

## Encounters with medical professionals: a crisis of trust or matter of respect?

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**Abstract** In this paper I shed light on the connection between respect, trust and patients' satisfaction with their medical care. Using data collected in interviews with 49 women who had managed, or were in the process of managing, their risk of ovarian cancer using prophylactic surgery or ovarian screening, I examine their reported dissatisfaction with medical encounters. I argue that although many study participants appeared to mistrust their healthcare professionals' (HCPs) motives or knowledge base, their dissatisfaction arose not from a lack of trust, but from HCPs' failure to treat them as persons or take their concerns seriously. I conclude by describing how respect, as evidenced by "being taken seriously", is important for the development of trusting Patient–HCP relationships.

**Keywords** Trust · Respect · Informed consent · Interviews · BRCA1 and 2 · Breast and ovarian cancer

### Introduction

Trust is an essential feature of life in the twenty first century: Giddens (1991) argues that without trust in complex systems and the experts who people those systems, we would be overcome by anxiety. Trust is a relational concept. It is associated with: situations of uncertainty and risk, relations of dependency between non-experts and experts and expectations about future behaviour/interactions (Calnan and Rowe 2004, 2006a; Giddens 1991; Rowe and Calnan 2006). Healthcare professional (HCP)–patient

relationships are prime examples of trust relationships. The interactions between patients and HCPs normally involve uncertainty about prognosis, diagnosis, and treatment of disease and are characterised by a degree of dependency that arises from an imbalance of power between the participants.

Although power imbalances may create dependent relations, this does not necessarily guarantee the development of trust relations. Cook et al. (2005) argue that it may be difficult for the powerful to convince the less powerful of their trustworthiness and suggest that the development of trust in unequal relationships requires two things: (1) both parties must acknowledge and "take to heart" each other's interests and (2) the more powerful party must treat the less powerful fairly and with respect.

Trust relationships are particularly important within State-funded healthcare systems, where a tripartite relationship exists between patients, HCPs, and the State. Patients trust HCPs to act in their best interests and both HCPs and patients trust the State to provide the resources that will allow trusting and respectful relationships to develop (Alaszewski 2003).

Crisis? What crisis?

Over the last few years we have heard much about developing crises of confidence in medicine and science in the UK. Three high profile medical scandals in Hyde Manchester, Alder Hey Children's Hospital, and Bristol which culminated in public inquiries in the late 1990s (Shipman Inquiry, 2001–2005; The Royal Liverpool Children's Inquiry, 1999–2000; and The Bristol Royal Infirmary Inquiry, 1998–2000), have led the media to suggest that the British public is in danger of losing trust in the medical profession (Boseley 2001; Vandeveldel 2003). In an effort

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to shore up public confidence following Bristol and Alder Hey, a new system of clinical governance was introduced within the UK (Department of Health 2000), which, amongst other things, stresses the necessity of ongoing performance monitoring and the use of generalised clinical guidelines. The implementation of *The NHS Plan* has created an ‘audit’ culture in the National Health Service (NHS), which fundamentally changes the dynamics of the relationship that exists between members of the public and the NHS (Alaszewski 2003). This audit culture shifts the emphasis from a doctor–patient relationship based upon interpersonal trust to a more abstract relationship of institutional trust between the citizen and healthcare system. The dynamic nature of trust-relations is underscored in the work of Rowe and Calnan (2006), who argue that changes in the mode of healthcare delivery and the rise of the ‘expert patient’ have led to the development of new (more complex) forms of trust relations, for example, a rise in what they term “informed conditional trust” in HCPs.

While some suggest that trust in the medical profession is on the wane (O’Neill 2002; Royal College of Physicians 2005), others note that patients do not mistrust individual doctors (primary care or hospital specialists) or nurses (Calnan and Rowe 2004, 2006a). Arguably, what we are witnessing in the UK may be a growing lack of trust in the institution of medicine in general, rather than a lack of trust in individual HCPs (MORI 2003). Indeed, a recent questionnaire study which assessed public attitudes about the NHS in England and Wales (Calnan and Sandford 2004) suggests that not only are high levels of trust vested in HCPs, but also that two of the major determinants of the public’s confidence in the NHS relate to HCP–patient relations, namely, whether patients: (a) are taken seriously and (b) receive enough attention from HCPs. Interestingly, these two aspects of patient-centred care were scored more highly than items relating to professional competence, quality of care, and communication and information.

Of course, questionnaire studies of trust have methodological limitations. Questionnaires may not have the required sensitivity to measure complex concepts such as ‘trust’. For example, it is unclear that “being taken seriously” is an indicator of trust per se, although “being taken seriously” may be a prerequisite for a trusting relationship. Second, it is impossible to determine the extent to which recent experiences inform respondents’ answers. However, despite these limitations, Calnan and Sandford’s (2004) study, in common with others, shows that trust/confidence in HCPs in the UK remains high, when compared with trust in health service managers or healthcare institutions.

The nature of trust in healthcare relationships is the subject of a recent systematic review, which suggests that the development of interpersonal trust in HCP–patient relationships is dependent upon characteristics of the

*relationship* rather than the *patient* (Calnan and Rowe 2004). Gilson (2006) notes, that interpersonal trust is relational insofar as it requires both patients and HCPs to exhibit behaviours in interaction that will foster trust in each other. Not surprisingly then, continuity of care—the presence of an ongoing relationship—is seen as important for the development of trust, along with a range of interactional variables including information-sharing, respecting patients’ views, and making patients feel they are taken seriously (Calnan and Rowe 2004).

Many empirical studies underscore the importance of mutual respect for building trust between HCPs and patients. Robb and Greenhalgh (2006) observed that trustworthy HCPs were perceived as empathic, caring, respectful, and professionally competent. Beach et al. (2006) found that physicians provided more information and expressed more positive affect towards patients they respected and their patients, in turn, indicated that they were aware of the extent to which they were respected by their physicians. Being treated with respect emerged as an important factor in Joffe et al.’s (2003) recent US study: these researchers found that being treated with respect and dignity are rated as more important to patients than having an involvement in medical decision-making. Thus, the research suggests that respect is important to HCPs and patients alike, and that trust and respect are seen as inextricably linked.

#### The importance of trust

There are many reasons why trust is regarded as an important aspect of healthcare, not least, because it enables the cooperation that is essential for the delivery of healthcare and the production of health (Gilson 2006). There are also organisational benefits associated with the presence of a trust relationship between HCPs and patients including: increased patient satisfaction, a reduction in complaints and litigation, increased job satisfaction for HCPs, and the facilitation of informed consent (Calnan and Rowe 2004). Given the increased focus on informed consent in the UK following the introduction of the *Human Tissue Act* (2004) in England and Wales—which criminalises the use of human tissue without consent—understanding the relationship between trust and consent is critically important (O’Neill 2002, 2003).

O’Neill (2002) observes that we have witnessed a shift in the nature of the doctor–patient relationship during the twentieth century. This relationship was traditionally paternalistic—doctors were the active partner in treatment decisions and were trusted to act in patients’ best interests. In recent years, this model has been replaced by a more egalitarian view of the HCP–patient relationship. Today, responsibility for medical decision-making is delegated to

patients, who are provided with information about treatment options and required to determine which course of action is in their best interests. Thus, the role of the patient has changed; they are now seen as autonomous agents or active consumers rather than passive recipients of medical services. Indeed, patient choice is foundational to the *NHS Plan*. These developments have given rise to a new form of trust relationship within medical encounters, one in which patients are required to trust HCPs, not to make decisions on their behalf, but to provide them with information about the range of available treatment options. Accordingly, trust is now vested in HCPs' expertise (their ability to communicate salient and accurate information) rather than in their authority.

O'Neill (2002) points out that the rise of the patient-consumer in the latter half of the twentieth century has been facilitated by the prioritising of informed consent and the reification of "individual autonomy" as the basis of consent. According to O'Neill, obtaining informed consent to treatment/research is ethically important because it provides "... reasonable assurance that a patient (research subject, tissue donor) has not been deceived or coerced" (2003: p. 5). She argues that the amount and type of information necessary for obtaining informed consent should be determined by patients, not HCPs, because allowing patients to specify the information they need to give their consent, ensures they are not deceived. As far as guaranteeing that patients are free of coercion, O'Neill argues that they should be made aware that they can revoke their consent during treatment (if this is feasible). In other words, genuine consent is only possible if patients can have some control over the amount and types of information they receive and what is done to them. Here is where trust becomes important: O'Neill (2002, 2003) points out that in order to ensure patients can obtain the degree of understanding that is a prerequisite for genuine consent, they need to be able to trust their HCPs to provide them with enough information to reach their decision. In other words, although patients may be responsible for the final decision, HCPs still retain an implicit role in decision-making for they have an obligation to provide patients with unbiased information that will facilitate this process.

#### Putting this research in context

In the mid-1990s some of the genes (*BRCA1* and 2) involved in increasing individuals' susceptibility to breast and ovarian cancers were identified. Shortly thereafter, DNA-testing for *BRCA1/2* mutations was introduced as a clinical service for affected women and potential mutation carriers in the UK. Those who were regarded as at high risk because of their family history were referred to cancer genetics clinics where their risk of carrying a mutation and various risk

management options (ovarian screening or prophylactic surgery, DNA testing) were discussed. At that time it was assumed that prophylactic ovarian surgery (bilateral salpingo oophorectomy), after the age of 35 years and once child-bearing was completed, would reduce the risks of developing ovarian cancer in high risk women. This presumption has since been confirmed (Rebeck et al. 2002).

The interviews on which this paper is based were undertaken between 1997 and 2000 with the aim of exploring women's decision-making about their ovarian cancer risk management and establishing their information needs about prophylactic ovarian surgery. When I began this research I did not intend to investigate the women's feelings about their interactions with HCPs, however, many women spontaneously reflected on the nature of these encounters during the course of the interviews. Clearly, their treatment at the hands of a range of HCPs had a profound effect on many women, this was something they not only wanted to talk about, but also felt very passionate about; these data are the focus of this paper.

#### The study

Following receipt of ethical (LREC) approval, participants were recruited by letter from the United Kingdom Coordinating Committee for Cancer Research's Familial Ovarian Cancer Register and two cancer genetics clinics based in London hospitals. Inclusion criteria were as follows: age 45 years or less at the time of surgery/interview, pre-menopausal prior to the operation/interview and a family history of ovarian cancer (plus/minus breast cancer) consistent with hereditary breast ovarian cancer (HBOC).

#### The participants

Twenty three women who had undergone prophylactic ovarian surgery because of their increased risk of ovarian cancer (*Surgery Group*) and 26 who had decided not to undergo this procedure for the present (*Screening Group*) were recruited to the study. 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 28–50 years at the time of interview (mean 36.5 years). All women had at least a 25% risk of carrying a cancer susceptibility mutation. Thirty nine (80%) women had either a mother or sister who had had ovarian cancer and 42 (86%) women had a grandmother or aunt diagnosed with this disease. The women reported between 2 and 9 cases of breast/ovarian cancer within their family. Four (8%) women had a personal history of breast cancer.

Only 11/23 (48%) in the *surgery group* had attended a genetics consultation to discuss their family history and

only 6/23 (26%) had done this prior to their surgery. Sixteen (70%) women had both their ovaries and uterus removed (total abdominal hysterectomy), but not necessarily at the same time and 7/23 (30%) only had their ovaries removed. About 19/26 (73%) women in the *screening* group had attended genetic counselling prior to their interview in this study. About 24/26 (92%) women in the *screening* group were having annual ovarian screening, one had recently ceased and another was about to begin screening at the time of the interview.

Eleven (22%) women had worked in a medically related occupation at some time in their lives (for example, General Practitioner, Nurse, or Receptionist in a gynaecology outpatient clinic).

### Data collection and analysis

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. Most participants 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 between 1 and 3 hours and were tape-recorded with consent.

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 about their risk since they became 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 transcripts of the interviews 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 which was used to analyse the interview transcripts. Atlas-ti (Muhr 1994), a qualitative data analysis software package, was used to manage the interview data. Self-chosen pseudonyms are used throughout this paper.

### Findings

The decision to undergo prophylactic surgery is not experienced as an easy one. Women who are considering this option

need a great deal of support in the form of information-giving from HCPs (Hallowell et al. 2001). However, as I discovered, for many women in this study the *type* of information they received from HCPs was not regarded as important as *the ways in which it was given* or *the ways in which they felt they were perceived* by their HCPs. When talking about their experiences with different HCPs these women expressed a degree of frustration and/or anger about the way they had been treated by their general practitioner and/or a hospital specialist.

### Dealing with healthcare professionals: a trust relationship

In describing their attempts to access screening or surgery, women often expressed frustration, which, in some cases, appeared to derive from a lack of trust in their HCPs. Mistrust was manifest in these interviews in two ways. First, there was evidence in a minority of cases that the women mistrusted their HCP's motives and thus, queried whether their HCP had acted in their best interests. For example, Suzanne and Angela questioned whether their gynaecologists' recommendation that they should have HRT delivered via subdermal implants following surgery rather than in another form (patches/tablets) was motivated by financial rather than therapeutic considerations.

Suzanne: Um ... but I'm definitely going to look into seeing somebody other than him, because as I say, he gets sort of ninety quid when I see him, and I—that's all wrong. Yes, I think I will. Because, as I say, Mr X's only interested in the old ready monies. When [nurse] is pumping up my arm and he's putting the thingummy in and telling me where they've been on holiday, and back to Florida, and they've got a home in Florida, and I'm thinking, this is where all my bloody money's going! You know? I mean then I get a bill, because the blood test is seventy-five pounds each time, which is crazy.

Angela: Yes, and I thought that was a bit cheeky, and I wondered whether it was—perhaps it's very bad of me, but I thought, from what I know now, people go back and have repeat implants, and he does them, and I thought it might have been a bit of a knock-on effect from the income point of view. I don't know. I didn't like to say that, but I did wonder! [laughter] I'm not being slanderous, I hope, but, you know, it just crossed my mind. Well, you know, he's got a regular patient here and regular income from it, if I keep going back for another implant. But it may be just that in his mind that was the best thing to do.

Only a few women expressed scepticism about their HCPs' motives, but many more reported that they mistrusted

the information they had been given. In some cases this was directly linked to their mistrust of their HCPs' motives—namely, they were of the opinion that their HCP wanted them to have the operation and had tailored the information they gave them to engineer this outcome.

Angela: Although I don't bear any ill will or any malice to consultants, because I made a quick decision, I do wonder whether, you know, him going on holiday to Australia, I wonder whether there was, as with the implant really, whether there was some manipulation to get me to make the decision quicker than I might have done.

Likewise, Sally B, after reading about the increasing rates of hysterectomies, questioned whether her gynaecologist had manipulated the facts to avoid any repercussions if she developed ovarian cancer.

Sally B: ... like I just put my trust in Mr Y, that he was telling me the right thing. And there was a small part of me that thought, well, is he just doing this so that there isn't egg on his face? And [my sister] and I discussed this, you know. Because you just—because he is scanning us, and he's scanned us for so long, if we do go down with ovarian cancer and he's not—well, not suggested we have the operation, then he's going to have egg on his face ... There was a small part of me that wondered about that, very much so ... but you still read that they are doing an awful lot of hysterectomies, and are they unnecessary?

Finally, another group thought their HCP had presented the facts in a biased way in order to obtain the outcome they viewed as in the patient's best interests.

Sue: It was just—I mean I know it maybe isn't the case, but when I saw the gynaecologist, before, was it, or maybe just after I'd had Joshua, and he said then about having a hysterectomy, and after that I saw Mr X, about having a breast check, and I told him about having a hysterectomy, and he says, 'Oh no! That causes other problems.' And then I went back to see the gynae, and he says about doing these tests, and I went with that. And then when he said about this third test being a bit iffy, and nobody else seemed to know what this third test was, and I thought, I mean it's maybe really stupid but I thought, 'Is he just saying that because he thinks a hysterectomy is the best way, and by telling me one of the tests was a bit iffy he knows I'll have it done? Rather than trying to talk me into having it done'.

While the women who thought that their HCP had deliberately manipulated the facts to engineer a particular outcome were in the minority many more commented upon

their HCP's lack of knowledge or failure to answer their questions. In many cases, this resulted in them questioning their HCP's expertise and, as a consequence, mistrusting the information they received.

Melanie: Well, I did go and see my GP while my mum was still alive. And believe it or not, he said to me, you had regular scans while you were pregnant, which I thought was a bit of a nonsense really because you're only scanning the baby. So I left it.

Others reported that their HCP had indicated that they were uncertain of the best way of managing ovarian cancer risk or adjuvant treatments such as HRT following oophorectomy. At the time that many of these women had undergone surgery there were no evidenced-based guidelines on the management of high risk women, and there was medical uncertainty about the use of HRT following oophorectomy in this patient group. So to this extent, in expressing their ambivalence and uncertainty about post-surgical risk management, these HCPs were, in actuality, presenting these women with the received medical opinion. However, it was apparent that these women neither expected, nor liked, to hear that their HCPs were unsure about the best course of action in their particular case.

Rita: When I questioned the specialist at the hospital about it, his opinion was that more women who are having HRT get monitored, and that more breast cancer shows up, that there wasn't actually an increased risk at all. I wasn't at all convinced. [laughter]

NH: *Why weren't you convinced by that?*

Rita: Because I didn't think he really knew! It's simple, he didn't know. He told me he didn't know. He really told me he didn't know. He hadn't had long enough to know yet.

Furthermore, receiving conflicting advice from a number of HCP's served to undermine women's trust in individual HCP's judgement. For example, Tonicha, like many women in the study, reported receiving conflicting advice from a range of GPs (primary care physicians) and specialists (gynaecologists).

Tonicha: Now, my own doctor [G.P.] said today to keep using it [HRT] So he's sort of going on still. Now, about seven years ago, he didn't want to know about it really. He was the one that told me, oh, you're doing this, you're doing that. So I think the doctors are educating themselves as well. But before, there were so many—and one doctor told me, not so long ago, if I eat a well-balanced diet, I shouldn't need HRT. ... So one told me one thing, and another

told me another. But he said, if there's no brittle bone in your family, that I shouldn't be at risk. So I'm still none the wiser! [laughing] You know, I'm still none the wiser!

Similarly, Katrina described how, following her attendance at genetic counselling in a London clinic, she had asked for a referral to different hospital (LDGA) when she returned home, because she did not trust the HCPs' opinions in her Local District General (LDGB) Hospital as she felt their knowledge and practice was out of date.

Katrina: I go to [LDG A] for um to have the mammogram done every twelve months. At [LDG B] they won't talk about it at all. They don't even agree with screening. They think it's all—they—I don't think they really even accept that it's—that you can get it genetically. I don't know why. They seem to have this backward view at [LDG B]. I find it very frustrating talking to them. [LDG B] is useless. I mean it's like something from the troglodyte zone. They just haven't—I wasn't that confident about having my ovarian screening, at [LDG B], because they do it on your tummy, the same as if you're pregnant, not vaginal. I didn't feel that was as good. I was told at [London clinic] that the inter-uterine device [transvaginal ultrasound] is better.

Arguably, when faced with conflicting advice or, in some cases, little or no explanation at all, one might expect these women to question their HCP's expertise, however, a few women said they had found this very difficult. Linda's GP had referred her for a CA125 serum marker test and then failed to explain the results properly, causing her a great deal of anxiety. She thought the test results indicated that she had ovarian cancer but could not get any clarification from her doctor: "Because I can't question. She's the doctor, isn't she?". Similarly, Sarah expressed dissatisfaction at the amount of information she had received from her HCPs, but said she felt unable to question them and ask for further information.

Sarah: I found it a bit—(sighs) which I suppose it would be—one-sided, giving them information, this is the doctors, but I didn't feel as though I was getting much back apart from this one remark about, well, when you've finished your family, about thirty-eight or forty, you should think about having your ovaries removed. And I ... and perhaps that's because they're very busy people, they've got other things on their minds, but I didn't feel as though I was getting much back, and I wondered whether they were withholding—almost—information (laughs). They probably weren't. But whether they were withholding information. And when she said—said that, I thought, oh, why are they saying

that? What's made you make that judgement? And I didn't feel it was appropriate to question or challenge her at the time, because I wanted to be there. ... Maybe I should have said, oh, why did you say that? But it was like me trying to interview her, when I'm going there and asking them to help me type of thing. Do you understand what I'm saying? So I didn't feel it was appropriate to start sort of questioning her.

Finally, other women expressed scepticism about scientific advances in genetics and the translation of research findings into the clinic.

Jane: I sort of feel ... how much do they really know? Because I know they are still researching and trying to find out all the time they are saying they are researching into genetics and genes and trying to find out what causes what. And I sort of feel they only know like the tip of the iceberg really because they are still ... {I.yes?. laughing} ... there is still so much research to do.

Despite the fact that many of these women talked about how they had sought firm answers to their queries, a small group of women now accepted (with the luxury of hindsight) that knowledge about ovarian cancer risk management was fairly rudimentary at the time they had undergone surgery and/or attended genetic counselling. Indeed, one woman, Helen, even reframed the uncertainty surrounding cancer risk management as a positive attribute. As she said, the most important thing she learnt from her recent genetics consultation was:

... the fact that there's a lot of questions that he can't answer. And that's positive as well as negative, because it means that if I was going to worry about it, then it's pointless because nobody else knows.

Medical encounters in the twenty-first century are characterised by increasing patient autonomy and decreasing paternalism. If HCPs are to facilitate patients' decision-making, they must not deceive patients about their situation (O'Neill 2003). Moreover, as O'Neill (O'Neill 2003) notes, if informed consent is to work, then patients should feel able to ask their HCPs for information and expect to receive an answer that they can trust. Indeed, if the ability to control information is as important to ensure informed consent as O'Neill maintains, then the above data suggest that the quality of consent given by some of the women in this study may have been compromised by their inability to question their HCPs.

Dealing with patients: treating them as persons

"Lack of respect, though less aggressive than an outright insult, can take an equally wounding form. No insult is offered another person, but neither is

recognition extended: he or she is not *seen*—as a full human being whose presence matters” (Sennett 2003: p. 3)

“The medical professionals, they say their facts, and they think you’re a piece of meat. They don’t realise you’re a person.” (Victoria, study participant)

Informed medical decision-making requires trustworthy information, a trustworthy information-giver, and a trusting patient–HCP relationship. But, if HCPs are to be seen as trusted experts who can be questioned, then they need to perceive their patients as autonomous agents. However, while a great deal of recent bioethical debate has focussed upon the nature of autonomy, much less has focussed upon respect for persons which was previously seen as a foundational issue within bioethics (Beach et al. 2006; Joffe et al. 2003).

As Beach et al. (2006: p. 348) note, the principle of respect for persons has come to be redefined within bioethics in recent years with the result that it “... is commonly manifested by the protection of patient autonomy” namely, ensuring that patients are able to make decisions about their treatment. In other words, ‘respect for persons’ has come to mean ‘patient choice’ (see also Joffe et al. 2003). The women in this study, in contrast to bioethicists, talked less about having a choice, or being able to make a non-coerced decision, than how they felt they had been mistreated by some of the HCPs they encountered in their attempts to have their risks of cancer confirmed or to access ovarian screening or surgery. One of the main problems they identified was that they felt that they were not respected as persons by their HCPs.

Many women became very distressed and angry when talking about how their HCPs had dealt with their anxieties about their family history over the years. Helen, for example, described her experience of having ovarian screening at two different hospitals. In the first (LDGX) she said felt that her cancer anxieties had been downplayed or ignored by HCPs, whereas in the second (LDGY) she felt that they were acknowledged and taken seriously; as a result she felt confirmed and respected by the HCPs in the second hospital.

Helen: The person doing the scan was—understood why I was there [LDGY]. I didn’t—I wasn’t made to feel you’re wasting my time or anything. Whereas when I had it done in [LDGX], the gynaecologist was—you know?—she just couldn’t be bothered whether I was there or not. So that really put me off, I think, there, and I think maybe if I had stayed in [LDGX], then I wouldn’t have followed it up, I would have—or I would have asked to have been referred to somewhere else. You know, it sort of certainly made me feel it’s wasting your time, there’s no evidence to

prove that this is going to help and, you know, they’ve got plenty of other women waiting, blah-blah-blah. So at least here [LDGY] I feel as though people are listening to me and, you know, respecting my views, sort of thing. Which I think helps a lot.

When asked what type of information she thought high risk women required to make decisions about prophylactic surgery, Helen focussed less on women’s need for substantive types of information (e.g. information about the risks of surgery/screening or the effects of HRT) than the ways in which they should be treated. She stressed that HCPs need to treat their patients with respect—provide them with emotional support and personal confirmation. As she said, doctors need to:

... take these women seriously. And, you know, some women don’t want to know, but the women that do what to know, I think they need—their views need to be respected, and, you know, not—oh, she’s—you know?—she’s just some obsessive woman, sort of thing. ... I think it’s just for them to, you know, to listen to these women and to respect them for what they’re asking about.

The need to treat individual patients respectfully and not make them feel as though their anxieties and fears are ill-founded or, even, pathological was repeated in many of these interviews. For example, Jenny, a general practitioner, was aware of her family history of ovarian cancer and had learnt that this might pose a threat to her health in a lecture when she was a medical student. She described what had happened some years earlier when she went to discuss this with her GP:

So I went to my GP, and she said, “Don’t be stupid, you’re being neurotic. Because your mum died at an early age you’re neurotic, and you’re always going to be neurotic, and just go away and get on with your life.” So I hadn’t ever seen her before, and I’d been registered with her three years. So I didn’t really think that made me neurotic. But anyway, I have it now on board. That one woman has made a big impression on me, and she makes me think that I’m neurotic ...

This GP’s response had had a long lasting impact on Jenny and she remains angry about the way she was treated.

... you wonder, don’t you, whether that’s how you’d be perceived, as neurotic, paranoid, barking mad, whatever adjective you choose... I felt like slapping her. But I feel very bitter really... I’d like to write to her and say, one callous comment has made such a big effect on me and my perception of me, um, and sticking a label on me that I don’t now need.

Jenny regarded her recent cancer genetics consultation as a turning point in life; she said that it had confirmed her suspicions about her risks and in so doing *allayed* her anxieties because:

It gave me permission to be concerned about my health, really. And the rest of the stuff I'd more or less worked out for myself. So really it was—it was the permission, the sort of formal giving of permission that I can be concerned, and it is not a manifestation of a neurotic personality. And—and I suppose all these people saying over the years, oh, you're neurotic, it's quite scarring. It—I mean I must have said that word about eight times, mustn't I? And isn't that awful, to make somebody feel that way?

The idea that expressing one's anxieties about the family history of cancer to HCP might generate a label of neurosis recurred throughout these interviews. As Olga said about her attempts to obtain a referral for ovarian screening from her GP:

No, I've really had to pump them all the way. Because, you know, I said to them, "I'm part of this thing, I'd like to do the screening" And so they sort of—I said," could you write this letter and stuff?" Because I don't go to the doctor very often, and when I go, in and out pretty quickly. And trying to sit down and have a conversation about—and as I said earlier, I don't think they probably know enough about it. And I'm not sure, they might just think, oh, it's some neurotic woman wanting sort of—I don't know, they might not. I'm probably being awful about them. [laughs] And, you know, "just don't waste my time".

Others talked about how their HCPs had failed to engage with them on a personal level to the extent that in some cases, the consultation had felt like a scripted performance.

Lesley: Well, the arrogance of Professor Z ... It's like an act, you know, it's like the beginning, the middle and the ending, and it's all sort of perfect, like a Shakespearian play. But that was a finale when he—I think he was about to quote William Blake or something, I don't know, you know, 'Onward Christian Soldiers' or something. I found him a most obnoxious and unhelpful man. I didn't like him at all. He treated me like I was not even worth looking at.

Lesley, a *BRCA* mutation carrier, had not only encountered Professor Z, but a range of other breast surgeons, oncologists, gynaecologists, in her quest to obtain screening, and have her anxieties taken seriously. She reported that she her treatment was so depersonalised in some of these encounters that she felt she was treated as an inanimate number or a collection of disposable body parts.

Lesley: ... Because I found Miss B—they're flippant, you know, they forget about you, you're a number.

NH: *Has anyone suggested that you have the ovaries removed?*

Lesley: Oh God! Prof Z. One of these dreadful times, yes, and he said well, these professional people, you know, they're talking about your body and your life, and you'd think they're talking about a bag of chips or something! And he said, "oh yes, well, we will have to remove them," ... .

Finally, some women thought that they had been identified as a 'troublesome patient' for other reasons and therefore, would not be taken seriously when voicing their anxieties concerning their cancer risks.

Angie: You've never got time to explain things with the doctor [GP]. You've only got a five-minute block appointment. They'd seen me walk in and it's like, oh Christ, it's her again! I go in with all the kids and me, and—oh!

As the above data indicate, many of these women had encountered GPs, breast surgeons, gynaecologists or ultrasonographers whom they felt had failed to treat them with respect. Arguably, these feelings arose because the HCPs they approached for help failed to acknowledge their anxieties about their cancer risks or at the very least respond appropriately, which, in turn, made them feel as though they had not been taken seriously or fully recognised as persons.

## Discussion

In this paper I described high-risk women's feelings about the ways they were treated by the HCPs they had consulted during their quest to obtain information about ovarian surgery or screening. While the data show that a small number of women mistrusted their HCPs' motives or were sceptical about their knowledge of cancer genetics, there was no indication that this had prevented these women from making a decision about their cancer risk management (although it must be born in mind that they might have made different decisions had they had greater confidence in the information they had received). Furthermore, there was no evidence that mistrust of individual HCPs was generalised to HCPs as a group. In the main, women's dissatisfaction with medical encounters stemmed, not from a lack of trust, but the lack of respect they felt they had experienced from certain HCPs. In the final sections of this paper, I explore the important connection between respect and trust in medical encounters and discuss some of the implications of this connection for informed consent.



### Patient expectations: treat me right or give me the right treatment

In some cases an HCP's inability to answer patient questions or provide them with unequivocal answers led patients to mistrust them. In other words, the women in this study wanted certainty and when none was forthcoming their trust in their HCPs was undermined. This reaction to HCP uncertainty reveals high expectations about individual HCP's expertise and a misunderstanding about the way in which the evidence base in medicine exists, functions and, more importantly, changes. Clearly, many of these women did not like uncertainty, and did not like their HCPs being uncertain. However, in some clinical specialties, particularly those which involve new technologies, such as clinical genetics, where the knowledge base is evolving at a fast pace, uncertainty and a lack of agreement amongst practitioners is the norm.

The idea that mistrust may be linked to these women's expectations of their HCP's expertise or their understanding of the nature of medical knowledge is an interesting observation, requiring further exploration. Potential misconceptions, or misconceived expectations, about the nature of medical expertise/knowledge may be stimulated by two things. First, holding an outmoded view of the HCP–patient relationship—one in which the HCP's knowledge, expertise and authority is seen as paramount, and patients are seen as having a responsibility to defer to their expertise (Parsons 1951). Second, the fact that we live in an era that is characterised by high, or even unrealistic, expectations about biotechnology, which are continuously fuelled by media speculation and hype about developments in genetics and genomics, in particular (Martin and Frost 2003; Nightingale and Martin 2004).

### Trust and respect: an ambiguous relationship

As I noted in the introduction, the paternalistic model of HCP–patient interaction that dominated medicine in the early twentieth century was contingent upon the structural inequalities of the HCP–patient relationship. In other words, an HCP's authority was determined by their position within the social structure/relationship and, thus, trust was dictated by structural factors. Contemporary HCP–patient relationships, in contrast, are more egalitarian. Patients are active consumers of medical services and the HCP's task is to facilitate patient choice. Trust, in this instance, derives from personal rather than structural factors; it is vested in individual HCPs' expertise rather than their structural position (Giddens 1991). However, it must be noted, that even with the advent of the internet-informed 'expert' patient, we still assume that HCPs have the most (relevant) expertise in this relationship, thus, personal

factors cannot be seen as entirely independent of structural position. In other words, despite the emphasis on personal expertise, the development of trust is still (implicitly) influenced by structural features.

Bearing these observations in mind, we can explore the organisational features which encourage the development of, or undermine, trust in HCP–patient relationships. In the present study, for example, women who undergone prophylactic surgery in the private sector were more positive about the way they had been treated, had received more information pre- and post-operatively, and were provided with more long-term follow-up than those treated in the public sector (Hallowell et al. 2001). Clearly, we need more research that looks at how different medical systems (state-funded or insurance backed) and different medical specialities (primary versus secondary care) foster or discourage trusting and respectful relationships.

The view of trust outlined above ignores the dynamic and relational nature of trust. Empirical research suggests that trust is as an emergent feature of relationships—an interactional variable (Calnan and Rowe 2004; Gilson 2006). Many commentators have argued that respect is crucial for the emergence of trust, particularly in relationships characterised by structural inequalities (Cook et al. 2005). A number of studies demonstrate that treating patients with respect is regarded as an important aspect of trusting HCP–patient relationships (Beach et al. 2006; Calnan and Rowe 2004, 2006a; Gilson 2006; Joffe et al. 2003; Robb and Greenhalgh 2006), but this research fails to specify the nature of this relationship between respect and trust. Do they exist independently or are they fundamentally interrelated?

When answering this question we need to bear in mind that trust and respect are grounded within interaction and, as such, must be seen as dynamic and evolving within the social context. Arguably, aspects of this context—the power, expertise/knowledge, and expectations of the participants affect the promotion of trust and respect. Furthermore, there is a bidirectional flow of trust and respect in medical encounters. The reports of HCPs failing to answer patients' questions in this study, which most women interpreted as indicating a knowledge deficit, could, alternatively, be read as the HCPs deliberately not revealing the ambiguous state of medical knowledge in order to promote trust in their expertise. These comments highlight the need for more observational studies of HCP–patient interaction that explore the ways in which HCPs and patients negotiate trust and respect during medical encounters.

While this study did not intend to explore the nature of the relationship between trust and respect, the data that emerged compliments earlier research by pointing to the links between trust and respect in HCP–patient relationships. For

example, Calnan and Sandford's (2004) empirical work suggests that 'being taken seriously' is seen as a marker of trust, whereas I interpreted the complaints about 'not being taken seriously' made by the women in this study as indicating a lack of respect. These differences in interpretation suggest that the relationship between these concepts is not straightforward and requires further exploration.

### Trust, respect and informed consent

O'Neill (2003) argues that if we want to guarantee genuinely informed consent, then we have ensure that there is no room for deception and coercion in HCP–patient relationships. One way to do this is to see these as trust relationships. O'Neill (2002) notes that the development of trust relationships may be facilitated by the adoption of a Kantian view of autonomy. She observes that Kantian autonomy is fundamentally based on respect for humanity and, thus, is a much richer notion than the isolated 'individualism' which has come to be identified with "autonomy" in the bioethics literature. From the Kantian perspective, each person is seen as a source and creator of value (Korsgaard 1992), and a person's value-creating capacity must not be violated through coercion or deception. The Kantian orientation, therefore, promotes respectful and trusting relationships, which are based on mutual obligations, or respect for persons, rather than on externally imposed rules.

HCP–patient relationships can be seen as archetypal trust relationships. They involve individuals who have different types of expertise and, thus, different amounts of power, and are typified by a degree of interpersonal dependency, uncertainty and risk. Stirrat and Gill (2005) note that, adopting a Kantian view of autonomy in healthcare relationships requires that patients ... " should be treated as people" (p. 129), namely: treated with respect, properly informed, listened to, not coerced into giving consent and have their privacy respected. It is these qualities that make informed consent possible.

My study shows that respect is an important aspect of HCP–patient relationships. Patients want to be treated with respect—they want to be taken seriously and treated as persons. Respect and trust can be seen as interdependent concepts: respect leads to trust which in turn generates respect which consolidates trust. If trust is necessary for informed consent, then respect, as a feature of trust relationships, also has a role to play. It all comes back to the Kantian project of treating people as ends in themselves; treating people—in this instance patients and health care professionals—as having intrinsic value.

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### References

- Alaszewski, A. 2003. Risk trust and health. *Health, Risk and Society* 5: 235–239.
- Beach, M.C., D.L. Roter, N.-Y. Wang, P.S. Duggan, and L.A. Cooper. 2006. Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviour? *Patient Education and Counseling* 62: 347–354.
- Boseley, S. 2001. Grotesque breach of trust at Alder Hey. *The Guardian*, 29 Jan 2001. [http://www.guardian.co.uk/uk\\_news/story/0,,430248,00.html](http://www.guardian.co.uk/uk_news/story/0,,430248,00.html). Accessed 21 June 2007.
- Calnan, M., and R. Rowe. 2004. *Trust in Health Care: an agenda for future research*. The Nuffield Trust. <http://www.bristol.ac.uk/hsrc/research/projects/trust/agenda-change.pdf>. Accessed 25 June 2007.
- Calnan, M., and R. Rowe. 2006a. Researching trust relation in health care: Conceptual and methodological challenges an introduction. *Journal of Health Organization and Management* 20: 349–358.
- Calnan, M., and R. Rowe. 2006b. Trust relations in health care: An agenda for future research. *Journal of Health Organization and Management* 20: 477–484.
- Calnan, M.W., and E. Sandford. 2004. Public trust in health care: the system or the doctor? *Quality and Safety in Health Care* 13: 92–97.
- Cook, K.S., R. Hardin, and M. Levi. 2005. *Cooperation without trust*. New York: Russell Sage Foundation.
- Department of Health. 2000. *The NHS plan: A summary*. London: HMSO. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4010198](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010198). Accessed 25 July 2007.
- Giddens, A. 1991. *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.
- Gilson, L. 2006. Trust in health care: theoretical perspectives and research needs. *Journal of Health Organization and Management* 20: 359–375.
- Glaser, B., and A. Strauss. 1967. *The discovery of grounded theory*. Chicago: Aldine.
- Hallowell, N., I. Jacobs, M.P.M. Richards, J. Mackay, and M. Gore. 2001. Surveillance or surgery? A description of the factors that influence high-risk premenopausal women's decisions about prophylactic oophorectomy. *Journal of Medical Genetics* 38: 683–691.
- Joffe, S., M. Manocchia, J.C. Weeks, and P.D. Cleary. 2003. What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics. *Journal of Medical Ethics* 29: 103–108.
- Korsgaard, C.M. 1992. Creating the kingdom of ends: Reciprocity and responsibility in personal relations. In *Philosophical*

- perspectives 6: Ethics*, ed. J. Tomberlin, 305–332. Atascadero: Ridgeview Publishing Co.
- Martin, P., and R. Frost. 2003. Regulating the commercial development of genetic testing in the UK: Problems, possibilities and policy. *Critical Social Policy* 23: 186–207.
- MORI. 2003. *Public retains great trust in doctors*. <http://www.ipsos-mori.com/polls/2003/bma.shtml>. Accessed 25 June 2007.
- Muhr, T. 1994. *Atlas-ti*. Berlin.
- Nightingale, P., and P. Martin. 2004. The myth of the biotech revolution. *Trends in Biotechnology* 22: 564–569.
- O'Neill, O. 2002. *Autonomy and trust in bioethics*. Cambridge: CUP.
- O'Neill, O. 2003. Some limits of informed consent. *Journal of Medical Ethics* 29: 5.
- Parsons, T. 1951. *The social system*. Chicago: Free Press.
- Rebeck, T.R., H.T. Lynch, S.L. Neuhausen, S.A. Narod, L. Van't Veer, J.E. Garber, G. Evans, C. Isaacs, M.B. Daly, E. Matloff, O.I. Olopade, B.L. Weber, and The Prevention Observation of Surgical End Points Study Group. 2002. Prophylactic oophorectomy in carriers of BRCA1 or BRCA2 mutations. *New England Journal of Medicine* 346: 1616–1622.
- Robb, N., and T. Greenhalgh. 2006. You have to cover up the words of a doctor: The mediation of trust in interpreted consultations in primary care. *Journal of Health Organization and Management* 5: 434–455.
- Rowe, R., and M. Calnan. 2006. Trust relations in health care: Developing a theoretical framework for the “new” NHS. *Journal of Health Organization and Management* 20: 376–396.
- Royal College of Physicians. 2005. *Medical professionalism a force to improve patient care*. [http://www.rcplondon.ac.uk/news/news.asp?PR\\_id=295](http://www.rcplondon.ac.uk/news/news.asp?PR_id=295). Accessed 21 June 2007.
- Sennett, R. 2003. *Respect: The formation of a character in a world of inequality*. Harmondsworth: Penguin.
- Strauss, A., and J. Corbin. 1990. *Basics of qualitative research*. London: Sage.
- Stirrat, G.M., and R. Gill. 2005. Autonomy in medical ethics after O'Neill. *Journal of Medical Ethics* 31: 127–130.
- Vandeveld, H. 2003. Public opinion: Why carers get a hostile public. *The Times*, 02 Dec 2003. [http://www.timesonline.co.uk/tol/life\\_and\\_style/career\\_and\\_jobs/seniorexecutive/article1005637.ece](http://www.timesonline.co.uk/tol/life_and_style/career_and_jobs/seniorexecutive/article1005637.ece). Accessed 21 June 2007.