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Varieties of suffering: Living with the risk of ovarian cancer

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Abstract

Risk is a defining feature of late modernity. While it is acknowledged that risk has come to mean danger, the sociological literature suggests that risk is becoming abstracted from reality and presents it as lacking emotional content. This paper argues that the lived experiences of risk should no longer be overlooked. Using data collected in a qualitative interview study of women who have a family history of ovarian cancer, it demonstrates that women's understanding of risk is framed by their previous experiences of death and dying and perceived as connoting a future of suffering and loss for themselves and others. It is argued that managing risk in this context may be less an act of rational self-management than the response of an emotional and relational self.

Keywords: *Risk, ovarian cancer, qualitative, emotion, genetics*

Introduction

The abstraction of risk from reality

According to Mary Douglas¹ (1992) our understanding of risk and hence, our everyday use of this term (Wittgenstein 1953) has transformed over the years. It is no longer a neutral term connoting the probability of losses and gains associated with an event, but is primarily used to refer to negative outcomes. As Douglas notes, '... *risk* now means danger; *high risk* means lots of danger,' Douglas (1992: 24). Douglas argues that risk also constitutes a forensic resource. It is used to explain misfortune, as a means of holding persons accountable for their actions (cf. Beck 1992) and, as such, has gained a moral meaning (see also Lupton 1993).

Although Douglas regards risk as a culturally and historically determined concept, she argues that the social construction of risk, i.e. determining what events/things come to be seen as risks or count as risky, should not detract from the fact that the dangers risk alludes to are real dangers. As she notes, like the risks of traditional or pre-industrial societies, '[T]he risks in the industrial world are equally real' (Douglas 1992: 29). The importance of this point cannot be overlooked, for it can be argued that the ways in which risk has been theorized within the sociological literature has resulted in the presentation of risk as abstracted from reality and the real and present dangers it connotes. Thus, although it is widely acknowledged that risk has lost its neutrality (Lupton 1993) and risk awareness is still regarded as intimately related to anxiety (Wilkinson 2001); in much of contemporary sociological discussion risk is presented as a sanitized concept lacking emotional content.

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It can be argued that the sanitization of risk within sociological writing has been influenced by the increasing individualization of risk in contemporary society (Douglas 1992), particularly in the field of health and illness. For some, living with risk has been reformulated as an identity problem. Giddens (1991), for example, regards risk as central to the reflexive project of the self: the creation of an ongoing and forward-looking self-narrative. For Giddens, risk estimation involves the 'colonization of the future,' the presentation of the future as a range of possibilities/probabilities. Risk information is mediated by expert opinion and the management of risk involves rational calculating actors crafting their futures in the light of this expert knowledge. Thus, as far as Giddens is concerned, risk management is less the response of an emotional subject than the rational management of self-identity in the face of the odds. Alternatively, those who adopt a Foucauldian perspective see risk discourses as increasingly implicated in the regulation and control of individuals. Through the use of disciplinary techniques such as normalization, risk discourses define certain behaviours or attributes as risky rather than dangerous (Castel 1991), as requiring individual self-management, and as a result produce certain types of subjectivities with their attendant responsibilities (e.g. Novas and Rose 2000, Petersen and Bunton 2002, Polzer *et al.* 2002). According to the proponents of both of these perspectives, risk fundamentally shapes our lives at an individual and societal level. However, as Lupton (1999) notes, both the followers of the 'risk society' thesis and those who adopt a Foucauldian approach have a tendency to overlook the lived experiences of those who are dealing with the dangers which characterize their everyday lives. Arguably, this omission is, at least in part, responsible for the portrayal of risk as a dispassionate concept within much of the sociological literature, for although the dangers and hazards of the modern world are acknowledged by these perspectives, the fear, the 'adrenaline rush,' the excitement, the terror and an array of other emotions we may experience when we confront risk have been expunged from their analyses.

This paper tries to right the balance by arguing that the lived reality of risk should no longer be overlooked. It concentrates upon the subjective experiences of living with inherited risks and, as such, can be seen as an attempt to bring the danger and its attendant emotions back in. Using data collected in a qualitative study of women who have a family history of ovarian cancer, it demonstrates that women's understanding of their risks of developing cancer is emotionally and temporally framed. It describes how individuals' awareness of the risk of ovarian cancer is influenced by their reflection upon the past, their experiences of death and dying in their family, and how these experiences influence their perceptions of their future and the decisions they make in the present. It will be observed that, for the women who took part in this study, living with and managing risk was less about the rational management of self-identity than coming to terms with others' pain and suffering and taking steps to avoid a future of pain and suffering for themselves and their families. Finally, it will be argued that if we are to provide a more nuanced account of the meaning of risk of within contemporary social life, then we need to attend to the relationship between risk and human suffering.

The realities of doing research on ovarian cancer: Entering the (emotional mine-) field

The research upon which this paper is based was carried out between 1997 and 2000, with the pragmatic aim of determining young pre-menopausal women's information needs and views on prophylactic surgery as a way of managing their risks of developing hereditary ovarian cancer. The study involved in-depth interviews with two groups of women, those who had previously undergone surgery and those who had decided not to pursue this option

for the present. While I had been working in the field of cancer genetics for 3 years before the start of this project and was, therefore, familiar with the issues facing women who have a family history of this disease, it soon became apparent that I was totally unprepared for undertaking these interviews.

It was clear from the first interview that my project had opened up a can of worms for many of these women and that I had underestimated their desire to talk about death, loss and their existential fears. My initial question was a very general prompt, which invited them to talk about their family history and their experiences, and was included to put them at their ease and give them the opportunity to set the interview agenda. I had not predicted the types of responses this would generate. In almost every case, the women launched into a poignant and graphic description of their mother's or sister's illness, treatment or lack of treatment and, in most cases, eventual death from ovarian cancer. They told me what had happened, how it had happened, what they wished they had done, what they had done and always how guilty and sad they felt. While I could have changed my approach, it was clear that these were the things that these women wanted to talk about; in some cases these stories would surface even before the interview began. They would launch into their tale either in the car when they collected me from the station or while they made me tea or a cold drink in the kitchen before we sat down turned on the tape recorder. So from the start I knew that this project was not going to turn out exactly as I had anticipated, for these encounters were extremely emotionally charged. Most women became very upset and cried when they talked about their relatives. Although I had expected sadness and loss, I had totally underestimated the degree of fear, anger and frustration I witnessed. These women were so angry. Angry at their relatives' doctors for having ignored their relatives' pleas for help until it was too late. Angry at having to fight the medical profession in their efforts to get their fears about their family history taken seriously. Angry about the insensitive ways their fears about their risks had been dismissed. Angry about the ways in which prophylactic surgery had been discussed. Angry about the lack of information they had received about the physical and socio-emotional after effects of surgery and fearful of its (potential) impact on their lives. Angry that they had not been told about HRT and fearful of its risks. Angry that their concerns about their children's risks had been ignored and fearful for their children's lives. They were very angry and upset. There was little I could do to help except offer to stop the tape and listen. I felt more and more impotent in the face of their emotions.

The interviews progressed over the next couple of years and I got used to listening. By the beginning of 1999 I had collected all the data and was busy producing a report for the Funders and writing up my findings. I deliberately concentrated on the practical aspects of the research. I focussed my attention on the parts of the interviews that dealt with surgical decision-making, information needs, knowledge of menopause and the after effects of surgery. I coded these parts and ignored the rest; reading the interviews made me cry. I wrote an information booklet for the Funders to distribute, it was clear, practical and, best of all, the women liked it. I began to talk in public about the research. I talked a lot, to gynaecologists, geneticists, genetic counsellors, nurses, academics and anyone who would listen, and I became angry too. But anger was not the only emotion I felt, I also felt guilty because I was still unable to read my transcripts and notes in their entirety, I could not face revisiting the anguish they contained. So for me, this paper is a rather belated attempt at describing what living with the risk of cancer meant to these women. In a world in which genetic technologies are portrayed as having the power to alleviate future pain and suffering, it is a tale that needs telling. Hopefully by retelling their stories I will go

some way towards discharging my obligations to the women who gave me their time and shared their experiences. While I know I can never do justice to their accounts, I feel that it is time to try.

The risks of Hereditary (Breast) Ovarian Cancer (HBOC): Expert knowledge and advice

What risk means for the women who took part in this study will be explored below. But prior to detailing their experiences, it is perhaps expedient to provide an account of expert knowledge regarding the risks faced by women whose family history suggests they are at risk of hereditary ovarian cancer.

Research suggests that between 5% and 10% of cases of epithelial ovarian cancer are inherited. Some of the genetic mutations (*BRCA1/2*) which are responsible for increasing individuals' susceptibility to this disease have recently been identified. It is calculated that mutation carriers' ovarian cancer risks are increased from a population risk of 1–5% to between 28% (Ford *et al.* 1997, Whittemore *et al.* 1998) and 60% (Easton *et al.* 1995). In addition, mutation carriers also may have an increased risk of developing breast cancer, which may be as high as 80% (Easton *et al.* 1995). Women (and men) who have a family history of ovarian (+/– breast) cancer are referred for genetic counselling, where their risks of inheriting and/or passing on a genetic mutation and developing disease are calculated and different forms of cancer risk management are discussed.

The confirmation of genetic risk status in genetic counselling is usually based upon the type of family history presented (i.e. the number, type and ages of affected relatives in the family). Although predictive *BRCA1/2* DNA-testing for an inherited susceptibility to ovarian cancer is now available in the UK, these tests are usually confined to people from multi-case families whose affected relatives have previously been identified as carrying a particular mutation. Despite the fact that a relatively small number of individuals are eligible for predictive testing, many more are identified as at risk of hereditary disease on the basis of their family history.

All at risk women, confirmed *and* potential mutation carriers, are advised to adopt ovarian cancer risk management practices (National Institute of Health 1994). The clinical management of at risk women includes either annual screening (transvaginal ovarian ultrasound with blood serum CA125 measurement) or prophylactic surgery (bilateral oophorectomy, the removal of healthy ovaries) once childbearing is completed (National Institute of Health 1994, Burke *et al.* 1997, Eisinger *et al.* 1998).

The rationale for screening high-risk women is that cancers may be identified at an early stage when the prognosis is good, thus reducing the risk of dying from cancer. However, there are no data to indicate that ovarian screening is effective in reducing morbidity and mortality in high-risk groups. Indeed, screening carries risks. Interval cancers may occur between screens or screening tests may fail to detect cancers. It also may have iatrogenic consequences, the rate of false positives is significant, and this may result in women having to undergo unnecessary exploratory operations.

At the time that this study was conducted there was no evidence to suggest that prophylactic ovarian surgery led to a reduction in mortality rates in high-risk groups.² Nevertheless, it was assumed that oophorectomy had the potential to reduce one's risk of developing ovarian cancer, despite evidence that intra-abdominal peritoneal carcinomas may still arise following this surgical procedure (Tobacman *et al.* 1982, Piver *et al.* 1993). Furthermore, it has been suggested that the risk-reducing benefits of ovarian surgery only offsets the risks associated with a surgically-induced menopause (i.e. the increased risks of cardiovascular disease and osteoporosis; Burke *et al.* 1997) in premenopausal women if

HRT adherence is 100% following surgery (Schrag *et al.* 1997). Moreover, there are medical risks associated with surgery, such as the risks associated with anaesthesia and post-operative complications such as infections.

The study³

The women were recruited from the United Kingdom Co-ordinating Committee for Cancer Research's Familial Ovarian Cancer Register and two Cancer Genetics clinics based in London hospitals. The criteria for inclusion included: age 45 years or less at the time of surgery/interview, pre-menopausal prior to the operation/at time of interview and a family history of ovarian cancer (+/– breast cancer) consistent with HBOC.

The participants

Twenty-three women who had undergone prophylactic ovarian surgery (Surgery) and 26 women who had decided not to undergo this procedure for the present (Screening) were recruited to the study by the clinicians or the Register Data Manager. The ages at which women had undergone surgery ranged from 31 to 45 years (mean 38.8 years). The age range of women in the screening group was 28 to 50 years at the time of interview (36.5 years). All of the women had at least a 25% risk of carrying a cancer susceptibility mutation. Thirty-nine women had either a mother or sister who had had ovarian cancer, and 42 women had a grandmother or aunt diagnosed with this disease. The women reported between two and nine family members with breast or ovarian cancer.

All of the women in the surgery group had children, whereas only 19 (73%) of those in the screening group were mothers. Eleven women had worked in a medically related occupation at some time in their lives (for example, General Practitioner, nurse or receptionist in a gynaecology outpatients clinic).

Data collection and analysis

The interviews took place between November 1997 and June 1999. With the exception of two women who requested to be interviewed by telephone, all interviews were carried out face-to-face at a location of the participant's choice. Most chose to be interviewed in their homes, the remainder elected to be interviewed in public houses, local hotels or at their workplace. The interviews lasted 1–3 hours and were tape recorded with consent.

The study was carried out according to the principles of grounded theory research (Glaser and Strauss 1967), which entails simultaneous data collection and analysis. At the start of the interview, the women were asked to provide a narrative account of their experiences of cancer in their family, and to describe what they had done since they had become aware of their risk status. Although few women required any prompting during these interviews, some were asked to expand upon specific themes, for example, their understanding of their risk of ovarian cancer, their perceptions of ovarian screening/surgery, the factors that had influenced their risk management decisions and the (perceived) impact of prophylactic oophorectomy on their lives. In addition, a series of exploratory questions was used. These focussed upon knowledge of ovarian function and menopause, understanding and recall of information received pre- and post-surgery and information needs.

Verbatim transcriptions of the interviews were obtained and these were read through many times to enable the identification of recurrent themes both within and between participants' accounts. The method of constant comparison (Strauss and Corbin 1990) was used to

develop a coding frame with which to analyse the interview transcripts. Atlas-ti (Muhr 1994), a qualitative data analysis software package, was used to manage the interview data.

Findings

Recognizing risk: Reflecting on the past and securing the future

The idea that certain diseases or behavioural traits are genetic in origin has a long history (Richards 1996). Prior to the advent of DNA testing, individuals' risks of inheriting particular diseases were determined by the analysis of the family tree or pedigree. Indeed, in these days of health care rationing, the pedigree still plays a major role in identifying those who are at risk of disease and thus eligible for genetic testing or bodily surveillance. As such, family pedigrees have been described as inscription devices (Prior *et al.* 2002), for it is through the production of a pedigree, which details the family history of disease, the number and types of affected relatives, that individual patients come to be identified as 'at risk.' The women who took part in this study also regarded their family's history of ovarian cancer as confirming their risks, but in a more immediate way. Risk was not revealed to these women by the clinical auditing of disease within their family during genetic consultations (Armstrong *et al.* 1998), but rather it was something they had witnessed first-hand as illness, dying and death. Their accounts revealed that observing the physical effects of cancer as it killed their mothers and/or sisters had had a profound effect upon these women. Victoria described how the last 7 years of her sister's life involved an ongoing round of diagnosis followed by adjuvant treatment followed by a disease-free period followed by another diagnosis and so on, finally culminating in a painful and protracted death from ovarian cancer in her early forties.

Victoria: Well, she had an ovarian cyst that was about 8 or 9 years ago . . . And then the year later she had breast cancer. She had a lumpectomy. And then she was clear for 18 months. And then she had a second primary, and they gave her a lumpectomy again. And then they said, 'We'll either give you radiation, or give you chemotherapy on the ovarian—on your ovaries.' . . . Why the hell didn't they take the whole blooming lot out? You know, my mum's died of cancer, ovarian cancer, at 50. My aunt's had breast cancer at 38, 39, whatever. My other aunt, at the time she was alive, Auntie Jean, well and healthy, nothing. I mean she—from 6 weeks, beginning to end, done, Auntie Jean. It was a quickie, thank God. You know, if you're going to die, then that's the way to go. Not the way my sister went, fighting for every breath, wanting an extra day all the while. My mum was the same. I remember the last 6 weeks of my mum's life were horrendous. The last 2 months of my sister's life were horrendous. My mum and my sister, exactly the same, apart from the age.

Eve: I mean, my sister when she was dying, my children [went to see her] and she apologised to me. I mean she was sitting there, she looked like she had just walked out of Belsen, not a hair on her head, and my children went up to her and kissed her and hugged her. Now I was nearly crying because she apologized then for frightening them, but she couldn't wear the wig because her head was too hot and . . . it was a shock to me . . .

As these accounts illustrate, nearly all of the interviews included a graphic account of the pain and discomfort that their relatives had endured during their illness. In many cases women talked about the effects of this disease and its treatment on their relatives' bodily integrity and the physical suffering this entailed. Many women used metaphors to emphasize

the dehumanizing effects of ovarian cancer. Some women talked about how their relatives had literally wasted away, and likened their mother's and sister's bodies in the end-stages of disease to those of concentration camp inmates (Eve). Others described how their relatives' bodies had swollen to abnormal proportions as the disease progressed,⁴ and used animal metaphors, for example, 'looking like a beached whale' (Pam), or described their menopausal mother's bodies in 'grotesque' ways (e.g. 'looking 9 months pregnant') to stress the extent of their bodily disintegration.

In a few cases, like Victoria's sister, illness and dying was reported as a long drawn-out process, however, in most cases the women reported that the period between diagnosis and death was a few months/weeks because their relative's doctors had failed to recognize symptoms as ovarian cancer in time. For example, Sylvia, a nurse, described how she, in contrast to her mother's clinicians, had realized that her mother had ovarian cancer:

Sylvia: And er she came to stay one summer and said that she'd been feeling really tired, and she was getting very fat, so she'd decided to go on a diet. And this was about August. And in the October she phoned me and she said, this is a really weird diet, Sylvia, she said, because I've lost weight on my arms and legs and everything, she said, but I look about 7 months pregnant. And um the alarm bells rang immediately with me. That was the point that I realized, it all fell into place. And I said to [husband] I think I'm going to lose my mother. And he said, why? And I said, because I think she's got ovarian cancer, and I said I think it's too far-gone. She'd been having investigations for diverticulitis, because she had tummy rumblings . . . And I told her, you know, on that phone call, I told her to go straight to the doctor, because she'd had a barium enema, which showed diverticulitis, diverticulitis and nothing else, and I said to ask for a second opinion straight away . . . I went up—I think it was the first time I'd actually seen her . . . And I knew, just looking at her, I'd been nursing long enough to recognize the eyes and the sunken cheeks and the big tummy. And she was an open and close. The consultant um rang my father that night, and I was staying there, and he told me that she had widespread cancer. He asked me if I wanted to tell my father, and he said he'd removed some of the tumour but it was just everywhere and he wasn't very hopeful but he was going to try chemotherapy and radiotherapy.

The media frequently describes ovarian cancer as 'the silent killer.' Silent because symptoms are relatively diffuse, unspecific and difficult to recognize and killer because diagnosis frequently occurs after the disease has advanced and is untreatable. As noted above, for many of these women, this metaphor was frequently born out by their experiences; many relatives had not received a diagnosis until the disease was too far progressed to warrant anything more than palliative treatment. For example, Kim and Pam's mother was diagnosed with ovarian cancer 13 days following her admission to hospital for exploratory tests and died 48 hours later.

Kim: Then they'd moved her from the main ward into the side ward, and she was starting to feel very hot. Her body was stone cold, but she was chewing on lumps of ice and—'Oh God, I'm really boiling, I'm really boiling.' 'But mum, you're cold.' 'No I'm not, I'm boiling, listen.' And we had all the windows open, we had two fan heaters blowing at her, and she still kept saying, 'I am boiling, I'm boiling.' Meanwhile, Pam had gone to the doctors' room, and they said the biopsy came back this morning, and she has got cancer. So we said, 'well, what can we do?' And I sort of said to them, I said, 'well, what about chemotherapy?' And they said, 'sorry but it's too far gone. It's gone from the ovaries around all the intestines. She's literally being chewed all the way through.' So we said,

‘well, what’s happening?’ And they said, ‘well, we don’t hold out much hope.’ In 48 hours we lost mum.

Witnessing others’ pain and distress, coupled with the shock of their death following a relatively short illness, not only brought with it feelings of sadness and helplessness, but also intense fear about their own future health and intimations of their mortality. As Sally said: ‘I don’t want to die. I don’t want to go through what my mother went through. I couldn’t bear it. The illness, the pain, the pain and the agony, for what?’ Similarly, Julie reflected:

I don’t want to go through what my mum went [through]—when you see somebody who has suffered so much, and they’re knocked back with chemotherapy and the radiotherapy, and the operation itself was—it was horrific. And it—that was it. I thought, I’m not going to be like my mum. I don’t want to go all through what she went through. And that really—I could just see her when I thought about it, in hospital, and all the chemotherapy, I used to go with her, and how she was. And she was so poorly. And it’s not fair on anybody. And if it was [a dog] we’d put it down. It’s just cruel. So it was—I really think it was because I didn’t want to—I didn’t want to suffer like my mum. It was horrible. It was really ugh! Nasty!

Seeing others’ pain and the ways in which cancer and, in some cases, its treatment had ravaged their relatives’ bodies brought their risks of ovarian cancer home to these women in a very immediate way. Along with the recognition of their risks came the realization that they needed to be proactive in dealing with this threat to their mortality. Pam and Mary, like Julie, said that their experiences of seeing the physical effects of cancer and the agony their mothers had experienced had stiffened their resolve to take steps to manage their risks if possible.

Pam: I think knowing that—how my mum looked, and what she suffered, or what she must have suffered, I thought, there’s no way I’m going to do that. I mean the poor lady, I mean they drained 19 litres of fluid off of her, and it still came back. She was like a beached whale. And I thought, how can anybody suffer like that? And how long had this been going on? And they say it’s one of the fast-growing ones, because it’s hormonal. And I thought, well, there’s no way, because I wouldn’t want my children to see me go through that agony. I’ve actually had a few relatives here had ovarian cancer. When you’ve seen them come in, they’ve had screening done, they’ve had this done, they’ve had a bit of chemo done, and they’ve still died. And that’s an awful thing, to watch somebody lose their hair, go through all that trauma. And I just think, no way you could do that.

Mary: I mean I don’t want to end up in the pitiful state that my mother was in. I’ve seen that, and I remember her suffering. I can see her crawling across the floor on her hands and knees, because she was in so much pain. And after seeing something like that, if hysterectomy is the answer, then I’ll go for it. Yes, no doubt, no doubt... having seen people with it, and just what it does to them, and the family round them, I don’t want to go—I’ve no intention of going through that, if I can help it. So if they said, you’ve got to have your right arm off at the same time, I’d do it. I’d do it.

Risk awareness was provoked by witnessing the death and/or illness of a close relative and in many cases this had led to an examination of the causes of death within the wider family. For many of these women, this ‘research’ revealed that cancer had not only ‘infiltrated’ or

‘chewed’ its way through the bodies of their mothers and/or sisters, but it had also infiltrated and decimated their family, thus, confirming their worst fears about their risks:

Pam: I mean obviously the first we knew about ovarian cancer in the family was my mother died at 51. Then when we looked back, and we knew her mother had died at 36, but at that time they said that it was an ovarian cyst . . . And as the time’s gone on, we’ve realized that my mum’s aunt had died, probably about 5 or 6 years before my mother had died, of ovarian cancer . . . So we knew there was quite a strong gene of some sort, or a hereditary thing, that might be passing through. And as one of five girls, I thought, whoops!

Caroline: one of my cousins in [Place], her mother had died with it, and [cousin] had actually had cancer of the breast, twice actually, since. And there was also another cousin which, I think it was about 2 or 3 years ago, she had cancer of the breast, and she died. And it was leading up to this cousin that died, and when my auntie phoned up and told me, and I just thought every time I got a phone call, it seemed to be somebody going in hospital with cancer. And then it all sort of went, all the aunties, and then suddenly it started on the next line, only one cousin had died but another one had had it, and I thought, you know, it can’t go on.

For some women, like Vicky, the family history of disease confirmed their risk and provided immediate clarification about what they should do to secure their future, as she said: ‘[B]ut with ovarian cancer being a silent cancer . . . I thought to myself, well, it’s in my family, two or three people have died of it, I’m going to go and have surgery and get it out of my life.’ In other cases, witnessing other’s death and dying and learning of the family history generated profound feelings of existential uncertainty which were difficult to dispel, for none of the risk-management options on offer—ovarian screening, prophylactic surgery or genetic testing—were seen as offering these women the security they wanted. Thus, for some, the certainty promised by the new genetics (Koenig and Stockdale 2000), namely, the ability to control risk, was seen as an illusion, primarily because the available risk management options were regarded as entailing a different set of uncertainties (see also Hallowell and Lawton 2002). As Jenny said:

But I realized that I can’t do a lot, because nothing’s—nothing’s that certain. The longer I keep my ovaries, there is more chance that, are they going to go bad, but at what point do I—when do I make the gamble? When do I say, right, I’ve had enough of them, I’m going to dice with HRT?

Cathy was similarly ambivalent about undergoing genetic testing to confirm disease susceptibility, as she was aware that the results could potentially destroy her own (and others’) hopes for the future.

Cathy: It’s a big thing [genetic testing], you’re like living on an edge of a cliff, and you know you’re going to get closer and closer to it. Now, are you going to jump? Are you going to lose your life? Or is somebody going to stop you and say, no, you’re OK? And it’s very hard, very hard . . . I’m frightened to death for my nieces, petrified.

Katrina, unlike Cathy, was initially more positive about the benefits of genetic testing. She perceived herself as currently existing in a liminal state (see Gifford 1986), unsure of which

way to proceed with her life, and thus described genetic testing as providing a degree of certainty or a clear steer for her future.

Katrina: I think not knowing is the worst really, because it just preys on your mind . . . It's just that not knowing is like being in limbo really. If I knew I had the gene I'd just deal with it and get on with my life. If I did not have the gene, I'd just be quite happy and still get on with it . . . Not knowing is worse really. It's easier to deal with it if you know in any one direction . . . But it would be easier because I could—it would be in black and white, basically. See, at the moment it's very grey and not known . . .

However, on further reflection, she conceded that the costs and benefits of testing were more complicated. While she acknowledged that having a genetic test could clarify these uncertainties and provide some hope for the future, she admitted that this would be highly contingent upon one's carrier status, for she recognized that if she was confirmed as a carrier, her future would remain characterized by uncertainty.

Katrina: It's just that you worry at what stage will it happen, if you've got the gene. You want to know if you've got it, for starters. And secondly, if you have got it, you can't do anything, you're hopeless, because you can't remove the gene, you know. So you're just thinking, at what stage will it mutate?

These data suggest that these women's realization that they may be at risk was dependent upon their reflection upon the past (others' embodied suffering) and their recognition that this may indeed be a portent of their future. But while their resolutions to attend to and manage their risks may have been motivated by their efforts to avoid physical pain and suffering, there was evidence that all of these women, including those who were ambivalent about the efficacy of screening and surgery, were also influenced by their recognition of some of the potential social consequences of developing cancer.

Dying from ovarian cancer: Lost relationships

The interviews suggested that while dying from ovarian cancer may be perceived as involving physical pain or embodied suffering it was also seen as entailing a disembodied or 'invisible' form of suffering (Lawton 2000). According to Lawton (2000), the suffering experienced by cancer patients is not confined to bodily changes, which they find frightening, humiliating and painful, but also arises as a direct result of the termination of their social relationships, in some cases, prior to physical cessation. In other words, dying is both a physical and social phenomenon (see also Lock 1997). Social death, or the effect of cancer on social relationships, was an ever-present theme in the present study. It constituted a form of disembodied suffering or emotional pain, which these women voiced as loss (Frank 2001). Loss was described in two contrasting, but interrelated, ways during these interviews.

In the first, the many women reflected upon their personal experiences of loss and talked about how they felt about the loss of a mother or sister. In this sense, suffering was experienced directly, as grief over a lost relationship. Victoria, for example, compared her experience of losing her mother at 18 with that of her cousin Sally, whose mother had died when Sally was in her mid-30s. Victoria believed that her suffering at the death of her mother was all the more profound because her mother, unlike Sally's, had not seen her

grow up, had not met her family or been there to provide support when she gave birth and raised her children:

Victoria: you can't know it all unless you've been there and done it. You have to actually have the experience. And because Sally lost her mum from ovarian cancer—but her mum was 67, and she [Sally] had children who were grown up—not grown up, but they weren't—you know, she was an adult. There's no comparison. She'll often make comparisons, but there's no comparisons. Lose your mum at 18 . . . She never met my husband, she never met any of my children. You know, at least with Sally I think [her son] was 15 and [her daughter] was 13 when her mum died. All right, they're young, but—you know? And all the support while they're growing up. Every weekend her mum had them, and—you know? And things. And they're at the mitzvahs, and they're at—you know? So there's no comparison.

However, although many women missed their relatives and were sad and angry that they had not been there to support them through, or witness, particular rites of passage, it was not only their personal loss they talked about. A life cut short by ovarian cancer was perceived as a loss, not only to those who remained, mourned and missed the dead, but also seen as a life in which one's familial obligations remained unfulfilled. Many women reflected on their relatives' loss, how they had lost out on their lives because they had failed to see their children grow up and mature, marry off them off, be a grandmother or relax with their partners in retirement, and the emotional pain they had experienced as a result of their realization that their life was ending. Ovarian cancer was seen as preventing their relatives from satisfying their potential or realizing their destiny (Langer 1997). Pam talked about her fears that ovarian cancer could foreshorten her life and mean that she, like her mother, would fail to fulfil her destiny as a mother or become a grandmother.

Pam: I didn't really want to get to 51 and not ever see my children, if they have any children, grow up. Because my mum never did. And it was just so sad to think of somebody at 51 at the end of their life. I mean when we went to, after she died and we went up to see the, and she went back to Blackpool . . . And we went back up there, and I couldn't think—at 51 years, and all I had was her contents, which literally fitted in the boot of my car. And I thought, that's no life.

A few women described how their mothers and sisters had 'fought' ovarian cancer, surviving beyond medical expectations, in their efforts to discharge their obligations to family members.

Janet: But when you've got children it's—I think it makes you fight. That's what my mum said, that, you know, I can remember her saying to me, I want to see the grandchildren grow up, you know. Because one of them, my sister had just had a baby. And she wanted to see my dad retire. And she fought, fought, fought for these things. And, you know, she was doing it. She was getting there. And she saw my dad retire. But she said, that will be what I want to do, see your dad retire, and I'll die happy. And she did, and she made it, and she was determined she was going to.

Managing risk: Living for others

While all were aware of the physical suffering they could experience if they developed ovarian cancer, the emotional pain and grief that this might entail for themselves and others

who might witness their illness and death, appeared to be a major influence on these women's risk management decisions. For example, Julie described her decision to undergo surgery as motivated by her desire to be a mother and grandmother:

Julie: I had the operation because I didn't want to die. And I wanted—my mum—I was only—I was 22 when my mum died, and I didn't want to do that to my boys . . . And I had the operation selfishly, because I wanted to be a mother to my children, and I wanted to watch my grandchildren grow up if I did have them.

As Julie's comments suggest, 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. As Chris said 'You know I think that is one thing that I thought about, you know if I didn't have it done [surgery] and I do get it [ovarian cancer], then it won't only be me, but I have a son, a daughter, a husband and it will affect them.' Many women talked about how they did not want their children, partners or parents to have to witness their illness and death or endure the grief and loss they had experienced when their relatives died:

Victoria: Once the [genetic] test was positive, I knew I had to have it [surgery], because of the chances. But I never felt that I would actually get it [cancer]. I couldn't take that chance, and my husband didn't want me to. And if it did happen, I didn't want my children to suffer how I suffered with my mum and even more so with my sister. You know, I think when you're younger you cope with it [death of a parent] probably better, although it does have a damaging effect. When you're older, you suffer more.

Nina: So what do you think are the pros of screening?

Anna: Well, I think the pros are just that at least you are making an effort to do something to protect yourself. I suppose I'm very conscious of the fact that I do have young children, you know, and I know what it's like having a parent die and, you know, I'd hate it to put that on them. So if I can do something that will prevent them suffering in that way as well.

Others, like Janet, said that they felt they had an obligation to their partners and children to take steps to manage their risk to ensure their children were not left to cope without them:

Janet: Life's too precious, isn't it, to just bypass all these things and—especially when you've got a family. I perhaps wouldn't be so worried about it if I hadn't got the children, if it was just me to think about, and [partner], and he's fine, I mean he's big enough to look after himself. But when you've got children it's—I think it makes you fight . . . I think I owe it to my children and my husband to do what I can to preserve my life really and I mean it's going to cause major traumas if I'm not here to look after them and bring up the children and—no, I think I owe it to the kids to do something to—to do everything I can really to be here for them.

While many women were anxious to avoid causing their children and partner (potentially unnecessary) suffering, a few claimed that their risk management decisions had also been influenced by their desire to prevent their father from seeing their child die. For example,

Sylvia described how her awareness of her father's anxiety about her health following her mother's death from ovarian cancer had contributed to her decision to undergo ovarian surgery:

Sylvia: I did it because my dad loves me . . . I don't think he would have coped. It's given him a lot of reassurance to know that at least I—it's one less cancer to think about . . . he doesn't worry about me in that special sense at all any more. And I think it's helped him. And at that time, as well, [daughter] was 15, and I thought I couldn't bear her to see me go through this.

In summary, although all of these women regarded their bodies as potentially compromised by the risk of ovarian cancer, these interviews suggested that living with the risk of ovarian cancer was perceived as involving more than just a rational exercise in risk management. Living with risk required these women to confront their own mortality and fight their fears of developing cancer and the physical suffering this entailed, and to contemplate the disembodied suffering that cancer could generate for themselves and others. Thus, these data suggest that living with genetic risk involved these women taking decisions in the present which, they hoped, would subvert a future of pain and suffering for both themselves and their family. In this sense, living with risk was seen as a family affair, and managing risk was perceived by many as offering emotional prophylaxis not only for themselves, but also for those they loved and cared for.

Living with risk: Managing self and caring for others

As was noted above, many authors have argued that living with risk constitutes an identity problem. According to Giddens (1991), self-identity is not fixed throughout the lifespan, but is actively managed in response to lived experiences. Giddens argues that the ongoing reflexive activity that generates self-hood, what he terms, 'the reflexive project of the self,' is triggered by particular experiences (e.g. retirement, birth, death, illness) which threaten ontological security and, therefore, require us to redefine ourselves. Such experiences or events culminate in 'fateful moments' in our lives, points at which we are forced to take decisions to actively manage ourselves in the present in an effort to maintain continuity of self in the future (Giddens 1991).

The data presented above suggest that witnessing a relative die from ovarian cancer, in the context of wider family history of this disease, is perceived as a threat to 'ontological security' (Giddens 1991). For most of the women in this study, the presence of ovarian cancer in their family threw their taken-for-granted future into question and thus was seen as necessitating some form of action on their part. However, while the ways in which these women attended to, and their subsequent decisions to manage, their risks could be construed as a rational attempt at identity management and thus, as support for Giddens' thesis, such an explanation ignores the emotional and familial context within which risk awareness develops and actions are taken.

For the women who took part in this study, ovarian cancer was undoubtedly a biological and material fact, a real-life danger (Douglas 1992), not an abstract risk revealed by experts (Armstrong *et al.* 1998). For them, it constituted a matter of life and death. It was a disease that had rampaged through their families to devastating effect, destroying the bodies of those they loved, causing untold physical and emotional suffering. Nearly all had witnessed the suffering caused by ovarian cancer first-hand, and wanted to avoid it at all costs. Thus, for many of these women, risk management was motivated by their fear of developing what their

prior experience had suggested was an untreatable and deadly disease. They did not want to die in pain.

As Lawton (2000) observes in her summary of the recent literature on death and dying, the focus of our existential fears has shifted in recent years, with the result that we are less afraid of death itself than the actual process of dying. Thus, she observes that the patients in her study of hospice care were less fearful of death than experiencing ‘... a drawn-out period of dependency, decline and social disengagement prior to death’ (Lawton 2000: 171). The data collected in the present study suggest that those who are at risk of ovarian cancer, like Lawton’s patients, were similarly fearful of the dying process—the suffering that they might experience if they developed cancer and the fact that others might suffer through witnessing their bodily disintegration. However, there was also evidence that these at risk women feared death itself or, more particularly, the effects that their death from ovarian cancer could have on pre-existing or future relationships.

As was noted above, these at risk women were not only aware of the physical effects of this disease, but also mindful of social consequences of dying from ovarian cancer, the fact that it would leave children motherless, grandchildren grandmotherless and parents childless. Their need to fulfil their destiny, to mother their children, become a grandmother, retire with their partners and/or care for their parents, was cited as a major influence on their decisions to engage in ovarian/genetic screening or surgery. Such observations would seem to support Giddens’ (1991) view that managing risk constitutes the rational response of an autonomous agent who is trying to ‘... keep a particular narrative going...’ (Giddens 1991: 55). Indeed, many of these women invoked their desire to continue mothering their children as a prime motivator for their actions. However, such an interpretation overlooks the more altruistic justifications that were frequently given for their risk management decisions. While managing their risk undoubtedly provided these women with some form of ontological security, in nearly all cases risk management was justified as a way of maintaining their relationships with others, which in turn enabled them to guarantee to provide ongoing care for others. Thus, while risk management may have been motivated to secure some form of continuity of self-identity, it was also undertaken for others’ benefit, so their family would not suffer as a result of being left without support or having to witness them succumb to a painful disease. Indeed, even those who were sceptical about the efficacy of screening and surgery or worried about the psychosocial effects of a surgically-induced menopause (see Hallowell and Lawton 2002) had engaged in some form of risk management, sometimes despite their better judgement, because they recognized they had an obligation to care for others which meant that they had to take (physical) care of themselves. It can be argued that caring for themselves by managing their risks allows women who are at risk of ovarian cancer to preserve their social relationships, fulfil their obligations to family members and demonstrably care for those they loved (Hallowell 1999).

Living with risk: Facing danger and confronting suffering

Suffering is ... dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of no thing, an absence. We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be (Frank 2001: 355).

This paper has tried to articulate what it meant for these at risk women to live with the knowledge that one day they, like their mothers and sisters before them, might succumb to a

disease, which, in many cases, is untreatable, painful and leads to what can only be regarded as a grisly end. But although the analysis outlined in the last section, may have presented a relatively coherent sociological account of living with the risk of ovarian cancer, it is an account that is lacking, for it expunges the lived experience of risk. Living with risk may, indeed, be reducible to a rational exercise in identity management, as Giddens (1991) maintains, but, as the data presented above reveal, it also involved something more in this case, it required these women to confront human suffering.

This paper suggests that risk awareness is, at least in part, dependent upon the recognition of suffering in oneself and others and managing risk is, among other things, an attempt to avoid suffering in the future for oneself and other family members. Thus, it can be argued that, by focussing upon the affective aspects of living with the risk of ovarian cancer, this paper has highlighted the relationship between risk and human suffering; a relationship which, as Wilkinson (2005b) notes, is all too often overlooked in the sociological literature.

For these women, living with the risk of ovarian cancer was a matter of life and death. It was about living with the memory of others' suffering. It was about making sure the future did not recapitulate the past. It was about saving oneself from pain and sparing others from witnessing agony. It was about avoiding death so one could nurture others' lives. It was about families, those to come and those who had passed. It was about fear, loss, illness, disease, self and others, but primarily, living with the risk of ovarian cancer was about avoiding suffering and staying alive. To ignore these things is to devalue their experiences.

Wilkinson has recently observed that a sociology that fails to confront human suffering is a sociology that fails to address '...fundamental questions of human values, origins and purpose' (Wilkinson 2005a: 14). As he notes, in many instances media presentations of risk and hazard are frequently accompanied by images of suffering: the limbless victim of a suicide bomber, the grieving mother and the starving child. Suffering, it could be argued, is the public manifestation of danger, the human face of risk.

Wilkinson argues that if we are to achieve '... greater insight into the forms of experience engendered by the knowledge of risk...' (Wilkinson 2005b), then we need to take into account human suffering. However, if suffering is to be incorporated into the sociology of risk, as he suggests, then we need to address the problem of authenticity in articulating suffering. Frank (2001) argues that the inner sense of suffering as lived experience is an 'unspeakable' transcendent phenomenon that defies linguistic expression. Thus, according to Frank, our efforts to write suffering into sociological accounts of human experience are doomed to failure and, ultimately, demean the experiences we are trying to capture.

However, it can be argued that although we may feel that words may fail to capture the lived reality of suffering, such intuitions say less about these experiences as a manifestation of human existence than our (unrealistic) expectations of what language can do or what meaning is. Of course there may be some private sensations that we cannot communicate verbally or non-verbally, and these may be the aspects of suffering that we cannot talk or write about or communicate in a nonverbal way; however, the existence of such sensations does not render suffering ineffable or meaningless, it can be communicated and understood (see also Kleinman and Kleinman 1991). Following Wittgenstein (1953 S. 304, S307ff.), it can be argued that the meaning of suffering rests in public criteria, shared linguistic and non-linguistic signs, what cannot be shared, the private sensations we experience, those seemingly inexpressible feelings of emptiness and loss, are irrelevant when it comes to communicating our own suffering or apprehending suffering in others. The haunted look in the eyes, the droop of the shoulders, the tears rolling down the cheeks, the description of life in communist China (Kleinman and Kleinman 1991), the inability to talk about one's loss (Frank 2001), such things are how we communicate, understand and come to recognize suffering.

To conclude, the ‘rational–technical’ language of the social sciences may indeed be inadequate for representing the ‘brute facts’ of human existence, such as poverty, oppression, pain, grief, fear and loss (Kleinman *et al.* 1992, Frank 2001, Wilkinson 2004). However, this does not mean that social scientists should not try to confront these things in their writings, nor that they are necessarily doomed to failure when they do. In this paper, I sought to relate these women’s experiences of living with the risk of ovarian cancer. What I have been unable to convey is the depth of pain and sadness that was etched on their faces, the haunted look in their eyes or the tears they shed as they talked about how they felt, what they had seen and how frightened they were for themselves and their children. But does this matter? Their words, I would contend, speak for themselves. Even though at times they struggled to describe what they had seen or to put their feelings into words, I always got the message: they hurt, they were still hurting and maybe they always will.

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Notes

- 1 For Douglas (1992), the problem of risk is one of justice thus, one of her main concerns is to show how risk has become politicized within our culture (see also Beck 1992).
- 2 Recently published research confirms that prophylactic oophorectomy reduces the risks of developing cancer in *BRCA1* and 2 mutation carriers (Rebbeck *et al.* 2002).
- 3 The study was approved by the Cambridge University Psychology Ethics Committee and the Cambridge, Royal London Hospitals and Royal Marsden LRECs. Self-chosen pseudonyms are used throughout this paper to preserve participants’ anonymity.
- 4 Ascites, the build up of fluid within the peritoneal (abdominal) cavity, is commonly associated with ovarian disease and the development of metastatic cancer of the peritoneum.

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