional boundaries of the discipline, there are few means to give such bodily phenomena a voice – except through descriptive commentary drawn largely from biology itself. The general assumption is that such basic bodily functions are unaffected by, and have little affect on, interactive exchanges. The ‘machinery’ of our organ and nervous systems is thought to be self-operating, while our overt actions are seen to be generated and governed by social and cultural forces. Such Cartesian dichotomies permeate our common categories of thought about the body... Yet, these basic ‘animal’ functions are fundamental to bodily being and have an important role in *complex interactive processes*. Their import needs to be acknowledged and better integrated into sociological accounts [my emphasis] (Lyon, 1997, p. 91).

Her words are relevant today and to my thesis, since it is these smallest and least remarked upon processes of bodily being, such as breathing, that produce shared corporeal and temporal familiarity and family. Family, as I have suggested, exists and persists as bodies, or parts thereof, in relation. Tiny, unremarkable, yet wholly necessary acts, like breathing, link the partial bodily activity of one, with another, to produce the patterns that unite bodies and yields the ‘family.’ The importance of these habitual interactions has been recognised by anthropologists such as Carsten (2000, p. 697), who asserts that ‘kinship is constituted out of everyday small acts and events in time.’ Similarly, Lyon (1997, p. 97) surmises, this vital sharedness of biological rhythms ‘becomes clear when one consider[s] the role of the bodily function of respiration in the establishment of common interactional rhythms and synchronous behaviour in groups.’ Linking breathing to affectivity, Lyon notes that the interlocking rhythms or synchrony of respiratory capacity is:

[o]ne of the basic bodily capacities which functions for the social integration of individuals, and which is an important mechanism for the continual process of the shaping of the emotions among individuals in social context. It is possible therefore to conceptualize the continual generation and modulation of emotion in the context of social relations and group processes through a concept such as ‘affective order’ which reflects, through the concept of emotion, not only the various bodily mechanisms implicated but also the role of emotion in the generation of social order (Lyon, 1997, p. 97).

An example of this integration of emotion and bodily mechanisms in enabling sociality was described by my informant Penelope. She spoke of how her recent difficulty respiring curtailed her ability to interact and emote with others. She recounted:

I was just sick, here in the Philippines and I am still getting over it, bronchitis, and with the pollution I am still trying to recover because the air pollution is so bad. But I felt like everyone is out going about their lives and life is happening outside but there are things I want to do but I can't. Sickness is a lonely experience because life goes on but you can't participate.

My fieldnotes are replete with examples of how the most unremarkable of bodily capacities were disrupted and made un-syncoated by the threat of illness, specifically cancer, and risk reduction and how this impacted on relationality especially within the family. Lucy, a 42-year-old British Australian with a BRCA2 gene mutation told me about her experiences with multiple surgical complications after her risk-reducing mastectomy. These complications meant she could not participate in the commensal rhythm of the family; of eating dinner together, putting her children to bed and lying beside her partner. She explained:

It was a bit of a surprise for me and the surgeon that I didn't heal as quickly as expected because I am healthy. I don't have any big health problems, there was nothing. I was a bit overweight but that was because of the anxiety medication. I came off that, I was taking zinc and magnesium, the weight was coming off slowly. But within 24 hours I knew something was very wrong. I had this stabbing pain and couldn't breathe...The pain was huge for the first couple of weeks after. I stayed in hospital for a week which was unexpected and then they gave me morphine because it turns out a nerve was damaged.

Lucy returned home for a few weeks before more problems arose. She developed a seroma in her reconstructed right breast that wept incessantly. 'I can't remember what happened but it was in the afternoon when I was driving home [from work to pick up her kids] and [the surgeon] phoned me and said "don't go home, you are going into hospital and we will take that bit of skin out and put another drain in. Go home and have dinner and then go into hospital and you will be first cab of the rank in the morning." So that's what we did.'

After this corrective surgery, Lucy returned home, however it was not long before her surgical site began to ooze again:

I had the drain removed a second time and we were going out for dinner. It was five in the evening, we were getting ready to go out for dinner and as I was doing my hair and makeup in the bathroom mirror. I looked down, I don't know why, and my breast was like a teardrop. I called the surgery and they said I had to come back in and I was like 'gah we are going out to dinner, we haven't been out to dinner for months and this is our first time' and eventually I begged and begged to go to dinner and enjoy the evening. I said it wasn't pouring out anymore as it had been, the surgeon was concerned about infection but in the end I won as long as I put sterile dressings on it and called his mobile if anything changed in the meantime. And they would see me first thing Monday morning.

For Lucy, the need, the desire, she held to once again participate in the minute rhythms and syncopated behaviours of commensality with her loved ones trumped her surgeons concern for possible infections and further surgical complications.

The significance of shared rhythms of commensality was also expressed to me by Lily. Early in my fieldwork, Lily emailed me with an example of how her BRCA2 mutation disrupted the rhythm of her social life, within and beyond the family. She wrote:

I had another random thought about how being BRCA2 affects me socially and I often get annoyed when people look at me like I'm a psychopath because I don't drink alcohol (not often, if at all). I've never been a massive drinker and have generally always been a bit annoyed at the social norm and peer pressure surrounding drinking but these days I explain to people that I don't need to increase my risks of getting cancer even more by drinking and they look at me like I'm crazy. It's also a bit socially awkward if/when I tell people that drinking alcohol increases your chances of getting cancer in general and then they all stand around drinking alcohol. I'm shocked at how people don't know this tidbit of information already.

Melissa, as mentioned in the previous section, likewise experienced the unravelling of familial rhythms after receiving her mutation status. She told me 'I didn't realise the effect that [the genetic result] was having on my family, I didn't consider how they would feel or where they were coming from, I didn't expect that it would impact them as much as it did.' Once she realised how being at-risk of cancer was impacting on her

family, especially her children, she made the decision to undergo risk-reducing surgery. Ironically her initial reluctance to undergo such surgery was tied to her concern that it would impact on her familial routines. She was worried about ‘who was going to take the kids to soccer, and to netball.’

For Leanne, it is the uninterrupted unfolding of her own ‘temporal arc’ that was put at risk by hereditary cancer (Mattingly, 1998). This shared time was important for relating her to her children and her partner. Her mother’s illness was etched upon Leanne’s own body in ways that exceeded the harmful genetic mutation she inherited. To prevent the illness cycle from continuing in the future, Leanne excised the bodily parts that held such potential cancerous futures. Furthermore, if we think back to Leanne’s earlier comments, we see how she takes her own actions in regards to her body and its screening as providing a guide for her sons’ bodily choices in the future. By choosing to undergo risk reduction, she hopes that her sons will make similar choices in regards to their predisposition to bowel cancer, in essence projecting her actions, rendered in the flesh, forth. Despite having her breast tissue removed and her breasts reconstructed through transverse rectus abdominis flap surgery, Leanne continues to undergo yearly screening to monitor any breast tissue that may remain. For Leanne, the timing of such surveillance is a point of great deliberation:

I do it at a time when, if the results come through, its, yeah, kinda not going to impact on certain things. Like you don’t get it done too close to Christmas, you don’t get it done around your birthday or anyone else’s birthday. And there is no way I am going to get it done around the anniversary of Mum’s death. And it’s those little things that I would think about, the impact that a potentially positive result would have on people. Which is an interesting way of looking at it, rather than going ‘when does this fit in with my busy social life,’ instead it’s like ‘when does this fit into having the less [negative] impact on people?’ Cause you don’t want to go, ‘oh it’s the older boy’s birthday’ and I am going home with a diagnosis of cancer. Or just before Christmas and at Christmas dinner I’m going to say, ‘hey everybody guess what?’ And they are the things that you think of, the potential impact that a diagnosis is going to have on the people around you... Normally I am quite an optimistic person but it’s always in the background that we time it [the screening] in case it’s a negative [outcome].

Leder (1990) has written at length about how, in our day-to-day life, we remain mostly unaware of our body, its parts and functions. It is not until a variance occurs, Leder argues (1990); pain, discomfort, dysfunction, that the body dys-appears and we become hyper-aware of it and its potentially catastrophic failings. In attending to the experiences of women at-risk such as Leanne, I believe that we can extend this notion of dys-appearing further to consider how the potential failings or demise of the body due to cancer also generates a hyper-awareness of the sharedness of time, particularly within the family. In looking at the experiences of Leanne, we can interrogate the temporal dys-appearance that she experiences as a result of her hereditary cancer risk status and how she works to counteract this hyper-awareness of time and its properties. Leanne's chooses to plan her screening so as to avoid getting results around the significant and shared times of her family; birthdays, Christmas and the like. In doing so, she organising screening outside of the linear intervals recommended by national guidelines. For Leanne, these events are crucial milestones for the family – both cherished, like birthdays and Christmas, and mourned, like the death of her mother, and thus require her intervention to ensure that they continue as such. She does not want them to take on the added significance of being the time when mum was diagnosed with cancer.

Like Leanne, Joanie worked hard to fit the required schedule for regular screening into the rhythm of her family life. Forty-three-years-old and carrying a BRCA2 mutation, Joanie was enrolled in a regime of surveillance:

I am currently having regular monitoring – twice yearly breast ultrasound, annual breast MRI and regular pelvic ultrasound and ovarian cancer blood test. However, as I work and have four children and four stepchildren I find this schedule isn't really working for me – it sounds ridiculous to say so, but I find it hard to fit the necessary medical appointments in, although I know they are a priority.

For Joanie, this rhythm of regular screening does not fit in with the micro-temporalities of her large family. While we could read Joanie's comments as suggestive of her self-sacrificing her health for her children and to fulfil her responsibilities as a mother, as Hallowell (1999) might suggest. I think we can approach her experiences from a

different direction, one that is attentive to the shared body and time of the family. To continue to participate in the shared rhythms of the family, Joanie decided to undergo a seemingly more 'radical' mode of cancer prevention. She removed her ovaries altogether. Removing the ability to menstruate and give birth [again] by entering into surgically induced menopause in their thirties and forties, at-risk women like Joanie complicate established models of linear temporality, especially in terms of ageing. However, Joanie resists the archetype of 'production, waste, decay and breakdown,' Martin (1987, p. 173) sees ascribed to women in menopause in Western societies. Rather Joanie, as Martin describes, finds:

in the concrete experiences of [her] bod[y] a different notion of time that counters the way time is socially organized in our industrial society. In the universe of cultures, there are different ways of conceptualizing time that contrast with the one familiar to us, in which we measure it, treat it linearly, and think of it as something to be saved, bought and sold (Martin, 1987, p. 20).

To stay in sync with the current micro-temporalities of her life, her work and her family, Joanie made the decision to undergo surgery; 'for this reason,' she told me, 'I have made arrangements to have a bilateral salpingo-oophorectomy, which doctors advise me will also significantly reduce the breast cancer risk.' Although such surgery means that Joanie will experience surgically induced menopause, for her, this change in her bodily rhythms pales in comparison to the disruption to her familial rhythms that ongoing, invasive surveillance necessitated.

Kat, a 26-year-old nurse and BRCA1 mutation carrier, also experienced how being at-risk and undergoing risk-reducing surgery altered some of the temporal rhythms of her familial life with her new husband. Kat lost her mother when she was a teenager to ovarian cancer after various misdiagnoses. Kat decided to undergo a risk-reducing bilateral mastectomy in her twenties. Interestingly, her experiences recovering for her surgery were instructive of the types of micro-rhythms she did and did not want to share with her spouse. She told me, 'I don't want to play the sick role. I did for a while, I just wanted to be looked after because I had just had surgery so I milked it. I made my

husband do everything, I didn't have to get up and I made my husband shower me and take me to the bathroom and all of that.'

She then reflected on how the disruption of those ordinary rhythms of showering and toileting for herself had profoundly influenced the affective rhythm of her new family. She felt it was not supposed to be the case that her body was attended, at least for any extended period of time, by her husband when she showered and went to the bathroom. Having him entailed in her corporeal beats, having him syncopated into her toileting as he had been during her recovery had highlighted just how odd it was for them to make familial rhythms out of private acts. This entailment, she felt, was especially odd given that they were both young and recently married. The sharing of these most intimate bodily rhythms had brought the reality of cancer and cancer treatment home to them in a way that was fully appreciable to them. It had fundamentally disrupted the established rhythms of their family, inserting ones of reliance into the ordinariness of their familial routines. Kat said:

I don't want it [assisted toileting and showering] to be my life. In no way. I want this to be a portion of my life that yes, has defined me, and no doubt has a huge impact on my family. My family is the way it is because of our experiences with cancer. The whole way that we communicate with each other and show emotion and everything and the way that we view everything in the world is not to take things on face value ever and all that, it's because of this cancer and all that. I'm pretty sure my dad was a lot more easy-going and happy to accept anything before all of this happened. And now he is like 'don't trust anything,' 'make sure it's the right way' and 'how do you it's the best doctor?' and 'how do you know it's this' and 'how do you know it's that,' because this has happened but I don't want it to be like that anymore... Because it has been in my life.

Like Kat, Anita spoke to me at length about the ways in which her risk of hereditary cancer had upset the established temporal rhythms of her day-to-day life, forcing her to worry about the passing of time. When I met with Anita for coffee in a Boston café, she was the same age as Kat. Anita, whose mother died from breast cancer a few years before, described how the expected and established rhythms of her life – studying, finishing her degree, paying off her mortgage, getting married, having children – had been disrupted by her mother's death. The absence of her mother and subsequent

disruption of the rhythms that had been entailed in their relationship resulted in something she called 'recklessness.' This recklessness was exacerbated when she was informed of her need to undergo genetic testing for a hereditary cancer syndrome. Anita was also diagnosed with ulcerative colitis during this time, a diagnosis that compounded her feelings of being unmoored and adrift. She felt her temporal arc fundamentally curtailed as she expected her death to come early, as it did for her mother:

It's been [rough]... well after my mother died... for those first three years, I was in this period of grief and so you already are experiencing that grief of losing your parent to cancer in weird ways, and even at that time, doctors were telling me that I need to get genetically tested and that I would have a risk because she died so young. But I remember engaging in really high risk behaviours even then, like not caring, you know. And then after I got diagnosed with this disease, I was already in this mode. I used to live alone, I didn't have any security, I travelled a lot alone, I didn't care about dying. Cause I was like 'seize the day, seize the moment, live in the most you can,' you know, all of the clinches of 'you are going to die any moment so why not live the most?' And it is not the same feeling of immortality that teenagers and people in their twenties have, it's a feeling of accepting your mortality but also defying it by taking ridiculous risks. Still in a very immature way. But that is what I was doing, and I was just like, well I am probably only going to live till I am 45 too [Anita's mother died aged 45] so I am going to do things accordingly...

These momentous changes to Anita's life rhythms and temporal arc after her mother's death, her feeling that her lifespan would be truncated likewise, caused her to rearrange the affective properties usually attending life milestones, like getting engaged, beginning a post-graduate degree, buying a house and getting divorced. She explained:

I am doing very well in my life. I am successful academically and professionally, I have bought a house. And I also very recklessly got married a year and a half ago and then half a year ago I got divorced. I was married for less than a year. And it was all part of this reckless behaviour. I am not able to be as rational about major decisions as other people. After, when the divorce and separation happened, I ended the marriage like this [snaps finger], I ended it as quickly as I went into it. I ended it and that's when I decided to see a therapist because I realized I was not making decisions properly. Like I see a pattern, I was with a Danish guy for four or five years and we were living in Copenhagen and had an apartment and were going to make our life together and I just left him to go to Afghanistan. And then I came back from Afghanistan and within five weeks of meeting someone [new]

he proposed to me. So within five weeks of knowing each other we were engaged. So it's like, you see, I was like 'I am out of control.' I appear very successful but deep down my personal decisions and the way I conduct my life are so reckless because of this fear of my mortality.

Experiencing her mother's untimely and painful death from cancer and her own possible risk of developing the disease made the rhythms of life dys-appear for Anita (Leder 1990). She fretted over her own mortality. She worried about what she could and would do with the little time she assumed she had left. As her existing temporal regimes became un-syncopated, she struggled to re-assert some sense of shared temporality and time with others in her life. Yet her decision to marry quickly and re-establish a shared time with a partner only worsened her feelings of being out of control. For Anita, her sense of time had been thrown into disarray by her mother's passing as she felt she was now living an accelerated life she could not, despite her best efforts, slow back down to its once habitual and shared state.

## **Conclusion**

In this chapter I have critiqued Timmermans and Buchbinder's (2010) concept of 'patients-in-waiting,' suggesting that it, whilst attending to the sense of liminality experienced by at-risk women, re-asserts the bounded, discrete individual as the subject who experiences illness and disease. I posited an alternative, partial approach to understanding time and the body as experienced by the at-risk woman. Particular body parts, namely breasts and ovaries, are significant in creating and maintaining the fleshy collectivity that is the body and thus, their roles in these acts of caregiving and receiving are replicated or replaced to continue the temporal rhythms and partial relations of the family. Like ovarian and breasted sociality, I have suggested that time unites bodies across generations and space, which would otherwise be seen as linearly arrayed. In examining the experiences of at-risk women such as Angelina Jolie, we can see how bodies are co-present. Parts of bodies come to inhabit each other just as genes unite bodies to bodies. Temporal dimensions, Munn (1992, p. 116) reminds us, are fundamental to everyday life, they are 'lived or apprehended concretely via the various meaningful connectivities among persons... [these] continually are being made in and

through the everyday world.’ Drawing on my informant’s experiences of breasted and ovarian sociality in their day-to-day lives, I have suggested that time, like the body, is profoundly familial and shared. It is not the sole burden of an individual nor the profoundly linear register that is put forth by Timmermans and Buchbinder (2010). I have detailed the micro-rhythms through which the family is forged, these temporal rhythms generated by the syncopated, habitual and partial deployments of bodies and body parts in concert with other bodies. These rhythms of family life; of shared meals, holidays and school drop offs, are of importance to women at-risk of hereditary cancer. Women at-risk of hereditary cancer attempt to protect and maintain these shared, syncopated and habitual family rhythms in the face of the disruption that cancer presents to them. In the next chapter, I flesh out the ways in which this bodily co-presence and the temporal rhythms of the family manifest in the circulating and often messy attempts to care in the face of hereditary cancer. I will suggest that caregiving and care-receiving are, like temporal experiences, familial, partial, and co-constituted.



## Chapter Three

### Care in the meshwork

In this chapter I argue that acts of caregiving are partial, collaborative and familial. They are fundamentally shared experiences as are those of time and the body as I have discussed in the foregoing chapters. In opposition to the general thrust of the literature on caregiving in hereditary cancer contexts, I critically question the role of the bounded individual as the sole bearer of information that she then uses to array caring relations with others. I do so in order to critically respond to the claims made for and of the 'individual' in paradigmatic anthropological work regarding illness experience. The figure of the individual is a leitmotif of the literature, which pushes analysis into particular and well-rehearsed directions of either selflessness or selfishness in decision making. Decision making is seen through the lens of either obligation or responsibility to the self, or to the other, or both. To reiterate, I am not denying the existence of the self as a site of 'agency, consciousness, interpretation and creativity,' a unique becoming in the world (Rapport, 1997, p. 5). What I am interrogating is the figuring of the individual as both bounded and discrete, arraying relationships, experiences of time and the act of care in reference to other bounded, discrete individuals. In this chapter, I respond against the figure of the individual as foundational to understandings of illness experience, and closely examine what caregiving might look like if it, too, was considered in the terms of partial relationality and fleshy familiarity.

This analytic position turns up a rather broader range of options than selfish or selfless decisions, and reveals a world in which caregiving is located in, with and through the often messy bodily relations made by persons in familial contexts. Caregiving, as Kleinman (2015, p. 240) suggests, is 'a form of "doing" or a mode of "acting" on different levels and in different registers: more verb than noun.' A key feature of the anthropological literature of caregiving in the context of hereditary cancer is that care is routinely considered to issue *from* the potentially-ill woman to the rest of her family. There is a lacuna in this literature of circulating care. The family or friends that care for

the women as she is tested for a BRCA mutation or as she convalesces after risk-reducing surgery remain absent from the literature despite their importance in my informant's accounts. This, I think, has to do with the analytical grip of gendered understandings of the woman as caregiver, and how she might operate in that role in the face of the cancer that might limit it (Glenn, 2010). I also posit that this lacuna has to do with the grip of the individual as the key figure of analysis.

While a gendered approach is no doubt valuable in examining the structural constraints and pressures felt by women as they care for others in the face of illness, it risks overlooking the complexities of care in the familial sphere. As Putina (2011, p. 108) submits in her study of same-sex parenting in Latvia, focusing on 'gender role categories [is] just *one* possible means of relating and describing human relationships in a significant way.' To trouble both these understandings, I recast Mauss' ([1950] 2010) theory of the gift from classical anthropology to consider how a concept of circulating caregiving challenges the individualising forces ascribed to the ill body by anthropologists. In doing so, I also revise the ways in which the gift-giving act of care does not, as a strictly Maussian reading would suggest, circulate between individual, discrete bodies. Alternatively, I consider care that circulates as a resource in and through the collective and partial body of the family. 'By giving, one is giving oneself, and if one gives oneself it is because one "owes" oneself – one's person and one's goods – to others' writes Mauss ([1950] 2010, p. 46). Caregiving is, like the gift exchange, an 'intersubjective relation' that requires the 'participation of multiple parties' (Buch, 2013, p. 602). We need, however, to extend beyond this line of thought to see caregiving as a form of relationality that requires the participation of multiple *parts* in the sense of Lyon and Barbalet's (1994) concept of the family. It is these necessarily partial bodily acts that sustain the family. Moreover care, being in this sense a verb, creates and maintains the family as a fleshy and embodied collectivity, co-constituted within time, as parts of bodies meet with and are enfolded into parts of other bodies (Kleinman, 2015). Like bodies, care is already and always communal.

In examining the experiences of caring in the family, we can discern the circulation of care not as a whole or discrete 'thing' that issues from one person to another. Just as

Lyon and Barbalet (1994) propose the family as issuing from the partial deployments and relations of the body, I suggest that care is a multiplicity of acts that by definition has no singular form nor place of issuance. The act of caring, in this sense, comprises both a multitude of physical acts; 'touching, embracing, steadying, lifting, toileting, and so on,' as much as 'the way we look at someone, and receive their return gaze; the way we connect... the quality of our voice, our very presence' (Kleinman, 2015, p. 240). Paradigmatic anthropological approaches to hereditary breast and ovarian cancer locate care as a discrete property that moves outward from one to another, linking them as discrete parties. It is this approach that allows for women's decision making to appear as inherently selfish or selfless. Developing upon Lyon's (1997) exploration of emotion as the force impelling bodies towards one another, I conceive of care as an impelling force that is not held by one single person but rather is a resource that the family holds in common. Care in this sense is participatory, inchoate and characterised by flows.

To explore this flow of care, I rework Mauss' ([1950] 2010) theory of the gift by attending to another of his concepts, techniques of the body. Mauss' ([1950] 2010) theory of the gift is helpful in drawing attention to the way in which caring is a solidarity-enhancing exchange. Recognising this reciprocity of care-gifting, however, can only take us so far. In existing anthropological accounts to hereditary cancer, the exchange of care takes place between identifiable partners. As such, care in these readings passes from one bounded, discrete individual to another and, consequently, falls into the selfish/selfless dyad in which one is owed and one owes care. In the paradigmatic anthropological approach to caring in this context, this manifests as women being givers of care, family members being the receivers of care. As such, a system of credit or debit operates within the family: one is owed or owing care. The offshoot of this neat theoretical approach to caregiving is that it overlooks the reality of care within the family. Caring, as my informants often told me, is messy. Things go wrong. Best intentions may not translate into action. The unexpected and the random throw careful plans into chaos. Despite concerted efforts, things fall by the wayside. People are unable to give the care they thought they could. People feel uncared about. People get tired of caring. People tire of being cared for. The resources for caring diminished are or were not sufficient in the first place. Tensions arise. Caring is hard as much as it is rewarding.

To apply wholesale Mauss' ([1950] 2010) theory of the gift to caregiving overlooks this inherent messiness of care particularly within the illness experience. In trying to fit caring into models of gendered responsibility or gift exchange, existing anthropologists of hereditary cancer come to classify people as givers or receivers, creditors or debtors, selfish and selfless. This form of categorisation is consequential. In our need for analytic neatness and boundaries, we overlook the messiness of everyday life. The 'individual' or the gift, as units of inquiry, make for analytic neatness. We need, however, to unhitch care from the individual to appreciate the mess that goes on in the social. In this social realm of the family, care is an enfolded thing, a verb, as Kleinman (2015) reminds us. Rather than taking care as an abstract entity that one gives to another, we can come to appreciate the messy meshwork in which care operates, in profoundly partial, embodied ways, within the family. In this chapter, I put forth an alternative understanding of care that stresses its participatory qualities, considering it as a resource that circulates and is shared within the messy meshwork of the family rather than directed outwards to others and then, necessarily, reciprocally, directed back.

## **How at-risk women care for the family: an overview of the literature**

As detailed in Chapter One, the idea of genetic kinship figures prominently in the anthropological literature of caregiving in the context of hereditary cancer. This manifests in the sense that at-risk women are in possession of genetic information that can be used to provide others with a foreknowledge of possible disease and access preventative healthcare. As Gibbon notes in her study of at-risk women in the United Kingdom:

Offers may be made to patients in the clinic, who are mostly women, to extend a programme of 'care,' screening or monitoring to include relatives. In fact, attentiveness to the social context of the family, and the provision of care for others is not just about demonstrating a capacity for empathy or the holism of practice but is, like care for the future, vital and instrumental to predictive knowledge... in this sense knowledge and care is predicated on the shared actions and obligations by those considered most likely to yield predictive foreknowledge for the family or conversely those considered most at risk because of such

foreknowledge. Situated as gatekeeper and moral guardian for the health of others, 'care' for the woman in the clinical encounter... perceived by her in terms of more regular mammography screening, is, as a result of her visit, now complexly caught up in other possible interventions by and for her father and two sons. (2007, pp. 74-76)

In this extract, we see Gibbon (2007, p. 76) worry about a version of gendered care that forces the at-risk woman to act as the 'gatekeeper and moral guardian of her family.' This particular version of gendered caregiving, Gibbon (2007) purports, both reflects and advances oppressive regimes of female nurturance and caring. For Gibbon (2007), genetic kinship and its promulgation by clinicians is foundational to this convergence between medical and social modes of caregiving. She writes:

Family trees in predictive medicine are far from univocal... but are in fact put to work in a variety of ways. That is, these tools are tied to a discourse about care that is subject to and a locus for traffic between the natural and the social in which a particular kind of 'born and bred' kinship... powerfully intersects with *naturalised and socialised ideas of female nurturance*... On the one hand clinical discourse or practice about the family and the future helps to make predictive medicine more explicitly synonymous with 'care' in a euphemistic sense associated with all hospital or medical practice. At the same time these pastoral modes are also instrumental to the utility and pursuit of genetic knowledge itself, where an orientation towards the idea of the patient as the family and *notions of female nurturance as care towards others are both implicitly assumed*. As a result, the promissory, familial and gendered modalities of pastoral care, so central to clinical breast cancer genetics, articulate particular kinds of patienthood... It is a willingness that must in part be linked to culturally valorised ideas of female nurturance... [my emphasis] (Gibbon, 2007, pp. 74-77).

Above we see Gibbon (2007, p. 85) identifies a conflict between the mode of 'responsible, self-actualising individualism of preventative health' integral to the culture of preventative medicine and the culturally valued ideals of female nurturance. Female nurturance in this sphere, Gibbon (2007) purports, involves a recognition of shared responsibilities and obligations to others whom are likewise implicated in the possibility of familial illness. This situation, Gibbon (2007) concludes, lodges the at-risk woman between the pull of individualism and the collective. Such tension, according to Gibbon (2007, p. 93), can only result in 'a disorientating flux' by which the 'awareness and pursuit of one's own health in going to the clinic' comes into direct conflict with the

‘necessarily more collective notion of patient identity required as a result of such a visit.’ On the one hand is ‘a neo-liberal ethic of being pro-active in relation to one’ own health’ (Gibbon, 2007, p. 93). On the other is ‘the family’ both in the sense of the affectively formed up family, of one’s own choosing, and the pre-given genetic family. The at-risk woman, in this reading, must attend to both of these demands: ‘female nurturance [is] inimical with care and concern for others’ (Gibbon, 2007, p. 94). Consequently, the woman is wedged between the responsibility to master her body, to take care of her body as a neo-liberal citizen and to fulfil the responsibilities and obligations associated with female nurturance, that is, to care for others *before* herself (Greco, 1993).

According to Gibbon (2007), this situation produces a fundamental imbalance. Women at-risk of hereditary cancer tend more toward the collective responsibility mode than they do to their own healthcare rights as individuals. They are thus selfless and self-sacrificing, a point that Hallowell develops. In her work *Doing the right thing: genetic risk and responsibility*, Hallowell (1999) elaborates on the self-sacrificing figure of the female patient. She argues that her data collected in the United Kingdom:

indicates that women who attend genetics clinics perceive themselves as having a responsibility to their kin (past, present and future generations) to establish the magnitude of their risk and the risks to other family members, and to act upon this information by engaging in some form of risk management. It is observed that in acknowledging their genetic responsibility for their kin these women not only relinquished their right not to know about their risks, but also committed themselves to undertaking risk management practices which may have iatrogenic consequences... [T]he construction of genetic risk as a moral issue can be seen as limiting the choices which are available to women who attend genetic counselling (Hallowell, 1999, p. 597).

In Hallowell’s (1999) view, the individual here is subsumed under the moral weight of genetic responsibility and the needs of her affective, and genetic, kin. As a result of genetic counselling and risk-management, Hallowell (1999, p. 599) argues, at-risk women are positioned as ‘responsible for their own health but also for the health of others.’ This responsibility, Hallowell (1999, p. 599) suggests, referring to Steinberg (1996, p. 270), is exacerbated by the role at-risk women are perceived to play in both carrying and giving birth to children who are likewise at-risk of such genetic ‘defects.’

Consequently, the woman is seen as 'almost single-handedly, bearing the responsibility for passing on their own and their partner's genes' (Steinberg, 1996, p. 270 in Hallowell, 1999, p. 599). In Steinberg's (1996) reading, women, by dint of their gender and child-bearing role, are more likely to shoulder the responsibility and blame for issues arising from genetic inheritance.

Hallowell (1999) recognises that the at-risk woman may not be entirely autonomous or discrete in regards to her relations. The at-risk woman, she submits, is not individual as isolate 'but [is] repeatedly constructed in-relation to others' (Hallowell, 1999, p. 610). She is 'interdependent,' in and through her obligatory connections with family of choice and family of genes (Hallowell, 1999, p. 610). 'Genetic information,' was, however, perceived among her informants 'as information about "the family" and as such, they reasoned that they had an obligation to ensure that all their kin had access to this information' (Hallowell, 1999, p. 610). The burden of this responsibility, Hallowell (1999) purports, resulted in women subordinating their own needs and concerns to meet the perceived needs of affective and genetic kin. At-risk women, in Hallowell's (1999) study, acted selflessly in sharing genetic information with their kin. Consequently, for Hallowell (1999, p. 610), the pressures of genetic responsibility for others 'ultimately threatened [at-risk women's] autonomy, insofar as they constrained their choices.' For Hallowell (1999, p. 610), it was the at-risk woman's kin, her 'interdependence' on others, that fundamentally curtailed her individual autonomy.

Another example of this gendered reading of care in the context of hereditary illness is evident in the work of Sachs (2004). For Sachs (2004, p. 26), biotechnologies and genetic medicine have produced the 'new age molecular family,' not unlike Finkler's (2000) 'molecularisation of the family' discussed in Chapter One. According to Sachs (2004, p. 26), knowledge generated by genetic medicine presents women with the 'responsibility of... deciding what to do in order to avoid possible future disease.' Yet she must simultaneously strive to 'understand genetic assessments and interpret medical facts so as to be able to communicate with significant others in the family.' Under this burden, the at-risk woman is likely, just as Hallowell (1999) suggests, to sacrifice her own needs for her family. As such, she fulfils the responsibilities and obligations

associated with her role as female nurturer, lending such actions to a reading of selfless behaviour.

We also see such reasoning promulgated by d'Agincourt-Canning (2006). In her work on at-risk women in Canada, d'Agincourt-Canning (2006) writes of the iatrogenic consequences experienced by women as they feel compelled to undergo surgery on the basis of their gendered responsibility to others. We can question, she writes, 'whether a decision or action taken out of responsibility for others is truly autonomous if the factors that shape responsibility are overlaid by oppressive norms' (d'Agincourt-Canning, 2006, p. 114). The strength of this perceived duty and obligation to kin, d'Agincourt Canning (2006, p. 144) submits, leads some women to 'experience their efforts as oppressive and denying choice.' Such selflessness, Aureliano (2015, p. 282) posits, may even come to hinder the wellbeing of the woman, as he observed in his study of Brazilian cancer sufferers. His informants 'embraced their roles as caregivers for others, even while they themselves were suffering, because such roles made them feel useful.' In another recent study, Hallowell and her colleagues (2015, p. 193) comment on the competing demands experienced by women at-risk. They suggest that women at-risk of hereditary cancer struggle to achieve a balance between 'the demands of their body – the need to reduce/manage or remove inherent risks – against the demands of society or their ongoing social obligations: being a mother, partner and employee' (2015, p. 193). In these readings, at-risk women are seen to be caught between two conflicting paradigms; care of their own body and wellbeing and care for the other, a situation in which one must, necessarily, outweigh the other. This reading makes for a very narrow range of options for women at-risk; she is selfish or selfless, she prefaces the individual or the social/collective. As outlined in the introduction and first chapter of this thesis, these selfish versus selfless, individual versus social dyads are pervasive within the anthropological literature of hereditary cancer syndromes.

I turn instead to what might be on offer, ethnographically and analytically, from an attendance to the relational space between persons, which equally resists the blockish power of 'the social.' Ethnographically, I attend to people's experiences within the home, at the playground, in shopping centres, in cars, at cafes as well as in the clinical settings

that feature prominently as the primary ethnographic setting from which current anthropological data is drawn and analysed. One immediate problem of the literature that I have just described is that it bounds and contains the experience of care as a discrete part of life. However, as Mauss ([1950] 2010, p. 3 in Graeber, 2001, p. 153) notes, '[t]he first voluntary, contractual relations were not [solely] between individuals, but between social groups; "clans, tribes, and families."' Nor could such relations have been described as restricted to or bounded by one area of social practice, say, politics or economics, rather they were 'total.' These 'total prestations' or 'total services' brought together domains we might otherwise differentiate as religious, legal, moral, economic, or, in the case at hand, medical, or illness induced (Mauss, [1950] 2010, p. 4). In this instance, restricting data collection to the clinic rather reinforces the view that a single illness/medical suite of experiences is the base from which to analyse illness relations, gendered obligations and accompanying forms of caregiving. In contrast, my own data draws from a broader set of socialites, something which perhaps helps to illuminate the range of messy, lived experiences of caring into which knowledge about illness was placed and activated. These are small, ordinary, unremarkable contexts, the stuff of everyday living with cancer or its threat, as opposed to the high pressure clinical setting which women often attended alone. What comes of an analysis of bodies caring in these mundane and everyday contexts is a different notion of care from that discussed or observed in the clinic alone. In this view, fleshy partiality is paramount to the circulation of care within the family.

## **The gift's receiver**

A key problem stemming from these approaches to caregiving in the context of hereditary cancer, has to do with the single direction in which care is seen to flow. In these works, we see one body – the at-risk women – isolated from the collective, whose dutiful acts to her kin are then fully equated with the entirety of care occurring within the family. Care flows *from* the woman, ensnared within relations towards which she is inclined and for whom she feels responsible. There is little sense in this literature that any caring relations might be returned. As my own ethnographic data suggests,

circulations of care are difficult to exclude from the ordinary operations of familial life, and certainly caregiving within it. The creation of permanent relationships across gene and affectively related kin members certainly entails reciprocity. As Mauss ([1950] 2010) notes, the demands one side of the gift exchange could make on the other were open-ended because they were permanent. This is why Mauss ([1950] 2010) considered them ‘communistic.’ they corresponded with Blanc’s phrase, ‘from each according to his abilities, to each according to his needs [sic]’ (1851 in Graeber, 2001, p. 218). Most of us treat our family and closest friends this way, and my informants were involved in familial relations in such a mode. No accounts needed to be kept, because these were ‘timeless relations of open-ended, communistic reciprocity’ (Graeber, 2001, p. 218). These exchanges create a solidarity and enduringness in which no ledgers are required, as such relations are treated as though there is no foreseeable end point. In this configuration, the giving of a gift that embodies some ‘human quality’ creates permanent and enduring relationships. The gift exchange forms an ‘open-ended agreement in which each party commits itself to maintaining the life of the other’ (Graeber, 2001, p. 162). The family, Graeber (2001) writes, is the main locus of this form of open-ended commitment through gift exchange and, I posit, one of the most commonplace forms and sites of giving and receiving care. The family is, as Ochs and Kremer-Sadlik (2007, p. 5) suggest, the ‘prime intimate social unit.’

These particular remarks about gift giving stand in contrast with the paradigmatic anthropological literature on the at-risk woman. In these accounts, the at-risk woman relentlessly gives to her family and receives nothing in return, largely by reason of her gendered position. The benefits do not flow equally. Or the woman might get back negative responses, say from her genetic kin, if the information on genetic risk was not welcome or well received. This concern is voiced by d’Agincourt Canning and Baird (2006) who see women as unfairly burdened by genetic information on illness predisposition on the basis of their gendered roles as caregivers. They write:

in emphasizing the duty to disclose genetic information, most ethical analyses appear to be based on relationships between kin who are faceless and interchangeable. Yet, because of their care giving roles, women will most likely assume this responsibility to a greater extent than men. Although this is part of a

social practice that already assigns women disproportionate responsibility for family care, justice would require that the burdens as well as the benefits of disclosure be distributed fairly (d'Agincourt-Canning & Baird, 2006, pp. 119-120).

But notions of reciprocal gift giving, as Mauss ([1950] 2010) might conceive of them, are indeed directly applicable to this figure. She may well, for instance, receive negative responses when she provides information to genetic kin, but their reactions may well be conceived as negative reciprocity. This reciprocity is of equal return force in response to the unwelcome gift, in this case, of unsolicited knowledge of illness risk. As Narotzky and Moreno (2002, p. 282) put it, 'contrary to classical postures concerning a "social contract," we do not believe that negative reciprocity should be framed in terms of an absence or transgression of reciprocal relations.' The figure imagined in the anthropological literature that I have just reviewed may well look as though she sacrifices herself to give and give, and she may ostensibly appear to receive nothing. She might, for instance, make the sacrifice of relinquishing her ovaries so that she cannot receive the gift of children. She may array her own choices surrounding risk reduction to least impact her family. She may be the victim of anger and stigma from family members for alerting them to their possible genetic risk. But Mauss' ([1950] 2010) insights suggest that she does not go uncompensated, nor is she alone. Indeed, these sacrifices of giving to and for the greater good only make sense if the individual is regarded precisely as that, the individual. Caregiving, however, resists reduction to individualism and neo-liberalism. We need to recognise care as a practice, 'a daily need and a way of living' that is premised on the recognition of 'vulnerability, interconnectedness, dependency, embodiment and finitude as fundamental characteristics of being human' (Sevenhuijser, 2013 in Martin, et al., 2015, p. 628). What would happen to our analysis of care if we were to complicate the analytic neatness of the 'individual' caregiver? In the following section, I return to themes explored in the first half of this thesis, namely, the inherently partial construction of the person and the family. In complicating the discrete, bounded at-risk 'individual' I set the stage for considering how care circulates in the family rather than unidirectional outputs or even reciprocal exchanges. Just as the body is made up of partial inputs of others, be they through genes or the partial deployment of body parts in concert, care too restricts

confinement to a single site of issuance. It is this partiality, of the body and of care, that we risk overlooking in our existing approaches to illness experience.

## **Parts of bodies, parts of care**

It is an interesting feature of the gendered terrain that female bodies bear the greater social and analytic weight of reproductive matters and the care they involve. Consider the words ‘teenage pregnancy.’ Perhaps more often than not, these words conjure the singular image of teenage mother who carries, bears and cares for the child. Perhaps less present is the teen father, who was equally involved in the conception and often the rearing of the child. This trend has been noted upon by Strathern (1992a, 1992b) in her work on English kinship. In Euro-American kinship, she (1992b, p. 254) writes, the ‘mother is recognized; the father, by contrast, is constructed... in short, the mother is constituted in her connection with the child, where fatherhood is constituted in his relationship to the mother.’ This certainly seems to be the case in the anthropological literature pertaining to cancer previvors. The woman who makes caring decisions towards others is already very much compelled to do so by dint of her gender. She is the one who will supply the ovaries to make that child and the breasts to nourish and nurture it. She will bear the responsibility of relinquishing these bodies parts in due course and the effects this act may have on her family and children. And yet, as Dudgeon and Inhorn (2004, p. 1382) remind us, creating families ‘always involves more than one individual,’ it involves people ‘*in relationship to each other* [my emphasis].’ Perhaps reproductive creativity is so confounding to analysts because its consequences are borne more obviously in one body than another, as Strathern (2011) suggests. It is clearly the case that children are the result of relations with others that come to be internalised within the very fabric of a woman’s physical being. It is equally clear, however, that such potential cannot realise itself, at least, not in any particularly significant way, except in coordination with another. The matter and output of these acts are fundamentally social. The same can be said for decisions taken about ‘my’ ovaries or ‘my’ breasts. One selfish or selfless ‘individual’ only ostensibly makes these decisions in linear relation towards another.

The decision to start a family together was something that 32-year-old Jodie and her husband considered for a long time. Jodie told me about her and her partner's collective discussion around how to create their family with the knowledge of Jodie's BRCA2 mutation:

We looked into that [pre-implantation genetic diagnosis for BRCA1/2 gene mutations], my husband and I.<sup>10</sup> We knew we had BRCA and I was pretty determined not to pass it on. I really, really, really didn't want to pass it on. At the time I was about 25, 26 and was like 'let's do IVF.' We spoke to a couple of geneticists and the PGD people and it was going to cost us, at the time, around \$7000 just to harvest my eggs. I can't remember the rigmarole but it would have been something like four injections for a couple of months and then harvest the eggs out. But they can't promise you that you are not going to produce any eggs that don't have the gene [mutation], so you could produce 20 eggs and they all have the gene [mutation] or maybe one or two don't. The next tricky thing is whether the eggs will keep so do you put one in and hope for the best or put two in for a backup or get twins. It was more uncertain than the BRCA gene. At least with BRCA we were told that there was a 50/50 chance that we would pass on the cancer gene [mutation]. IVF was just all over the shop, they had no idea. So we ummed and ahhed over it for ages, almost lamented over it is probably the right word for it and in the end I remember, we were catching a train in [to the fertility clinic] as they were located in the city. My husband and I were sitting on the platform a bit dejected as we tried to figure out what the plan was, as we were overwhelmed about what was the right decision to make. Do we not have kids even when we both wanted to have kids? Do we have kids and risk giving them the gene [mutation]? Which is what we ended up doing as we had them naturally or do we go down this horrendously expensive path... and see if that works? But at the time we were 26, we had a mortgage, we had bought a house just after I found out I had the BRCA gene. We still had a mortgage, we still were both working full time. The genetic specialists were all saying to me 'it's a 50/50 chance and in 20 years, science and medicine are going to be so different you may as well have them naturally.' That's honestly what we were told so I had kids young to stop me getting sick and I just really hope that, if one of them or both of them have it, you know, science has changed.

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<sup>10</sup> Preimplantation genetic diagnosis (PGD) through in vitro fertilisation (IVF) and embryo biopsy was created to screen pregnancies for serious and life-threatening genetic diseases such as cystic fibrosis. More recently, PGD technology has been extended to test for low penetrance, late onset hereditary cancer syndromes such as hereditary breast and ovarian cancer, allowing patients to test embryos for BRCA mutations before implantation (Menon, et al., 2007, p. 1573).

Together, Jodie and her husband deliberated on the decision as to how and when they would have children. While it seems an obvious insight for me to make, the sharedness and mutuality of the decision to have children together or not is precisely what is not included in most anthropological literature of hereditary breast and ovarian cancer. Rather, it casts such decisions as solely the responsibility of the at-risk woman as she is the bearer and carer of both gene and baby. It is she, in these accounts, who feels the pressure to have children at a young age. It is she who has to sacrifice her ability to have children at all. It is she who will care for them with all her efforts and energy as a means of making up for the genetic mutation they may inherit. Consider the comments made by Valerie, as she explained how she and her husband deliberated over having another child. After having her first child through IVF, Valerie had her ovaries removed. She would have to undergo IVF and hormone treatment to carry a second child:

We already have the eggs ready [from previous IVF cycles]. If I have hormone replacement therapy, I can still carry the child [without my ovaries]. [Pre-implantation genetic diagnosis] was an insane amount of money, so we choose not to test [the embryo of their first daughter for a BRCA mutation]. The clinic we were using said they had an 'ethical issue' with testing for BRCA. We could have pushed for it, but we decided we didn't want to be tested. We didn't test for our first child, so is it unfair to test our next? Part of me wants to do the test for the next one, but we don't have a huge amount of embryos [left], pragmatic as it sounds, but if we discard [an embryo] because it is positive [for a BRCA1 mutation], we don't have many left. We don't have many chances for a future child, we will take what we have... Hopefully we will be able to say to our future child why they were born [with this mutation]. We are not helping eradicate it and we have to be ready to explain our decision to our children with our heads held high. Overthinking it wrecks your head.

In this recount, Valerie refers to a 'we' who decided whether to undergo PGD, a 'we' who weighed up the drawbacks of the procedure and its possible flow on effects. In Valerie's account of family planning, it is not 'she' alone making the decisions on how to proceed, despite that fact that it will be her body in which the embryo is implanted and it is her body that will physically bear their next child. Significantly, this joint input into both the creation of the family and the decision to remove parts and reproductive capacities of the at-risk women's bodies is not limited to heteronormative configurations of the family. Leanne, for example, explained how she and her partner Jane made a collective

decision concerning the risk reduction Leanne would undertake, informed heavily by their shared experience of caring for Leanne's parents:

I think the fact that we had gone through a few things earlier with my mum [made things clearer]. She passed away about five years ago now, not due to cancer but related to. She had about four or five colonoscopies in a period of three months trying to get a biopsy for some suspicious polyps and ended up with a perforated bowel. She was in hospital in a coma for about ten days and we didn't think she was going to pull through, but the survivor that she was, she pulled through for six months and then she ended up with overwhelming sepsis. They removed her bowel but the external part got infected because she had renal problems and was on steroids. So we went through that together, and then prior to that, she had cancer of the kidney, she had the two breast cancers and a few other bits and pieces. And then my father was diagnosed with bowel cancer and so we had had a few things to go through, so anything that we could do [to reduce the risk] we would do it. My partner just said I can't cope with you getting cancer, I can't cope with you being sick and I can't cope with you dying and I can't cope with the children having to go through that so we will do what we have to do and I will support you all the way...' I am so thankful I have a wonderful partner... We work to be happy and live our life as full as we can. We make sure our home is filled with love. This is not as easy as it sounds. It's actually hard work and we have to remind each other and ourselves all the time

In removing *her* breasts and *her* ovaries to reduce the risk of developing cancer like her mother, Leanne speaks of a 'we;' a 'we' who cared for dying parents during multiple cancer diagnosis and unsuccessful treatments; a 'we' who made the decision to remove Leanne's risky breasts and ovaries; a 'we' who created their family of two mothers and two sons; a 'we' who will support Leanne through her surgeries and recovery and a 'we' who work hard to fill their family with love and happiness. It would be easy to read Leanne's decision to undergo risk-reducing surgery as a response to her gendered responsibility and obligation to her partner Jane and her two sons. She removes *her* body parts so that they will not have to cope with her becoming sick or dying. To do so, however, would run the risk of evaluating such decisions as selfish or selfless, and thus ignore the joint production of Leanne's family.

We can take this a step further to consider how, in these accounts, we see an experience of the body that is not bounded nor discretely 'individual.' What I am suggesting is that Jodie's ovaries, just like Valerie's uterus, Leanne's breasts and the materials produced by

these parts are not, wholly, their own in the context of their relations and caring. We need to take seriously the comments made by Jodie, Valerie and Leanne regarding the collective decisions that were made in regards to body productions and body parts that are only ostensibly their 'own.' In doing so, we can get closer to appreciating how care, as a practice, defies the individualising forces that are often ascribed to the at-risk body by anthropologists. Recognising the joint production of the family, and of the person is a necessary step in acknowledging the circulation of care that operates within the familial sphere. My informants' body parts and their capacities are considered from at least a joint perspective. Just as is the case for something I've previously termed 'ovarian sociality,' it is not necessarily an analytic problem that Jodie's and Leanne's ovaries or Valerie's uterus are located firmly inside their bodies. The terrain of the interior can defy sole ownership. Indeed, the very notion that it cannot depends entirely on our recognition of the boundaries of the body as constituting its very parameters. An ovarian potentiality, reaching beyond the bounds of the singular, bounded female body who bears them, is instead in play here, permitting the collective discussions and decision making that characterised the ethnographic interviews I conducted with participants. As Birke (1999, p. 45) reminds us, internal organs, tissues and other interiors 'constantly react to change inside or out, and act upon the world.' Indeed, with the advent of medical technologies such as screening, MRIs and ultrasounds, the inside of the body has become no more private than its external parts. Scans make the interior public and one's familiars make it shared (Lundin, 1999, p. 15).

Merleau-Ponty (1968) has theorised how bodies are effectively 'completed' for their 'owners' by others. We may think of our own bodies as precisely that – our own as Billie does in the following example. For Merleau-Ponty (1968), however, the fact that one's own body cannot be held in one's own self-conscious attention made the body socially constructed in the most fundamental of ways. The see-ers and those seen are inextricably intertwined with one another:

As soon as we see other seers we no longer have before us only the look without a pupil, the plate of glass of the things with that feeble reflection, that phantom of ourselves they evoke by designating a place among themselves from whence we see them: henceforth through other eyes we are ourselves fully visible; that lacuna,

where our eyes, our back, lie, is filled, filled still by the visible, of which we are not the titulars. (Merleau-Ponty, 1968, p. 143).

Elements of this complex idea are drawn out by Toombs (2001, p. 7). 'One's experiential awareness of the body,' she writes 'is limited in a variety of ways.' The body's 'orientational locus' makes it impossible for one to visually apprehend all aspects of their body directly; 'I cannot walk around my body to view the back' (Toombs, 2001, p. 7). Exactly the same can be said for the way the internal body and its capacities are absolutely seen, often by externally located expert see-ers. In the act of seeing what the bearer of the body cannot – either because it is out of her own sight, or because she must disregard seeing herself in order to move about competently in the world – these other see-ers, come to complete it for her. In terms of the first idea, that one cannot see one's own back except by recourse to extra visual equipment and effort, I have direct experience. I have a cluster of freckles in the middle of my upper back which my family call my 'dragonfly tattoo.' Unless I make an explicit attempt to see this mark, positioning myself in front of the mirror at the correct angle, I am mostly unaware of this feature to which my familial others are so accustomed.

Even in circumstances in which the body is not under specific visual regard, and even when it is not a whole body being unreflexively filled in by other see-ers, Merleau-Ponty's (1968) sense that bodies are not discrete entities, stands. Indeed, bodies may be completed by others who do not even regard themselves as consciously filling in such bodies as we can see in the example of Billie. Twenty-eight-year-old Billie, who carries a BRCA2 mutation, found out about her mutation status when she was 25. Her mother was diagnosed with breast cancer when she was 32 and underwent chemotherapy and a mastectomy. Billie decided to have a risk-reducing bilateral mastectomy and reconstruction with implants not long after testing positive for the same mutation as her mother.

Billie's family had some opinions on Billie's breasts which, up till now, had remained in the background. Even as they became nameable discrete parts that could be discussed as medically problematic, Billie's family continued to understand her breasts as socially

connected to the bodies of others – even as sick parts, they could not be disconnected from others. Although in this state of possible disease, Billie’s breasts were indistinguishable from Billie and from her current and potential social relations, as they were for Billie herself. She explained:

My family were somewhat supportive. There were some that questioned my choice [to remove my breasts] and thought that I would regret it and they kept saying like ‘wait till you have kids, wait till you have kids,’ but my whole thing was I want to be around to have kids and stay around and they were worried because I was not married and I wasn’t in a relationship... I don’t know, to me, it made more sense to do it before I got into that because that way I wouldn’t change in the middle, like I would be what I would be forever, at the start, and that would be okay.

It is worth noting here that medical advice led to Billie having her breasts removed. Clearly, the medical call necessarily sees potentially diseased breasts as sick parts that must be removed. Of course, medical and social priorities can sometimes be different as Abram (1996) informs us. The body parts separated and diagrammed by medicine and biology, he writes, are experienced differently from the body as lived (Abram, 1996). As Abram explains:

This breathing body... is very different from that complex machine whose broken parts or stuck systems are diagnosed by our medical doctors and ‘repaired’ by our medical technologies. Underneath the anatomized and mechanical body that we have learned to conceive... dwells the body as it actually experiences things, this poised and animate power that initiates all our projects and suffers all our passions (Abram, 1996, p. 4).

However, as her family members’ responses suggest, even when Billie’s body was diagnosed as at-risk and became medically present as broken parts, it was still nigh on impossible for near located others to see it that way. Billie’s family continued to complete her body for her, in and through its present and potential relations with others, including those yet unborn – in the form of eggs.

In these comments we see that Billie's body is indeed her own – hers to intervene in and upon – as she decides to remove her breasts before she finds a partner or has children.<sup>11</sup> As will be expanded upon in Chapter Four, Billie experienced her body and its potential social relations as becoming increasingly present in her attention. She could no longer dwell in the comfortable disattendance and habituality of her body as she worried about its cancerous potential and its ability to relate with others in the future. Billie's natal family, however, also experienced the dys-appearance of Billie's body to use Leder's term (1990). They worried that the key connective tissue in the maternal relationship, the breasts, would be absent from the relationship Billie would have with her children, and that she and the child might be poorer for their absence. They seemed equally to worry that breasts would factor in the caring relation between husband and wife or her capabilities to secure a partner. The usually unreflected upon parts of Billie's body became a central concern for Billie's family. Overall, they worried that Billie was taking decisions about her body in the absence of the socialites that would provide necessary, fundamental context to those decisions – if she made them in isolation, she'd 'regret it.' Billie operationalised an alternative understanding of her future, one in which her body would return to a state of disattendance and habituality. For Billie, and for her family, her body and its functions and capacities had become too present, a source of consternation and worry.

In removing her breasts, Billie worked to return her body to a state of disattendance for herself but also her family. In removing parts of her ostensibly 'individual' body, Billie hoped that it would fade back into insignificance, as a vital yet unreflected upon aspect

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<sup>11</sup> Billie spoke to me about her attempts to have her eggs frozen before undergoing her risk-reducing mastectomy. Her hopes of having her eggs frozen, however, were thwarted by the cost of the procedure and the fact that she did not, yet, have cancer: 'I got denied right away for [egg freezing], they were like "no that's not going to happen," that wasn't covered at all and then I tried to go through... someone connected me with another organisation that helps to fund women to preserve their eggs and help eliminate some of that financial load because it so much money. It's ridiculous, I called every reproductive or infertility doctor that we could find and they said, "oh well when she gets cancer we will help her." Isn't that kind of backwards? I'm doing this so that I don't get cancer but I still want the option to have kids so it's like how much cancer are we talking, how much cancer do I have to have.'

of her day-to-day life. Yet Billie's body was still, profoundly, a body located within social relations. Billie's family likewise worried about the increasing presence of Billie's body and that the absence of its ability to breastfeed or connect with her future husband, would ironically render it present. Billie thought otherwise. Her body would be the orbital disc in a sociality arranged around absence of certain parts but the presence of a person. This, she optimistically mused, would attract the best of husbands. She joked about the arrival of such a candidate, wondering aloud, 'how do you start handling dating like when do I tell you I have fake boobs?' In other words, Billie was never without sociality, and never without something we might call breasted (or in other cases, ovarian) sociality. Her body, like all of ours, was not and could never be 'her own' – it was completed by see-ers and feel-ers both present and in the future. Billie was and is, as Merleau-Ponty (1968) suggests, fundamentally constructed and completed in concert with others.

Further, as Billie's comments suggests, already existing or future circulations of care issuing from parts of bodies to the parts of other familial bodies, as Lyon and Barbalet (1994) advance, are not necessarily compromised or diminished by the removal of these parts integral to breasted or ovarian socialities. Rather, Billie is concerned about protecting her ability to cultivate new socialities of care with her possible future husband and children, of creating a familial body together that is not impaired by a constantly present, dys-appearing body. It does not matter, for Billie, that these socialities centred upon her body and its partial relations are not yet in existence. In fact, these future socialities of care she surmises will be more genuine as her partner will accept her body as a locus of love and will reciprocate care regardless of its altered form. Despite appearing as a bounded, discrete body all of Billie's own, her experience of preparing for risk-reducing surgery and her family's concern for her wellbeing bespeak the co-construction of the body and the seemingly 'individualised' decisions pertaining to it.

## Re-reading the clinical encounter

To underscore this alternative reading of care and the body, I include a somewhat lengthy extract from my fieldwork notes, detailing a consultation I observed at a cancer genetics and prevention clinic in Boston. Susan's body, like Leanne's, Valerie's, and Jodie's was not, solely, her own nor was the flow of her care unidirectional, even though it presented precisely as such at Dr Turkle's consultation rooms. At the time of the consultation, Susan was in her late thirties, worked as a receptionist and had yet to be tested for a BRCA mutation. After introductions, Dr Turkle skimmed over her file. 'So you were referred here today to talk about your risk of breast and ovarian cancer?' 'I want to be proactive,' Susan asserted, 'I have three young boys, two with special needs who are nine and six and the youngest who is one. I need to know about my risk.' Dr Turkle began, as was common practice in the genetic counselling sessions I observed, with taking Susan's family history. Susan's maternal grandmother passed away from stomach cancer. Her maternal aunt was diagnosed with breast cancer in her early forties that later metastasised to her brain and she died aged 47. Her maternal cousin was also diagnosed with breast cancer at 40 but tested negative for the BRCA gene mutations. Two other maternal cousins tested positive for a BRCA mutation though Susan could not remember the specifics of either mutation. When asked about her father, Susan said that she did not know much about his health or family, as he left her mother and siblings when she was a child. Susan's mother passed away when Susan was a teenager from liver sclerosis, a result of an addiction to pain medication and alcohol. 'They did an autopsy on her body,' she recalled, 'but I don't think they found any cancer. Maybe because she died so young it didn't have a chance [to develop].' Susan's brother died when he was 23 from endocarditis caused by a pain medication addiction that began in his teenage years. Susan's sister, aged 34, is currently healthy. 'It doesn't look good for me does it doc?' Susan sighed, as she counted the number of symbols on her genealogy marked by a diagonal line.

'Don't fret,' Dr Turkle replied. After explaining the categories of low, high and super-high risk for hereditary cancer, he suggested that she was likely to have around a 25%

chance of having a BRCA1 or BRCA2 gene mutation. 'But that is still quite high,' Susan responded as she poured over her family history rendered into squares and circles before her. 'They said I had a 1% chance of having my boys the way they are, and I did,' she said with a nervous laugh. 'But what if I have surgery, will that get rid of that [risk]?' 'Woah,' Dr Turkle replied with a chuckle, 'I wasn't going to get to that for another few minutes. You come late and hit hard.' Susan offered a sheepish grin and said:

Do it, take it all out. I am done having children. I am sad if I give it [the gene mutation] to my kids, but if I am positive, I am going to get rid of them [breasts], and get a brand new set. I have already nursed three kids, I am done. I already had two C-sections and I was fine, I have read the stats, I am happy with taking it all... I mean I pray that I don't have the gene, I pray we don't have that gene. But we are a small family you see, my boys don't have much, I can't go anywhere!

Dr Turkle assured Susan that, if the need were to arise, they could help her reach the right emotional state of mind to remove her breasts and ovaries. 'But I was in the right state of mind a few years ago,' Susan proclaimed, 'I was ready but then I got pregnant with my next boy and things just got away from us. I have thought about it for a long time.' Dr Turkle seemed eager to steer the conversation away from surgery and back to ordering a genetic test. He recommended that, rather than doing the single site testing for the BRCA mutations, Susan undergo a panel test that examines DNA for 25 different mutations linked to familial cancer syndromes and other hereditary diseases. Susan seemed ambivalent about panel testing. They had taken their oldest son, she told us, to be tested when he was a few years old to try and figure out what was causing his developmental delays:

They did this whole test and it cost us like \$1500 and after all of that he came back negative. It was a bit of a surprise, we thought it might help figure things out, to get help... My husband and I joke that I gave him my ADD and he gave him his ADHD and together it produced autism. We think that he inherited all of our bad traits and then they were amplified! But the tests showed nothing. So then we had our second son and it turned out that he was affected too. With my older boy, it was more obvious from the beginning, but with the second you wouldn't know to look at him, but gosh the meltdowns, they are so much worse... If we had known that it was going to be like this, maybe we would have stopped after the first, which I know sounds horrible, but... it is hard and expensive, you know. But then we had the third, and he is fine.

Dr Turkle nodded sympathetically. There is a mutation that occurs in the gene ataxia-telangiectasia, he explained, that some researchers believe may be linked to both an increased risk of breast and other cancers and developmental disorders such as autism. The panel test, he suggested, does look for this specific mutation and may offer some information about the link between her family history of cancer and her sons' developmental delays.

Tugging on the skin of her neck, Susan paused for a moment before replying. 'I think... well I do want to know whether the cancer and the autism, whether it might be linked but I am worried... the boys already are different, will it [the knowledge of a mutation] affect them in the future, like their ability to get jobs or insurance?' Massachusetts State Law, Dr Turkle explained, protects patients against genetic discrimination but if she was concerned, there were things that could be done. If Susan tested positive to a specific mutation, her sons could, when they are of age, request to be tested for that single mutation at the out-of-pocket cost of \$200. By doing so, they would bypass the insurance companies and thus be able to 'own the information.' 'But with testing,' Dr Turkle concluded, 'we can benefit your health acutely compared to how much we can damage it from insurance issues. The panel will allow us to track mutations and provide information for future generations of your family.' Pausing for a moment, Susan decided that she will have the panel test and signed the consent form for her blood to be drawn. When her test results were returned from the laboratory, it was revealed that Susan carried a mutated ataxia-telangiectasia gene (ATM), one of the more recent gene mutations linked to hereditary cancer syndromes. It is currently unclear as to the role of ATM mutations in breast cancer etiology however, at the time, Susan made another appointment to begin the process of risk reduction through surgery (Mangone, et al., 2015).

Despite being younger than the age recommended for these surgical interventions Susan was prepared, and had been for some time, to remove her breasts prophylactically. Susan considered the removal of significant bodily parts worth it because it would assure her ability to continue being a part of her family, to care for and

be a presence in the lives of her sons and her partner. These body parts in particular, have been important in creating and maintaining the relationality Susan experiences with her children and her partner. They are the breasts that nourished her three sons. But they have done their job in this sense. As she told us; 'I am going to get rid of them and get a brand new set. I have already nursed three kids I am done.' Susan recognised how she and her partner are fundamentally entwined in the bodies of their sons, having passing on their traits to them for better or worse. In being tested for a genetic mutation, Susan may receive information about her own health and the cause of the developmental difficulties her sons' experience. Yet to solicit such information, Susan surmised, may impact the care her sons receive in the future, putting them at risk of discrimination by marking them as different and vulnerable. Susan had already experienced the disappointment of a genetic test that she hoped would open up avenues for accessing support and care. Or she worried, it may impact on her family's ability to care and be cared for in the future were they to be denied insurance.

There are certainly both external social and economic structures that exercise control over Susan's life and what is at stake for her in undergoing genetic testing and risk-reducing surgery. Susan and her husband bear the brunt of care for their sons. Susan has a diminished family network of support as a result of hereditary cancer and drug addiction. Nakano Glenn (2010) is one of a number of scholars who have argued that women, especially women of poor and racial minorities, often shoulder the responsibility and many burdens associated with caregiving. 'The social organisation of care,' Nakano Glenn (2010, p. 5) argues, is steeped with such multifarious forms of coercion that often it is women who 'assume responsibility for caring for family members.' Certainly, the practice of sustained caregiving is no easy feat, a reality Susan recognises in her own experiences of caring for her children with developmental delays. Caregiving is hard, as Susan proclaims. It is relentless, requiring time, energy, resources, money, unfaltering commitment and resolve (Kleinman, 2015). It can produce tensions between people, within families and the broader community that can leave the caregiver and their loved ones vulnerable. Susan is aware of these risks, voicing concern over her children's possible discrimination if they were to carry a genetic mutation. Yet it would be misleading to think of Susan's determination to undergo risk-reducing surgery and

thus ensure her ability to partake in family life as merely the result of an externally imposed set of conditions. It is not enough to say that Susan is being coerced into caring for her sons and partner as a result of her status obligation as mother and wife. Modes of subjectivity, write Biel, Good and Kleinman (2007, p. 14) are certainly influenced by external forces, 'the vagaries of the state, family and community hierarchies... medicoscientific experiments and markets.' Yet this does not mean that one's actions are only the result of socialised and inherently gendered regimes of control. I think we can read Susan's concerns about undergoing genetic testing as an example of the messiness of care in the meshwork of the family. This view of care is more complex than wholly generosity or self-interest; of Susan being selfish if she was to decline testing or self-sacrificing by putting her family over and above her needs.

## **Mesh-work**

To appreciate the messiness of care experienced by cancer survivors such as Susan, we need to think of a fleshiness that is a little beyond the reach of the Maussian version of reciprocity. We could easily fit Susan's experiences of caregiving into a Maussian reading of the gift. Susan will remove her breasts to ensure her ability to care for her family in the future and they, in return, will care for her as she recovers from surgery. But what if, as Susan worried, her sons are unable to receive or give care in the future on the basis of their mutation status and intellectual disabilities? What if her small family was to lose yet another member to cancer or disease? Who would care then? Here is the problem with a strictly Maussian reading of care as a gift exchange as it suggests that the ability to reciprocate equally and in kind is necessary for the solidarity-enhancing exchange to occur. However, if we consider the notion of care as a resource that flows within the 'meshwork' of the familial body, as something that both creates and maintains it, we can come to appreciate the reciprocity of care in a more fluid sense (Ingold, 2008, p. 1806).

In his work on lines, Ingold (2008, p. 1806) posits the idea of meshwork to describe the ways in which humans relate with one another and the environment. I think this

concept of meshwork is applicable for understanding the partial construction of the person and the family. Humans, Ingold (2008, p. 1806) posits, are not 'externally bounded entities' relating in a network but are better understood as 'bindles of interwoven lines of growth and movement, together constituting a meshwork in fluid space.' We can read Susan's experiences of care as illustrative of this idea of meshwork. The skin, Ingold (2008) writes, appears to us as a singular, discrete unit. To a 'casual observer,' it is a 'coherent, continuous surface...' encasing an 'individual' within it (Ingold, 2008, p. 1806). If we are to look more closely, however, we see that the skin is a 'texture formed of a myriad fine threads, tightly interlaced.' As such, Ingold purports, the skin:

like the land, is not an impermeable boundary but a permeable zone of intermingling and admixture, where traces can reappear as threads and vice versa... It is not, then, that organisms are entangled in relations. Rather, every organism – indeed, every thing [sic] – is itself, as they become tied up with other strands, in other bundles, make up the meshwork... Let us imagine the living being, then, not as a self-contained object like a ball that can propel itself from place to place, but as an ever-ramifying bundle of lines of growth (Ingold, 2008, p. 1806)

Susan's body, just like Ingold's (2008, p. 1806) skin, is not a discrete 'self-contained object.' Her body is not fully her own, neither are her partner's or son's.' Not only do they share genes, such as the mutated genes for cancer or the genes for 'my ADD' and 'his ADHD,' they partake in a shared and circulating sociality of the care that constitutes their very being. It is crucial for Susan that her family, her 'small family,' goes on in the face of depleted resources of care – missing grandparents, uncles, aunts and so forth. For Susan, it is vital that the flow of care that she helped to create and in which she partakes, keeps circulating through partial bodily engagements. Despite how hard, time-consuming and tiring caring is, it is more important to Susan than the opportunity to possibly discover the genetic cause for their misfortune. We could easily see Susan as a bounded, discrete individual, the central node of a network of care, in which she directs her care out to her sons and to her partner that may or may not be reciprocated. In doing this, Susan could be seen to fulfil her gendered responsibility to nurture. I think however that we can reconsider how Susan, and other at-risk women, experience

themselves and the circulation of care in the family as a form of meshwork. In attuning to the ‘intermingling and admixture’ of partial bodies that care for each other in complex and multi-directional ways, we can come to appreciate how the multitude of messy strands of caring bundle together to create both a familial body and the person that is formed by these relationships.

## **Techniques du corp**

To flesh out how care operates to create and maintain the meshwork of the family, I begin with another of Mauss’ ([1935]1973) key concepts, techniques of the body. Attending more evidently to these partial relations that persist between caring, enmeshed bodies also serves to further disrupt the notion of the bounded female patient who wholly and unilaterally delivers her care out to others. These intricacies of care are something that we do not get much of a sense of in the literature that draws its data primary from the clinical encounter alone. We rarely get a sense of the day-to-day caring for someone with cancer or someone recovering from preventative surgeries. In accounts based solely on clinical data, we often get a version of care that is, as Brenner (2001, p. 353) submits, treated as if it was ‘merely sentiment or attitude, void of cognition, skill and particularised relationships.’ Care, in its fleshed out form, is attuned to specific care practices that ‘contain within them knowledge and skill about everyday human needs for recognition, nurturance, shelter, food, hygiene, protection’ and so on (Martin, et al., 2015, p. 625). Importantly, for this thesis, it is this embodied ‘doing of care’ in its often messy and inchoate forms that creates and maintains the meshwork of both person and familial body (Kleinman, 2015, p. 240).

In deploying this expression, techniques du corp, Mauss ([1935]1973, p. 75) meant to indicate ‘the ways in which from society to society men [sic] know how to use their bodies... the body is man’s first and most natural instrument... [M]an’s first and most natural technical object, and at the same time technical means, is his body.’ This body is communicative, beyond speech. This communicative body may be recognised, as Jackson (2013, p. 55) notes, ‘in the way our earliest memories are usually sensations or

direct impressions rather than words or ideas, and refer to situated yet not spoken events.' Jackson ties Mauss' techniques of the body to relations, to other bodies and things, noting that, 'habits are interactional and tied to an environment of objects and others' (2013, p. 62). He continues:

Forms of body use ('techniques du corps') are conditioned by our relationships with others, such as the way bodily dispositions which we come to regard as 'masculine' or 'feminine' are by our parents and peers encouraged and reinforced in us as mutually exclusive patterns (2013, p. 62).

These learnt communicating and communicable gestures or 'techniques du corps' are, as Merleau-Ponty (1962) critically asserts, profoundly and inherently relational. They bespeak the:

reciprocity of my intentions and the gestures of others, of my gestures and intentions discernible in the conduct of other people. It is as if the other person's intention inhabited my body and mine his [sic]... There is a mutual confirmation between myself and others... The act by which I lend myself to the spectacle must be recognized as irreducible to anything else. I join it in a kind of blind recognition which precedes the intellectual working out and clarification of the meaning (Merleau-Ponty, 1962, p. 85).

Families are a key site of Merleau-Ponty's (1962) communicable and reciprocal gestures. These techniques of the body, come to inhabit the fleshy collective, the meshwork, of the familial body. Young (2002) has explored how, in particular, these family dispositions are inscribed on and enmeshed in the body. The embodied habits of the family, Young (2002, p. 26) writes, are a crucial way in which the child learns to be in the world. Bodies memorise and learn the family's way of being in the world and as such 'the body is one of our family traditions' (Young, 2002, p. 26). This enmeshed familial body stretches across temporalities, constituted of others from past, present and future. Held in this familial body are the 'ghosts' of one's ancestors. Body parts such as breasts and ovaries come to inhabit and be inhabited by 'other images' as we saw in the preceding chapter – bodies are primary co-constituted (Young, 2002, p. 45). This inhabitation of our body by parts of others, this entanglement of tissues, is a 'constant [and] persistent familiar' in our everyday lives (Young, 2002, p. 45). Enmeshed bodily

relations, as previously discussed in reference to Ingold (2008), are enabled by the permeability of the skin and the thickness of the flesh (Merleau-Ponty, 1962). '[B]etween my body looked at and my body looking, my body touched and my body touching,' writes Merleau-Ponty (1962, p. 141), 'there is overlapping encroachment, so that we must say that the things pass into us as well as we into the things.' While the skin may ostensibly mark the boundary between the bodies, it is ultimately *permeable*, as both Merleau-Ponty (1962) and Ingold (2008) suggest. Techniques of the body, such as those involved in caring, demonstrate the permeability between what are only ostensibly bounded bodies (Thrift, 2000, p. 38). The body praxis that make us up 'have come down to and inhabit us, passing into our being, passing our being back and forth between bodies and passing our beings on' (Thrift, 2000, p. 38). It is these partial bodily exchanges, these bodily techniques of care, that constitute the meshwork of the familial body.

We need to expand on Mauss' ([1935]1973) perspective on techniques of the body to appreciate the body as active and intercommunicative in the meshwork of familial care. In Mauss' scheme, Lyon (1997, pp. 89-90) writes, 'there is no general representation of the place of emotions in social life.' For Mauss, she writes, 'the social conditioning of bodily techniques is harnessed to the rationalist enterprise' (Lyon, 1997, pp. 89-90). His view of techniques of the body overlooks what Lyon (1997) considers to be a crucial element of what activates bodies towards and in syncopation with familial others. 'Active bodies' writes Lyon (1997, p. 90), 'are emotional bodies; emotion is embodied.' Attending to emotion, Lyon (1997) submits, enables an appreciation of the sociality of bodies beyond biological and physiological explanations. By addressing emotion as a force impelling parts of bodies to act in collectivity, we can come to appreciate how body techniques play a crucial role in sustaining the family. Bodily capacities driven by emotion are fundamentally involved in this creation and structuring of relationality as Lyon reminds us:

The body, after all, is the instrument of perception and the experience of feeling... Indeed, the concept of emotion includes bodily, cognitive and other components which are implicated in the evaluation of experience both external and internal... [B]odily aspects of emotion cannot be separated out from social action more

generally because they partly constitute that action, and this action is part of what constitutes emotion (Lyon, 1997, p. 96).

Emotion is thereby, for Lyon (1997), a key part of social relations that are likewise constituted through bodily means. Taking lead from Lyon (1997), I argue that care is both a driving emotion and a bodily technique crucial to the social relations of the family. Sociality, Lyon (1997, p. 91) concludes, is embodied in complex ways because 'society exists partly as bodies *in relation*.' Social relations, she writes, entail 'emotion in both its phenomenal and physical aspects' (Lyon, 1997, p. 97). Basic bodily functions and processes, the 'machinery' of our body, may appear on the surface as having little to do with the 'interactive exchanges' that make up the entanglements Ingold (2008) describes. In developing upon Lyon's (1997, p. 91) findings, we can reappraise the concept of emotion to understand the sociality of bodily functions that would otherwise appear solely biological. In taking a more critical and attentive approach to the body's mechanisms, including its affective orders, we can come to appreciate the role of the body as both physical and phenomenological in fostering sociality and care.

The collective yield of Lyon (1997), Mauss ([1935]1973), Merleau-Ponty (1962) and Ingold's (2008) thinking here is that bodiliness can unite and form the grounds of an emphatic sociality. Bodily techniques driven by the emotion of care and caring both constitute and sustain the family. Following Lyon and Barbalet's (1994) technical understanding of how, exactly, this comes to pass, I argue that the partial relations between bodies enact and maintain both the collective of person and family in some sort of social unity – a meshwork of care. Techniques of and for this social body are both the bearers of and receptors for 'care.' This circulation of care proceeds from and to a social body and thus cannot issue from one whole individual to another whole individual. Care flows in and through the partial, fleshy relations of the family, driven by emotion. Caring is thus a form of bodily engagement, a necessary act of relationality that treats the person not as an isolated and bounded entity but as an 'entanglement, a tissue of knots' (Ingold, 2007, p. 101). In recognising the 'ever-ramifying' knotty entanglement of relations in the meshwork of the family, we also create a space in which

we appreciate the very messiness and inchoateness of caring in the everyday as was described to my informants (Ingold, 2007, p. 101).

## **Enfleshed, enmeshed care**

In the following ethnographic excerpts, I detail the ways in which at-risk women described their experiences of care. In these examples, we see care in the messy meshwork of relations, variously arrayed. These accounts challenge assumptions on caregiving as neatly or lineally array and accompanied by an expectation of reciprocity. Laura underwent her risk-reducing mastectomy about a year after giving birth to her first daughter. Working at a pet rescue mission, Laura was able to take time of work to recover after her surgery and her husband took leave to help care for them. 'He was amazing' Laura told me:

He knew [about the mutation] as soon as I did. We talked about it before [the surgery] and how we would be but he said he would much rather do this and have me around for longer. He was with me when we watched mum die and he said he never wanted to see me go through that. So he has been amazing. He helped me tape my scars and everything and if I am not doing something right, like I wasn't doing my exercises, he would be like 'have you done your exercises?' He was really on to it, I didn't have a choice [to slack off] as he was on my back, which was really good.

This scenario of care seems very different to the accounts of the at-risk woman sacrificing her own needs and wellbeing to fulfil her obligations and responsibilities to her familial others. Nor does it fit within a model in which Laura, having been cared for by her husband, now has a debt of care to be repaid. In this instance, care flowed in a multitude of directions within the family, circulating between Laura, her husband, her child and her dying mother. Together they cared for Laura's mother and grieved after her death. Laura's husband took time away from his work to help care for Laura after her surgery and made efforts to remind her to do her physical therapy even as her enthusiasm waned. His hands reached out to her torso, covering her surgical scars with protective tape and it was he who reminded her to take care of herself and her ability to move post-surgery.

Fifty-year-old Bree, a BRCA1 mutation carrier, described to me her extensive family history of breast and ovarian cancer. Her mother, Hilary, developed breast cancer when Bree was only two years old. Hilary underwent a radical mastectomy and total hysterectomy but developed primary peritoneal cancer 25 years later, passing away in 1991. Three of Bree's aunts passed away from breast and ovarian cancer, all before the age of 60. Bree's six first cousins contracted breast cancer as well as ovarian and peritoneal cancer. They all passed away between the ages of 32 and 42. Bree decided to be tested when two of her cousins found they were positive for BRCA1:

Unfortunately, my test came back positive for BRCA1 as well... It is weird but I expected the result to be positive so when they told me, I didn't really feel anything. It was like 'I knew it.' It was a bit of a shock seeing it on paper but I wasn't upset or freaked out. I knew I was going to test positive! The most major impact was growing up with it all around me. I was two when my mother was diagnosed with breast cancer and I still remember bits of that time. I remember visiting my mother in hospital and going with her in the pram to have scans done and seeing her go into the big machine. I apparently started stuttering at this time out of nowhere which I think must have been caused by the stress at the time, as I overcame that before I went to school. I remember my aunt being diagnosed with terminal liver cancer when I was 11. She had undiagnosed breast cancer (in both breasts apparently) that had already spread. It was an awful time! My mother made her fruit salad every day as it was all she could keep down and we made cassette tapes for her to brighten her days. I remember yet another aunt being diagnosed with breast cancer when I was 14. She had six children. I saw her go through it all as well and pass away when I was 17. I saw my beautiful cousin who was only 32 go downhill from her advanced cancer. She was told it was a 'blocked duct' as she was breast feeding at the time. The doctors wouldn't refer her for a mammogram at all. The same thing happened to my cousin who passed away last year from ovarian and breast cancer at 46.

Ever since she was a toddler accompanying her mother to her breast cancer treatment, Bree has partaken in the bodily acts of care that created and maintained the meshwork of her family. When her aunt became ill, it was Bree and her mother who tried their best to bring her comfort, making tapes and food with the hope of rendering her hospice more bearable. In all the pain and suffering that Bree's family experienced because of hereditary cancer, they continued with their best efforts to provide the small and everyday acts of caring for one another. Care did not issue forth from Bree to her dying

aunt, mother or cousins to be reciprocated in due course. This was not possible. No ledger was kept of who owed whom care. What we see in Bree's family is a sociality of care, of family trying to comfort each other in the face of death. As family members died, others came to take up their cares. Care continued to flow throughout the family despite its many losses. Care constituted their very familial body in the partial and practical acts of helping each other; witnessing, recognising and participating in the prolonged pain and suffering of a cancer diagnosis. These flows are illustrative of care in the meshwork of the family.

For Jo, 49-years-old, risk-reducing surgery came with unexpected complications. Over the space of a year, Jo underwent seven surgeries beginning with her mastectomy and ending with her hysterectomy. During this time, she also underwent reconstructive procedures to correct her post-mastectomy infection, necrosis and hematoma:

This period has affected my nuclear family a lot as I have been in the hospital or recovering a lot. My husband shouldered much of the house and childcare duties during this time. Having my mastectomy was psychologically a relief but physically difficult. The post-surgical complications have been very difficult to live through.

We could easily read Jo's experience of recovery as suggestive of the iatrogenic consequences of at-risk women undergoing surgery to fulfil the gendered responsibility they have to care for their family. But this reading leaves very little room for appreciating the flow of care as it circulates in and through the meshwork of the familial body. Karen, aged 43, had a similar experience of an unexpectedly long recovery after surgery. On the surface, it would appear that Karen's experience fits nicely with the Maussian notion of the gift. Karen sacrificed her body parts, her breasts and ovaries, to mitigate her risk of cancer, and thus continue the life she built with her husband. Her husband in return, reciprocated this gesture by caring for her while she convalesced for what was expected to be six-week recovery period. But this tidy theory of exchange masks the messy, complex realities of care permeating the meshwork of Karen's family. Upon return from hospital, Karen found that her body, particularly her chest muscles, struggled to accept her implants. She started to experience full body spasms. For two months she was at

home bed-ridden. During this time, she contracted an infection that put her in a hospital isolation ward for two weeks. Medical staff and her husband could only enter her room in full surgical attire. After her hospitalisation, her husband gave up his job to be her full-time carer. Although she was told by her doctors that this severe reaction was likely to occur if she was to have her ovaries removed, Karen had scheduled the procedure for the month following our interview. Karen knew that, given the difficulty she had in recovering from her mastectomy, she was likely to once again need her husband's help to recover. Together they had made the decision that Karen's best chance to remain cancer-free was to undergo surgery despite the side-effects she would likely experience. Just as care had come to create their family, so too, she maintained, would it carry them through the threat of cancer and the difficult recovery period. It was not so much a situation of reciprocal caregiving, of equal parts and efforts to give and receive care. While Karen appreciated her husband's dedication to care for her, and he appreciated the sacrifice she made in removing her breasts, the care they experienced was not a neat, reciprocal exchange. Moreover, it makes little sense to separate the individual giving and the individual taking. Caring in the meshwork, as we can see, is more complicated than these neat formulations allow.

## **The messiness of caring**

The messiness of care as it circulates within the familial body was perhaps best clearly illustrated to me by a Polish-Australian mother and daughter I met in late 2014. Alicja, aged 47, had long suspected that she had a genetic predisposition to breast cancer. Investigating her possible risk of hereditary cancer had been particularly painful for the Polish doctor as she told me:

I had two sisters who died young from breast cancer, one was 29 when she was diagnosed and the other was 34 and one lived for two years and one lived for four years. I made the decision on my own to go to the genetic counsellor and they told me I had very low risk which doesn't make sense. It was bullshit, I think I have very high risk, and they did all this computing and said I wasn't high risk but gave some form of comfort that there was something I could do and one of these was mastectomy. And I woke up a few days later and thought I am doing this and I did it. And that was fine and then unfortunately one of my sisters died, one then

another one and I was like 'okay so there is nothing else to do, how about I just go and get a genetic test.' And I was told I have very low risk so I was like 'great and we can celebrate that I don't have the gene.' So I got the blood test [to be sure] but I had to pay the \$2000 because they said I was very low risk, but I said I have to do everything possible because I have children. So we were eating at this French restaurant and I was telling my friends 'oh its great I don't have the gene.' But then I got the call for the results and it had come quite quickly I was like 'woah, I was told it would be six weeks' and I got the call after three weeks. And she told me I had BRCA2. It was a few years ago. And so then I decided I would get my ovaries out at 42. I am 47 now. So five years ago. And so I hated the genetics, Nadia was studying genetics and I would see the books and I hated it. I hated this, I can't stand it, I can't stand the genetics department or those people. And then I went again [to the doctors] and now she said I have less chance of getting breast cancer than any other women so in the end it was positive but I have to say I found it a very bad experience. Even I am a doctor but I found it a terrible experience, I hated it and this woman, oh I hate her, whatever we will call her. She was so negative, [telling me] 'you have to tell your daughter,' and I was saying 'she is in Year 12 now, she has so much stress already' and I was pouring my eyes out I was crying and she was so... I found it quite an unpleasant experience the whole thing.

Despite her best efforts to keep the news of her BRCA mutation, her surgeries and her traumatic experience of being tested from her children, the information come out one day when Nadia and Alicja were having an argument. Meeting Nadia and Alicja for dinner in early 2015, they explained how the confrontation came out. Here, I quote directly from my fieldwork notes:

Nadia: I found out in a fight we had, remember, it popped out.

Alicja: Well you wanted to move out so you had to know.

Nadia: And then we went to the genetic counsellor and yeah

Alicja: Nadia decided to move out, which for me was worse than giving birth, it was such a raw experience, and then she was more and more [angry] and she was like 'I am leaving, I am taking everything' so really I said 'well if you are moving out [I am going to tell you],' because it was so emotional

Nadia: I think I was angry that you didn't tell me anything

Alicja: But what difference would it make? You were going into year 12, it wouldn't make a difference. [When I got my ovaries out], I didn't tell Nadia, nobody knew, I couldn't tell anyone, I couldn't say... I am surprised I am here, I am talking about it as I couldn't talk about it. Only one of my close friends knew. I couldn't talk for years about what happened to my sisters. I had a book club and one day I told them and they were like 'what?' they didn't know. But for me it was very traumatic experience. Also because my sisters, I don't think they got the right treatment. They were in Poland and I don't think... It was just a complex experience for me

Nadia: And in Poland they only test for BRCA1

Alicja: It is very rare to have the BRCA2 there so they just weren't tested for it. So I told her I had the gene and she needed to know it. And then she came and said 'OK that means I have a 50% chance of having it.' And she said she wanted to know straight away. So we got an appointment quickly

Nadia: I was like I want to know

Alicja: Yes, we went the next day. And then it was the holy days, Christmas, and I said 'let's go together [to get your results]' and she went on her own. She didn't want me to go with her to get the results. And she didn't tell me for a long time about the results either

Nadia: Wonder who I got that from [laughs]. I told you eventually. I did a very dramatic tearing up of my results

Alicja: Yes, we went to the coast and she said 'I have to talk to you' so we went to the beach and she showed me the results and then we went to the rocks and she tore it in half and then we tore it in many bits and threw it in the ocean.

In the preceding exchange, we get a sense of the complexities, the messiness of care as it circulates in the meshwork of the family. Nadia found herself unexpectedly excluded from the sociality of care, of being able to care for her mother during her time of need. A sociality founded on the partial deployments and techniques of bodies; hands reaching out to change bandages, of applying post-surgical tape and helping to hold drainage bags was kept from Nadia by her mother. Her mother worried that if Nadia was to give this care, it would impact on her ability to complete her final exams and achieve her aim of studying at university. For Alicja, withholding knowledge of her mutation and her surgeries from her daughter was a means of caring for her. She felt she was protecting Nadia from any undue distractions, worry and stress about her mother's health and by extension, her own, during her exams. Nadia, however, saw this withholding of information as an affront, almost a denial, of their relationship of care and their fundamental entwining. For Nadia, her mother had not only hidden the truth about her health, but had denied her the opportunity to care for her during her time of need. Alicja saw herself as caring for Nadia by shielding her from the emotional anguish she herself experienced during her sister's treatments, subsequent deaths and her own genetic testing. Nadia, however, considered this secrecy as an insult to the circulation of care that should flow within a family. Consequently, Nadia chose to exclude her mother from her own experience of being tested. Given the importance of care in constituting the sociality of the family, to be denied the opportunity to give care to her mother was felt by Nadia to be a denial of their very co-entailment.

Two years after our first meeting, Nadia, underwent a risk-reducing mastectomy at the age of 25. She spoke to me about her recovery experience differed from her mothers. Nadia had moved in with her boyfriend before the procedure and, as she told me, was very open with him during the entire process. He helped hold her surgical drains as she showered to keep them from getting wet or from tugging on her sensitive skin around the insertion site. He would lift her in and out of the bathtub as her chest muscles were too weak and tender. We see the techniques of the body, of lifting and holding, as central to these caring exchanges between Nadia and her boyfriend. Her mother, however, also took part in caring for Nadia but in a different way. During her time in hospital, a mere 48 hours after her operation, Nadia was visited by the hospital psychologist. The psychologist, Nadia told me, spoke to her for a full hour about the importance of re-establishing a sexual relationship with her partner after recovery. Nadia was left feeling overwhelmed and upset. Within half an hour, her mother appeared at the hospital to give the psychologist a very thorough dressing down for her insensitivity.

Despite the difficulties their relationship had weathered, the feelings of betrayal and injustice, of hurt and rejection, Nadia and Alicja still found ways to express their love and care for one another. They tried to re-establish the flow of care that had, at times, faltered. While the physicality of care, the bodily techniques of changing bandages, of lifting in and out of the bath, was not part of their relationship as it was for Nadia and her partner, they still found ways of 'being there' for one another. They worked to witness and respond to each other's needs. Care, as we see in this exchange, is profoundly messy. Alicja sought to care for Nadia in the way she thought was best. Nadia felt uncared for as her mother would not accept, or allow, her care. Nadia rebuffed her mother's attempts to care for her in accompanying her to her appointments. It was Nadia's partner whose techniques of the body reached out to and received Nadia's tender torso. It was Alicja's fiery words that, in defending her daughter's privacy, cared for Nadia's emotional wellbeing. In the meshwork of the family, we see how care flows throughout the knotty entanglement of people, how it takes on a variety of forms that resist any confinement to a single 'individual' giver or receiver.

## Caring in the face of cancer

In ignoring the intricacies of care, Martin et al. (2015, p. 625) inform us, ‘we might not only lose what is generative in care – what makes care possible – we would also elide the ways that care works to animate and activate inquiry and analysis.’ Ignoring the complexities and messiness of care in everyday life may have analytic consequences. We risk leaving intact binaries that organise our world into ‘legitimate and illegitimate knowledge,’ ‘the rational over [the] sensory and affective,’ the individual versus collective, selfish versus selfless (Martin, et al., 2015, p. 625). In the last section of this chapter, I offer a detailed example of the multidirectional flow of care that took place within one family profoundly affected by hereditary breast and ovarian cancer. In and through it, I hope to reveal a world in which caregiving is not defined as care issuing solely from the individual woman to the rest of her family, driven by her need to fulfil gendered expectations. Nor do we see care as a straightforward, reciprocal gift exchange where care is returned in kind. Rather, in reading the experiences of Gwen and her family, we can see how collective, partial and embodied acts of care circulate in and through the meshwork of the family. For Gwen, giving care was not burdensome by dint of her gender. Caring was indeed immensely challenging but also sustaining, incredibly difficult but profoundly meaningful.

I met Gwen late in 2015. She and Lily had been neighbours some years prior and had bonded over their shared family history of cancer and their love for card games. Lily invited me along for a cards night with her, James, Gwen and her husband Kim, after discovering my love for canasta. I was taught by my father and played together as a family every Christmas. After a long night of Gwen and her husband Kim, a good-humoured couple in their 60s, patiently explaining to me the ins and outs of Skip-Bo (and generously overlooking the multiple times I ‘accidentally’ cheated), Lily suggested that I interview Gwen for my project. Several of her family members had been diagnosed with cancer – her mother, elder sister and twin sister. Gwen kindly agreed to speak with me.

Gwen talked me through her family members' diagnoses and the mixture of 'sadness and anger' she felt during these times:

When my elder sister was diagnosed with ovarian cancer 12 years ago, my twin sister and I both immediately had a complete hysterectomy. We lost my sister ten years ago, and the anger [I felt] was because we had not insisted that Mum take the same precautions we had. Initially I was always hoping for the 'cure' to arrive [after her mum was diagnosed]. Mum had a hysterectomy straight away and a bout of chemo. She was okay for a year or so but then it came back. I think she had another go at chemo, but she was just getting weaker and weaker. As well as my mother and elder sister passing on, my twin was also diagnosed with breast cancer about seven years ago. Thankfully she is fine now. My father's sister died at 45 from a cancer which they believe may have been breast to begin with. There may have been a distant cousin on my mothers' side also. Mum's elder sister died from pancreatic cancer about eight years ago.

Gwen's mother, Ester, had been the main caregiver for her older sister Elaine when she was diagnosed with ovarian cancer. With Gwen's father, Ester helped Elaine during her treatment and until she passed away. When Ester was then diagnosed with cancer, Gwen's family came together to ensure Ester received day-to-day care. Gwen described the sense of mutuality she felt in caring for her ailing mother, in helping in whatever way she could to minimise her mother's pain and suffering. Gwen, her father and her sister were determined to help Ester stay at home for as long as possible just as Ester had done for Elaine a few years prior. Caring for her mother, as Gwen explained, involved her entire family as well as professional nurses:

Initially Dad was the primary caregiver for Mum, then, in the last six months, it became too hard for him. They were living [down the coast], so my sister and I took it week by week to live with them and care for Mum. Although it was incredibly hard to watch my mum in so much pain, it was also an enormous privilege to be in a position to care for her. I felt like I was repaying her for all the care she had given me my whole life. It was the least I could do. Mum had a community nurse visit each day and she had a port which helped alleviate the pain. Naturally, her biggest concerns were the daily routines such as toileting. I distinctly remember Mum attending to my elder sister before she died, it reminded me of coming a full circle - the way you would wipe your toddlers after they had been to the toilet. I figured I had come that full circle with mum also. Towards the end, mum was eating very little. She would struggle out of bed each morning, get dressed and lie on the couch all day. I think she felt that if she could just make it out of bed, then she would last another day. She was very determined

to remain at home as long as she could and to this end the community nurses were fantastic. In the end, Mum was only in hospital overnight before she passed on... I guess I was always hopeful that Mum might be one of the few to survive ovarian cancer, but that was not to be.

Care, writes Kleinman (2009), involves an attendance to the extreme vulnerability of others. It requires both the materiality of assisting with bodily functions and 'empathic imagination, responsibility, witnessing and solidarity with those in great need' (Kleinman, 2009, p. 293). Attending to her mother's needs was incredibly tender for Gwen, as she tried her best to help the woman who raised her, who shaped her, who was, literally, part of her very being, during prolonged periods of suffering. In many ways, Gwen feel grateful that she had the privilege to care for her mother. She felt honoured to be able to help her stay in the comfort of her own home, surrounded by her family, for as long as possible. Gwen recognised a sense of circularity and flow in caring for the woman who cared for her since she was a child. Gwen assisted with the physical tasks of toileting that her mother had done for her some 60 years prior. It was care come 'full circle.' Gwen explained the great privilege she felt in being able to fulfil her dying mother's needs but also immense pain of seeing her struggle:

I think one of the hardest [parts of it all] was the fact that she had just done all this caring for her own daughter, now it was her turn. She had led an active life both physically and socially and it was hard to see her so debilitated. And she had tried for so long to try and beat this disease and remain upbeat, but it got her in the end anyway. I have always loved and admired my mother and this was in no way diminished by having to care for her – it just increased my respect and admiration. I guess in one way, it was better than her dying, say, in a car accident in that I had time to tell her how much I loved her, but I would not wish that slow death on anyone.

Care, as Gwen described, was almost reciprocal in the family but not in a positive sense. Ester cared for Elaine as she died and then Gwen took up Ester's place in caring. Seeing her twin sister and then her mother in pain was incredibly upsetting for Gwen and her family. Nobody wishes to see someone they love suffer. And yet, these acts of caring and sustaining Ester, just as she had done for Gwen as a child, increased the 'respect and admiration' she felt for her mother. Care in a family affected by hereditary cancer does not easily fit into neat categories of gendered responsibility or the gift. It is too complex,

too multifaceted, too messy. Gwen found caring for her mother increased the love, respect and admiration that she felt for her. And yet having to care once again for a loved one as they approached death was a situation she wished on no-one.

After Ester's death, her family continued to care for one another during and beyond their period of grieving:

Mum was always the homemaker in the family, as were most women of that era. Three years on from her death, Dad is coping much better than initially. He still talks about how much he misses her whenever we visit, but it is becoming later in the conversation. Because of the prevalence of the cancers in the family, we have always been close, especially the extended family. Because I live the closest to Dad at the moment, our relationship has probably strengthened as I see him fairly frequently and he knows I can be with him should he need me. [My sister and my] daughters are frequently in touch and very proactive in managing the potential threats to themselves. We all talk very openly about what's available and when things should be done.

Losing her mother strengthened Gwen's relationship with her father and her extended family. As noted by Peters (2004) and Strathern (1992b), after the death of a member, the family is likely to continue on, albeit in different configurations. Care continued to flow within Gwen's family even though her mother's and sister's absence remained acutely felt. Caring for her mother, elder sister and twin sister during their protracted treatments and deaths for cancer also crystallised for Gwen the type of care she did not want her daughters to one-day give to her. Although she felt privileged to care for her mother and sister as they died, she would not wish this upon her own daughters. Nor did she want her family members to have to do so over and over again. To prevent this cycle of suffering from continuing, Gwen, like many of the women in the previous chapters, decided to remove those body parts that, although crucial to creating and maintaining the family, also threatened its undoing. In reading Gwen's experiences, we are made aware of the problem of considering caregiving as actively given and passively received or as reciprocated between discrete, bounded individuals. This was not the case for Gwen and her family. As sisters and mothers fell ill, daughters, husbands and siblings came together to answer the call for care. They offered both the practical assistance needed, of ambulating limbs, dressing and toileting but also the request made for love

and for empathy. They witnessed the seemingly senseless and endless suffering brought about by hereditary cancer and tried to alleviate it in any small way (Kleinman, 2015). Care, as Gwen's example suggests, resists neat theoretical containment. Care often eludes definition, complicates measurement and pervades evaluation. Yet for all its difficulties, care is a profound part of human life and thus demands our attention. As human beings, Brenner (2001, p. 354) argues, we live in worlds that are crafted in and through care and our reliance on others. We are suspended in the meshworks of care that 'make up our lifeworld' (Benner, 2001, p. 354).

## Conclusion

Without care and its attendant concerns, Brenner (2001, p. 354) argues, we would 'rattle around capriciously in a vast, random universe, lacking the structures in which to ground our actions and choices.' While care may appear as moral striving common to most human experiences, it takes on particular significance for at-risk women. Having witnessed many generations of their close family members suffer from cancer and being identified as at-risk of the same fate, exposes at-risk women to the fundamental fragility of life itself, not only biologically but more significantly, socially. In this chapter, I have developed a notion of care that circulates in and through the meshwork of the familial body. I use this version of care to redress current anthropological approaches to care that see it directed unilinear-ly from the at-risk woman to her family members. In reducing care to the gendered responsibility or obligation to care for one's genetic and affective kin, we risk overlooking the ways in which care impels bodies, specifically body parts, towards one another in ways that create and maintain the family. I have suggested that we need to move beyond understandings of the at-risk woman as the central node in a network of caregiving, in which her care issues out to the discrete, bounded individuals in her family. I have put forth the notion of the meshwork to describe the ways in which the partial body and its cares are fundamentally intertwined and constitute the family. Care, in this sense, is not given and received in necessarily equal measure. This situation is not feasible in a family decimated by cancer. Care, is a collective of partial deployments that form up the meshwork of the family. It circulates

in and through bodies that are already, necessarily, constructed in and through one another. In appreciating the meshwork of the person and the family, we are able to move beyond understandings of care that see it as a whole or discrete 'thing' with a singular place of issuance. This view also allows us to move beyond the unhelpful selfish/selfless dyad characteristic of anthropological understandings of caring in the context of hereditary breast and ovarian cancer.



## Chapter Four

### An Absent Presence

It was around June of 2016 that I was sitting in Lily's lounge room with her daughter Lizzy. I had agreed to be part of her 'hairdressing salon' which I quickly discovered involved her dividing my hair into two very high pigtails and adorning them with bedazzled clips, ribbons and brightly coloured bands. From the bathroom, Lily called out to me, asking if I could spare a moment away from my 'makeover' to have a look at something. On Lily's bathroom counter was a breast pad that she had just removed from her maternity bra. She pointed to the centre of the pad. 'Does that look red to you? Like blood?' Sure enough, in the middle of the white pad was a small smear of red. 'Yeah it does,' I replied. 'Great,' Lily replied, 'I thought it did... Shit.' For breastfeeding women, blood on a nursing pad is likely to indicate that the nipple has become cracked during feeding. For Lily, however, the presence of blood on her nursing pad triggered alarm bells. Blood or discoloured discharge from the nipple can be a symptom of breast cancer. In the days following this discovery, Lily made an appointment to see her doctor. The doctor assured Lily that the blood was most likely associated with breastfeeding rather than breast cancer. Over the following months, Lily breasts came to occupy much of her thoughts. Lily already thought about her breasts quite regularly while she was breastfeeding. She was aware of when they were heavy with milk and it was time to feed her son. After discovering blood on her nursing pad, Lily's breasts assumed a different presence in her day-to-day life. They became a source of concern as she worried she had developed breast cancer while pregnant or nursing. What had been a pleasurable awareness of her breasts as connecting her to her baby, nourishing him and helping him to grow, transformed into a presence more troubling, one that she carefully monitored and scrutinised. She wished her breasts, she told me, back into habituality, into the time when she thought about them as a source of nurturing rather than disease.

The centrality of the body and its parts, writes Sharp (1995, p. 377) often 'hinges on the degree of control that we feel we can exercise over them, or that they have over us.'

‘During times of distress and disease’ she continues, ‘we suddenly become aware of the body as an integral part of *us*’ [my emphasis] (Sharp, 1995, p. 377). In the last two chapters, I made dual claims, for the ways in which parts of bodies care in habitual relation to and with one another to form fleshy collectivities or meshworks, and for the ways in which time becomes, equally, a fleshy collective that makes bodies, at times, blurred. Both these positions trouble the bounded individual, the progression of time and the direction of care that characterise most anthropological accounts of hereditary breast and ovarian cancer. In the previous chapter, I used both notions to critically assess the notion of ‘care,’ arguing that, contra to anthropological literature of previvorship, care does not issue from a singular individual source towards others, resulting in assessments of actions as either selfish or selfless. Care, rather, issues from and is directed to a collectivity of body, pain, suffering and survival that need not ‘result’ in anything. Care is administered and received in the most unremarkable of contexts and places, a resource that sustains something called ‘the family.’

In this chapter, I extend this notion to demonstrate how women at-risk of hereditary cancer deal with the risk of dying. Rather than focusing on the *individual* ‘rational actor’ and choices they make to reduce risk, I begin with the idea that previvors want, overwhelmingly, to be present among the bodies that *collectively* form their families. They wish to be a *part* of the familial *whole*. They want to ‘be around’ for their loved ones as Lily told me. It is important to focus on something known as ‘one’s presence’ rather than ‘the individual,’ since the use of the latter term suggests a whole and discrete body that relates to other bodies in a network as such. However, the presence I speak of here is sometimes not a ‘whole’ body, characterised as it is by the absence of ovaries and breasts, in favour of one that is able to ‘be around’ as a *part* of the family. Thus I dispel with the bounded, discrete body to make sense of the collectivity of parts that form the meshwork of the family, this being permeable to change and flexible to the inclusion or exclusion of new members.

As I have argued in previous chapters, some parts of the body are more important than others in creating and maintaining the family. However, it is also the case that these body parts and movements are replaceable and replicable using other actions and even

stand in parts, such as implants, to ensure breasted and ovarian sociality can continue. What is not replaceable, however, is the multiplicity of partial relations the person conducts as a member of the family. Indeed, it is this very multiplicity of actions that come to form up the person. This is so because these partial deployments are driven by emotion, the same driver that makes it necessary for those especially important body parts to be replaced or replicated in some way. They may be replaced or replicated through a technology such as an implant or a new technique of the body (Lyon, 1997, Mauss, 1973[1935]). Indeed, as Mazis (2001, pp. 202-3) reminds us, the body is where 'emotion[al] investments are located.' The continued affective presence of the person, their ability to 'be around,' is assured when the parts that threaten to eliminate them, that is, potentially cancerous breasts and ovaries, are removed. Because these parts are replaceable and replicable, the affective presence of the person remains and so too does the family. The at-risk woman remains a part of the meshwork of the family rather than a hole, an absence. With all of this in mind, I engage critically with the Cartesian mind/body dualism, that is, the notion that minds remain even as bodies become fractal, a point of contention for anthropologists of hereditary breast and ovarian cancer.

## **Minds and Bodies**

Cancer scholars such as Kavanagh and Broom (1998) argue that living with the possibility of developing cancer and undergoing the risk-reducing regimes it engenders exacerbates the Cartesian divide between body and mind. The mind, for Kavanagh and Broom (1998) is synonymous with what they call the 'self.' In their view, parts of the body come to be understood and talked about as objects able to be excised from the bodily whole (Kavanagh & Broom, 1998). At-risk women, they conclude, come to experience their own body as 'potentially dangerous - as liable to destroy her' (Kavanagh & Broom, 1998, p. 442). This fear, they suggest, creates an ambivalent, even disassociated relationship between the body and mind/self (Kavanagh & Broom, 1998, p. 442). As such, they ascertain, the at-risk woman clearly 'separated her *self* from her

*body*. Her body could be dissected, hazardous parts identified and removed, while the self remained - no longer under threat from the body.' They continue:

with corporeal risk a part of one's body poses a threat to the self resulting in a dissociation between body and self. By contrast, with environmental and lifestyle risks body and self are at risk simultaneously so there is no separation. In the case of abnormal Pap smears, corporeal risk is managed by surveillance and sometimes removal of the dangerous part which is cast as separate, 'other' from the threatened self. The woman who developed symptoms after diagnosis may have been engaged in a symbolic effort to reunite her body with herself. At the extreme, the disconnection of body and self manifested in one woman's desire to remove all potentially hazardous body parts... Cancer amplifies the Cartesian split between body and self; cancer which is part of one's corporeality literally attacks the self (Kavanagh & Broom, 1998, p. 442).

This line of thinking is well-established in approaches to hereditary breast and ovarian cancer. Hallowell and Lawton (2002, p. 430) express a similar sentiment, writing that women at-risk come to see their breasts and ovaries as 'dangerous objects.' McEwan (2011, p. 40) likewise purports a splitting along Cartesian lines amongst women at-risk of hereditary cancer in New Zealand. She argues that such a divide allows women to 'separate their bodies from themselves' in order to make decisions about risk-reducing surgery (McEwen, 2011, p. 40). Gibbon (2007, p. 37) in her work on at-risk women in the United Kingdom, states that the readiness and ease with which her informants considered and underwent risk-reducing mastectomies revealed 'a sense of detachment and disconnection from their bodies.' In a similar vein, Scheper-Hughes (2011, p. 184) in her work on organ trafficking, speaks of the compartmentalisation and rationalisation of the body that is required and subsequently produced by medicine and science. These practices, she writes, necessitates and creates bodies that can be 'broken down into fragments, disarticulated, de-personalized, and rendered anonymous' (Scheper-Hughes, 2011, p. 184). The body, she argues in reference to Weber, becomes 'disenchanted' (Scheper-Hughes, 2011, p. 184). For Hacking (2007), like Scheper-Hughes (2011), the development of biotechnologies associated with Western medicine; organ transplants, cochlear implants, gene therapy and the like, only exacerbate what he terms 'neo-Cartesianism.' He argues that, in the West:

The body on the ventilator is, we solemnly assert (or decree), not the person! Just a lot of tubes and wires (to use Cartesian images), vessels and nerves and remaining organs being kept pumping by being plugged into a wall socket. This is just an instance of our return to Cartesian instincts. We are Cartesians when engineering cannot save organs but only preserve them. We are equally Cartesian when we engage in feats of surgical engineering for large body parts. Here is an unpopular inference: with the ongoing advances of technology, neo-Cartesianism is bound to win in the end (Hacking, 2007, p. 105).

In the work of the aforementioned scholars, we see a propagation of the idea of the part-able body produced by medical and scientific technologies as symptomatic of a refashioned Cartesian mind-body divide. In this vision, parts of the body must be separated from the bodily whole if the self, here synonymous with the mind, is to remain intact. While Hacking (2007) and the like make convincing arguments for neo-Cartesianism as a result of biotechnologies of medicine and the body (in which body parts are replicable and replaceable while the mind or self remains intact) I think we can approach the idea of the part-able body differently. To reduce the experience of the part-able body to a consequence of the various modes of biopower and governmentality excised through the structures of biomedicine, science and government fails to appreciate how at-risk women come to understand their bodies as fundamentally, necessarily part-able within their local moral worlds.

It is of interest here that even though they speak of identifiable parts such as breasts, and ovaries, these theoreticians take the whole of 'the body' to be set against 'the mind,' with the boundary of the flesh the main site of conflict. As I have argued throughout this thesis, I take the body to be foundational to these only ostensibly 'minded' notions like 'the family.' In my view, the family is an affectively driven arrangement of partial bodily interactions, and a 'will to live' that only appears to rely on the idea that the body is something to be overcome with minded determination. Rather, as I will suggest below, the will to live and to live *with*, seems to issue from a kind of body-ness, in several senses. This body-ness includes a body that is intended to remain present alongside others, part of the familial collective. It is in this sense that bodily experience both creates and maintains something called 'the mind,' but also the thing for which at-risk women want to keep living – the family. 'The whole' Strathern (1992b, p. 105) informs

us, is 'composed of parts.' The person is made up of a body and bodily parts. The family is made up of bodies living in proximity, impelled towards each other by emotion. What is important to acknowledge is that the totality, be it the person or the family, is *not* found 'in the logic of the individual parts' (Strathern, 1992b, p. 105). It is not a mind or a body nor does a mother or father, sister or brother make the family. What is crucial to understanding the experience of these entities is rather the 'organizing principles and relations' that lie between and beyond them (Strathern, 1992b, p. 105). Such an approach can produce a different viewpoint than one that is deduced from whole or part alone. Rather than producing a chasm between the mind and the body, the threat to the security of the embodied, familial relations surrounding the at-risk women brings to the fore the very importance of the body (and its parts and its dispositions) in the routine creation and maintenance of family.

### **From mind-body to presence-absence**

Instead of a Cartesian divide, I propose a distinction between two bodies that appear to us in two different kinds of awareness. As briefly outlined in previous chapters, Leder (1990) in his work *The Absent Body* describes how two versions of the body appear to us: the present body and absent body. He writes of how, in our day-to-day life, we remain mostly unaware of our bodies. They are absent, beyond our conscious awareness, and they must remain so in order for us to live our lives competently. As discussed in the previous chapter, this 'habitual' body as Merleau-Ponty (1962) suggests, falls behind one's self-conscious attention in the course of everyday life. This required, habitual absence of the body and its machinations remains, lying below our constant awareness, until something provokes it to surface. At this point the body becomes 'present.' Lily's breasts became present to her as they bore the weight of her accumulating milk, ready to feed her son. Her breasts also became present to her when they produced the worrisome spot of blood. It is not the case that the whole of the body becomes present. As I have made clear above, I have an issue with those who would treat attention to one part of the body as representative of its totality. The provocation or 'affective call' that makes a body part present is, as Leder (1990) notes, very often

pain or the potential to cause pain. According to Mazis (2001, p. 205), pain draws attention to what is often only 'very indirectly ever perceivable.' Pain announces the body, but 'not from the body as an isolated mechanism, but rather as at the heart of all the relationships of the person to the activities, things, and people within his/her world' (Mazis, 2001, p. 205). In stark contrast with absent bodies, then, present bodies invite reflection and allow persons to discover their own activity 'in shaping the world as it is discovered through our perception' (Langer, 1989, p. 32). Dennis has explained this awareness and its partiality:

If I am walking down the street, for instance, I usually do so unreflexively, simply permitting my feet to interact with the street – to so do is to walk competently. But this disattendance is rudely disrupted if, say, I suddenly stub my toe. The pain means instant self-awareness of my foot and its failure to have performed its unaudenced dance with the pavement (Dennis, 2016, p. 110).

This sudden awareness of the body that Dennis describes in something that Connolly (2001, p. 181) takes issue with. Connolly (2001, p. 181) concludes that attempts to return the present body back into a state of absence or habituality is symptomatic of the 'disembodied status quo' of society. The dysfunctional body 'must be treated, cured and returned to its normative docility' (Connolly, 2001, p. 181). While it is certainly the case that Western society values productivity and the functioning, well body, I read my informants desire to achieve an absent body differently (Connolly, 2001, p. 181). For the participants in my study, the potentiality of pain and dysfunction caused by carrying a genetic predisposition to hereditary cancer brought particular bodily parts into sharply present attention. It was in and through the concern for possibility cancerous breasts and ovaries, for instance, that my informants came to realise just how crucially important these parts were in connecting them with their familiars, and how important they were to the operation of the family. It is with this difference, between absent and present bodies, that I replace the Cartesian divide utilised by other theoreticians such as Kavanagh and Broom (1998). It is not so much the case that women felt separated from their bodies. It was more that they had to work to reconcile uncomfortably present bodies and body parts with the habitually absent ones they longed to occupy. It was by having an absent present body that my informants felt they could 'be around' for their

loved ones. Present bodies may come to be displaced from their 'usual contexts of engagement, of concerns, loves, hates, tasks – lost somewhere in a time and space' (Mazis, 2001, p. 209). This ability of illness to fundamentally reorganise daily experiences was often made sharply obvious to at-risk women as they cared for their ill family members (Mazis, 2001, p. 209). In taking this view, I follow Toombs application of Leder's (1990) foundational principles of presence, absence and partiality, which she sets out in the following excerpt describing her own experience of multiple sclerosis:

Illness changes our relationship with our bodies. In health we take for granted that we have control over our bodies. If I am seated at the dinner table and I want some water, I am confident that my arm will respond when I begin to move it towards the glass and that my hands and fingers will perform the various motions required to raise the glass to my lips in order that I may drink. Indeed, I am so certain of this bodily compliance that I pay absolutely no attention to my body as I accomplish this task. As I reach for the glass, I am probably listening to my dinner companion and I am only vaguely aware of the location of my arm. Under normal circumstances, I am even less conscious of bodily functions such as breathing, seeing, hearing, or the beating of my heart... Bodily disorder destroys this taken-for-grantedness... It was not just that my future bodily capacities were questionable, but that all my projects, plans and relationships were now in jeopardy... The familiar [and familial] involvements of everyday life – the workplace, the social world of friends and colleagues seem a 'world' away (1995, n.p).

For many of the women in my study, the ability of cancer to shrink one's world, making ever-present and aware one's bodily capacities and their taken-for-grantedness, as Toombs (1995) describes, has been made evidently clear. They had witnessed and experienced the limiting capacity of illness as they cared for their familiars during treatment regimens and underwent their own risk reduction. They saw how difficult, nigh impossible, these present bodies made it to 'be around' for their family. In attending to the experiences of at-risk women, we can extend this notion of the disappearing body that is offered by Leder (1990) and developed by anthropologists such as Toombs (2001). To do so allows us to consider how the potential failings or demise of the body due to cancer also generates a hyperawareness of the relationships of care and of family that are a part of such bodily being. It is this very nature of being a body, of being a sensitive body, that equips us to truly *be with* others.

## Not a Cartesian divide nor a neo-Cartesian divide

The ability of illness or potential illness to produce a hyper-awareness of the body's role in creating and fostering sociality was experienced by Khloe as she contemplated starting a family with her husband. Khloe, the 32-year-old Jewish American actress we met in Chapter One, spoke of what it was like to grow up in a family touched by hereditary breast and ovarian cancer:

My dad is the only living survivor in his family. He is BRCA1 positive. Everyone else has died of various cancers. His first sister died at 32, when he was in his early twenties. I was born nine months later. My family called me a miracle baby but that is a lot of pressure to put on a tiny child, like 'oh I am the reincarnation of my dead aunt who I have never met, okay, great.' But I wore it as a badge of honour. But growing up in that world, I thought 'oh I am going to get breast cancer.' It was just a way of thinking like 'you have blue eyes, you have diabetes, I am going to get breast cancer.' It was very matter of fact but also very horrible, a very difficult feeling. My dad's family was two older daughters and a younger son. That is my family now. My sister is 27 and my brother is 21 and I just turned 32 so I grew up as a child thinking 'well one of us will get cancer,' just as it happened in my family. I did a lot of comparing, I was scared of death, I would say 'I love you so much' whenever I left a room because I was afraid what if something happened and one of us died. So I lived in that fear but so did my family...

Growing up, Khloe considered breast cancer to be part of her very bodily constitution just like her blue eyes. Khloe did not consider her potentially ill body as separate to herself, rather it was central to her collective existence as a member of a family with a hereditary cancer syndrome. To Khloe, her body was like her father's and her aunts', in fact, it was what linked her to her namesake, her deceased aunt. As we will see below, Khloe was not a mind in a faulty body. Witnessing her father's family, so alike in composition, both genetic and affective, as her own generation, brought to the fore the importance of her body in the creation of her family in ways she had not expected. When Khloe got married, she was convinced that she would have children and then undergo risk-reducing surgery:

I love to eat organic, I was very earthy crunchy so I was convinced we were going to breastfeed so I decided we are going to have babies right away. So any time there was a quiet moment I was like [speaking fast] 'well let's have kids now so I

can breastfeed and have the mastectomy' and that was how I was living my life which isn't really fun or sexy to a newlywed couple... I remember thinking I cannot wait till I am 45 or 50 years old to have a mastectomy. And I knew that wasn't the right way to live. I knew I would be so mad at that stage if I waited till 40 to have it and be scared this whole time. So I told my husband I think I want to have a mastectomy and I think I want to have it soon and he was like 'great!' He was so relieved. I was like 'aren't you worried about breastfeeding' and he was like 'no I wasn't breastfed' and I wasn't either and I was remembering all these other women who didn't breastfeed and I was like 'okay that is an option...' So I [sat] down with the doctor and the genetic counsellor and said 'This is emotional because I am going crazy and this is really hurting my relationship and my family planning and my future...' The genetic counsellor said 'I completely agree with you.' Because I waited till I was ready to have my kids [rather than having before surgery], I didn't feel pushed and I was so happy. And now I am so happy with them in my life.

It would be quite easy to read Khloe's decision to undergo a risk-reducing mastectomy through the prism of the selfish/selfless binary. Khloe felt it was selfish of her to have her breasts removed before breastfeeding her future child and this caused her great emotional distress. However, as we see in Khloe's explanation of her decision making, there were many more factors that came into play, factors that bespeak the very collectivity of her body and of its reproductive capacities. Khloe's increasingly present breasts and ovaries came to interrupt, to alter, her relationship with her new husband. She felt pressure to use them to produce new relations, the relations of bearing and nourishing a child, before their cancerous potential could be realised. For Khloe, her breasts had become too present. They were not however separate from herself as a Cartesian reading would suggest. Khloe still saw her breasts, and her ovaries as important in creating relations with her husband and her child, but in a form that could be, rather had to be, replicated and replaced by implants. It was more important, for Khloe, to be able to reside in an absent, habitual body. This body would allow her to relate to her loved ones in a way that was not under persistent and increasing temporal and emotional pressures. Khloe could no longer live in such an accelerated temporal regime. She could no longer cope with the pressure she felt to hastily create relations through procreation and breastfeeding so that her present breasts and ovaries could be returned to a state of habituality.

Leanne explained to me how her two young sons, both under the age of six, reacted to the news that she was undergoing risk-reducing surgery and how they responded to her during her convalescence:

They were pretty much really good... They knew mummy was having surgery but we didn't go into it. There was something on the news about a women having breast cancer and the older son had said 'so what is breast cancer?' knowing that my mother had had breast cancer. So we sat down and talked about what breast cancer was and what could happen with different cancers. And we thought, 'well this is the time,' so we said, 'well mummy has high risk of getting breast cancer because of things that have happened in our family and this is the type of operation she is going to have. So she is going to have her boobs cut off and she is going to have new boobies made from her belly and that is going to hopefully stop the fact of her getting breast cancer.' And there were a lot of questions asked after we talked about it. And then that was it, there were no more conversations about it and we thought 'okay we will see how it goes' And they came to visit a couple of times when I was in hospital and I came home with the drain so I think that really helped that they could see, I had my little bag with the drain in it, so that helped them to be more gentle ... I think having that visual reminder for the first week I was at home was really good. But they were delightful, my oldest would grab my arm if we went to walk across the road, and he would walk me across so that I was okay. It was just so sweet I thought to myself 'why can't they be like this all the time.' It went on for a while, they would be like 'Mummy do this,' and I would say, 'well I can't do that but I can do this instead.' Or it would be like 'give me a cuddle but we will put pillows everywhere.' They took it really well. And they went to school and the eldest one said 'my mummy is in hospital having her boobs fixed up.' And I was like 'oh great' but we told their teachers as well to warn them just in case they got upset. But they are quite intelligent children so I think they took it in and understood. They were really, really good 'tak[ing] the little old lady across the road [laughs].'

Leanne's sons did not see her altered body, or her absent breasts, as separating or changing who Leanne was or is as their mother. Incidentally, the visual cue of their mother's surgery, the drains hanging from her chest encouraged the boys to be even more careful and considerate of their mother. Other parts of Leanne's body came into service to sustain the relationships of care and love that create and maintain her family in the absence of her hugging breasts. Her hands were still what her children reached out to hold and guide across the road, pillows were enlisted to pad and protect her surgical site so that she could snuggle with her sons. What appears out of these comments of Khloe and Leanne is the ways in which previously unreflected upon

interactions such as cuddling and having sex as a newlywed couple make very present the breasts, for example, as creating and maintaining these relationships. When the threat of hereditary cancer is made known, these parts dys-appear, they come into consciousness in a way that cannot be easily suppressed into a comfortable absence. All the relations that these parts are normally and habitually involved in cannot be overlooked. Bodily disorientation, weakness, pain and suffering, Mazis (2001, p. 205) writes have the ability to undercut our habitual bodily avenues of involvement. It disrupts 'all the projects that were echoes of what my body could do without any thought – that constituted my past and future horizons of engagement.' Yet this does not mean that these parts or the body that they constitute are spliced from the mind to be diffused of their risky potential. Bodies and families created by them adapt. Parts crucial to these relationships are replaced or replicable, so that they may return into habitual absence, ensuring the continuance of the familial unit.

### **Remembering present body parts**

Pain and illness, Leder (1990, p. 73) submits, reorganises 'our relations with others and with ourselves.' As genes and gene mutations are passed down, mother to son, father to daughter, so too are the embodied experiences of living with illness and caring for those who suffer most acutely. These shared memories are rendered upon the flesh of the diagnosed but also those loved ones that are intimately enfolded in such familial skin. The pain associated with cancer leaves an indelible mark upon those at-risk regardless of their diagnosis or lack thereof. They may not be fully 'healthy' nor yet 'diseased' but their bodies are nevertheless heavy with the memories of caring for their dying loved ones. They remember raising spoons to the mouths of their loved ones, carrying limp bodies from the bed to couch and back again, placing ice on blistering tongues and peeling skin burnt from radiation. These embodied memories as just as pertinent as those of embracing during times of joy and laughter, commensality and camaraderie.

Khloe worried about her body becoming too-present, of it becoming diseased like her aunts, and rearranging her relations with her family in ways she did not want. Mia

likewise recalled how present her mother's body parts became when she was sick and how much this presence of her breasts disrupted the relations that those parts helped facilitate. Like Khloe, Mia, aged 31, worried that her baby would not be able to 'snuggle in' to her after she had a risk-reducing bilateral mastectomy with breast reconstruction. Mia had tested positive for the BRCA1 gene mutation when she was 22 years old. Mia explained that she had always felt ambivalent about breasts, hers included. Breasts had become something that she associated with pain and suffering after seeing her mother suffer through multiple rounds of chemotherapy, radiation and surgery when Mia was a teenager. Mia's mother was diagnosed with breast cancer when she was 43 and had a total of three different primary breast tumours in the space of five years. Mia saw her mother's present breasts in many other women as she worked as a nurse in anaesthesia and on the ward in a large women's hospital. 'I know breasts from that aspect, distorted, the source of pain and death... I don't love my breasts, they are huge after breast feeding and in the end they are just going to end up in the grave.' However, she said after a pause, 'I think I might mourn mine once they gone.'

Following the recommendations of their doctors, Mia and her twin sister decided to undergo a regime of heightened surveillance for a few years after they tested positive for the mutation. This was not Mia's original plan. Mia told me how she and her sister had sworn that, if they received a positive result for their gene mutation tests, they would get their breasts 'just chopped off.' Mia explained that surveillance was largely done to appease her mother who often spoke to her about the 'beautiful thing' that was breastfeeding children. Mia said that she would have undergone the surgery much sooner if it had not been for her mother's insistence to wait until she had children to undergo surgery. After meeting her partner, an army officer ('he didn't run when I told him about me and my family,' Mia said with a laugh), the couple had two daughters. Mia had given birth to her second child three months prior to our meeting. Mia explained that she and her partner were planning to have a third child within the next 18 months [Mia gave birth to her third child in mid-2015]. Six weeks after the birth of her second daughter however, Mia spoke of having an overwhelming feeling in her body, something 'indescribable:'

Something in my body was overwhelmingly telling me to have surgery, so that I would definitely be here for them. If it wasn't for this gut feeling I would keep them [her breasts], so I can breastfeed my next baby. But I just had this gut feeling that it was time for them to go.

'I adored breastfeeding my girls,' Mia choked up as she spoke. 'I will miss the feeling of breastfeeding, of being with my baby, and I am scared the next baby is not going to want to snuggle in [but] I have to do what is right for me and for my children at the time.' After spending much time and energy deliberating, Mia decided to undergo a risk-reducing mastectomy with direct implant reconstruction. Although she had considered undergoing flap surgery, in which a part of tissue is removed and reconstructed to form breasts, Mia worried about the recovery time for this procedure. 'My two babies love to be cuddled, I can't take that away from them. Six weeks without being able to pick them up will be horrible enough, I couldn't cope with the three-month flap recovery.' With direct implants, she informed me, the recovery would be much shorter, so she could pick up her girls; 'at least with implants, my kids can snuggle me.'

The thought that her body parts, specifically her breasts, may become present in the way that her mother's had was, somewhat ironically, making other parts of body present to her. Before making the decision to undergo the risk-reducing mastectomy, Mia had been experiencing weekly debilitating migraines, vomiting and nausea from the stress she associated with her hereditary cancer risk. Her husband, during these times, took leave from work to help look after her and the children. Not all members of her family, however, understood Mia's need to make her increasingly present breasts absent. Her father, she recalled, protested when she told him of her intentions to undergo a bilateral mastectomy. 'Why would you do that? You might not get cancer and if you do you can deal with it,' he said. Even her mother who went through multiple breast cancer diagnoses and treatments struggled to understand or accept why Mia chose to remove what she thought of as 'healthy breast.' Mia remembers finding her mother's response particularly frustrating and upsetting as she was the one person she thought would understand her decisions. Mia remembers vividly how, while still in her teens, she would go and sit with her mother during her radiation treatments. She saw firsthand the immense pain she was in and the 'blisters on her tongue.' Mia thought that her

mother probably did not realise what it meant for her to question Mia's decision. Mia knew deep down that her mother 'wouldn't want me to go through the same thing' that she did.

In this example, we see that Mia does not want her breasts to become present like her mothers and the women who she cared for in the hospital. She does not want them to be a source of suffering and pain nor does she want her own daughters to remember her breasts or see their own in the same fearful light. Mia's concern that her breasts may become too-present, as sources of pain and suffering, does not however equate with a mind-body spilt. It is not the case that her ambivalent breasts are excised from her bodily bounds to protect her mind. Mia's decision to undergo her surgery was initiated by what she described as a profoundly embodied and somewhat indescribable bodily sense that it was time for her to remove them. It was not, for Mia, a minded, rational calculation of risk versus benefits. Mia was also astutely aware of forms of relationality that have been created and nurtured by her breasts as they nourished her daughters and created a bosom for them to snuggle into for comfort. It is with this in mind that she chose a reconstruction method that will allow her most rapidly to once again cuddle and pick up her children. Mia did not want her breasts to become present like her mothers' nor want her children to remember their presence in ways other than sources of nourishment and connection. This desire however was not understood by her parents. For Mia, her breasts were not just 'healthy breasts' as her father argued. Yet many other at-risk women did understand this complex and ambivalent relationship that Mia had with her breasts. Breasts and ovaries, for many of my informants, carried more than one meaning. Mia's breasts were important in creating relationships with her daughters, to the degree that she worried that her next child would not want to snuggle in to her, to be comforted by her breasts. Yet they were also parts that were present in another sense, as sources of suffering, of pain and of disease. These parts could become so present that they would in fact destroy the relationships that they had helped create. They could impede Mia's ability to 'be around' long into the future. Mia had to make her breasts absent so that they could not come to assume a presence like her mother's had.

## From absent to present body to body who is an absent presence

What Mia's experiences illustrate are the ways in which parts of the body, like the 'ticking time bomb' breasts or 'silent killer' ovaries, become present or become known to be present when the risk of hereditary breast and ovarian cancer is made known. What many of my informants reported was the emergence of a present body, or bits of it, and the relations in which it is entailed as they were made aware of their cancerous potential. This awareness or presence of body part does not necessitate a separation of mind and body, a splitting along Cartesian lines as would be expected if we were to read their experiences along the lines paved out by Kavanagh and Broom (1998) and Hacking (2007). Instead of experiencing a fundamental separation of themselves from their bodies, women at-risk of hereditary cancer want to return to the absent body, and absent time, as things run along habitually beyond their conscious attention. In what is a cruel irony, the means of achieving this habitual, absent body primarily entails removing the problematic body parts, that is, cutting off the breasts and recreating them or cutting out the ovaries and replicating their hormonal regulation through chemical alternatives.

As Tricia, a 34-year-old BRCA1 carrier, knew, it was absolutely critical to remove the breasts that had played such an important role in her relations with her family because if she did not, she would never be able to make them absent again. They had to be absent again, in order for Tricia's family life to be 'normal.'

My mother went through a number of different cancers and passed away from them and I was there with her throughout the whole journey. At the time, I also wanted children and wanted to ensure that if at all possible I could prevent them going through what I went through and watched Mum go through... I have two young children and I want to be around to look after them and watch them grow. I don't want to go through what my mother went through, nor do I want this for my family. I decided to have the surgery because having the check-ups every six months is like waiting for bad news and it is a constant reminder that I could get cancer.

No one wants to be constantly reminded of cancer, no one wants to have breasts so present, for the consequence would be its constant, lurking presence. Tricia required her breasts absence, so her family could go on.

Diana, aged 32, remembered when she first told her in-laws that she was having a risk-reducing bilateral mastectomy after she tested positive for a BRCA1 mutation the year before. For them, Diana recalled, her decision to have surgery was drastic, and overly cautious. They suggested that she 'just do screening' to wait and see what would happen. Yet, Diana explained, waiting to see what would happen was not an option – she knew what would happen. Her mother died of breast cancer at 40, when Diana was only five years old and during her childhood, Diana remembered knowing that this was 'not normal.' She knew from an early age that she and her sisters should be concerned. 'I don't want to get cancer, I don't want to go through what my sister did [her eldest sister was diagnosed with cancer in her forties], I didn't want to get cancer or have chemotherapy' she told me. Thinking about what could have been her reality, Diana held back tears as she spoke. She remembered that her husband's parents did make an effort to come and see her at the hospital and were very nice. But they 'didn't understand [the gravity of the situation] as they didn't have the experience of cancer.' About a year after her sister was diagnosed with breast cancer, her stepmother whom had raised Diana since she was a toddler was also diagnosed with breast cancer. 'This [diagnosis] felt like some kind of cruel joke. I couldn't believe this was happening to our family again, especially to my dad... this was another factor in my decision to have the surgery. If someone who doesn't have a genetic flaw can get it, what chance did I have!' Diana wanted to be proactive. She had the surgery, so she could forget about her breasts, forget about that 'sword that hangs over you.' Diana wanted to make them absent. By making her breasts absent, literally casting them off from her very person and the cancerous potential they possessed, Diana realised how living with such present parts had impacted on her life:

I realized after I had surgery, I realized that I thought I would end up like my mother, I didn't think I would make it past that age. I didn't want children because I didn't want to die on them. I didn't realize that this was why I felt like this until

after my surgery. I did not grow up as a kid knowing that I wanted to one day be a mum as I didn't think I would live long enough to see them if I had them.

Melissa, like Diana, felt like she had a 'time bomb in her body' as she wondered when she would get cancer and if it would be aggressive. Melissa decided that she would be 'better off to get a double mastectomy and be off for a few weeks' than develop breast cancer. Melissa was waiting to undergo her procedure at the time of our meeting. She told me that she often thought of how difficult it would be to explain breast cancer to her autistic son without scaring or upsetting him. However, she also worried about what would happen if her surgery went wrong, as it did for her sister, and thus failed to make her breasts sufficiently absent. Her sister contracted a number of infections after undergoing her risk-reducing mastectomy. Melissa was her primary caregiver and as such, Melissa's children saw the suffering their aunt experienced. Melissa spoke of how she would hate for her children to see her suffering in the same way. However, she remained vehement that the alternative, getting cancer, would be much worse. She planned to 'just keep going' till her risk was 'less than one percent.' She did wonder if the surgery would impact or change her relationship with her husband and her children. Being a major operation and physical change, she wondered whether her family would look at her differently. She had always had a 'love-hate relationship' with her breasts. She loved them because she 'had 32 years with them,' they were a part of her and were crucial in the creation of her family. Yet at the same time, their overbearing presence made her hate them. 'I hate them,' she declared, 'as they are going to make me sick.'

There is no denying that body parts such as breasts and ovaries are important in ways that are inherently gendered as Lily explained to me. 'I hate the thought that one day a doctor might say to my girls (assuming they were carriers) "you should have kids early, breastfeed for ages and then rid yourself of everything that makes you a woman."' These parts are important and present in the creation and maintenance of the family in multiple ways as Lily suggests. They cannot, however, come to be nor remain too present if the family is to continue on in syncopated habituality. As I have said previously, this is the rub of previvorship – that one needs to cut off the very parts that play a crucial role in relations so that they can continue as a presence, and more

importantly, an absent presence. As Billie et al (2010) argue in their work on loss and bereavement, the relationship between presence and absence is more complex than merely a relationship between two antonymic categories. They note that a paradox ‘exists in the properties of presence and absence showing that they inherently depend on one another for their significance to be fully realized and conceptualized.’ By holding absence and presence in concert, they take on meanings that ‘are local, complex, and not necessarily consistent’ (Bille, et al., 2010, p. 9). This seeming contradiction between absence and presence takes particular form among my informants, all of whom are striving for a particular type of presence. They want to be *absent*, as in habitual, absent as in ‘I don’t think about my breasts as ticking time bombs anymore.’ And yet they want a *presence*, as in ‘I’m still here.’ This previvor is still here, still in the family, but not haunted by the relentless anxiety her breasts might otherwise present to her as present parts. A present presence is undesirable; imagine worrying yourself sick each and every day, that cancer will raise its head as it did for many of your family members. And absence, in the form of death is, of course, the worst of all the scenarios. An absent presence – that is what previvors want.

## **Being around**

As the preceding ethnographic excerpts indicate, women at-risk of hereditary cancer experience the parts of their bodies that threaten to develop cancer as increasingly looming presences in their lives, preventing them from operating in habitual terms. This presence of, say, the breast, or the ovary, has the effect of making women realise just how important those parts are to making and continuing in social relations. Remember the ovarian sociality that lets women share in the experience of menopause as a collective and the breasted sociality that links babies and lovers with mothers and wives. One of the primary ways in which my informants returned things to normal, made present breasts and ovaries habitual, was, in fact, to make them absent – by cutting them off. But often cutting them off or out was not sufficient to make them absent in the way Leder (1990) speaks of, not sufficient to make them habitual. Women in my study had to find ways of replicating what those parts had done and been involved

in. Had they not, then the absence of those parts would, ironically, have made them continually present. Recall the examples I've utilised so far, in this and previous chapters, in which breasts are replaced so that lovemaking can continue in its habitual way. Or remember the ways in which cuddles are rehearsed so that other elements of touch – hands to backs, cheeks to cheeks – can be made of sufficient substance to bear the affective role of the hug, sans breasts. It is only when the relations between bodies can safely ignore the absence of a part that absence, in the true sense in which Leder (1990) means it, can return to familial relations. What these women I interviewed and spent time with want the most is to be present – present without cancer and for the long haul – in their families, but they want that presence to be characterised by habituality and an absent body. It is the absent body, fully present and alive in the family unencumbered by cancer or cancerous potentiality, that the women in my study wanted.

After undergoing her risk-reducing mastectomy, Laura felt that she was finally almost an absent presence. She explained how she was, for the moment, an absent presence, something she never thought she would experience after testing positive for a BRCA mutation:

It used to consume me, the breast cancer risk. My nan died of bowel cancer, or it could have been ovarian. It was a while ago so they didn't know. But it used to consume me, I always knew I was going to die of cancer, I have always known that. But ever since the surgeries I haven't thought about it at all. I am so glad [about my decision], the relief I felt straight away, the first three days are killers but it was so worth it. I was the first grandchild for my grandmother and she died a month before I was born and the same with my daughter, she would have been my mum's first grandchild but she died a year before she was born so I never expected to see my grandchildren or they never saw their daughters get married so I thought I would never get to see my children get married but now I am kinda excited for it. Because I think now I actually have a chance to see it, to see them grow up. I have broken this curse by doing this stuff. So it does get me a bit excited because I never thought I would see this day. I have that hope that I will make it there now instead of just expecting not to make it.

The deceased, Scheper-Hughes (2011, p. 178) writes, are uncanny; 'they inhabit rooms, closets, attics and clothing.' They also inhabit body parts in ways that challenge

understandings of bodies as ‘indivisible, inalienable, integral containers and signifiers of human existence’ (Scheper-Hughes, 2011, p. 178). As discussed in Chapter Two, women at-risk of hereditary cancer often experience their bodies collectively, inhabited by others across time irrespective of linearly arranged time regimes and the supposed boundaries of the flesh. As Laura felt most acutely, her body parts was haunted by her deceased mother’s and grandmother’s body parts – their cancerous breasts and ovaries. Their parts came to consume her. Her breasts, as reincarnations of theirs, became too present. It was only by removing and replacing them did Laura feel that they would recede into absence, breaking the curse that would allow her to become an absent presence – one that would be around to see her own children marry and have children.

Ashley was on her way to being an absent presence for herself and her family. After being tormented by cancer lying in wait, many parts of her body had been almost unbearably present. But now they were becoming increasingly absent, as was her sense that she might remain alive and be present in her family for the long haul:

I do [think about my risk] more now that I am contemplating the next surgery [a risk-reducing salpingo-oophorectomy], but I go through [periods] not thinking about it too much until something pops up or I have a decision to make, like at the moment. But generally I go through life not thinking about it and not thinking about breast cancer much anymore. I am trying to enjoy life and plan lots of holidays with the family and our time ahead... I guess when I first [found about the double mutation] I was a bit scared about looking forward to the future as I didn’t know what was going to happen but now there is a bit of space... there were times when it was really tough to think [positively] but in the end I was sick of worrying... I think we will travel and have holidays and I really love working, the last few weeks have been great. And my husband wants to get into the police force. He quit his business and sold the equipment. So it is all happening. We have allocated a holiday fund so we can do holidays. We definitely now have that mindset that family time is so important and that we need to have good memories and doing things with the kids. And that is another reason my husband sold the business as he didn’t get much time at all with the boys and now he is a house husband and he is loving being at home with Tylor and dropping Ben at school. So I think, through all the hard times, we now have a really good balance. We have family time, time with the kids instead of always working. And onwards from there every year [we will travel], it’s all about having good times together.

Now that her breasts and soon-to-be ovaries have receded into absence, Ashley finally feels that she can begin to once again plan her life and her family around shared times and activities. She makes plans around being together and enjoying the syncopated family life of going on holidays and taking the kids to school. Now that her body, and the body of her sick child, are slowly returning to absent presence, she feels able to appreciate the time they have together as once again unrestrained or limited:

I thought going through [cancer] with my mum, I was already cherishing things more but now that I have gone through [surgeries] I cherish things even more. Time with my boys is special and enjoying life is important. Like at work, I am so happy and I would never have been like this before. I am so happy, just getting out I am so happy. I think having a tough time with Tyler over the last two years and the times I couldn't get out because I was dealing with a chronically ill child, I think that was really tough. That was even a lot tougher than a lot of the cancer stuff. But now that he is well and I am getting out and working, I am like this is awesome, life is really good, I am not dealing with all of this anymore. I have to write that down so I can remember it, it is just so good having everything go well at the moment. It's a long journey... But you never know how things are going to work out. So hopefully by not panicking, hopefully it will all work out.

Bridget, 33, was also becoming an absent presence like Ashley after she underwent risk-reducing surgery. After going through a period of recovery and adjusting to her reconstructed breasts and their role in intimate relations with her husband, she found she did not think about her risk or her breasts anymore. She explained how her BRCA2 mutation and cancer risk:

consumed my thoughts for most of 2013... I'm a stay-at-home mum to four young kids so the decision to have surgery and not be able to 'work' for periods of time was a big deal. [My husband] had to take a lot of time off work and do a lot at home while I was recovering. We've had to deal with emotions and new ways to be intimate. [But] it doesn't impact my day-to-day life now.

For Kat, having undergone her risk-reducing mastectomy and experiencing what she described as life playing the 'sick role,' she was likewise relieved to be able to resume an absent presence in her everyday life:

For me, it's over. Once I get my ovaries out it will be over. That gene will not affect me... We had the shittiest year last year but now, in two months time we are

travelling for four months and we decided not to have nipple reconstruction and to use that money for our holiday as well. So there are all these things that are a positive thing, I think.

But sometimes, the presence of potentially cancerous body parts did not go away as expected despite undergoing risk-reducing surgeries. Vanessa, 51, could never again take up a position of comfortable absence, could never watch the calm receding of presence back behind the horizon of absence after beginning surveillance for cancer:

I just think when's it going to stop, when will it stop?... I think it's something we are always going to deal with. I saw my doctor on Thursday and he still wants to keep my appointments to every six months because apparently the liver is part of BRCA2 which I didn't know. So he wants to keep an eye on my liver and I am thinking 'oh no, now it's the liver! If only they could eliminate every body part then I would be set.' That would be good. It would be great. But I can't do that.

Like Vanessa, Lucy felt exasperated by her situation. Suffering from multiple surgical complications following her risk reducing mastectomy, she felt that she would never achieve the absent presence she sorely craved:

It's like as many surgeries I have done, there is still more to do. Like after I have my ovaries out, my doctors are talking about bowel scans. How many more body parts do I have to worry about? How many more can be removed?

For Vanessa and Lucy, bearing a mutated BRCA2 gene meant that they felt a constant presence of body parts. They experienced an ongoing cycle of presence, removal, absence only for another part to take up presence – the liver, the bowel. For other informants, it was less of a cycle of parts dys-appearing as present and receding as absent as their potential cancer risk was identified but rather that body parts attained a new type of presence as a result of risk-reducing surgeries. No longer present as a result of their cancerous potential, these parts dys-appeared as they took on new sensory qualities. Often reconstructed parts felt different, making their presence known, in a way that could not be ignored. Kathryn, 55, spoke of the ways she felt physically different after her risk-reducing mastectomy and reconstruction many years after the surgery:

My body does feel different, my muscles are on top of the implants but they still get really sore and numb even now. When I bash my implants [into things] I still can't feel it. My ribs also often hurt. I look the same as I did before but it feels very different. It's hard to explain to people, they ask 'are you better now?' and I have to explain, no it is ongoing.

Billie also felt her reconstructed breasts to be very present, not for their cancerous potential, but in the way they did not feel, did not have sensation, as they previously did. Their physical absence, ironically, made them very present, somewhat akin to the phenomenon of 'phantom limb' described by Merleau-Ponty (1962, p. 76). For Merleau-Ponty, when someone experiences phantom limb, it is because their body remains open to the kinds of acts that involved the limb if it were still operative (1962 in Toombs, 2001, p. 201). This is true of Billie, who continues to feel the sensations of her natural breasts such as itching although all of her feeling breast tissue has been removed and replaced by a non-feeling implant:

It took me a little while to get used to how they felt. Some of it is just... it's weird to know that something is there but not feel it. It would be weird, I would feel an itch but there is nothing there for me to be itching but I could feel it and just the way they move when I move in certain ways, you know, even still sometimes when I pick something up or I don't know, I lean on one side, you know. And underneath the muscle, everything just kind of goes up and I'm still a bit self-conscious. I'm more aware of that than I probably need to be because I feel it. I feel like everyone else can see it.

Remember back to Chapter One and to Anne's efforts to remove the body parts that had become too-present as a result of her BRCA2 mutation but also their former role in creating and maintaining a relationship with her now-deceased, adulterous husband. Despite removing her breasts and choosing not to reconstruct them, they remained a present reminder of the relationship she had with her husband before his pornography habit and cheating was revealed. Her body, even without these body parts, still remembers what it was like to be sexual with her husband and to feed her children. They remain, for Anne, an uncomfortable presence despite her best attempts to render them absent:

While I don't have my breasts I can still feel the sensation of them being there, I can still relate to being a sexualized being, of having erect nipples, especially after exercising when my muscles become tight. I get false breast feeling. Sometimes my remaining muscles react like they did when I was breastfeeding or having sex. If I massage the area I can help make it relax but that's not something I can really do in public!

For some informants, it was not the physical changes to the body part after surgery that prevented them from returning to habitual absence. Rather it was the ways in which these parts bespoke relationships to others, both desired and cherished relations and those that were unwanted, ready to be cast off. Despite their best efforts to return to a state of absent presence, women such as Billie and Anne still struggled to achieve the habitual disattendance with their bodies they sorely craved. The pain, frustration and sadness that accompanies the inability of a body to recede back into habitually as an absent presence was something that Anya Silver felt most acutely.

## Death and absence

Anya Silver (2014), poet and literary scholar, wrote the poem *The Hazel Tree* for her son Noah:

The mother died and grew into a tree.  
Through the loam, she webbed her roots,  
bones branching, leafing, ripe with sap.  
In time, her body fruited, rich and brown,  
each nut a word she'd grown to tell her son  
now that her speaking human voice was gone:  
that she'd chanted stories in his blood,  
sown language in his eyes so he could dream.  
He hears the cooing of the mourning dove,  
its black band pulsing as it sings. The day-  
light's gold and glass and soft gray wings.

Anya was diagnosed with inflammatory breast cancer, a rare and aggressive form of cancer, when she was 35 years old and pregnant with her first child Noah. Despite undergoing chemotherapy while pregnant and continuing extensive treatment following the birth of her son, Silver's cancer returned after five and half years of

remission. Silver now has terminal metastatic breast cancer. While her physicians suspect she may carry a genetic mutation linked to her diagnosis, she tested negative to both BRCA1 or BRCA2 mutations. In *The Hazel Tree*, Silver writes of the legacy that she wants to leave behind for and through her son. She speaks of the gift of stories, memories, language and creativity that she has, through creating and giving care, inscribed into his very being. These gifts, Silver envisages, will live on in her child long after she is gone. They too will manifest into the tree that she plans her ashes to be buried beneath. She will become part of the root ball that will be taken up by the tree, becoming the nutrients that will help the tree to fruit, leaf and nut, just as she hopes that the skills, the stories and the love she planted in her son will continue to sprout long after her death.

When is it, Derrida (1995) asks, that we are most aware of our own mortality? It is when facing the likelihood of death, he concludes and, more importantly, of those social relations that are inextricably tied to our fleshy existence; both in the sense of its embodied and biological existence as Anya so poignantly expresses. Thanatophobia, that is the fear of death, of one's own mortality, is often drawn upon as symptomatic of modernity, as more people look to medical technologies as a way of overcoming their own mortality (Beck, 1992). The fear of death was certainly spoken about in my informants' explanations of their decision to undertake risk-reducing surgery or regimes of surveillance. If we look beyond the death of the person however we can consider what such a fleshy demise might mean for the social relations in which the body is inherently entwined and how this is directive towards particular forms of action. The significance of this particular approach is in the insights it yields for understanding how women make sense of the impending loss of the potentiality of shared flesh, this being instrumental in creating relations of the family. It is at this point that Derrida's theorising of death is pertinent. Facing death and absence, Derrida (1995) writes, is a situation in which one's entanglements with others is most deeply felt. The surrendering of one's own life is not sufficient to ensure another's immortality. However, Derrida suggests, one's very being in the world, as a social body created and maintained through fleshy interactions with others, inculcates a certain type of relationality (see McQuillan, 2005). In quoting Levinas, Derrida writes:

I am responsible for the death of the other to the extent of including myself in that death. That can be shown in a more acceptable proposition: 'I am responsible for the other inasmuch as the other is mortal.' It is the other's death that is the foremost death (Levinas in Derrida, 1995, p. 46)

Here, we are not only talking about a physical death, but rather a death of the bodily relations of sociality that are crucial to creating and maintaining people in familial configurations. As the examples I have detailed above suggest, this recognition of the fleshy, partial collective of the family, produces a situation in which women at-risk of hereditary cancer remove certain, and significant, body parts to ensure continuance of the family and their absent presence within it.

Drawing on Heidegger's phenomenological insights into death and being-towards-death, Peters (2004) submits that fear of death exposes the inherent sociality or collectivity of fear. The fear of death itself is surpassed by fear of the fear experienced by loved ones who will live on in your absence. He writes 'but what if the fear of fear was not a fear of one's own fear in the face of death but the fear of the other's fear?' (Peters, 2004, p. 4). Fear, Jain (2015: 182,199) asserts, is a 'central, understudied aspect of cancer... that sticky, primal emotion, cements so many unspoken elements of the cancer conglomerate.' Peters details the existence of a dire need felt by those dying to attend to other's fears and one's own fear of this fear, it being:

a genuinely intersubjective solicitude concerned, primarily at least, not with the demise of the self, but, rather, the fear the other has in the face of that demise. It is the other's loss, their suffering, their pain that opens such fear out... The thought of (let us say) my own death is fearful to me to the degree that I am able to empathize with the fear of my child whose fear is not for my fear (the necessary dissymmetry that both interrupts and enlivens all empathic ambitions) but for my absence. Not my absence as a body, as a father/mother figure, but *my absence as a particular weave within my child's internal time consciousness, my absence from the future and futurity of their identity – their own partial death*. It is this fear that might compel me, when death is certain and definite, to intensify my engagement with the future in an effort to 'keep alive' for the other [my emphasis] (Peters, 2004, p. 4-5).

We see this intensification of engagement with the future and one's future absence in Anya's attempts to instil her presence in and through her son in the form of words, stories, embodied memories and bodily acts of care. For her, these seemingly mundane but crucial acts represent a means of writing herself into her child's future identity, of 'being around' for him despite her physical absence. Anya sought to prevent what Peter's calls the 'partial death' of elements of her child that may accompany her own passing. She endeavours to live on in some tangible form, as a tree, a nut, a fruit that can communicate with her son and her partner when her 'speaking human voice was gone.'

As Peters (2004) ascertains, the family as a social unit is likely to continue onwards after the death of a family member such as the mother or father. However, it will be fundamentally different to what it was, and what it could have been, had the person lived on. He continues:

the futurity of death is not conceived of instantaneously as absolute discontinuity, but, rather, as a *fearful hollowing out of continuity as one among many futures comes to an end...* Thus my child's fear in the face of my death is not only the fear of my absence but of an *absence that exceeds me, that opens out onto a plurality of past futures that I carry within me...* These are 'part of me' as that which I never was or will be, a pluralisation of my absence... [my emphasis] (Peters, 2004, p. 12)

In this pluralisation of absence, the death of a loved one issues forth a partial death in one's familial others that is not only of the 'now' but extends into futures, curtailing certain possibilities and trajectories. As a loved one passes away so too do the physical, material and the *embodied* connections that created and maintained the family as a site of part-ial engagements, whatever form it takes. Loss is thus co-constituted and shared not unlike the body. The recognition of this death of key, partial relations may prompt the dying person to make efforts to protect these relations and the ways they will be remembered and memorialised:

the dying man or woman [may] compress a 'life' into a discourse of memory that significantly heightens the sense of loss. To 'die well' in this sense... [is] providing the other with a life that is capable of being lost, it is to provide the other with the material necessary for their own suffering (Peters, 2004, p.10).

The death of the person becomes the death of a certain configuration, experience and embodiment of the family. After death, this configuration transforms into embodied memory, a point that Peters makes when he suggests that 'my absence' is an 'absence that exceeds me, that opens out...' onto others. One's physical death does not necessitate the destruction of all connections with the living, as Peters (2004), Desjarlias (2016), and others remind us. Indeed, we need, as Bille et al (2010, p. 5) argue to pay closer attention to the 'ability of such absences,' of a person or thing, 'to imply and direct attention towards presence.' Losses are able to have a 'powerful presence in people's lives precisely because of their absence.' Losses change and alter the family in profound ways. Strathern (1992b), in her work on kinship in England, observes these ways in which the presence of an absence fundamentally alters possibilities for ongoing relationality in the family. 'At death' Strathern (1992b: 108) asserts:

the deceased [is] colloquially 'cut off' from a stream of existence that was more than him or her, as he or she was cut off from an active part in social relationships. Death terminated the enjoyment of relations, such as marriage, that remained thereafter frozen in the record.

Death forecloses particular temporal horizons and modes of relationality. Taking note of phenomenological understandings of temporality, Geertz in 1966 put forth the notion of social time as an awareness of the passing of time that is marked by the disappearance of concrete persons. This notion of time as experienced by the passing of significant others has particular relevance for those belonging to a family affected by hereditary cancer, as they often come to face mortality at an early age. Witnessing this 'disappearance of concrete individuals,' of grandmothers, mothers, aunts, sisters, fathers, in prolonged and painful ways, and living with the enduring emotional weight of such embodied absences has a profound effect on at-risk women (Geertz 1966:374). To curtail the chaos and suffering, the enduring presence of multiple absences that may accompany generations of cancer diagnosis, at-risk women work to ensure that the endings foreshadowed by hereditary cancer syndromes do not eventuate. As I detailed in this chapter, this endeavour often entails the decision to forego parts of one's body, those that are so crucial to making the familial unit. Felt memories and bodily archives of the breasts', ovaries' and wombs' (partial) role in the enfolding of familial others are

set to be removed, surgically, from the body, bringing to the fore feelings of loss, grief and uncertainty. However, attempts to secure an absent presence sees that the removal of such parts may in turn prevent a breast or an ovary, from becoming its opposite, a destroyer of the social body and familial relations by allowing its fatal cancerous potential to be realised.

Let us return to Anya. She spoke directly to the notion of presence, as she worried that she might not be present for her son's progression from childhood to adulthood. She told me:

I definitely feel that with my son... I have to give him a foundation and certain value system now and I can't wait to instil certain things in him because I have to put him on this path now in case I die, you know. There is this constant feeling like I am performing. The way I feel in life is that I'm always performing for other people's memories and I feel that especially with my son. I want to do things and behave in certain ways so that he'll remember me in a certain way when I die. So it's like I'm outside of my life looking in on this performance of my life, this performance for other people... And that is the problem with death because you become intangible. And even if you're a religious person, you're still intangible and I think, like last night, he said to me 'can you kiss my pillow so that I have a kiss on my pillow forever'... There is a sense in death that you want to hold onto something and give your child something to hold on to and that's why I want be buried in a tree [chuckles]. I want there to be this tree he can go to and say 'my mum is in this tree, this tree is my mum.' I want there to be something living.

Anya wanted desperately to be present in her son's life. She wanted to 'be around' for him for as long as she could. But the treed presence she told to me, material and tangible as it was, could not be the absent presence that all my informants wanted to obtain. This absent presence is not only one we can describe as 'habitual,' and 'behind present attention,' but one characterised equally by the relations that absence enables. The absent breasts, cut off and yet still present as they had been replaced by implants that women such as Ashley and Laura, were now presently absent, for their lovers and their kids, entailed fully in a sociality of the family. A sense of belonging arises from joint experiences of real parts or, indeed, replacement parts that stand in for the relations that were once issued from and received by real breast flesh. Reconstructed breasts do not just replicate the swelling one needs to wear a sweater, so that the ravages of pre-

cancer are conspicuously absent to the casual observer. They also collect up the enfolded relations that breasts once did, sufficient enough for an absent body, sufficient enough to be a continuing presence.

## **Conclusion**

In this chapter, I have argued that, rather than causing a Cartesian divide between mind and body, being at-risk of hereditary breast and ovarian cancer makes women aware of how integral their bodies are to the making and caring of the family. At-risk women feel bodily parts as dys-appearing, that is, becoming increasingly present, in a way that interferes with the habitual interactions of the family (Leder, 1990). While the 'present' breast or ovary draws attention to their role in certain socialities, it impedes these operations in the everyday – it threatens one's ability to 'be around' for their loved ones. One of the key ways that my informants sought to make these body parts absent, to achieve an 'absent presence,' was to remove them from their bodies. Removing the part, however, was alone sometimes not enough to make them absent. These parts were replaced and replicated, so that their absence would not infer a presence. What my informants really wanted was to be present in their families unencumbered by cancer or death. These women wanted to be an absent presence, to be part of the habituality of the family borne in and of the fleshy interactions of everyday life. To be fully present and alive in the family was what the at-risk women I met wanted most.



## Conclusion

But worse than any of this is the appearance of other mothers' mothers. . . Other mothers' mothers. I devour them more jealously than a wife devours the anatomy of a husband's mistress. Their thickening waists. Their sensible footwear. Their silvered hair, cut expensively in stylish bobs or plainly chopped. I study their skin, which menopause has turned parchment thin or plump and glabrous. How would my own mother have been? I wonder... So I stand in the playground studying the other mothers' mothers... Afterward, I have auditory hallucinations of their voices.

- Sarah Gabriel (2009, pp. 195-197), *Eating Pomegranates: A Memoir of Mothers, Daughters and Genes*.

Sarah Gabriel has experienced firsthand what it is like to live without one's mother. She covets, from afar, the mothers, now grandmothers, that take their place at the playground, watching their grandchildren dance, skip and scurry about. Gabriel can only wonder what her mother would look like, sound like, move like and dress like as a grandmother, having lost her decades prior to cancer. She is haunted by these other mother's mothers. Their voices follow her, reminding her of what she does not have.

In this conclusion, I want to reiterate the importance I have placed on informing socioemotional dimensions of hereditary illness in and through what genetic relatedness can tell us about bodies. I have taken this stance throughout the thesis, and in closing, I want to attend to pain, suffering and death to make it once again. The basic tenets of genetic inheritance inform us that the body is anything but bounded and discrete. The person is a product of the partial inputs of others (in the form of genes) that recombine to yield a hybrid being. In paradigmatic anthropological analyses of genetic and hereditary illness, the bounded and discrete 'individual' is the key figure that experiences the pain and suffering of pre-cancerous life. While it is, of course, the case that the at-risk woman feels pain in her own body as no one else can, and while it is she who may die when other bodies go on living, these experiences are relational. Taking my cue from Strathern's (1995) reimagining of the body as hybrid, I have argued that to understand the illness experience of women at-risk of hereditary cancer we need to attend to body as something that is inherently partial, porous and always relational.

I want to return here to an important distinction I have argued across this thesis. The concepts of individual, person and self, as I outlined in my introduction, are often conflated or used interchangeably within anthropology (Harris, 1989; La Fontaine, 1985). In this thesis, I have sought to distinguish between what I identify as the key analytic unit used by anthropologists of hereditary cancer, that is the bounded and discrete 'individual,' and what I consider to be the broader but more appropriate term 'person.' The person, I argue, is a more useful concept for approaching illness experience as it encompasses the partial, permeable and interconnected body that was described to me by my informants. In using the term person, rather than individual, I am not suggesting that the self, that is, the experience of one's own existential 'someoneness,' as Harris (1989, p. 601) describes, does not exist. Nor am I suggesting that attending solely to 'the social' can encompass the fact that one physical body will bear the brunt of pain, suffering and may die. Indeed, it would be foolish to do so given that my ethnography is comprised of the stories of people such as Beth, Lily and others who, just like Sarah Gabriel, experience the death of their loved ones as precisely the loss of a unique person. The pain of cancer treatment or pre-treatment – radiation, chemotherapy and surgery – and the death of the person from cancer are, necessarily, borne out in one body that will hurt, and will die.

Pain and death, in this sense, are inarguably experienced by an identifiable person. It was Sarah's mother who endured multiple rounds of chemotherapy and radiation and Sarah's mother who died from her metastatic cancer. However, insisting on the singular bounded and discrete 'individual' that suffers and dies, does not encapsulate the entirety of the experience of living with hereditary breast and ovarian cancer. Even when an identifiable 'individual' suffers from pain and dies, these experiences do not stay bounded. The spectre of cancer, suffering and death are deeply embedded in the familial bodies which, through their partial deployments, create and constitute one another. Recall how Lily described her breasts as entailed in her relations to her children outside of their nutritional functions. She would be 'furious,' she told me, if her breasts, once removed and reconstructed, 'got in the way' of her playing with her children. By returning to the stories of Beth and Lily, I refer to the key analytic themes that I have

developed over and across this thesis. In and through their reflections, I hope to lay bare my re-envisioning of the body as necessarily partial – not discrete, nor wholly ‘individual.’ This approach allows for a recasting of the family as founded in the partial relations of the flesh. The family is produced from partial, bodily inputs of others just as the body itself is yielded by partial, genetic contributions of others (in the form of genes). Bodies, in this sense, are always and already enfolded into the bodies of others.

## Shared insights

In critiquing biomedicine and genetic technologies, anthropologists of hereditary cancer have cultivated a relationship with genetic medicine that limits our understanding and appreciation of the complex illness experience. In adopting a combative stance to genetic medicine, anthropologists have maintained that they possess a fundamentally different understanding of the body that is required as a corrective to biomedical and genetic approaches. These critiques have an historical genesis in disciplinary concerns over the misuse of genetic knowledge as evidence of inherent racial differences and in service of eugenic programs and ideologies (see Fujimura, et al., 2008). Anthropologists, Fujimura et al (2008, p. 644) posit, have vehemently asserted the need to study racial differences ‘as political, social, cultural, and psychological processes,’ rather than genetic information. These concerns remain relevant. Recall Abram’s (1996) comments upon which I drew in Chapter Three. These remarks attended to the differences between medical and experiential understandings of sick or malfunctioning body parts. As Abram (1996, p. 4) asserts the ‘breathing body ...is very different from that complex machine whose broken parts or stuck systems are diagnosed by our medical doctors.’ This is indubitably the case. The issue I take in this thesis is with anthropologists of hereditary cancer who assert that medical knowledge can *never* inform how the discipline understands and analyses everyday life.

As anthropologists we need to see what concepts are shared between anthropology and genetic medicine and how they can inform disciplinary enquiry. I have taken a genetic motif in this thesis, the idea that partial contributions (in the form of genes) make the person and shown its continuation into the realm of the social; that is, partial

deployments of the body parts of persons make the family. Some parts, like breasts and ovaries, forge powerful socialities with parts of other bodies. These parts, diseased or potentially diseased for my informants, shift from unreflexively foundational to familial life to frighteningly present. One of the key wishes of my informants was to return present body parts to absent presences. If they do not, it means that the sick part will remain the subject of concern. If they cannot, it means they may die – they will not be absently present but deathly absent.

Adopting a social and partial concept of the person, and the family, allows for insights into previvorship that provoke a reconsideration of the antagonistic stance taken by anthropologists towards genetic medicine and rearranges the foundational concepts of existing anthropological approaches. By adopting partiality and collectivity as key motifs throughout this thesis, I have departed from established anthropological analysis of precancerous lives that pivot around the individual who acts either selfishly or selflessly in her relations to others. By attending to partiality, I have been able to draw attention to the importance of significant body parts in creating the sociality of the family, albeit often unreflexively. The need for these parts to operate habitually and in syncopation with familial others is crucial and is what makes removing these very same parts to secure an ongoing presence in the family so worrisome.

Anthropologists involved in establishing the theoretical foundations for considering hereditary cancer such as Finkler (2001, 2003), as well as influential others, such as Sachs (2004) and d'Agincourt-Canning (2006), have shown great trepidation towards genetic medicine and its propensity to 'medicalize' the individual and the family via genetic testing. For Finkler (2003, p. 405), genetic medicine transforms the body into 'abnormal, disconcerting states, thereby separating the individual from the rest'. In worrying over the individual being isolated from her social and cultural context anthropologists have, somewhat ironically, fallen back on the individual as the key analytic figure through which to understand illness experience. This is ironic given the concern routinely voiced by anthropologists such as Finkler (2000, 2001) and Novas and Rose (2000) over the capacity of biomedicine to produce the 'individual as isolate.'

Indeed, Helman outlines such critique of individualism as a core research agenda of medical anthropology:

A feature of much of the medical anthropology literature since the 1980s has been its criticism of modern Western medicine (often termed *biomedicine*), especially for its reductionism, mind-body dualism, focus on the individual rather than societal problems and its view of 'diseases' as universal, cultural-free entities (2008, p. xiv).

And yet, as genetic thinking reminds us, the 'individual' is anything but isolated in any bounded, discrete sense. Bodies are made of the 'combination of materials' from unique persons which 'create new and unique persons' (Edwards & Petrović-Šteger, 2011, p. 11). Genetic inheritance, as such, bespeaks relationality and the co-construction of the person. As Strathern submits:

At the molecular level, *genetic elements recombine*; at the level of the organism, the joining of sperm and ovum creates offspring identical to neither biological parent but *containing elements of both*. Persons, in this worldview, are 'natural hybrids' (Strathern 1992b: 111[my emphasis]).

The very making of the person, Strathern (1992b) reminds us, hinges on relationality as the partial input of other bodies recombine to create anew. In jettisoning genetic knowledge of the body as both inherently composite *and* unique, anthropologists have overlooked the usefulness of such perspectives for understanding how at-risk women make sense of risky bodies. Such oversight into the partiality of bodies has had a significant impact on the ways in which anthropologists have interpreted women's decisions to undergo genetic testing or risk-reducing surveillance and surgery.

## Shared bodies

One consequence of framing the at-risk women as a bounded, discrete individual who relates to other individuals in a network is that it lends itself to particular readings of her actions as either selfish or selfless. Existing analyses of women's decision making inherently invoke the categories of selfish or selflessness to explain risk reduction as a consequence of her mutation status and her gendered duty to care for her affective *and*

genetic kin. In the existing literature, the at-risk woman is selfish if she does not disclose her risk to her relevant genetic kin nor participate in a regime of risk reduction. She is selfless if she gives up her reproductive desires to prevent the gene mutation transmitting to future generations or sacrifices her cherished body parts to prevent cancer from developing. This reading, as I described in detail in the introduction and first chapter of this thesis, is common in the anthropological literature. Such an approach, however, offers very little insight into the ways in which women experience their bodies, their families and their risk of hereditary cancer in the everyday, outside of the high-pressured clinical encounter. Indeed, much of the anthropological research completed to date has taken the clinical setting as the primary ethnographic site for data collection and analysis, a space the at-risk women often attend alone.

By taking a perspective on the body as constructed from the partial input of others, as is the case in genetic medicine, I put forth an understanding of the partially constructed person. This approach allows me to give attention to the experiences of living with the risk of hereditary cancer outside of the clinical, biomedical setting and within the spaces of day-to-day life. In the first and second chapters, I drew upon the work of Lyon and Barbalet (1994) to craft an understanding of the family that is premised on the habitual deployment of body parts to receiving body parts, these movements driven by emotions such as that of care. We see this emotion of care as impelling bodily interaction in Lily's description of caring for Beth during her treatment in the vignette below. The family emerges as an institution that is created and maintained in and through the fleshy relations existing between acting body parts – Lily's hands reaching to Beth's arms to stabilise her walk back to the car after chemotherapy, Lizzy's chubby fingers writing cards for Beth eyes as she convalesces in bed. As I suggested, particular parts of the body are more important than others in crafting this intercorporeal sociality. Breasts and ovaries, the parts most at-risk of developing cancer for women carrying BRCA mutations, are highly significant in creating and maintaining the family. I developed the notion of breasted and ovarian sociality to describe the ways in which these body parts reached out to and encompassed others to create the fleshy relationality of the family. Breasts were met by the mouth of babies, ovaries produced the eggs that, when met with sperm, would create children. In the process of risk reduction, at-risk women often

removed these significant body parts. In the absence of breasts and ovaries, approximations of these body parts, in the forms of implants, altered techniques of the body or hormone replacement therapy, were deployed to ensure that the socialites hinged on them could continue unimpeded. This circulation of body parts reaching out to and being received by those of familial others illuminates the collaborative construction of not only the family, but the person herself.

Recall the comments Lily made about her ovaries in regards to her young daughters in Chapter One. A few months after our initial discussion in which she voiced her concern about losing her fertility, Lily elaborated on her fears. She told me:

Thinking about risk reduction surgery makes me second guess myself a lot. I am not a gambler but if I was, I would definitely err on the side of caution when it comes to cancer and potential risk reduction surgery. You'd never want to lose the bet when cancer is the result. But on the other hand, there's a 40% chance I may be removing perfectly healthy body parts... While I am probably going to have a hysterectomy, it saddens me that if one of my children ever had trouble with fertility, I wouldn't be able to donate an egg to help them. I am going to look into freezing eggs but again, I'm told this is costly.

Although Lily's ovaries dwell inside her body, they expand across both time and space to be taken up by her daughters as she, too, worries that hers will develop into her own mother's cancerous ones. As I discussed in Chapter One, we could read Lily's comments as indicative of her acting out her gendered responsibility to both surveil her own body and fulfil her obligations to provide for her family, especially her daughters. But to do so is to overlook the ovarian sociality that hinges upon her body parts or the potential lack thereof. For Lily, her ovaries and their functions are equally her daughters' just as hers may easily become her mother's. Body parts, in this reading, resist confinement to one bounded 'individual' despite their physical location in an identifiable body. As detailed in Chapter Three, Merleau-Ponty (1968) draws our attention to how one's body, comes to be created and completed by others, in a fleshy form of relationality. The actions of seeing and feeling complete the body by holding it in attendance. Instead of viewing Lily's comments through the prism of selfish or selfless behaviour, we can move beyond this reasoning and its reliance on a fixed, bounded and discrete 'individual' to

appreciate the ways in which her body, and body parts are co-constituted in concert with the partial deployment of others across time.

## **Shared time**

In offering forth this vision of the family and the at-risk woman as co-constituted and inherently partial, I examined how other aspects of the illness experience, such as time, are equally shared, fleshy and partial. In Chapter Two, I put forth Timmermans and Buchbinder's (2010) concept of the 'patient-in-waiting' as symptomatic of anthropological approaches to women at-risk of hereditary disease. In this concept, the woman dwells in a liminal time, waiting for cancer to come. The issue with such an approach is that it insists upon a linear arrangement of time as it pertains to the discrete, individual body. As evident in a number of my informant's experiences of part/ial relationships, time emerged as something that is fundamentally familial and shared, and as such, is not experienced in isolation. Time, similar to experiences of breasted and ovarian sociality, unites bodies and body parts in ways that do not respect discrete linear boundaries. In the stories of Valerie, Penelope and Masha Gessen and in the opinion piece of Angelina Jolie, we saw the ways in which bodies are co-present across time and space. Parts of bodies, a mother's cancerous breast, for example, came to inhabit and occupy the bodies of their daughters as they considered their risk-reducing options, just as genes fuse together to create new bodies in and across time. Time, for at-risk women, was experienced in shifting, cyclical and non-linear regimes, in moments of collision of past, present and future that upset our commonplace understandings of the linear unfoldings of day-to-day life.

Lily, for example, worried that her daughters would come to occupy the time regimes of sickness and disease that her mother experienced during her cancer treatment. What will happen, Lily wondered, if she too develops cancer like her mother and grandmother, and her daughters have to take up the role of caregiver as she is diagnosed with cancer and undergoes treatment. Will this cycle of hospitals and hospice, of pain and suffering, Lily worried, extend forth to them? Or what if her ovaries and then her

daughters' ovaries come to be diseased like her mother's? Lily explained how she concerned:

that [the] day will come when a doctor says 'there is nothing we can do' and that makes me sad. And while I hate stats and numbers, I often count the years since [Beth's] diagnosis... I worry that if I don't have risk reduction surgery, I might get cancer and then that will [likewise] impact [my children]. It sucks that there are so many members of one family that can be impacted - because it's genetic, of course. I worry that my kids (who are too young to understand a cancer diagnosis) would think that hospitals, surgery and regular visits were normal in every family.

Concerned that her mother, herself and her daughters will come to share the same diseased parts and same illness trajectory, Lily also stressed over how this cycle of cancerous becoming could impact on the day-to-day rhythms of their family. In Chapter Two, I considered how temporality is shared in and through bodies and thus produces the co-temporal body of the family and the habitual rhythms of familial life. I detailed the micro-rhythms through which the family is created and maintained. These rhythms are established through the habitual and partial deployments of bodies and body parts, in syncopation with those of others. As evident in the stories of women such as Lucy, Leanne and Kat, these familial rhythms were important and worthy of protection. Threatened to be disrupted by cancer and illness, these syncopated and habitual family rhythms dys-appear for women at-risk (Leder, 1990). At-risk women, like Lily, come to worry that the rhythms of illness, of hospital visits, surgery and enduring treatments regimes, will not only interrupt but replace the established rhythms of the family. These shared rhythms emerge as vitally important to the functioning of the family. The ability of illness or death to ultimately disrupt the syncopation of the family was something that many of these women had experienced as their own mothers and sisters were diagnosed with cancer. Women at-risk of hereditary cancer worked hard to re-establish the corporeal beat of their families, be it through establishing routines around surveillance and surgery that fit in with the sleeping, eating, travelling and working of the family or in planning milestones such as weddings, birthdays and Christmases to ensure that the temporal experience of family members, of the familial flesh, remained syncopated.

Consider again the experiences of Beth and Lily – despite an initially good response to treatment, Beth’s cancer returned in 2014 and she underwent another course of chemotherapy. Beth’s inability to engage in the habitual and syncopated rhythms of her family life became a source of great frustration and sadness for her. I witnessed the importance of being entailed in familial rhythms when we travelled to New York together with Lily, Beth’s brother and her niece to attend the FORCE conference. Having recently finished a round of chemotherapy and preparing for further gastrointestinal surgery, Beth was placed on a restricted low-fibre, low-fat diet and was advised to avoid public transport and crowds to limit the risk of catching an infection. And yet what seemed to frustrate Beth most during our trip was not the side-effects of her treatment; the fatigue, pain and digestive discomfort, but her inability to do things, to partake in the micro-rhythms of eating and moving with her family. Be it sharing the same meal with her brother, tasting the ridiculously decadent Manhattan desserts with her daughter, traipsing the streets of New York for hours or riding the crowded and stifling Metro at peak hour – for Beth, not being able to participate in these rhythms and activities of family life with ease, or without eliciting concern about her wellbeing by those who loved her, was most frustrating.

Indeed, Beth’s determination to continue to be a part of the habitual, partial and syncopated rhythms of family life in an unrestricted or uninhibited way was recognised by Lily. As we watched *The Bachelor* one night in late 2015, I asked Lily how her mum was coping with the clinical trial in which she was enrolled:

Mum still thinks she can do everything she used to do. Sometimes I get frustrated at her for not taking it easy but that is not likely to change... It was hard watching Mum get so frustrated when in hospital having surgery or recovering from it. As Mum is a 'doer,' it was hard to see her in a bed and not her usual energetic self.

For Beth, however, giving her all – her energy, her efforts, in the face of exhaustion – into maintaining normal life, normal, habitual *familial* life, was utterly paramount. Beth remains determined to have a presence, to ‘be around’ with and for her family despite the uncertainty and challenges brought about by her ovarian cancer diagnosis and reoccurrence. This type of presence – what I termed an absent presence – in which one

is able to disattend from their body and its potential failings, was not afforded to Beth's own mother. Beth did not want this to be her experience. In drawing attention to the shared and profoundly embodied notions of time as experienced by women at-risk of hereditary cancer, I challenged assumptions concerning the primacy of the discrete, bounded individual who experiences illness and, as such, illness time. Exploring my informant's stories of bodily co-presence, in which significant relational parts of their mothers', sisters' and childrens' bodies came to inhabit their own bodies, I drew attention to the shortcomings of strictly linear approaches to illness or pre-illness temporality such as those evident in Timmerman and Buchbinder's (2010) notion of patients-in-waiting. Time, whether it be of the illness experience, the minutia of everyday life or the syncopated, habitual rhythms of the family, refuses to be neatly contained, very much like genes and bodies. Time, like genes and bodies, are a matter of the family and of continued familial participation.

## **Shared care**

Care, like time, genes and bodies, is a familial matter. Caregiving in paradigmatic anthropological approaches to hereditary breast and ovarian cancer reflect the bounded, discrete individual that they take to be their centrepiece. Care, in such accounts, is something that is directed outwards from the at-risk women to her family, both genetic and affective. There is little attention given to the notion of flows of care, particularly in the space of the family. This lacuna, I think, derives from the strength of gendered analyses of the woman as the primary caregiver in the family and how she may feel burdened by this role when facing the risk of hereditary cancer. This gendered approach, evident in Hallowell's (1999) UK study, demonstrates how some at-risk women may and do feel, at times, obligated to and burdened by the care they give to their families. However, to reduce all forms of caregiving in the family to this unidirectional giving without receiving is misleading and overlooks the messiness of care in day-to-day life.

Moreover, these paradigmatic anthropological approaches to care within the family affected by hereditary cancer prefigure a version of care that is bounded and discrete, like the individual. Care, in these readings, is a property held by an individual who directs it outwards to another. While some anthropologists such as Graeber (2001) have explored the reciprocity of care as a form of gift exchange, drawing upon Mauss ([1950] 2010), I have argued that we need to develop this line of thinking further to consider how care flows within the family. In the stories of at-risk women, we can discern an understanding of care as something that circulates throughout bodies. Care, in this sense, does not have a single, identifiable place of issuance but flows through the complex and knotty meshwork of the family, impelling bodies, and specific body parts, towards one another in modes that both create and maintain the family. This flow of caregiving and care-receiving across generations – mother to daughter, daughter to mother, husbands to wives – was evident in Beth’s description of the care operating in her family as she underwent cancer treatment:

My family have been very involved right from the start. Thomas has been a rock and very supportive. When we went for doctor’s visits he always came, so there were four ears listening and if I came out of the appointment with a negative, he usually could turn it around to be a positive on the way home in the car. He was also very helpful on my bad chemo days, getting his own meals, helping with the housework (which he has done most of, ever since he retired). He also never tried to tell me what to do and would accept if I just needed a quiet day at home or couldn’t manage to go to a function – though I often pushed myself to go. Lily and Dylan have always listened, been there, encouraged me and visited me heaps when I have landed in hospital, travelling to Sydney to be with me. Thomas has taken me to Sydney for my trial visits, which for the first six weeks, were weekly visits. He has never questioned the financial side of these visits. Lily has also driven me up to Sydney for these visits. My brother and sister have had lots of contact with me over the last four years.

While it is Beth’s body that contains ovarian cancer, her body is not sealed off from those around her, those her body helped constitute. Beth does not experience the pain or suffering associated with her disease alone – neither did her mother Marie – it is most profoundly shared. Here we can take note from Livingston’s (2012) reading of Asad (2003) regarding the sharedness of pain. Pain, Livingston (2012, p. 121) suggests, is not an object that can be overcome by an ‘agentive individual.’ While the full depth of

someone's pain may not be fully accessible to others, those who suffer are, as Asad (2003, p. 85 in Livingston 2012, p. 121) suggests 'also social persons (animals) and their suffering is partly constituted by the way they inhabit, or are constrained to inhabit, their relationship with others.' Pain thus elicits, it demands, a response. While the physical pain and death caused by cancer are primarily experienced in one body, this containment do not encapsulate the whole experience of cancer. Even when the person experiences pain and dies, these things do not stay bounded – the spectre of death is embedded in others' bodies as they weight up what to do with their risky parts. Pain spills out and has to be dealt with by others – it demands response. What is important to note however, is that care is not necessarily given and received in equal parts. As I suggested in Chapter Three, this may not be possible in a family facing hereditary cancer. Rather, as we see in Beth's description above, care flows within the knotty meshwork of the family. Beth and her family's bodies are co-constructed, as is the care they provide. Paradigmatic anthropological approaches to hereditary cancer have framed care as a discrete or 'whole' thing that is given to another in the hope of reciprocity (see Hallowell 1999). The complexity of care in the family, as we see in Beth's description, does not fit into such neat analytic categories.

The flows of care within the family is evident in Lily's description of caring for her mother during her multiple cancer diagnosis. Lily and her family helped to make Beth as comfortable as possible during her ongoing treatment:

When Mum had her first chemo treatment she was very, very sick and in bed for days. I unfortunately had a cold so couldn't go near her and the only way I felt like I was helping was if I looked after her dog. So I would walk it so that she would feel better knowing that Ruby was being looked after (she loves that dog). I took Mum out a few times to do 'normal' non-cancer related things [like the] movies [and] shopping. My Dad did most of the physical helping and everyday tasks. I have often driven her to Sydney for appointments or sat through boring chemo or blood transfusions. It sucks to look around and look at all the other people, young and old, facing a shitty battle. I made cards for Mum's weekly chemo so that she had something nice to read and think about when she was having chemo. The girls would help me make cards or crossword puzzles or stories for her. I would also sit with her in hospital when she was recovering from her various surgeries... I have a new respect for my Dad as he is normally not a patient man but with Mum and her treatment he just waits and waits.

In this vignette, Beth does not emerge as the ‘individual-as-isolate’ as a result of her cancer diagnosis nor is she called upon to selflessly sacrifice her own needs for her family or else selfishly put her wellbeing first and foremost (Novas and Rose, 2000). Nor does Beth and her body appear as bounded and discrete. Parts of her body call out to those of her family and are met by the everyday and embodied acts of caregiving that take up many different forms. Alongside the more obvious acts of feeding, transporting and physical assistance, caregiving was a family affair for the Brooks. It flowed and circulated as each and every member worked to care for Beth and each other – including the family dog. Care and suffering are, as Lily suggests, most profoundly shared. What is also profoundly shared, is the sense of loss and absence that is felt in the wake of death of a loved one to hereditary cancer and the fear that this cycle of suffering will go on endlessly.

## **A life shared**

For families affected by hereditary cancer, absence is something that is known intimately. As Peter (2004) reminds us, the death of a loved one and the absence this creates, is also the partial death of oneself. For women at-risk of hereditary breast and ovarian cancer, this fact is experienced acutely as parts of the family, more often than not, disappear. It is this reality, this cycle of pain and destruction, of bodies becoming too present, that women at-risk of hereditary breast and ovarian cancer yearn to change. In the final chapter of this thesis, I considered the ways in which at-risk women made sense of the death and dying they face as a result of their hereditary cancer risk. I suggested that what at-risk women desperately wanted was to be present, to ‘be around’ for their families now and in the future. They wanted to be a part of their family in ways that were often not possible for their own mothers and relatives. Consider Beth’s comments about her own mother’s death from breast cancer and how her absence impacted on her life, long after her mother’s passing. For Beth, the impact of her mother’s absence, although felt acutely at the time of her death, had a cumulative effect. While she tried to push on with life as ‘usual’ in the first few years following Marie’s

death, taking on new roles and responsibilities in the family, it was when she herself became a mother that she yearned for her own mother the most. As major milestones in Beth's life – marriage, having children, the birth of her grandchildren – came and went, the presence of her mother's absence, her absence as a source of knowledge, as a part of the family, as a pair of hands that reach out to embrace, to nurse a child to sleep, was mourned by her daughter. She explained:

It was sad when she died and we all missed her, however because I had uni, had met Thomas and was going out with him and busy with my social life, we just all picked up and continued on...[T]he impact didn't seem to happen until I became older with my own children. Thomas and I got married two years after her death and it was not so good not having her at the wedding. Luckily I had a lovely mother-in-law who supported me a fair bit with cooking and parenting advice. I think I missed her more when I had Dylan and Lily, as I realised that she was missing out on the grandparenting thing and it would have been good to share their milestones with her. When I became a grandmother, I was once again sad that she had missed out on this part of life as well. It is interesting too, that I missed catching up with all her friends' news and some of them would ring me to see how I was doing and I really appreciated that and would visit them, especially when Dylan and Lily were small.

As Beth became a mother and then a grandmother, she came to feel an intense loss and sadness for what her own mother had missed and the relationships she was not able to enjoy with her daughter or grandchildren. This possible future, of such intercorporeal relationality with her daughter, as Peter's (2004) suggests, was curtailed by Marie's cancer and death, her passing becoming a plurality of absence as it opened out to her grandchildren who would never know the warmth of her embrace. Being identified as at-risk of hereditary breast and ovarian cancer, as I suggested in Chapter Four, made women aware of how important their bodies were in creating and maintaining this familial relationality. The risk of hereditary cancer made women's bodies 'dys-appear,' that is, they came to occupy an increasing presence in their everyday life in a way that impeded the habitual, syncopation of the family (Leder, 1990). Consider Beth's comments on how her body dys-appeared as a result of her ovarian cancer diagnosis:

The hardest bit... is the rollercoaster ride that comes with having cancer. I try not to worry about dying, however sometimes I do and I feel a bit anxious that I haven't done everything I want to do, haven't sorted out my belongings and I also don't

like the idea of not seeing the grandchildren growing up and seeing how my own children mature. I also sometimes worry about what will happen to Thomas. Having said that I also then reflect that I have seen a lot more than what my mother and father did and have outlived them both... My present trial is working very well and this is probably the best I have felt for two years. It is good to feel almost normal, as when you are having chemo, sometimes you really wish to just feel normal again and be not so tired and sick for some of the time... The rollercoaster side of cancer can sometimes be a bit challenging as you are not always sure what it is going to throw at you...

For Beth, her cancerous body had become a present presence. She yearned to feel normal again, for her body to recede into absent presence, so that she could enjoy the socialites that hinged upon her body. She wished to no longer fear what may happen if she would become an absence – if she were to die. For those at-risk who did not, yet, have a cancer diagnosis, the need to secure an absent presence, rather than a present presence or deathly absence was paramount. Women such as Tricia, Diana and Melissa removed risky parts of their body in hopes of achieving an absent presence. Often these important parts were replaced and replicated so that the sociality that depended upon them could continue. Body parts became replaceable so that the unreplaceable – the multiplicity of partial relations that form the person and the family – could continue unimpeded. The affective presence of the person and the family was secured when the parts that threatened its existence were removed and replicated. Risk management, in this sense, can be read less as the rational calculations made by an autonomous individual as an attempt to ensure a particular type of enduring presence, an absence presence, within the family. This absence presence allows for the habituality of the family fleshed out in the bodily interactions of everyday life to continue unencumbered by sickness and disease. It is this mode of ‘being around,’ as an absence presence, that was most sorely wanted by my informants – that is, a life free from the ongoing fear of cancer, that is sustained by the fleshy relations of others and that can participate fully in the family and the care that sustains it, across time. This form of presence, as a part of a fleshy intercorporeal collective known as the family, troubles the bounded, discrete individual that characterises paradigmatic anthropological accounts of hereditary breast and ovarian cancer.

## A final note

The collective construction of person, body and being in and through others has been demonstrated across this thesis, but I am not the first to identify and discuss it. As the functionalist anthropologists knew, kinship could not be reckoned via the discreteness of the individual, nor for that matter, could societies. The institutions – of family, politics, education and labour – they identified had their geneses in collectivity, as the key functionalist metaphor of the interconnected organs operating interdependently within the human body, attests. Each organ operates within an organised system to sustain the living organism. In this view, however, the individual body remains intact, the organs operate collectively within a *bounded corporeality*. Consequently, the whole body is interdependently organised with and against those of others. Such arrangement is borne out in current anthropological assessments of at-risk women's sociality and their decision making (as either selfish or selfless). In this thesis, I have tried to disrupt the integrity of that consistently imagined, discrete body, taking my cue from the disrespectful way that genes permeate the boundaries of the only ostensibly bounded 'individual.'

The body, Strathern (1992b) has argued at length, is the yield of the genetic contributions of others. 'The child's physical origins' she informed us, 'lie in the bodies of others, a link as indissoluble as its own genetic formation is normally deemed irreversible' (Strathern, 1992b, p. 165). Acknowledging the partiality of persons, in lines with the basic tenets of genetics, does not, however, necessarily result in genetic determinism or reductionism. Genetic linkages remain contingent on how persons act upon them as Strathern (1992b, p. 165) herself asserts. Indeed, as post-Schneiderian kinship studies have shown us, people enfold both genetic facts *and* affective relations into their lives as they form the family (see Strathern, 1992a, 1992b; Carsten, 2004; Marks, 2013 and Franklin, 2013). Existing anthropological approaches to hereditary cancer express a deep concern over the ability of genetic facts to surpass affective relations in forming the family. The 'individual' woman who tests positive for a BRCA mutation may lose her capacity to choose relations on the basis of affectivity as she

becomes responsible for the genetic burden she, and her genetic kin, now carry. By strictly asserting the need to protect this discrete individual who affectively arrays her own kin, anthropologists of hereditary breast and ovarian cancer have fundamentally overlooked insights that could be offered by the partial views of the person and body that genetic medicine has to offer. This idea of partiality – of body and family – is crucial to understanding the lives of at-risk women who deal with the possibility of having significant *parts* of their body removed. As my ethnographic material attests, my informants often talked about themselves as practitioners of fleshy, partial relations as they discussed how particular body parts connected them to their familial others, how these same parts came to impede the habitual operations of their family and how they made the gut-wrenching decision to remove them to ensure they could be a living presence in the family.

A key argument of this thesis has been that the person is made manifest in and through the partial contributions of others, who are themselves made manifest in just this way. It is hard to think of bodies as whole, bounded entities when they are considered at the level of the genes. But rather than continue the objections that anthropologists before me have made about the erasure of the discrete, bounded ‘individual,’ I have tried to demonstrate that, in fleshy life, the relations between people are always partial – we do not encounter others as discrete and complete wholes, nor even our own bodies as such. As Merleau-Ponty (1968, p. 143) informs us, the lacuna ‘where our eyes, our back, lie, is filled’ by the vision of others and they complete us. As Foucault (1977) reminds us, all institutions are the outcomes of the relations of partial bodily deployments – including, as Lyon and Barbalet (1994) argue, the family. Those partial relations, between hands and feverish foreheads, baby cheeks and breasts, are impelled by emotion – and we need not dispense with them in order to ‘rescue’ the person from cold, hard genetic facts. Indeed, as I hope I have shown in this thesis, such intercorporeal relationality may be at the heart of anthropological inspiration to reveal much more about a precancerous life than we know.

To live a life affected by hereditary breast and ovarian cancer is to experience pain and suffering. To struggle with the risk of hereditary breast and ovarian cancer is to confront

the existential uncertainty, the devastation and the incomprehensible elements of human existence. And yet to live with the spectre of cancer is also to live with others, to live for others; to be a relational being; to care; to find meaning in what may otherwise seem to be an incomprehensible and irreconcilable experience of suffering. It is these collective modes of experience that are overlooked in existing anthropological approaches to hereditary breast and ovarian cancer. The risk of hereditary cancer exposes as vulnerable the ability to continue as a fundamentally familial being, to 'be around' with and for loved ones now and well into the future. While disease and the pain it engenders will be borne out in an identifiable body, this pain and suffering is taken up by the bodies of others. In recognising the family as a sociality created and maintained in the fractal, fleshy relations between parts of bodies, just as the body itself is created from the partial, genetic contributions of others, we can produce new insights into precancerous lives and cancer illness experiences. These insights go well beyond the current, paradigmatic assertions of discrete and individual at-risk women who organises socially significant others consistent with selfish or selfless motives.



## Appendix A

Table 2: Informants information presented in order of interview schedule 2013-2015

<b>Name</b>	<b>Age at first interview</b>	<b>BRCA mutation status</b>	<b>Gender</b>	<b>Ethnicity/ Nationality</b>	<b>Risk reduction regime</b>
<b>Karen</b>	43	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Lily</b>	34	BRCA2	Female	Australian	Screening
<b>Beth</b>	67	BRCA2	Female	Australian	Screening, clinical trial and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Lewis</b>	75	BRCA2	Male	Australian	Bilateral mastectomy and tamoxifen
<b>Marcia</b>	49	VUS	Female	Australian	Bilateral mastectomy
<b>Anne</b>	62	BRCA2	Female	Australian	Bilateral mastectomy and risk-reducing total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Mia</b>	31	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Melissa</b>	32	BRCA2	Female	Australian	Risk-reducing bilateral mastectomy and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Fiona</b>	47	BRCA2	Female	Australian	Risk-reducing bilateral salpingo-oophorectomy
<b>Ruby</b>	30	BRCA2	Female	Australian	Screening
<b>Diana</b>	32	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Vanessa</b>	51	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction and bilateral salpingo-oophorectomy
<b>Celia</b>	33	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with tram diep reconstruction and bilateral salpingo-oophorectomy

<b>Leah</b>	37	BRCA2	Female	American, Ashkenazi Jewish	Bilateral mastectomy with implant reconstruction
<b>Valerie</b>	35	BRCA1	Female	Australian, Irish	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Christina</b>	36	VUS	Female	Australian	Bilateral mastectomy
<b>Bridget</b>	33	BRCA2	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Marilyn</b>	43	BRCA2	Female	British	Risk-reducing total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Jenny</b>	38	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with diem flap reconstruction
<b>Kathryn</b>	55	Not tested	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Jodie</b>	32	BRCA2	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Kat</b>	26	BRCA2	Female	Australian, South African	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Ashley</b>	36	BRCA1/2	Female	Australian	Bilateral mastectomy with implant reconstruction
<b>Becky</b>	32	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Leanne</b>	52	VUS	Female	Australian	Risk-reducing bilateral mastectomy with tram flap reconstruction
<b>Nadia</b>	23	BRCA2	Female	Polish Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Alicja</b>	47	BRCA2	Female	Polish	Risk-reducing bilateral mastectomy and bilateral salpingo-oophorectomy
<b>Tricia</b>	34	BRCA1	Female	Australian	Screening
<b>Luke</b>	31	BRCA1	Male	Australian	Screening

<b>Joanie</b>	43	BRCA2	Female	Australian	Screening and risk-reducing bilateral salpingo-oophorectomy
<b>Laura</b>	28	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Ellen</b>	56	BRCA2	Female	Australian	Risk-reducing salpingo-oophorectomy
<b>Janet</b>	39	Inconclusive	Female	Australian	Lateral mastectomy with implant reconstruction
<b>Khloe</b>	30	BRCA1	Female	American	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Brooke</b>	34	BRCA1	Female	American	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Kay</b>	55	BRCA2	Female	American	Risk-reducing bilateral mastectomy with implant reconstruction and bilateral salpingo-oophorectomy
<b>Jessica</b>	54	BRCA1	Female	American	Risk-reducing bilateral mastectomy and bilateral salpingo-oophorectomy
<b>Debbie</b>	58	BRCA2	Female	American	Risk-reducing bilateral mastectomy with implant reconstruction and bilateral salpingo-oophorectomy
<b>John</b>	64	BRCA1	Male	American, Ashkenazi Jewish	Screening
<b>Lenny</b>	37	BRCA1	Male	American	Risk-reducing bilateral mastectomy
<b>Kim</b>	61	BRCA1	Female	American, Ashkenazi Jewish	Risk-reducing bilateral mastectomy with SGAP flap reconstruction and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Penelope</b>	43	BRCA1	Female	Filipino American	Risk-reducing bilateral mastectomy with implant reconstruction and salpingo-oophorectomy
<b>Billie</b>	28	BRCA1	Female	American	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Patricia</b>	52	BRCA2	Female	American, Ashkenazi Jewish	Bilateral mastectomy with reconstruction and risk-reducing bilateral salpingo-oophorectomy
<b>Justin</b>	58	BRCA2	Male	America	Screening

<b>Anita</b>	29	Results pending	Female	Pakistani American	Screening
<b>Lucy</b>	42	BRCA1	Female	British	Risk-reducing bilateral mastectomy with implant reconstruction
<b>Paige</b>	36	BRCA1	Female	Australian	Bilateral mastectomy
<b>Gwen</b>	62	Inconclusive	Female	Australian	Screening and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Eric</b>	64	BRCA2	Male	Australian	Screening
<b>Chloe</b>	33	BRCA2	Female	Australian	Screening
<b>Bree</b>	50	BRCA1	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction and total abdominal hysterectomy with bilateral salpingo-oophorectomy
<b>Jo</b>	49	Inconclusive	Female	Australian	Risk-reducing bilateral mastectomy with implant reconstruction and total abdominal hysterectomy with bilateral salpingo-oophorectomy

Note: All names are pseudonyms

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