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**Rehabilitating the sick role: the experiences of high-risk women who undergo risk reducing breast surgery.**

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**ABSTRACT**

In recent years Talcott Parsons' work has come under renewed scrutiny by sociologists who argue that his concept of the sick role may have some role to play in current accounts of health and illness. In this paper we describe the ways in which Australian women who have undergone elective risk-reducing breast surgery (+/- ovarian surgery) talk about their convalescence. When describing their experiences women presented two contrasting recovery narratives in which the negative effects of breast surgery were either minimalised or emphasised. In an effort to explain these differences we draw upon the Parsonian concept of the sick role and argue that the extent to which women either embraced or rejected the sick role in their accounts is related to the amount of external legitimation they received from healthcare professionals. We conclude that the concept of the sick role may provide insight into high-risk women's experiences of risk-management.

**Keywords:** breast cancer, sick role, risk, genetics, Talcott Parsons

## Introduction

Twenty first century medicine regards patients as active consumers; responsible, autonomous individuals who can, or must, choose between competing treatment options. Moreover, neo-liberal public health policies highlight individual responsibility for health maintenance by emphasising the need for ongoing bodily surveillance or active management of disease risk (Petersen and Lupton 1996). This construction of the responsible and vigilant consumer of healthcare can be seen as intimately related to scientific and technological advances of the late twentieth century, particularly the development of cheap screening technologies, including genetic tests (Petersen and Bunton 2002; Novas and Rose 2000). Judicious use of these technologies, it is argued, will provide advance warnings of potential disease that can, in turn, facilitate individuals' attempts to manage their bodies and lives (Giddens 1991; Petersen and Bunton 2002). Late modern individuals are not only seen as having an active role to play in the maintenance of their health, but also in the creation of illness through their construction of reflexive narratives of illness experience (Williams 1984; Bury 1982).

The twenty first century patient is no longer seen as a passive body-object (Shilling 2002) whose sickness requires external validation (Parsons 1951), but as an embodied subject (Turner 1996) who plays an active role in the construction of their patient-hood (Williams 1984; Bury 1982). This view of individuals' relationship to health and healthcare stands in direct contrast to that outlined by Talcott Parsons in the nineteen fifties. (Crossley 1998).

As one of the founding fathers of sociology of health and illness, Parsons (1951) stressed that illness, in contrast to disease, is a social category, involving the adoption of a particular type of social role – the sick role. The sick role is governed by a range of social expectations and has its own set of role responsibilities. Sickness, within this scheme, is regarded as an undesirable or deviant state, and the sick – i.e. patients - have an obligation to seek medical help and to cooperate in trying to get better so they may return to normal activities as soon as possible. Parsons argues that the adoption of the sick role is important because it frees us from our normal social roles and associated responsibilities such as paid and domestic work, caring for others *et cetera*. However, entry into the sick role is not freely available or dictated by personal choice, but rather the exemption from, and resumption of, normal role responsibilities requires external legitimation. Bestowal of the sick role, according to

Parsons, is the work of medicine. Thus, Parsons sees the external conferment of the sick role by healthcare professionals as freeing individuals from the responsibility of being unable to fulfil their normal role obligations.

It has been argued that Parsons' view of individuals' relationship with medicine and medical experts is not particularly surprising, given the historical context in which he was working (Crossley 1998). Indeed, that Parsons (1951) regarded patients' passive and willing compliance as a necessary requirement for the effective practice of medicine merely reflects paternalistic assumptions about the nature of the doctor-patient relationship which abounded in the mid-twentieth century. However, Parsons' account has not only been criticised for its overt paternalism, but also because of its focus upon acute rather than chronic illness (Rier 2000; Turner 1996; Crossley 1998). As Rier (2000) has observed, contemporary medical sociology, with its focus on the construction of illness narratives (e.g. Williams 1984; Bury 1982), is able to provide a much better account of patients' experience of chronic conditions; a view which, as noted earlier, positions patients as active subjects rather than passive recipients of healthcare. Despite these observations, Rier (2000) acknowledges that his earlier rejection of Parsons may perhaps have been little hasty; observing that his time as a patient in ICU was better explained using a combination of the Parsonian account during the acute or critical phases and a narrative or post-structural account during his rehabilitation or the recuperative phases of his illness.

In this paper, following Rier (2000) and Crossley (1998), we will argue that by dismissing Parsons as outmoded, out-dated and irrelevant, sociologists could be charged with throwing the baby out with the bathwater because there are certain aspects of his account which may be seen as useful when it comes to explaining the experience of managing the risk of disease (Crossley 1998) and acute phases of illness (Rier 2000). By focussing upon the accounts of healthy at-risk women who have elected to undergo risk-reducing breast surgery we will show how the concept of the sick role is mobilised in their accounts of their recovery from surgery. We will argue that women's descriptions of the immediate post-operative period reveal the ways in which they negotiate entering the sick role. Moreover, following Crossley (1998), we will argue that these data suggest that the sick role is not necessarily proscribed by medical experts, but may be actively adopted or rejected by at-risk individuals.

### ***Managing the risks of hereditary cancer***

Women who carry a mutation in one of the breast and ovarian cancer predisposition

genes, BRCA1 and BRCA2 have a significantly increased lifetime breast cancer risk of 31% and 78% (Antoniou *et al.*, 2003). The risk of breast cancer can be substantially reduced using risk-reducing surgery – mastectomy (RRM) and/or pre-menopausal salpingo-oophorectomy (RRO) (Rebbeck *et al* 2004; Evans *et al* 2009).

A number of studies that have investigated the psychosocial sequelae of RRM suggest that many women are pleased with the outcome – the decreased anxiety (Brandberg *et al* 2008; Hallowell *et al* 2012) and the appearance of their reconstructed breasts (Borgen *et al* 1998; McGaughey 2006). However, a sizeable minority experience ongoing complications or are unhappy with the cosmetic result (Altschuler *et al* 2008; Bebbington Hatcher and Fallowfield 2003). While the long- to medium-term impacts of RRM on risk perception, gender identity, body image and sexuality have been well-documented (Frost *et al* 2000; Hallowell *et al* 2012), much less is known about women's experiences of surgery and convalescence. In this paper we report women's experiences of undergoing RRM, particularly their accounts of the immediate post-surgical period.

## **Methods**

### ***Recruitment***

A subset of participants from the kConFab<sub>1</sub> (the Kathleen Cuninghame Foundation Consortium for research into Familial breast cancer) Psychosocial study (Meiser *et al* 2003; Phillips *et al* 2005) were invited to participate in this qualitative study. These women were unaffected by cancer but at increased familial risk of developing breast cancer and had undergone risk-reducing bilateral mastectomy, on average, three years before they were interviewed. Of 24 eligible women, data were available from 21. Ethics approval was gained from the University of Sydney Human Ethics Committee and all participating kConFab sites.

### ***Data Collection and analysis***

Data were collected in semi-structured (open-ended) telephone interviews, conducted by experienced qualitative interviewers. These focussed on surgical decision-making, information needs, risk perception, experiences and impact of surgery in the long and short term, experiences of convalescence and overall satisfaction. All interviews were audio-taped and transcribed.

A thematic analysis using the method of constant comparison (Corbin and Strauss 1990) was undertaken. Members of the research team participated in a series

of data analysis workshops in which a subset of transcripts were read and discussed. This reading generated a preliminary list of codes, which we agreed captured women's experiences of surgery. This coding scheme was applied to a further set of transcripts and was refined to include a number of further codes and sub-codes which had emerged during this second reading. These emergent codes were used to code the complete dataset. Finally, the codes generated by the data (e.g. recovery time positive, recovery time negative, iatrogenesis, lack of support) were linked back to the higher order themes (e.g. adopting sick role, rejecting sick role). The robustness of the analysis was assessed by having a second researcher apply the coding schema to a subset of transcripts and cross-checking these analyses. NVIVO8 (Qualitative Solutions and Research Pty Ltd 2008) was used to manage the data.

### ***The sample***

This paper focuses upon data generated during interviews with the 21 women who had undergone RRM (13 had also undergone RRO at some time) (see Table 1) as a primary preventative option. Eighteen women had undergone RRM in the previous three years and two of these had ovarian surgery at the same time, the other 3 women had RRM more than three years ago. Nineteen women had breast reconstruction – 15 had implants and 4 an autologous (e.g. TRAM flap) procedure. In many cases breast reconstruction involved a number of interventions, for example, replacing or expanding temporary implants, constructing new nipples and tattooing.

### ***Table 1 about here***

## **Findings**

### ***Recovery narratives***

When talking about their experiences of surgery the women presented two opposing accounts of their recovery. In the first, recovery was presented as protracted and convalescence as prolonged. These women described their recovery as more difficult than they had expected and commented that they had been out of circulation and unable to perform “normal” tasks for much longer than they had anticipated. As B2 (B = breast surgery only) said:

“The first six weeks was the worst. ...coming home and realising I can't do anything I have to get my mum to do the washing, I have to get you to clean the house...make the beds...I can't pick my kids up...”

BO13 (BO = breast and ovarian surgery) similarly talked about the amount of time she had needed for ongoing healing, and the subsequent reconstruction procedures:

“I was home for a full 6 weeks I think, and when I went back to work I was still sore, so probably 3 months and they put, I had expanders put in and they really used to scratch against my chest wall.”

In the contrasting account, recovery was seen as swift and convalescence short, if it occurred at all. Women said they had needed very little time to get over surgery and begin to function as “normal” again. This group talked about how they quickly they had resumed their normal activities – strenuous housework, driving, child care and/or paid employment – following their operation. For example, B3 said:

“It took a couple of weeks. I had the operation on the 3rd or 4th of December and on the 18th I did a girl’s wedding make up for her”.

Likewise, B4 talked about her speedy recovery:

“I think I’ve been fairly well prepared about recovery time, the surgeons were very good, and in fact I think my recovery time was well within the time period that I probably responded quicker than they’d suggested.”

We were interested in the coexistence of these very different accounts in our data. Why were some women suggesting that this major surgical intervention had had little or no physical/social impact upon their lives, while others said they had required a much longer time to recover from this operation? In what follows we will argue that Parsons’ concept of the sick role may have a useful role to play in answering this question. However, before we discuss this, we need to first consider the context in which these surgical decisions are taken.

It can be argued that living with the risk of hereditary cancer can be likened to living with a chronic illness (Crossley 1998) in the sense that the risk of developing cancer can be seen as all pervasive and enduring (Hallowell 2000; Robertson 2000), not least because the timing or eventuation of risk (or symptoms) is relatively difficult to predict. In other words, living with a genetic risk of cancer, like living with HIV (Crossley 1998), is living in a state of perpetual uncertainty (Hallowell 2000; Robertson 2000). As Crossley (1998) notes, people find this type of uncertainty anxiety-provoking and may initiate action to reduce it. In her study of HIV positive individuals interviewees said they had undergone alternative therapies or joined self-help groups to try regain control of their risk status and manage the uncertainty

around HIV. In the case of the inherited risk of breast cancer managing uncertainty may result in one electing to have one's healthy, but risky, breast tissue removed, and this medical intervention requires one to relinquish normal activities or to become a patient. Arguably, it is the act of choosing to have a medical procedure that renders them temporarily unable to perform their normal social roles that is at issue in these accounts. In contrast, to the typical Parsonian account in which patient-hood is imposed upon individuals, the women in this study actively opted to undergo breast surgery and thus, their choices/actions require some justification. Consequently, when describing their experiences of RRM the women constructed accounts of surgery and convalescence in which they portrayed themselves as negotiating entry into the sick role rather than passively accepting this designation. Accordingly, adoption narratives describe periods of prolonged convalescence often resulting from post-operative complications, whereas rejection narratives construct medical procedures as simple and pain-free and recovery as extraordinarily swift and unproblematic.

***Entering the sick role: action or reaction?***

The women in this study, in contrast to those who have a mastectomy to treat a breast cancer, are in a situation in which they can be held accountable for subjecting their disease-free bodies to a major medical intervention. The difficulty for these women is that they have actively chosen or elected to forgo their normal social responsibilities and, as we will see, it was apparent that many of them felt they had to actively defend this choice. One way in which women tried to justify their ongoing exemption from their normal duties and role obligations following surgery was to provide accounts in which they were absolved of the responsibility for entry into the sick role; in these accounts women blamed their post-operative state upon others' actions or external circumstances rather than their previous choices.

***Adopting the sick role post-surgery: sickness was thrust upon me***

In a number of cases women described their adoption of the sick role as necessitated by post-operative complications, which meant that they needed a prolonged convalescence period following RRM. In these accounts, it was not the elective surgery *per se* that required one to enter the sick role, but rather getting secondary infections or sustaining incidental injuries. In other words, prolonged convalescence - i.e. sickness - was not seen as the result of choosing to have a mastectomy, but as determined by events that were outside an individual's control. According to BO12, the surgery that she had chosen to undergo:



“...probably wasn’t a big deal, it was more the fact because I was so sick afterwards I mean instead of being back on my feet within a couple of weeks I was in and out of hospital for several months because I’d lost a lot of weight and managed to pick up a few bugs and stuff like that along the way so I think that was probably the worst part of it.... a lot of it started pretty much straight away but it just kept going on and on... the mastectomy was in the December and I probably didn’t really get back on my feet properly until probably around the May or June of the following year....”

Likewise, B7 said that her convalescence was protracted and she was unable to return to work for over 6 months because she sustained:

“an injury from the surgery.... When they damaged a nerve in one of my hands...because of the position that I was laid out in for the 10 hours that I was in surgery... it was obviously in an awkward position because I was put into that position after I was asleep and it had cut off some nerves so I had lack of movement and feeling in one hand. And that lasted about six months. So I had some rehab and some pain management and some physio and stuff for all that.”

In all these cases women talked about having to occupy the sick role because their elective surgery had gone wrong in some way. It was not the surgery that they had chosen to undergo, but subsequent infections (BO12) or other injuries (B7) that had incapacitated them and resulted in them needing to be relieved of their normal role obligations.

B010 And I was going up every three days and getting um you know it was a kidney dish size...like five of those of fluid, bloods and that taken out of that side every two or three days.

*I Wow. So for how long?*

B010 It was um probably for um I’d say two months.

*I ...They’d obviously taken some lymph nodes when they’d done the mastectomy?*

B010 Yeah. They didn’t think they did but he seemed to think that he must’ve. And because the way they did the operation, because of my shoulders, they had to sort of do – they did it in sort of two parts – I’m virtually cut nearly right around, would you believe.... And I got golden staph and I’d had it over twelve months. And that had made and you know that had made things ten times worse.

The idea that entry into the sick role was driven by circumstances outside of their control, was stressed by other women who blamed their bodies, rather than the choices they had made, for their prolonged convalescence. For example, B5 emphasised the fact that all bodies are different, and how her body had needed a longer recovery time than the “norm”, something she could not have predicted when she initially decided to undergo RRM.

“Everyone’s body is different and mine took longer to recover and different things happened...I came home and was feeling okay and then I was you know starting to get better because obviously it was quite painful. Starting to get better and then it started to get quite very very painful again I think they just concluded that that was my body trying to get used to the implants. So just not the norm...”

***Rejecting the sick role post-surgery: I have no need to be sick***

Other women rejected the sick role by playing down the impact of mastectomy on their lives, referring to it as not such a big deal or portraying it as a pain-free or simple procedure that had required little in the way of post-operative care or pain relief. As B1 said:

“I knew that would be painful and I’d have trouble getting myself out of bed every morning .... But it really didn’t cause me that much grief, I didn’t take all that much in the way of pain relief because you know it was a bit painful at the beginning, but it was okay it wasn’t too bad.”

This group constructed RRM as a minor incident that had little impact on their life. They described surgery as an event that did not really require one occupy the sick role at all, or, in some cases, just for the briefest of periods. As BO4 commented:

“ ...they said with the mastectomy you could be in hospital five days or something, um I was surprised that I got out before that and I was surprised when I felt good like physically.”

Some described how they had returned to their normal activities quickly after surgery. For example, B6 talked about how she had resumed domestic work within a couple of weeks of RRM.

B6: “I came home and the second day out of hospital, so that’s 8 days after the operation, I tried to vacuum and sweep the floor.... I just wanted to get back to work and get on with it and be able to clean the house. “

Similarly, B3 said had resumed her (physically demanding) work as a beautician/hairdresser within the month even though she said that she had still felt unwell: “I had a month off work and when I went back to work I was still a bit fragile.”

In her study of HIV positive individuals Crossley (1998) argues that her interviewees rejected the passivity or dependence associated with the sick role by refusing to relinquish certain rights, rights that would necessarily be curtailed if they were to assume the role of HIV patient. She describes how her interviewees talked about “taking back their sexuality” (1998:522) by demanding the rights afforded to

the rest of society, for example, the right to bear children and/or have sexual relationships. Similarly, our interviewees, when describing their recovery from surgery, described how they took back, or resumed, their role as wife, partner, mother and/or worker very quickly after surgery. For example, BO7 described how she had deliberately ignored the instructions of her healthcare providers and resumed her domestic duties in the week following surgery “The next week [after surgery] I was hanging the washing on the line and making menus all the things I wasn’t meant to do...”

***Justifying one’s healthcare choices: reacting to others’ perceptions and reactions***

So why did these women construct these types of accounts? In some cases, women’s description of their adoption or rejection of the sick role appeared to be influenced by the actions or reactions of those around them. Many talked about how medical professionals were sceptical or even dismissive of their decision to voluntarily undergo such an invasive procedure on the basis of a possible risk rather than an actual cancer. In many instances women described having to argue their case for RRM with uninterested or unsupportive medical professionals and, in some cases, family and friends. B6 described how one of the doctors she encountered had described RRM as “equivalent of having your testicles off to prevent testicle cancer” and had gone on to ask her “Why would you do something like that?” Similarly, BO1 commented that some of the nurses on the surgical ward were unsympathetic about her anxieties prior to surgery, she said “I almost got the impression they [nurses on ward] think ‘this is really overkill, why are you doing this?’”

This perceived lack of support for their decision to have surgery could be interpreted as a failure of others to legitimate women’s entry into the sick role. BO9 and B3 said that the medical professionals they encountered saw them as entirely responsible for their situation.

BO9: “When I had the implants in 12 months ago, this nurse dropped me like a hot potato...when I told her I didn’t have cancer, I had prophylactic surgery, she had no sympathy for me, she was like ‘deal with it yourself, you put yourself through it’.”

B3: “Their [doctors’] view was I was the kind of radical over the top kind of approach to breast cancer. They have got ladies who have had breast cancer and had a lumpectomy or try to conserve the breast, so for someone coming in and wanting their healthy breasts removed ... I think a lot of doctors don’t have a very good bedside manner and a lot of the time I’d leave there just really upset.”

In some cases women felt that this lack of legitimation by medical professionals had compromised their medical care; for example, BO12 described how her recovery was impeded, and perhaps prolonged, by hospital staff dismissing her worries about bodily symptoms.

BO12: “Well I’d, actually the day that I was sent home I wasn’t well. And the right breast was actually quite large and I knew from having my left one done that it should have been flat. Um and I said to the nurses and the people that had come in to check me about it and they said ‘oh we don’t know, no, you’re alright you’re alright go home’. And yeah it wasn’t until I was sort of running to the hospital again a week later that they realised that I’d been haemorrhaging the whole time and they just haven’t bothered to look into it.”

Given the very obvious lack of validation from the medical profession that many had experienced, it is little wonder that some women constructed an account of in which they did not need to occupy the sick role, instead describing themselves as remaining well and maintaining their normal duties and obligations as wife, mother and employee throughout the post-operative period. Similarly, it can be argued that those who constructed an account in which they adopted the sick-role in the face of this scepticism only did so because they needed to, because they had sustained additional injuries or infections - i.e. more “legitimate” illnesses - that required medical attention.

***Justifying one’s healthcare choices: being an active consumer***

There is, however, an alternative explanation for the existence of these accounts that merits consideration. As noted above, Parsons’ account of the sick role has been criticised for its paternalism. According to Parsons the sick role is proscribed by those with medical authority and individuals passively accept this designation. In contrast, we would argue that most of our interviewees portrayed themselves as actively choosing to manage their risk by undergoing surgery and as actively rejecting the sick role. Arguably, this rejection is not only explicit within their accounts of their recovery, but also is implicit in the surgical decision itself. Indeed, we would argue that risk-reducing surgery could be seen as a form of pre-emptive rejection of the sick role. What do we mean?

According to Parsons being sick is a form of social deviance, hence, he argues, no one would willingly adopt the sick role and if they do, then they should try to relinquish this role as soon as possible. Bearing this in mind, it can be argued that these women were motivated to undergo RRM to avoid having to occupy the sick role

in the future. As B4 and BO2 observed, RRM enables one to avoid a diagnosis of cancer – or sickness – and remain healthy. “I’m not a sick person, so it’s [RRM] something, a decision that I’ve made to ensure that I’m a well person” (B4). In other words, these women took action in the present so they would be not cast into the sick role in the future. As BO2 said:

“...people say ‘oh you’re so brave [having RRM]’ and things and I’m thinking no I’m not, I’m avoiding chemo and radiotherapy treatment, I’m scared. I am not doing this because I am brave, I’m doing it because I don’t want that.”

It can be argued that because all of these women willingly subjected themselves to this medical procedure to avoid future illness, it would be contradictory for them to actively embrace, or adopt, the sick role for a prolonged period at this point, for they, and they alone, accept the responsibility for potentially putting themselves out of social circulation. Indeed, a small group talked about having to beg for the opportunity to undergo RR surgery. Arguably, these observations provide an explanation for why so many women in our study explicitly rejected the sick role and provided recovery narratives which suggest they are “super-human” and why the contrasting adoption narratives contained etiological explanations in which their resulting sickness was described as caused by other events, for example, others carelessness, accidental damage or random infection. In relation to these observations, Crossley (1998) notes that people with chronic illness, and within that we would include the at-risk, are less likely to gain exemption from social obligations and therefore are less able to adopt the sick role.

“... the situation of the chronically ill patient as one which is more complex than the ‘exemption’/‘obligation’ model associated with Parson’s concept of the ‘sick role’. This is because there is a continuous struggle amongst the chronically ill between ‘doing too little and doing too much’, between the demands of the body and the demands of society.” (Crossley 1998:524)

Crossley’s analysis can be seen as very pertinent, for the women in our study were put in a situation in which they had to balance 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. RRM, while satisfying the social obligation to actively manage their risks (Hallowell 1999) so they may remain healthy in the future, also requires them to enter into a situation in which they are forced to forgo other social obligations, such providing physical/emotional care or labour, for a limited period in the present.

## **Conclusions**

In this paper we have argued that Parsons' concept of the sick role can be used to explain women's experiences of managing their risk of inherited cancer, specifically their accounts of the immediate post-operative period. The concept of the sick role can help us understand why some women construct RR mastectomy as an easy procedure that prolongs, but does not interfere with, their normal life, while others see it as not only interfering with normal functioning but also as requiring them to relinquish other responsibilities during prolonged periods of convalescence.

In line with Crossley's (1998) findings, we argued that the majority of women in this study could be seen as actively resisting entry into the sick role, for, like the HIV patients in Crossley's study, most interviewees described how they taken back their lives or resumed their normal social roles as quickly as possible following surgery. We speculated that women's resistance to adopting the sick role may be seen as a direct response to the actions or reactions of those around them. Many talked about how healthcare professionals were sceptical or unsupportive of their decision to voluntarily undergo RRM and thus, can be seen as refusing to legitimate their entry into the sick role.

Indeed, it must be noted that the scepticism encountered by women in this study is semi-institutionalised in some jurisdictions where at-risk women who are considering this intervention are required to undergo a psychiatric/psychological consultation to discuss their decision (e.g. the UK, NICE 2013). While there is no official requirement for psychological assessment in Australia, women who approach a surgeon or GP seeking RRM are usually offered and encouraged to have genetic and psychological counselling beforehand. It can be argued that putting such "extraordinary" measures in place before a referral for this particular procedure can be accessed implicitly raises questions about a) women's competency to make such a decision and b) whether the decision itself is a reasonable decision.

Alternatively, we suggested that women's reluctance to enter the sick role may be due to the fact that they regard RRM as providing them with the opportunity to stay healthy. In other words, electing to undergo mastectomy before risk eventuates enables them to avoid a diagnosis of cancer, and thus, future patient-hood, consequently adopting the sick role for a prolonged period of time following RRM could be seen as paradoxical. Indeed, can be argued that these women unwittingly

find themselves on the opposing horns of a socio-ethical dilemma. On the one hand, they are encouraged to actively manage their health and modify their genetic risks by public health discourses which emphasise the need to behave as an active citizen, a morally responsible entrepreneurial subject (Robertson 2000; Novas and Rose 2000). These discourses construct genetic risk management, risk-reducing surgery, as the right thing to do (Hallowell 1999; Arribas-Allyon *et al* 2011), the action of a responsible subject (Robertson 2000). On the other, managing risk in this instance is not without social, or moral, costs, for it requires these women to voluntarily enter the sick role thereby relinquishing other social duties and responsibilities.

Of course, what we have overlooked so far in this discussion is the fact that all of these women were hospitalised while they had the surgery and were, therefore, patients, if only for the briefest of periods in some cases. However, this observation does not undermine our argument. Indeed, Parsons (1951) himself acknowledges that those who assume the sick role should want to relinquish it as soon as possible and resume an independent existence. On this basis entering the sick role in the short-term, i.e. being a surgical patient, may be seen as morally acceptable, not only because it demonstrates active risk management in the present (Robertson 2000), but also because it allows you to avoid adopting or inhabiting the (sick) role of cancer patient for a longer period in the future. What appeared to be less acceptable to our interviewees was remaining in the sick-role once their breasts had been removed, and those who continued to inhabit this role for longer periods blamed other people or random events for the fact that they were unable to fulfil their social obligations for an extended period of time.

Finally, we must note that the recovery narratives we have described here are a form of moral accounting. These interviews provided women with the opportunity to present an account of themselves and their actions, and we are more than mindful of the fact that that they may have been responding to a perceived pressure to present themselves as responsible and diligent persons, as active citizens. Indeed, their reported experiences of previous encounters with health care professionals and other members of their social circle suggested that they were used to having to justify their decision to undergo breast surgery despite the fact that they had not received a diagnosis of breast disease. While we would expect women in an interview situation like this to provide a narrative that justifies their actions (Williams 1984), the fact that

this group provided such contrasting recovery narratives was not, and could not have been, predicted.

In conclusion, in his efforts to rehabilitate the writings of Talcott Parsons, Chris Shilling observes that Parsons' conception of the sick role is informed by, and rests upon, his ideas about culture and, in particular, the value that we place upon "active instrumentalism" within late modernity (Shilling 2002:626). Shilling argues that it is possible to see Parsons as anticipating certain important developments in the late twentieth century, such as the rise in medical consumerism and an increased focus upon the body as a site of sociological analysis. However, he argues that despite this, Parsons' account of illness must ultimately be rejected because the only body that counts within his analysis is the diseased or pathological body; a body that is incapable of action. In this paper, contra Shilling, we have argued that Talcott Parsons' conception of the sick role is useful and can shed light on the experiences of those who live with and manage their cancer risks. However, while we would argue that Parsons' views may still have some purchase in the early twenty-first century, they do require some modification, not least his idea that individuals passively accept the designation of patient (Shilling 2002). This study demonstrates that high-risk women present themselves as actively adopting or rejecting the sick role in their recovery narratives, and in this respect they can be seen as the co-creators of health and illness.

### **Endnotes**

1 kConFab is a large epidemiological and clinical study of multiple-case breast cancer families from Australia and New Zealand (kConFab). Families were recruited after the index family member attended a consultation at one of 16 family cancer clinics (FCC). Eligibility criteria included a strong family history of breast cancer and/or ovarian cancer, or a documented *BRCA1* or *BRCA2* mutation (Mann et al 2006). Longitudinal follow-up and psychosocial data were collected from unaffected women, using three-yearly self-report questionnaires and a semi-structured interview (Phillips et al, 2005).

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## References

- Altschuler, A., Nekhlyudov, L., Rolnick, S. J., Greene, S. M., Elmore, J. G., West, C. N., et al. (2008). Positive, negative, and disparate - women's differing long-term psychosocial experiences of bilateral or contralateral prophylactic mastectomy. *Breast Journal* 14(1), 25-32.
- Antoniou, A., Pharoah, P. D. P., Narod, S., Risch, H. A., Eyfjord, J. E., Hopper, J. L., Easton, D. F. (2003). Average Risks of Breast and Ovarian Cancer Associated with BRCA1 or BRCA2 Mutations Detected in Case Series Unselected for Family History: A Combined Analysis of 22 Studies. *The American Journal of Human Genetics*, 72(5), 1117-1130.

- Arribas-Allyon, M. Sarangi, S. & Clark, A. (2011) *Genetic Testing: Accounts of autonomy, responsibility and blame* London: Routledge
- Bebbington Hatcher, M. & Fallowfield, L.J. (2003). A qualitative study looking at the psychosocial implications of bilateral prophylactic mastectomy. *Breast* 12, 1-9.
- Brandberg, Y. Sandelin, K., Erikson, S., Jurell, G., Liljegren, A., Lindblom, A., et al. (2008). Psychological reactions, quality of life, and body image after bilateral prophylactic mastectomy in women at high risk for breast cancer: A prospective 1-year follow-up study. *Journal of Clinical Oncology* 26(24), 3943-3949.
- Borgen, P.I., Hill, A.D.K., Tran, K.N., Van Zee, K.J., Massie, M.J., Payne, D., & Biggs, C.G. (1998). Patient regrets after bilateral prophylactic mastectomy. *Annals of Surgical Oncology* 5(7), 603-606.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.
- Corbin, J. & Strauss, A. (1990). Grounded Theory research - procedures, canons and evaluative criteria. *Zeitschrift Fur Soziologie* 19(6), 418-427.
- Crossley, M. (1998). 'Sick Role' or 'Empowerment'? The ambiguities of life with an HIV positive diagnosis. *Sociology of Health & Illness*, 20(4), 507-531.
- Evans, D. G. R., Baidam, A. D., Anderson, E., Brain, A., Shenton, A., Vasen, H. F. A., et al. (2009). Risk reducing mastectomy: outcomes in 10 European centres. *Journal of Medical Genetics*, 46(4), 254-258.
- Frost, M.H., Schaid, D. J., Sellers, T. A., Slezak, J. M., Arnold, P. G., Woods, J. E., et al. (2000). Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. *Journal of the American Medical Association* 284, 319-324.
- Giddens, A. (1990). *The consequences of modernity*. California: Stanford University Press.
- Hallowell, N. (1999) *Doing the right thing: genetic risk and responsibility* *Soc Health & Illness* 21, 597-621
- Hallowell, N. (2000). Reconstructing the body or reconstructing the woman? Perceptions of prophylactic mastectomy for hereditary breast cancer risk. In L.

- Potts (ed.) *Ideologies of breast cancer: Feminist perspectives*. London: Macmillan Press/St Martin's Press, 153-180.
- Hallowell, N., Baylock, B., Heiniger, L., Butow, P., Patel, D., Meiser, B., et al. (2012). Looking different, feeling different: Women's reactions to risk-reducing breast and ovarian surgery. *Familial Cancer* 11, 215-224.
- Kathleen Cuningham Consortium for Research into Familial Breast Cancer: KConFab. [http:// www.kconfab.org](http://www.kconfab.org)
- Mann, G., Thorne, H., Balleine, R., Butow, P. N., Clarke, C. L., Edkins, E. et al. (2006) Analysis of cancer risk and BRCA1 and BRCA2 mutation prevalence in the kConFab familial breast cancer resource. *Breast Canc Res* 8: R12
- McGaughey, A. (2006). Body image after bilateral prophylactic mastectomy: an integrative literature review. *Journal of Midwifery and Women's Health* 51, e45-e49.
- Meiser, B., Butow, P., Price, M., Bennett, B., Berry, G. & Tucker, K. (2003). Attitudes to prophylactic surgery and chemoprevention in Australian women at increased risk for breast cancer. *Journal of Women's Health* 12, 769-778.
- NICE (2013). *Familial breast cancer: Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer*. National Institute for Health and Care Excellence, United Kingdom.
- Novas, C. & Rose N. (2000) Genetic risk and the birth of the somatic individual *Economy and Society* 29 485-513
- Parsons, T. (1951). *The Social System*. London: Tavistock Publications.
- Petersen, A. & Bunton, R. (2002). *The new genetics and the public's health*. United Kingdom: Taylor & Francis.
- Petersen, A. R., & Lupton, D. (1996). *The new public health: Health and self in the age of risk*. London: Sage Publications.
- Phillips, K.A., Butow, P., Stewart, A., Chang, J.H., Weideman, P., Price, M., et al. (2005). Predictors of participation in clinical and psychosocial follow up of the kConFab breast cancer family study. *Familial Cancer* 4(2), 105-113.
- Rebbeck, T. R., Friebel, T., Lynch, H. T., Neuhausen, S. L., van't Veer, L., Garber, J. E., et al. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: The PROSE study group. *Journal of Clinical Oncology* 22(6), 1055-1062.

- Rier, D. (2000). The missing voice of the critically ill: a medical sociologist's first-person account. *Sociology of Health & Illness*, 22(1), 68-93.
- Robertson, A. (2000). Embodying Risk, Embodying Political Rationality: Women's Accounts of Risks for Breast Cancer. *Health Risk & Society*, 2(2), 219-235.
- Shilling, C. (2002). Culture, the 'sick role' and the consumption of health. *The British Journal of Sociology*, 53(4), 621-638.
- Turner, B. S. (1996). *The body and society: Explorations in social theory*. London: SAGE Publications.
- Williams, G. (1984). The genesis of chronic illness: narrative reconstruction. *Sociology of Health & Illness*, 6(2), 175-200.

**Table 1: Participant characteristics**

	<b>RRM = 8 (38%)</b>	<b>RRM+RRO=13 (62%)</b>	<b>Total=21</b>
<b>Age at RRS mean (range)</b>	34 (28-41)	46 (32-66)*	
<b>Months since RR surgery mean (range)</b>			38 (14-70)
<b><i>Relationship Status</i></b>			
<b>Married/de facto</b>	6 (75)	10 (77)	16 (76)
<b>Boyfriend</b>	1 (12.5)	0 (0)	1 (5)
<b>Single</b>	1 (12.5)	1 (8)	2 (9.5)
<b>Separated</b>	0 (0)	1 (8)	1 (5)
<b>Divorced</b>	0 (0)	1 (8)	1 (5)
<b><i>Women with Children</i></b>			
<b>Boys only</b>	3 (37.5)	3 (23)	6 (29)
<b>Girls only</b>	0 (0)	2 (15)	2 (9.5)
<b>Both</b>	3 (37.5)	6 (46)	9 (43)
<b><i>Employment</i></b>			
<b>Professional</b>	0 (0)	1 (8)	1 (5)
<b>Manager</b>	0 (0)	1 (8)	1 (5)
<b>Trades</b>	2 (25)	1 (8)	3 (14)
<b>Clerical/office worker</b>	1 (12.5)	1 (8)	2 (9.5)
<b>Semi/unskilled</b>	1 (12.5)	2 (15)	3 (14)
<b>Domestic duties</b>	2 (25)	2 (15)	4 (19)
<b>Retired</b>	0 (0)	2 (15)	2 (9.5)
<b>Invalid</b>	0 (0)	1 (8)	1 (5)
<b>Student</b>	2 (25)	1 (8)	3 (14)
<b><i>Education</i></b>			
<b>Secondary Education</b>	2 (25)	7 (54)	9 (43)
<b>Vocational training</b>	3 (37.5)	1 (8)	4 (19)
<b>University level</b>	3 (37.5)	5 (38)	8 (38)
<b><i>Mutation status</i></b>			
<b>Gene mutation positive</b>	4 (50)	12 (92)	16 (76)

\* age at last surgery i.e. the surgery that resulted in recruitment to this study, in 4 cases who had previously undergone RRM this was ovarian not breast surgery.