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THE CASE OF THE LADY WHO RISKED EXPLODING
A STUDY OF MULTIPLE CONSEQUENCES AND CONTESTED VALUES

(THE CASE OF THE LADY WHO RISKED EXPLODING)

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ABSTRACT

This paper explores the role of value judgements in personal risk management through an in-depth case study involving a woman's treatment for anal cancer. Julia (pseudonym) agreed to have her pre-treatment medical consultation recorded, and participated in two subsequent interviews. Delving into a single case makes it possible to understand why an individual makes decisions in relation to the overall nexus of risks and benefits which they identify even though their choices may seem irrational to others. According to the colorectal nurse research interviewer, Julia 'risked exploding' as a result of 'absconding' (her term) from hospital in order to have sex shortly after undergoing surgery. Although not to be interpreted literally, the above phrase encapsulates Julia's risk blindness from a clinical perspective. The paper will address the question of how one person came to put herself at unnecessary risk. The question will be considered in relation to non-communication about the interconnected web of issues which troubled Julia, including cosmology, mortality, being left with an unclean, leaky body, loss of economic viability, and harm to family members and to close relationships. This analytical framework complements the more usual one in which attitudes towards a particular risk object are compared across cases. The paper makes a contribution, within the limits of a single case study, to advancing knowledge about the neglected topic of individual risk consciousness. It will be argued that, in the absence of such analysis, personal decision-making about risks cannot be fully understood, appropriate advice given, or sensitive policies developed.

INTRODUCTION

The Royal Society (1992, p.1) defines risk as *'the probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge'*. This formulation implicitly treats 'adversity' as an externally observable and measurable property of 'events'. Reframing adversity in terms of negative valuing draws attention to the actively interpretive role of socially situated perceivers who *'ascribe values to negativities'* (Rescher, 1983, p. 27, quoted authors emphasis). Furthermore, the representation of adversity as an intrinsic attribute of events implies that consequence sets can be unproblematically identified. The present paper will address the generally unexplored problematics of multi-attribute cost benefit analysis (Peterson, 2007) through a case study of how a woman (pseudonym Julia) selected and responded to the risk issues which troubled her during the course of her successful treatment for anal cancer.

The specific focus of the paper is the intra- and interpersonal **processes** through which a single individual attempted to navigate a life-critical, partly self-generated nexus of risks and benefits. The question of how a person does actually combine multiple risk concerns has received relatively little attention in risk social science. This focus can be distinguished from two current research strands, the psychology of personal decision-making and thematic qualitative risk research. A major focus for risk psychology has been the supposed inability of de-cultured 'people' to make rational decisions in conditions of uncertainty. This perspective which underpins a huge body of research is exemplified by Breakwell's (2007, p. 79) assertion that *'humans appear to fail miserably when it comes to rational decision-making'*. The many failings identified from this standpoint, itself contested (Gigerenzer, 1996), include unrealistic optimism and reliance on misleading simplifications such as the availability heuristic (Slovic, 2000). This work raises the neglected issue of how consequences are to be identified (Peterson, 2007), and directs attention away from epistemological questions about rationality itself (Zinn, 2008). Crucially, it does not address the ways in which individuals **do** make decisions in relation to selected uncertain consequences which matter to them. Although individuals do not necessarily, or even usually, base decisions on conscious calculation (Bloor, 1995, p. 23), deliberative reflection does operate when new critical choices must be made, as when facing a serious health problem for the first time.

Thematic qualitative risk research has powerfully illuminated the diversity of social actors' risk and non-risk interpretive frameworks across particular domains such as preventing a health problem. It avoids the twin traps, alluded to above, of stripping 'humans' from their social context, and viewing their perspectives merely as deficits. One strand in this large body of work has investigated antagonisms between officially approved risk perspectives and those emerging from non-dominant sub-cultures. It can be illustrated only through *ad hoc* examples in a brief review. Gross (2010) has developed a case study of an Israeli, Jewish Orthodox woman who experienced strong health professional antagonism because she had declined to accept risky diagnostic

testing of her unborn child, who turned out to have Down's syndrome, despite screening at higher risk. Health professionals felt that she had been under an obligation to find out the chromosomal status of her offspring by taking the offered amniocentesis test even if she had ruled out terminating her pregnancy on religious grounds. Crawshaw and Bunton (2009) contrasted the official 'logic of practice' about illegal drug-taking with that of young men living in a deprived area of the UK who differentiated what they saw as recreational use of soft drugs and seriously risky addiction to heroin or crack cocaine. In this special issue, Caiata-Zufferey (2012) identifies a similarly valorised category differentiation among Swiss drug-users; and Barton-Breck and Heyman (2012) discuss the use of self-injury as a coping device.

Other relevant work has been concerned with individuals' thinking about multiple consequences across a defined population. For instance, African female sex workers have been shown to knowingly accept high risk of HIV infection in order to improve dire economic circumstances (Lees *et al.*, 2009). Gay Australian men who opted for subsequent retroviral prophylaxis were found to undertake condomless sex despite perceiving an associated HIV risk because other considerations, such as the implications for an intimate personal relationship, outweighed health concerns (Körner, Hendry and Kippax, 2005).

Thematic research sheds light on socially situated actors' own reasons for not complying with official risk prescriptions. But this work tends not to address the complementary, more social psychological, question of how encultured individuals generate overall views of multiple uncertain consequences. Some work is cited below, and other studies unknown to the present authors undoubtedly explore individual grapplings with risk and multiple consequences. Desmond (2012) has studied the ways in which individuals living in rural Africa synthesise medicine with witchcraft. This syncretism generates combinatorial emergent properties such as fear about the perceived fatal consequences of injections being mistakenly used against witchcraft. In a developed country context, Brown's (2008) analysis of communicative trust is particularly relevant to the present case study. He argued that service users develop this form of trust if they believe that professionals are oriented towards their best interests, i.e. they identify value congruence. Julia experienced only fragile communicative trust because she feared that non-medical risk concerns which were vital to her were being discounted.

Julia was presented with two antagonistic medical risks, each with different expectations attached to them: near certainty of cancer mortality in the absence of timely and probably effective medical intervention; and a 50% chance of having to live with a permanent stoma as a result of damage caused by the recommended radiotherapy-chemotherapy cancer treatment. In addition, Julia expressed strong concerns about risked social consequences of her treatment, including stress-related harm to family members, relationship breakdown and loss of livelihood. Two crucial and characteristic linked features of this consequence set are its wide heterogeneity and resulting incommensurability.

Determining which 'adverse events' are to be included in multi-attribute risk analysis is the first problem for anyone attempting to make real-life decisions involving numerous consequencesⁱ. Once consequences have been selected, it will almost always be necessary to weigh up combinations of 'goods' and 'bads', i.e. the co-occurrence of positively and negatively valued, qualitatively distinctive, uncertain outcomes.

Comparative valuations will vary personally, and will often be often ill-defined. Individuals are asked, in effect, to extrapolate to how they would feel if a particular contingency actually occurred. Living with a stoma provides a particularly good example of the a possible but unimaginable future. Furthermore, utility calculations require value conversions between consequences which are not only qualitatively distinctive, but also are associated with different expectations and time-frames. Peterson (2007, p. 81) concluded from an analysis of comparative value fuzziness, just one of the problematic issues which bedevil expected value quantification, that '*our present theories of rationality are not sufficiently well-developed*'. Case studies can shed light on the socially mediated processes through which individuals actually **do** select and calibrate multiple consequences when making personally critical decisions.

The paper will draw upon a number of concepts, the meaning of which can only be briefly explicated. The term 'rationality' will be used to depict a social actor's own reasoned explanation of their purposeful action, with no assumption that one analysis is better than another. Hence, the paper explores multiple rationalities. 'Cosmology' refers to ways of viewing human existence in relation to the material world, for example believing that outcomes express divine will, or that they are at least partly random. 'Risks' are generated within an interpretive framework in which an observer's uncertainty about events judged undesirable is projected onto the external world as chance (Heyman *et al.*, 2010, p. 19). Individuals will be considered to 'take a risk' when they knowingly accept a perceived probability of experiencing an event which they deem adverse; and to put themselves 'at risk' when an observer believes that their action generates an unacceptably high probability of them experiencing an undesired event, whether knowingly or not. 'Value' refers to how desirable or undesirable an outcome is to particular social actors, and may vary between people, or for the same person at different timesⁱⁱ. Values may be more or less well articulated, and may remain ill-defined as when a patient contemplates what it might mean to live with a stoma. This starting point puts 'emotions' back into 'objective data' which may merely conceal the value presuppositions on which they are predicated (Bowker and Starr, 2000; Slovic, 2012).

The Clinical Background: Anal Cancer and its Treatment

The term 'anal cancer' homogenises a range of malignancy types, most frequently squamous cell carcinoma, and cancer sites in the anus and anal canal. The anal cancer diagnostic category bifurcates an overlap with more prevalent, less treatable rectal cancers. Anal cancer is uncommon, with an overall annual incidence of about 1 per 100,000 reported in England (Robinson, Coupland and Møller, 2009) and elsewhere. However, global incidence is increasing rapidly, probably through greater sexual

transmission of the human papilloma virus (HPV)ⁱⁱⁱ and immunodeficiency resulting from the spread of HIV and medical use of immunosuppressants (Ryan, Compton and Mayer, 2000). Robinson, Coupland and Møller (2009) concluded that anal cancer is now more likely to affect women than men, a reversal of the previous trend, and that the average age of patients is declining.

Overall survival rates for anal cancer are better than for those situated further up the colorectal system, and have progressively improved (Jeffreys *et al.*, 2006). Similar trends have occurred internationally, although UK colorectal cancer treatment outcomes continue to lag behind those found in other European countries (Gatta *et al.*, 2000); and Europe is behind the USA (Ciccolallo *et al.*, 2005). Mortality risks are higher among older patients, and those from poorer socioeconomic backgrounds (Jeffreys *et al.*, 2006). However, the crucial survival factors are tumour progression and the development of metastases. In the USA, 80-90% of patients with stage one anal cancer (tumour <2cm in its greatest dimension) will survive treatment for more than five years, compared with less than 50% of those with stage three cancers (tumour > 5cm in its greatest dimension) (Wilkes and Hartshorn, 2009).

Julia, the focus of the present case study, received the current gold standard curative intervention of chemotherapy plus radiotherapy. Prior to treatment, a temporary stoma, an opening, was created so that her faeces would bypass the cancer site into an external bag. The stoma was used to speed the healing process and reduce infection risk. This treatment package, a modern medical miracle, yields an 80-90% long-term survival rate for patients like Julia with early stage anal cancer, most of whom would otherwise have died, but comes at a price. Some patients experience significant defecation and associated psychological problems after stoma removal (Taylor and Morgan, 2011), with over half of one study sample reporting serious difficulties a year later (Siassi *et al.*, 2008). Overall, their respondents experienced more problems after stoma removal than they had anticipated, an indication of possible patient over-optimism and/or surgeons underreporting likely problems. This finding resonates with Julia's fear that her partner/boyfriend^{iv} and surgeon might be underestimating the downside in order to present life-saving surgery as favourably as possible.

About half of treated patients whose temporary stoma has been removed eventually require a permanent one to be installed (Siassi *et al.*, 2008). The chance of this happening may be increased by the use of radiotherapy, creating a trade-off between mortality and quality of life risks (Lange *et al.*, 2007; Bruheim *et al.*, 2010). Those facing this risk at the time of surgery have to confront the sheer impossibility of imagining what it would be like personally and socially to live with such a radical bodily modification over the shorter and longer term. Patients in aggregate may overestimate the adversity of subsequently living with a permanent stoma (Bossema *et al.*, 2007), and some of the early problems appear to abate after a year of usage (Grumann *et al.*, 2001). Julia's negative feelings about the risk of having to live with a permanent stoma are discussed below.

THE CASE STUDY

The present case study involves the experiences of a woman in her early 40s during the year (2006) in which she was diagnosed with, and successfully treated for, anal cancer. The data were obtained from audio-recording and transcribing: the pre-operation medical consultation at which her partner/boyfriend was present; a pre-operation interview undertaken shortly afterward; and a post-treatment interview, carried out in November 2006. Data collection was undertaken by one of the paper authors, an experienced colorectal nurse academic. The data derive from a wider mixed methods study of living with a stoma (Nastro *et al.*, 2010), for which UK NHS ethical approval was granted. Julia gave specific consent for her case to be presented in a paper. Personal details about individuals included directly or indirectly in the case study have been changed to protect their anonymity.

Direct generalisations cannot be derived from a single case study. This one was not chosen on account of its typicality, since very few patients 'abscond' from hospital to have sex immediately after abdominal surgery. The case was selected because of its relevance to the question of why an individual might act in a way which others consider rashly dangerous. In addition, Julia was exceptionally articulate, and very willing to share her experiences. Although not representative, single case studies allow risk to be understood biographically in relation to one person's wider life.

Julia's year with cancer

A timeline for clinical interventions, outcomes and research events is provided in Table One below.

INSERT TABLE ONE HERE (see attachment)

Julia's treatment trajectory began when she visited her GP, in December 2005, with what she thought might be piles. Within a month, she had undergone an investigation under anaesthetic for suspected colorectal cancer. The results, which came back a fortnight later, indicated that she had a more treatable anal cancer. Julia was advised that chemotherapy combined with radiotherapy would offer her a 90% chance of survival. She was informed that she would have to rely on a colostomy bag for several months, and that she faced a 50% probability of needing one permanently. In February 2006, Julia spent ten days in hospital for an operation in which a temporary stoma was created. When the stoma had settled down, she underwent a 13 week programme of radiotherapy and chemotherapy (March to June 2006). After undergoing tests which showed that the cancer had been cleared, the stoma was closed in August 2006. Julia was considered to have made a complete recovery, and was able to begin a new job in December 2006. The data analysis below will explore this experience from Julia's perspective.

DATA ANALYSIS

During the treatment process, Julia expressed strong concern about the risk of eventually having to live with a permanent stoma. She was also anxious about the reactions of her sixteen year old son who sat his GCSEs that summer, the impact on the health of her frail elderly mother, and maintaining her relationship with her partner/boyfriend. Because the treatment left her too ill to work for most of the year, Julia was forced to close her business and live on state benefits. Despite holding a predominantly secular world view, Julia wrestled with the wider meaning of her affliction, considering it as possibly a punishment from God for various transgressions about which she felt guilty. This non-risk interpretive framework coexisted uneasily in her mind with a medical perspective. Immediately after the stoma removal, Julia 'absconded' from hospital and had sex with her partner/boyfriend whilst her stitches were still in place. Her action can be understood as a spectacular lapse in responsible risk self-management, an assertion of autonomy, and as a response to the repeated failures, outlined below, of those around her to acknowledge her multiple risk concerns.

Disease as God's punishment

Julia participated to some extent in religious practice, although she held predominantly secular views. Nevertheless, like many people who experience serious disease, particularly cancer, she considered the possible cosmological meaning of her condition, as documented below.

Julia: *Now I knew what a colostomy was because [relative of person she knew] had one last year. And I, in my normal delightful way, had gone, "Uhr, how revolting. How can anybody live with that?" And so, you know, it felt like punishment, due punishment when I got told I was going to have to have one [colostomy]. And I said, "But I can't. I'm only young" ... I cried ... So, by the time I got to see her [the consultant], I knew I was probably - life and that - I might as well just get on with it. So that's the way I greeted the information. (Post-treatment interview)*

Consideration of her illness as divine retribution was linked to the notion that it had occurred at such a young age^v. However, Julia then noted that her attitude quickly shifted to one of resigned acceptance. She also discussed other sources of guilt which she felt might be bringing divine punishment down on her, whilst at the same time dismissing this explanation as irrational.

Julia: *I suppose I do think it is a punishment, but I also know that is fantasy ... if this was a punishment it would be perfectly fair, but death, death isn't fair [Laughs]. (Pre-surgery interview)*

Despite rejecting the notion of divine retribution as fantasy, Julia still weighed the level of punishment on imaginary scales of justice, suggesting that death would be an

excessive penalty for her transgressions, whereas illness and suffering would be 'fair'. This tension between personalistic and science-based cosmologies can also be seen in the next quotation which partly recast divinity in terms of the ill person's own unconscious mind.

Julia: *It's a very difficult one indeed because, even if I don't think I'm being punished by God, I certainly feel that there's an unconscious which could provide this kind of counterweight to my own behaviours. Oh yes. So whether we query God or the unconscious, I certainly think these things can operate, and I don't think it's superstitious ... I mean, I'm also a pragmatist in so far as you can take one look out of the window and see the whole planet crawling with people like bacteria ... You know, populations come and go, they live and die, they eat each other up, we kill each other, that's the way humans are. That's the way creatures are. There has to be illness. Otherwise the planet would have exploded, you know, thirty centuries ago. Humanity wouldn't have lasted at all without illness. Of course, it belongs to the realm of the physical. But perhaps it's the only choice of illness might be determined by my unconscious. I have no idea. (Post-treatment interview)*

The first part of this instructive reflection, given after Julia knew that she had recovered, conditionally reframed the possible non-randomness of illness as an outcome of unarticulated personal agency. Julia then challenged her own person-centric account of illness by shifting to a large-scale Darwinian perspective in which disease serves to promote species survival. This interpretive framework invoked the blind working of chance. Finally, all three accounts of illness, in terms of divine punishment, the projection of unconscious guilt and population survival, were brought into juxtaposition when Julia raised the possibility that only the type of illness is determined by 'choice'. The coda reopened uncertainty about whether health problems result from divine will, unconscious personal guilt, the rolling out of evolutionary processes, or a combination of these disparate explanatory schema. The uncertainty about the meaning of her illness which Julia articulated so well may be characteristic of cultures in which risk-oriented science and religion co-exist as explanatory schema (Coleman and White, 2009). It provided the backdrop for Julia's selection and consideration of other adverse consequences of her illness and its treatment.

Mortality and morbidity risks

From a purely medical perspective, Julia faced two types of risk: firstly that she might die during surgery, or afterwards if the cancer recurred; and, secondly, that she might be left needing a permanent stoma, an outcome which would lead to her and others repeatedly encountering her faeces. These two risks had a counter-indicative relationship to each other since she could not reduce her mortality risk without accepting the risk of needing a stoma for the rest of her life.

Mortality risk

Julia placed her risk of dying in the context of 'other hazards' which, as discussed further below, related most directly to being left with a permanent stoma.

Julia: *I do know I can die [in surgery], but, apart from that, I don't know about any other hazards, but dying would simply be to do with accidents, as it were. I am assuming that that is the case. It would not be particularly to do with - because it's a stoma?*

Interviewer: *No, no.*

Julia: *It would just be because of the hazards of an anaesthetic, yes?* (Pre-surgery interview)

In the above quotation, Julia framed her chance of surviving surgery purely in terms of chance. Here she employed the cosmology of randomness which co-existed with those invoking divine justice and the working of the unconscious mind, discussed above. Julia's query to the colorectal nurse research interviewer asked him to confirm that the creation of a temporary stoma did not itself carry a specific mortality risk. The immediate risk of dying could be apportioned entirely to surgery, and so located in the category of routine, and therefore safe, operations. Her request for reassurance from the research interviewer after the pre-surgery consultation had taken place indicated that she had been living with uncommunicated worry about this risk. It can be distinguished from that of longer-term cancer mortality, first raised by her partner/boyfriend, Donald, in the pre-surgery consultation.

Donald: *Is she likely to completely recover or is it likely to recur?*

Ms S: (consultant): *No.*

Donald: *Is it likely to spread?* (Pre-surgery consultation)

This difference between Julia and Donald in outcome time-framing perhaps reflected the distinctive concerns of patients contemplating major surgery who focus on immediate survival and those close to them who are primarily oriented to the risk of losing a valued relationship^{vi}. The consultant (Ms S) responded to this question by attempting to quantify probability, but quickly floundered.

Ms S: *I don't have the numbers at my fingertips. It might be better if I can refer to them and give you the correct information when you come in on Monday?*

Julia: *About what? Prognosis?*

Ms S: *The viable prognosis and all that sort of thing. What is the ballpark that you are aiming?*

Donald: *Julia has been told something already, but it's -*

Julia: *I have been told about 95%. Is that true?*

Ms S: *I, I -*

Julia: *No, you should be cautious. I know that.*

Ms S: *I would have to be realistic, that I would be making it up on a, a wing and a prayer, and I don't think ... I would like to have a look at some of the studies to be able to give you a more correct ...*

Donald: *Should we, as it were, be hopeful and expect a positive outcome as we start all this?*

Ms S: *Absolutely. It's well over 50% ... but I, I, I don't want to tell you 70% if you have been told 95%. I would like to be able to give you the results of how many people have to have surgery after the operation.*

Donald: *All that stuff.*

Ms S: *All that sort of stuff.* (Pre-surgery consultation)

The discussion of probabilities was complicated by the number of outcomes which they could have referred to, including surgery mortality, requiring further cancer treatment, longer-term cancer mortality, and needing a permanent stoma. The consultant's opening statement about '*numbers*' backgrounded this question, treating risk as a directionless object, a tacit manoeuvre characteristic of naturalistic risk thinking. Julia's sharp follow-on question, '*About what?*', challenged this backgrounding, drawing attention to the multiplicity of outcomes under consideration. Ms S's response directed the discussion of probabilities to '*viable prognosis and all that sort of thing*'. She thereby foregrounded mortality risk, itself a source of multiple meanings depending on the time-scale considered, whilst leaving open the potential consideration of other issues. Her risk frame shifted at the end of the quoted interaction to the need for follow-up surgery which could refer to further cancer treatment or the need to fit a permanent stoma. Hence, the striving for probability quantification was undermined by confusion about which risk object was being measured.

Although opting to pose the question of individual recovery in quantitative terms, Ms S felt unable to cite a numerical probability of survival, postponing pronouncement until she could look up the statistics. She was particularly concerned to avoid undermining the credibility of the whole risk management process by contradicting other probabilistic information which Julia might have been given, thereby inadvertently highlighting its unreliability. The rather odd question about '*aiming*' for a '*ballpark*' invited her patient to indicate a mortality probability which she would consider acceptable. It might seem surprising that the consultant felt that she needed to consult the studies before offering a number. But the issue under discussion was by no means straightforward.

Whilst declining to offer precise quantification, the consultant attempted to frame the chance of survival optimistically as above 50%, which she pointed out might mean 70% or 95%. These figures, she implied, provided a clear pragmatic justification for undergoing treatment. Ultimately, risk management decisions require a binary choice between taking or not taking a considered line of action. Imprecision about consequence probabilities does not prevent decision-making from being guided by them providing that one alternative is clearly preferable across multiple risks. Donald attempted to background the multiplicity of risk concerns at issue as '*all that stuff*', offering Ms S an escape which she gratefully accepted by echoing his words. As documented below, both Donald and Ms S wanted Julia to consent to a package of medical interventions about which she expressed reservations. The uncertain status of the probabilities in question fuelled their contention. This highly instructive interchange

epitomises the fault lines of risk-based cultures which raise quantitative probabilistic questions that can only be answered at best to a limited extent.

The risk of needing a permanent stoma

Crucially for the purpose of the present paper which focuses on the issue of valuing multiple qualitatively distinctive consequences, Julia responded immediately to the above dialogue between the consultant and her partner/boyfriend by raising a different issue, that of her state after surgery.

Julia: *What my mother wants to know, and I suppose [partner/boyfriend] wants to know as well, and I would prefer not to know, but I suppose that I have got to know, is what kind of aftercare I am going to need, once after this operation? It sounds like none.*

Donald: *Yes. Julia's mother asked to ask this one.*

Julia: *Yes, actually because she wants me to go [into treatment], and it's no way, unless I really - [Ms S laughs.] (Pre-surgery consultation)*

The abrupt shift in risk orientation which Julia imposed on the consultation conveyed her worry about her functional state after surgery, thereby subverting Donald and Ms S's focus on long-term cancer survival. Julia at this point suggested that she felt pressured by those close to her into accepting treatment, and thereby increasing her survival chances, at the expense of being left disabled. She tailed off in a way which left open the specification of the adverse consequences which would preclude her accepting the offered treatment. The consultant's laughter indicated unease at this impasse, rather than humour. As documented below, Julia did not seriously contemplate declining a medical package which offered a good prospect of avoiding almost certain cancer death at the price of accepting a high, 50% probability of having to live with a permanent stoma. But she resisted attempts to persuade her to background treatment side-effects. She was also affirming her personal autonomy in the face of benevolent attempts to entice her onto a trajectory which would reduce her risk of early death at the cost of exposing her to other risks.

Julia had strong feelings of revulsion about living with a stoma which related to concern about her sexual attractiveness and, in turn, to maintaining relatively precarious close relationships, discussed in a later section.

Julia: *I think it's [a stoma is] the most hideous and revolting thing, and I don't want it.*

Interviewer: *OK.*

Julia: *However, I would prefer to live.*

Interviewer: *OK.*

Julia: *I'm not so sure, you know, I don't know if I would prefer to live with no sex life. And I don't know if I would ever be able to persuade a man to fuck me, excuse my language, with a stoma. Would you?*

[Long pause]

Julia: *I really don't know, because it's really bad news.*

Interviewer: *Right. Apart from the sexual aspects, is there anything else?*

Julia: *No.* (Pre-surgery interview)

This dialogue contained a blackly comic violation of conversational norms which silenced the disconcerted male colorectal nurse research interviewer. His abrupt topic change effectively censored the topic, leading Julia to bluntly decline his invitation to open up a new one. Prior to the interview, she had received a similarly inconclusive answer in the pre-treatment consultation.

Ms S: *We would expect you to continue with your normal life [after treatment].*

Julia: *A fully normal life, apart from having sex and living that kind of normal life, which I assume I won't be able to do?*

Ms S: *No, we would - I think, once your undercarriage has healed up.*

Julia: *I was looking forward to finding out the name of the whole business.*

Ms S: *Perineum is the posh word. Let me explain to you. I am currently doing a study on female sexual function after both radiotherapy and surgery to the pelvis. They [women] had [problems] with penetration, vaginal dryness, loss of interest in sex, alteration of body image and anorgasmia.*

Julia: *There is no actual, observable, measurable damage?*

Ms S: *I am absolutely honest in saying that we really don't know what it is for women.* (Pre-surgery consultation)

The euphemistic referral to her '*undercarriage*' again took the focus of the discussion away from Julia's embodied concern about her sexual attractiveness after stoma-forming surgery. This issue was bound up with multiple uncertainties about whether she would need a permanent stoma and how others might respond to its presence. The consultant's evasiveness appears similar to the nurse interviewer's silence and topic change, outlined above. Julia could have reasonably concluded that her expressed concern about this issue would not be addressed. Furthermore, the problem which she raised was not her own sexual functioning, the matter addressed by the consultant, but her ability to maintain an intimate relationship with a male partner. Her question about observable damage reflected this preoccupation, further documented below, as did her interrogation of the male interviewer about whether he would hypothetically view a woman carrying a stoma as a candidate for sexual intercourse. Such subtle reframings between multiple risk objects can easily be overlooked.

Wider social consequences

Julia's concerns about contingencies arising from treatment extended beyond her body. She also gave considerable attention to the indirect social consequences of treating her condition. These consequences will be considered in relation to her mother, her son, her livelihood and her relationship with her partner/boyfriend. The main aim of the analysis is not to demonstrate this obvious point, but to explore the interplay of multiple risk concerns.

Julia's analysis of medical risk extended beyond her own survival to that of her frail, elderly mother.

Julia: *From that moment on [colorectal cancer suspected], I believed that I was likely about 50% to die from cancer^{vii}. And the biggest fear was my telling my mother who has a medical weakness. And I really, really, I actually thought that she might die of a heart attack, not just react badly but die, because of the knowledge (Pre-surgery interview)*

At the time when she thought she might have colorectal cancer, Julia, according to her own account, felt more anxious about her mother dying from shock than about her own prospects. As this quotation demonstrates, even medical risk management, viewed from the patient's perspective, can extend beyond the individual who is being treated.

Julia also worried about the impact of her recovery from treatment on the emotional health of her adolescent son.

Julia: *So I like to think that I am going to be well enough to at least look and sound - even if I don't get up in the morning to get him off to school, I don't want him to come home to a sick and miserable-looking mother.*

Ms S: *I think you are better off to prepare him that he will come home to a sick and miserable mother.*

Donald: *Sick and miserable mother?*

Ms S: *But he will come home to his mother ... I would personally quite like him [to meet with me].*

Donald: *... We said he should go and stay with his father but then he said, "I would rather stay, stay with [Julia]".*

Julia: *No, no. Well actually, no. He didn't say, "I would rather stay with mum". He said, "I don't want to stay with dad". It's not the same.*

Donald: *That's interesting. He doesn't want to stay with your mother, does he?*

Julia: *My mother? You must be joking! (Pre-surgery consultation)*

In response to Julia's expression of concern about the impact of her treatment on her son, Ms S employed the dramatic device of emphasising adverse consequences, 'a sick and miserable-looking mother'. Such violation of the more usual euphemistic medical practice (in which agony may be labelled 'discomfort'), invited a query, duly supplied by Donald, which the consultant then rebutted by arguing that a sick mother was preferable to a dead one. This rhetorical device was intended to bring home the overriding benefit of accepting medical intervention. Ms S. then attempted to reduce the adversity of the impact on Julia's son by proposing to meet him, an offer which was ignored. Donald's proposals about alternative care-taking arrangements supported this endeavour. By sharply and satirically rejecting his suggestions, Julia sustained her perception of the adversity of her treatment for her son. She thereby kept in play the question of whether

she would accept treatment. In the subsequent pre-surgery interview, she reiterated this concern:

Julia: *I don't want him to see that I'm ill, so that also. I don't want him to see a droopy, tired, smelly mother. That bothers me.* (Pre-surgery interview)

Julia's anxiety about another consequence of treatment, for her economic circumstances, fuelled tension with her consultant.

Julia: *Well what I've said to my patients, I'm intending to work, returning to work fully and well in September.*

Ms S: *I think that's slightly unrealistic.*

Julia: *Do you?*

Ms S: *I do. The chemotherapy in my understanding, well, goes on a good six months.*

Julia: *Hang on. Well, this is what I have not been informed about. This pisses me off. I'm sorry. This makes me angry [louder voice].* (Pre-surgery consultation)

The unexpected length of her invalidity trajectory forced Julia to take the potentially irreversible step of closing down her practice.

Julia: *Now luckily, it seems that those who are employed can work here and there for a few hours. Unfortunately, because I am self-employed, nobody but me can. I can't hand it over to a substitute. I've actually had to close my practice, which means that there is nothing to go back to. There is no work to do.* (Pre-surgery interview)

Julia's fear that she would lose her livelihood proved well-founded in the short term, although she eventually found improved employment.

Julia: *The biggest problem has been ending ... my practice. And then, so, I had to be on income support because I had no money other than what I earned, and that was horrible. And, and then, when I got my clean bill of health, I've had to go on Job Seeker's Allowance. And now, thank God ..., I've got a job ..., and I'm working as a [therapist], and it's fantastic ... But I didn't know that, and it just seems like, kind of, a gift from God because I really didn't expect that. So that would have been the worst outcome, that I would have been kind of sentenced to, sort of, poverty really.* (Post-treatment interview)

Julia pointed out that she could not have anticipated that she would end up in improved employment circumstances after abandoning her previous work. Despite her predominantly secular belief system, Julia framed her unexpectedly favourable outcome as a gift from God. Similarly, the idea of being '*kind of sentenced*' to poverty invoked the calibration of adverse social consequences on an imagined scale of divine justice. However, these statements may have been used more or less as a metaphor for unexpectedly good fortune, rather than as a literal depiction of divine intervention.

Julia's negative feelings about undergoing life-saving treatment were bound up with her fear about the impact of bodily mutilation on her sexual relationships. This issue went well beyond *sex per se*, to the sustainability of an intimate personal relationship, as mentioned previously.

Julia: *I want to be seen as a sexual woman to the man in my life, ... and it [stoma] has a kind of association to a penis, and it doesn't feel like it belongs to a woman. Plus, all that kind of medical stuff. I mean, to me, medicine and sex don't go together. And because I have a lover and not a husband - again, if I had a husband who, you know, was the kind of person that I screamed at, or took the rubbish out for me, it might be more manageable. But the fact is it being a lover, it was out of the question.*

Interviewer: *Why?*

Julia: *Because I prefer to keep them in sugar, and I don't want them to know this kind of thing about me. All the secrets ... I don't mind him seeing my bad self, but a very bad body, yeah, I do mind, I mind a lot ... To actually see the wound or help me dress it would have been out of the question. That was far too private. (Post-treatment interview)*

Julia's concerns about keeping her partner in 'sugar' and concealing her leaky, damaged body resonate with feminist analyses of the sociology of the body (e.g. Grosz, 1994). However, Julia viewed her body-presentation in terms of relationship insecurity rather than gender, contrasting her present circumstance with that of having a husband who could be 'screamed at', or who 'took the rubbish out for me'. The overriding, gendered importance to Julia of maintaining the image of a good body was conveyed by its prioritisation over displaying a 'bad self'.

Risking an Explosion

Julia 'absconded' from hospital shortly after her final operation. By having sex with stitches still in place, she put herself at risk, according to the colorectal nurse interviewer, of her insides metaphorically 'exploding'. Julia's retrospective summary account of this event is presented below.

Julia: *I'm a very, very, very restless person, and throughout my treatment I've been peculiarly energetic. And when I had the last operation ... I was just as hyper-manic. And I kept getting out of bed. And my son had been away for a month, and he came home ... so I just left the hospital the day after the operation and came home ... I came home and had sex with my boyfriend ... I'd absconded from the hospital without telling anybody, and really upsetting them. (Post-treatment interview)*

Julia explained her state of mind in quasi-psychiatric terms as 'hyper-mania'. However, her restlessness may also have been linked to her risk concerns outlined above,

including developmental harm to her son, whose return triggered her absconding, exacerbated by others' evasions of the issues which she raised.

Julia suffered severe pain whilst at home after absconding, and felt guilt and shame when she returned to hospital the next day to be admonished by nursing staff.

Julia: *And I got up [after sitting with son, subsequent to absconding and having sex with boyfriend], and I had a pain, and ... it was excruciating. And I, because I felt so guilty at having absconded ... and I felt ashamed. And the nurses, I have to say [after she returned], ... were bloody awful. (Post-treatment interview)*

Julia's further retrospective reflections about her underlying reasons for 'absconding' were expressed in the next quotation.

Interviewer: *Why did you want to abscond?*

Julia: *... Well, I suppose, partly, I wanted to be annoying and disruptive. It's quite possible, 'cos there's an anger in me, 'cos I felt well. I mean I should know, up here [in head], if I'm not well. But I think it didn't really sink in that it was a so-called 'major operation', whatever a 'major operation' is ... And so my tenant is ... an ex-nurse ... and the sensible sort. And so, she was saying afterwards, "Oh well, yes, you know, this is a major operation, and they pull you about on the operating theatre, and perhaps they put you back in a funny way"...*

Interviewer: *Well, do you understand what they did to your bowel?*

Julia: *Only just, but I couldn't see why it would cause me to take my rest more seriously than any other operation. And given, they didn't say to me, "Even if you feel well, stay in bed", and, to be honest, I don't know if I should have stayed in bed ... They could have let me know that even if I felt well, I should have strapped myself to the bed, 'cos I don't know to this minute if it's true or not. (Post-treatment interview)*

This rich quotation raises a number of questions. It might be concluded that Julia did not intentionally 'take a risk' even though health professionals believed that she had 'put herself at risk'. As conveyed by the conversation with her tenant, Julia had not fully taken in the seriousness of the surgical procedure which she had undergone, and had experienced a disjuncture between her bodily feelings of wellness and the status as an invalid which others ascribed to her. Julia expressed regret that she had not been explicitly informed about the necessity of staying in her hospital bed. However, the angry responses of nursing staff conveyed a governmental response to risk, i.e. that a responsible person should not have required such advice to be spelt out. Julia's account of feeling guilty when she experienced pain at home does suggest that she understood before returning to hospital that she had intentionally violated a well-understood although unstated social norm, perhaps motivated by the anger which she mentioned.

Uncertainty about the consequences of this post-surgical adventure added to the conundrum. The non-occurrence of an adverse event does not *per se* confer absolution from the charge of irresponsible risk-taking. Conversely, an unwanted outcome does not

demonstrate that a risk should not have been taken. The severe pain which Julia experienced during her unauthorised home visit continued into the recovery period, but was abating at the time of the post-treatment interview. Julia wondered whether it might be due to sciatica and therefore unconnected to the surgery or her absconsion.

Julia: *And, to be honest I don't know if I should have stayed in bed, 'cos I don't know if that's what [brought on] the sciatica ... So the day after I went home, I think I'd taken one of my chairs to the consulting room, so I sat on a stool, in this position, having this conversation with my son. I've no idea. I mean, how do I know what caused it [pain]? It's seemed to me because I have a permanent lack of chairs. (Post-treatment interview)*

Whether medically valid or not, explaining her subsequent pain in terms of the risk factor-outcome link absence of chairs-sciatica absolved Julia from having actually caused herself suffering through acting rashly. Although others saw her as irresponsibly putting herself at risk, her actions need to be understood in the context of the other risks which troubled her, together with the failures of her attempts to discuss these risks with others.

DISCUSSION

From a purely medical perspective, Julia was offered a modern miracle, a high probability of being cured of an otherwise mostly fatal disease with a 50% chance of full functional recovery. Although she agreed to take the treatment trajectory, and indeed had little real choice if she wanted to survive, Julia by no means totally welcomed this flawed gift of science. None of the diverse risks which troubled her actually occurred, although she did experience post-operative severe pain. Retrospectively, Julia unreservedly welcomed the treatment she had received. However, prospective visualisation of contingencies which might come to pass shaped Julia's emotions and communications with others at the time that her treatment plan was being resolved and implemented. Julia feared that even if she recovered completely and quickly, she might suffer permanent knock-on consequences. These concerns arose ultimately from Julia's precarious position in the wider society as a self-employed, unmarried female parent with an elderly mother.

Many patients given a re-diagnosis from colorectal to anal cancer would welcome a higher chance of cancer survival, and background other risks. Julia declined to discount risked adverse consequences of the proposed cancer treatment, but instead articulated them to the discomfort of her partner/boyfriend and consultant. As documented in the data analysis, both offered solutions to the question of temporary care for her adolescent son which she dismissively rebutted. Her expressed concerns about her sexual attractiveness whilst living with a stoma, and about the implications for the sustainability of her relationships, were met with uncommunicative stone-walling. Understandably, healthcare staff and carers seek to minimise anxiety about unwanted consequences because they wish to ensure that the patient accepts necessary

interventions in as good a frame of mind as possible. Nevertheless, a degree of defensiveness can be detected, particularly in relation to the juxtaposition of dirt and sexuality (Douglas, 1966). In response, Julia may have used her emphasis on adverse contingencies to sustain a sense of autonomy against a campaign by her doctor and those close to her to persuade her to suppress her doubts about unreservedly welcoming life-saving treatment.

The case study illustrates a more general trend for health care professionals to attach less negative value to the side effects of treatments than do their recipients. In relation to cancer care, a reluctance '*to acknowledge, that a proportion of people will struggle day to day with relatively minor problems that collectively over time may become debilitating*' (Maher and Mankin, 2007, p. 743) has been identified. Similarly, a tendency for physicians to underestimate adverse effects of antidepressants (Kikuchia *et al.*, 2011) has been reported. Julia's challenging statements notwithstanding, she accepted that she had to participate in the gold standard treatment package. Her emphasis on inconvenient truths might be dismissed as a merely token rebellion. However, others' lack of engagement with what they might have viewed as side-issues provided the context in which Julia put herself at serious risk from the perspective of health professionals by 'absconding' immediately after surgery. What might have happened if the issues which she raised had been acknowledged cannot be known. This example provides a reminder that health professionals should not make the assumption that a patient, even one with curable cancer, will necessarily be oriented solely or primarily towards survival.

Most research into expected value has been concerned with its attempted quantification, in fields such as health economics (Nord, 1999); or, from a psychological perspective which identifies supposed rationality deficits such as unrealistic optimism and reliance on the availability heuristic (Breakwell, 2007, p. 79). Qualitative sociological research has mostly highlighted discrepancies between official and minority risk perspectives (e.g. Crawshaw and Bunton, 2009). These strands of work do little to illuminate the processes through which individuals develop their own rationalities when confronting difficult critical decisions involving multiple consequences, the impact of which is difficult or impossible to anticipate in advance. The present case study provides a window onto such socially situated but personal processes.

Claims to typicality cannot be made for single case studies. Julia stands out as articulate, challenging and determined to own her own life. The importance of case studies arises not from their representativeness, but from their potential to draw out phenomena of universal significance. The present study illuminates the general problems which arise when decision-making entails grappling with multiple risks and benefits. In relation to the theme of the present special issue of *Health, Risk & Society*, the two particularly relevant problems with utilitarian rationality which have been highlighted involve consequence selection and value fuzziness (Peterson, 2007). An adequate analysis of consequence selection needs to encompass not only direct but also identified indirect, knock-on effects of healthcare interventions, as with Julia's worry about the impact of treatment side-effects on her economic status and close

relationships. Value fuzziness may be expected for trade-offs between any qualitatively different outcomes, but most strongly in relation to never experienced health statuses. Colostomy provides a particularly apposite exemplar as most people will find the adversity level of this state impossible to anticipate.

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ⁱ Risk decision-making algorithms typically require consequences to be listed before their probabilities and values are assessed and expected values added, but the listing process itself relies on unexamined intuitive thought processes.

ⁱⁱ As Shakespeare's Hamlet put it, 'There is nothing either good or bad, but thinking makes it so' (Hamlet, Act II, Scene ii).

ⁱⁱⁱ Vaccination programmes against HPV may be expected to reverse this trend (Palefsky, 2010).

^{iv} This phrase will be used to depict the somewhat uncertain relational status of 'Donald' who attended Julia's medical consultation.

^v Research evidence for increasing prevalence of anal cancer at younger ages was cited in the Introduction. Julia would probably not been aware of this trend, and viewed cancer generically as predominantly an older person's disease.

^{vi} Patients with lung cancer have been found to prefer to avoid surgery which would increase their overall five year survival chances at the price of an immediate increased risk of death resulting from the operation (McNeil, Weichselbaum and Pauker, 1978).

^{vii} The specific information on which Julia based her initial belief that she faced a 50% chance of dying from cancer is not known. However, this estimate refers to the generally higher mortality rate for colorectal than for anal cancer. Revised diagnosis from the former to the latter generated a substantial increase in her estimated chance of survival.