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Ownership of Uncertainty: Health Care Professionals counselling and treating women from hereditary breast and ovarian cancer families who receive an inconclusive *BRCA1/2* genetic test result

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Abstract

AIM—To understand more fully how health care professionals deal with the uncertainty intrinsic in counselling and treating women from hereditary breast/ovarian cancer (HBOC) families who receive inconclusive *BRCA1/2* genetic test results (genetic tests which do not find a mutation to account for the family history).

METHODS—We conducted a small, qualitative, exploratory study using open-ended semi structured interviews of 12 geneticists, genetic counsellor/nurses, oncologists, gynaecologists and breast surgeons at a major UK cancer centre. We asked questions about: how these professionals dealt with the large amount of uncertainty raised by an inconclusive result, communicated the uncertainty involved and their feelings about presenting medical management options based on information fraught with uncertainty, the role of the media, differences in perspectives by specialty and personal feelings about the uncertainty.

RESULTS—Based on themes generated by the data, we proposed the concept “Ownership of Uncertainty” (sole, shared, diffused, normalised, transferred) to explain how the professionals in this study dealt with this high degree of uncertainty. A shared ownership of uncertainty was the dominant model during the presentation of information given by the professionals as part of their consultation with their patients. However, the final decision for management was left primarily to the woman seeking advice; even though several of the professionals reported feeling uneasy about this.

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CONCLUSION—The concept “Ownership of Uncertainty helps advance the understanding of how health care professionals deal with the uncertainty intrinsic to an inconclusive *BRCA1/2* genetic test result within the current social context.

INTRODUCTION

“Uncertainty creeps into medical practice through every pore. Whether a physician is defining a disease, making a diagnosis, selecting a procedure, observing outcomes, assessing probabilities, assigning preferences, or putting it all together, he is walking on very slippery terrain”(Eddy, D in Groopman, 2007, pp.151-2) .

While much argued over, there is no one definition of uncertainty, or risk, that is universally accepted by physicians and researchers. We use the term “risk society” to mean that we live in a risk society in which medical/technological advances, particularly in the field of genetic medicine, have become more complex, and systematically generate further questions and uncertainties making practitioners increasingly aware of what is still unknown. It is a society in which risk consciousness, referring to an uncertain future, becomes the dominant way of thinking about individual and societal problems Beck, 1992; Zinn, 2008).

In a risk society, risk calculations by individuals “...demand new reasonable strategies to manage uncertainties and ignorance” (Zinn, 2008, p. 220). Beck (1992) asserts that the growing complexity of modern knowledge production systematically produces “non-knowledge” which allows risks and dangers to develop. Many medical decisions involve multiple sources of uncertainty.

Researchers have different definitions of uncertainty, the sources of uncertainty and its measurement. Poleti et al. (2007, p. 682) cite five main types of uncertainty: “1) risk, or uncertainty about future outcomes; 2) ambiguity, or uncertainty about the strength or validity of future outcomes; 3) uncertainty about the personal significance of particular risks...;4) uncertainty arising from the complexity of risk information...; and 5) uncertainty resulting from ignorance.” Personal characteristics of both health care professional and client also affect how communications are delivered and received (Poleti et al, 2007). Counselling and treating women from HBOC families who receive an inconclusive *BRCA1/2* mutation genetic test in a “risk society” involves all of the above types of uncertainties.

These uncertainties can lead to an increased risk of making decisions that can then produce other risks e.g., negative physical and/or psychological side effects. Women have reported searching for health information, particularly on the internet and from women’s health groups, (e.g. Facing Our Risk of Cancer Empowered [FORCE] ; The National Women’s Health Network) stating that they find this information empowering (Kenen et al. 2007). Patients receiving genetic counselling have high expectations for firm genetic answers, partially due to reports in the media and normative expectations (Petersen 2001; Bubela and Caulfield, 2004).

In the area of genetic medicine, where the penetrance of genetic mutations can be significant but not absolute, health care professionals and patients are frequently left to choose treatment modalities based on ambiguous risk information. For example, although genetic testing for mutations in the *BRCA1/2* cancer predisposition genes has become quicker and more accurate, only about one third of women from HBOC families who have the genetic test, test positive for a *BRCA1/2* mutation (BIC, 2008). The rest of the women having the test receive an inconclusive result; and are no further forward in knowing why their cancer developed in relation to their positive family history. Furthermore, there is limited psycho/

social information about the course of worry and distress experienced by these women (O'Neill et al. 2006; van Dijk et al. 2006). Nevertheless, many women feel that having a voice and making a choice overcomes their qualms about possible uncertain or negative outcomes (Kenen, et al. 2007) .

Knowledge about carrier status is important information in determining whether medical interventions should be recommended, and if so, what kind. For example, it is already known that a breast cancer attributable to a mutation in the *BRCA1/2* gene is likely to have different tumour characteristics, different contralateral primary breast cancer risks and possibly different treatment implications (Lakhani et al. 2002; Armes and Venter, 2002; Moller et al. 2002; Sowter and Ashworth, 2005; Graeser et al. 2009).

As additional evidence is discovered, it becomes clearer that major life and health-care decisions (e.g., about pregnancy, surveillance, prophylactic surgery and medical treatment) may be influenced by whether or not the woman has a *BRCA1/2* mutation (Narod, 2006). Yet other genes are likely to be involved in breast and ovarian cancer predisposition whose impact is not yet known (Narod, 2006). Therefore, in HBOC families, both those women who have already developed cancer and are worried about second primaries as well as those who are unaffected by cancer often find themselves in a difficult position regarding management. Patients and unaffected relatives as well as the health care professionals may need to consider options based on uncertain information.

Though studies have been conducted about the practice and stress of “doctoring” and/or how physicians deal with uncertainty, no studies have dealt specifically with health care professionals having to interpret inconclusive *BRCA1/2* genetic test results (Fox, 1957; Geller et al. 1993; Ghosh and Ghosh, 2005; Polety, 2007; Koh, 2008; Swoboda, 2008; Travers et al. 2009; Zafar et al. 2009). To add to the conundrum, researchers have yet to identify best practices in communicating uncertainty to patients about harms and benefits from specific treatments (Polety et al. 2007). Furthermore, social change interacts with technological change and influences the evaluation of risk (Beck-Gernsheim, 2000). The rapid increase in genetic technology and ensuing new medical and surgical management options e.g., prophylactic surgery, chemoprevention, surveillance techniques, fit Beck's (1992) concerns about the growing complexity of modern knowledge production systematically producing “non-knowledge” encompassing its own risks and dangers. Thus, a study of cancer genetics professionals practicing in the context of a risk laden society would present an important missing component in the literature concerning the genetic testing of women from HBOC families.

This paper seeks to understand how health care professionals informing women of their inconclusive *BRCA1/2* genetic test result deal with the uncertainty intrinsic to this task and to develop a framework to aid in understanding uncertainties in *BRCA1/2* genetic testing and clinical practice.

METHODOLOGY

We conducted a qualitative, exploratory study at a major cancer centre in the UK of women from HBOC families who developed breast cancer and received an inconclusive *BRCA1/2* test result, their unaffected sisters and daughters as well as professionals counselling and treating them (Arden-Jones, et al. 2010). This paper focuses on the health care professionals interviewed as part of this larger study. The researchers sent letters of invitation explaining the research project, offering to interview them any time at their convenience and including an informed consent form for them to sign.

Interviews

In the interviews, we asked specific questions about the professionals' experiences with women who had an inconclusive *BRCA1/2* genetic test result using an open-ended, semi-structured interview schedule. 1) How health care professionals dealt with the uncertainty raised by an inconclusive result; 2) Their medical management advice for these women and the reasoning behind the advice; 3) Whether they believed that the women understood what an inconclusive result was; 4) How they endeavoured to ensure accurate comprehension; 5) Whether they thought there was disagreement among different specialists about the medical management of these women; 6) The role of the media and 7) The professionals' own emotional reactions to providing an inconclusive result.

We looked at the responses from each interview and noted all themes before conducting our next interview (Glaser and Strauss, 1967). We adjusted the interview questions in light of previous responses. This allowed for the discovery, identification and investigation of new variables as they emerged. The interviews lasted from 20 to 30 minutes. All interviews, but one, were conducted in the offices of the professionals. One genetic counsellor who was on leave was interviewed at home. RK conducted eleven of the interviews and EL conducted one. All the health care professionals provided written informed consent either by signing the form included in their letter of invitation or in person. The study was approved by The Hospital's Clinical Research Committee and Local Regional Ethics Committee. Direct quotes are used throughout the paper to illustrate the findings. The participants consented to tape-recording and transcribing of the interviews. Only pseudonyms were used.

Three members of the research team read and analysed transcripts of the interviews for recurring themes after repeated close reading of the material. They read and reread the interview transcripts, noted each theme and subthemes presented by the respondents, then compared and discussed their interpretations until agreement was reached. Only those regarding uncertainty are discussed in this paper.

Due to the lack of previous research on this specific population, we chose a qualitative research design because of its ability to capture complexity, process and meaning attached to individual action (Beeson, 1997). We used a simplified adaptation of grounded theory applying the constant comparative approach (Glaser and Strauss, 1967; Strauss and Corbin, 1990). For our larger study, we chose one medical setting which allowed us to compare women from HBOC families and health care professionals from the same institution. Unfortunately, this design precluded theoretical sampling until we were sure that saturation was reached because of the small number of health care professionals involved (Glaser and Strauss, 1967; Strauss and Corbin, 1990).

We used an inductive process involving coding and identification of recurrent patterns, relationships and processes in the data which emphasizes the participants' own accounts of their phenomenological and social world (McAllister, 2001; Bailey, 2007). Our audit trail consisted of data collection, note-taking, coding and memos. As we coded and wrote comments, we noted categories that might eventually link with other categories to form a core category. We also conducted our literature review before, during and after data collection. The use of an iterative inductive approach, however, does not assume that there is only one measure of reality that can be objectively grounded (Mathieson and Stam, 1995; Smith, 1996).

RESULTS

Sample

We interviewed 12 professionals from the following specialties: 3 medical geneticists; 2 oncologists; 3 cancer genetic nurse counsellors; 2 gynaecological surgeons; and 2 breast surgeons. The two oncologists also counselled patients. The sample consisted of seven women and five men. They ranged in age from their early thirties to their late fifties and ranged from being a registrar or recently graduated cancer genetics nurse to very experienced health care professionals with more than ten years of practice.

Themes

The main themes and subthemes that emerged were:

1. The Pervasiveness of Uncertainty
 - a. Handling uncertainty in terms of clinical management advice
 - b. Emotional reactions of professionals to providing inconclusive advice
2. Multiple Uncertainties
 - a. Increase in knowledge leading to increase in complexity of information presented to the patient
 - b. Understanding the meaning of genetic variants
3. Ownership of Uncertainty
 - a. Sole ownership
 - b. Shared ownership
 - c. Diffused ownership
 - d. Normalised ownership
 - e. Transferred ownership

The Pervasiveness of Uncertainty

All the geneticists, oncologists and nurse genetics counsellors expressed some degree of unease about the uncertainty of data on which they had to base the assignment of risk status and/or the risk reducing options they communicated to patients.

“... We know it’s [genetic testing] going to improve, but it’s not here yet, and that very first of all it’s frustrating, and because you like to practice evidence based medicine.. Secondly, you know that probably some people are having surgery unnecessarily, and thirdly...you would feel much happier about doing the screening measures or prophylactic surgery measure that were quite extreme, if this level of certainty was much higher.”

Dr. B, Oncologist

As Oncologist B stated above, cancer genetics health care professionals were practicing in an era where evidence based medicine was highly valued. Yet, they found themselves frustrated when their area of expertise could not yet achieve the current gold standard of evidence based medicine. They grappled with the uncertainty intrinsic to the current state of inherited breast/ovarian cancer knowledge both from an individual professional perspective and from the perspective of a patient having surgery unnecessarily.

The health care professionals described how the women's expectations for black and white answers added to their frustrations about the extent of uncertainty in their practices. They partially blamed the media for causing these erroneous expectations because patients often came to their sessions with information that they said that they had read in newspapers and magazines, or heard on TV.

The health care professionals also were aware that the media provided a social context for their patients, and played a role in their patients' attitudes toward risk management decisions.

"It's [the media] a very interesting area for them because young women with breast cancer is always newsworthy and women having their breast removed is always something that creates a fascination in the media and I think that you very rarely see a media piece where the uncertainties of new technologies are highlighted."

Dr. D, Oncologist

Multiple Uncertainties

Increases in knowledge about the human genome lead to an increase in the complexity of information provided to patients. The professionals who counselled expressed worry about explaining these complexities to their patients. Even the language is changing rapidly and it is a challenge for patients keep up with new developments and new vocabularies e.g. Genome-wide Association Studies (GWAS) studies, telomeres, linkage, variants, polymorphisms etc. And sometimes the explanations sounded convoluted as well as complex.

".... And then there's the group where there may be something going on but it's not absolutely conclusive so you can't necessarily say well we haven't found something but I'm sure there's something there. This is a, sort of, double sort of uninformative...well, we're not sure if there is a gene change that you've got. and anyway we're not even sure if there is one anyway. And I think that's even possibly harder to deal with."

Dr. C, Geneticist

The clinicians appeared to be trying to ascertain new and reasonable ways of managing the increasing uncertainties involved in the evolving complexity of genetic knowledge. They expressed how they are grappling with problems of determining the meaning of genetic variants and whether there is a gene change and if so, whether it is significant or a benign polymorphism.

The Ownership of Uncertainty

The themes that emerged from our analysis of the interview data led us to propose the concept of "Ownership of Uncertainty" as a core construct, or conceptual framework, to help explain how health care professionals in the field of cancer genetics, especially when a *BRCA1/2* genetic test result is inconclusive, handle the large amount of uncertainty involved in their tasks. The "Ownership of Uncertainty" concept also can be applied to many health care professional/patient interactions e.g., whether to take part in any sort of screening as advised by the Government including Prostate - Specific Antigen (PSA) test and decisions regarding prostate cancer treatment.

The concept "Ownership of Uncertainty" encompasses categories that are not mutually exclusive.

1. Sole ownership of uncertainty (health care professional controls information about uncertainty) This was more typical in the middle of the 20th century when the paternalistic model of the physician/patient relationship was the norm.
2. Shared ownership (health care professional and patient make decisions jointly). The health care professional and patient share information and responsibility.
3. Diffused ownership (team work). The genetic risk counsellors and breast and gynaecological surgeons each have their own domains.
4. Normalisation (uncertainty in a subfield defined by a high degree of uncertainty e.g., inconclusive *BRCA1/2* is not really that much different than the uncertainty found in general medical practice.).
5. Transfer of ownership (patient receives all the available information and decisions are left to her). This latter is frequently referred to as empowering the patient. But the flip side of the empowerment of information is the uncertainty intrinsic to the information. Thus, the patient now “owns the uncertainty”.

Sole Ownership of Uncertainty

Most of the comments of the professionals reflected the uncertainty involved and the seriousness and irreversibility of many of the decisions. A few of the surgeons were willing to tell their patients that they should have prophylactic surgery. Most of the health care professionals, however, did not seem to want the complete burden of being the sole “owner of uncertainty”. While they frequently expressed the advantages of prophylactic surgery, they also talked about possible negative side effects e.g., lymphoedema, severe early menopause symptoms, poor surgical aesthetics of these prophylactic choices.

“...some women with a really horrible family history will not consider surgery in any circumstance, where my own view might be that I would encourage them to do so...”

Dr.A Geneticist.

“Well, 50% risk is very easy. You know, the options are simple. You know, you have your ovaries removed or you have your ovaries removed...”

Dr. L gynaecological surgeon

Historical factors may play a role in how the health care professionals felt. The surgeons come from a medical background where paternalism was the norm for many years. Health care professionals counselling women from HBOC families primarily come from a counselling background of non-directiveness. The associated link with ovarian cancers for *BRCA1/2* carriers explains the statement of Dr L the gynaecological surgeon. The counsellors reported that they leaned toward supporting their patients desire to make their own decisions, if they believed that the women fully understood their decisions. The gynaecological surgeons who saw the havoc that metastatic cancer could cause appeared to be more comfortable pressing for prophylactic surgery.

Sharing Ownership of Uncertainty

Most of the health care professionals whether they counselled or performed surgery stressed the importance of carefully presenting options and risks to their patients and trying to make sure that they understood the implications and the uncertainties that they faced. Many believed that preparing the patient through education was the best way to deal with this difficult situation where decisions can only be based on family history, but where the

options should really be based on firm evidence that does not yet exist. They tended to believe that sharing the knowledge currently available was the best approach.

“... what I often do is involve the person in the uncertainty. I don’t know whether this is the correct approach, but I’m always completely up front with them.”

Dr. B, Oncologist

Among the respondents in this study, joint decision- making seemed to be the most acceptable compromise. This approach reflects a middle position that gives the woman some sense of power over her own life, yet does not relieve the health care professionals of their obligations toward the woman, nor does it place an undue amount of responsibility on the health care professionals. It appears to be a win-win decision for both client and health care professional. However, as discussed below under the “transfer of ownership” section, most of the counsellors pulled back at the end of a counselling session and told the women that it was their decision. Thus the professionals were sharing information, perspectives, and recommendations but not responsibility.

Diffusion of Uncertainty (team work)

The surgeons in general tended to divide the uncertainties their patients faced into two categories – surgical outcomes and risk estimations. They tried to opt out of discussing genetic risk. They left that up to the genetic counselling team members whom they repeatedly praised. In effect, they diffused their “ownership of uncertainty” by only claiming the uncertainties involved in surgery as being within their domain.

“I’m not sure it’s relevant to me [an inconclusive genetic test result]. I try and steer clear of counselling women on the risks of breast...of ovarian cancer...because as you know here we have a very good genetics team.... I try and talk about the risks of the surgery that I do and [leave] the risks of the cancer to the experts in that area. So...I suppose the way I deal with it is by not getting involved in it.”

Dr. L, Gynecological Surgeon

In the field of cancer genetics, many new genomic discoveries and surgical, biological and chemical prophylactic ways of attempting to reduce the risk of breast/ovarian cancer in women from HBOC families have been developed. Therefore, it is difficult for any one person to feel that they are an expert in every area. Specialisation has traditionally been a way that physicians have limited the amount of knowledge they need to know (Hunt and Newman, 1997). In major cancer centres that have a large number of patients, there is frequently a division of labour between surgeons and genetic risk health care professionals and even among breast and gynaecological surgeons, where one specialist refers to another kind of specialist when their expertise is deemed appropriate.

Normalising Uncertainty

Several of the respondents remarked that the field of genetics is filled with uncertainties and the area of inconclusive *BRCA1/2* test results is different in degree rather than in kind.

“I mean as geneticists we’re used to dealing with inconclusive test results because we have to do it a lot for other conditions as well....Am I going to get a report saying definitely yes, definitely no, or can’t say. The can’t says are probably a large portion of our test results in genetics. So I think we possibly have more experience in dealing with that than other specialties.”

Dr. G, Geneticist

The risk counsellors and surgeons did not refer to the same reference point when describing the way they normalize uncertainty. Those practitioners who counselled the women in the Cancer Genetics Risk Clinic tended to focus on the uncertainty found in other aspects of clinical genetic medicine, while the breast and gynaecological surgeons focused on uncertainty related to the surgical outcome in terms of the women's reaction to the finality and aesthetics of the surgery or hormonal changes which were not limited to prophylactic breast removal or oophorectomy.

Transference of Ownership of Uncertainty

The health care professionals reflected the need expressed by women from HBOC families to obtain information about their cancer risks. They all said that it was their job to inform and educate their patients as to options, risks, and uncertainties and to ensure that they understood the difficult material whether it had to do with genetic risk or outcome of medical intervention. They reported spending much of their counselling sessions on education, but when it came to making a decision, the various health care professionals seldom tried to influence the women's decision overtly even if they felt uneasy about it and remained unsure whether their patients fully understood the meaning and implications of an inconclusive *BRCA1/2* genetic test result.

....it's difficult, I mean, genetic counsellors are trained to be nondirective, and we are nondirective because we understand that people have to make decisions for themselves.... I tend to have an uncomfortable feeling about people who are definitely at a high risk of ovarian cancer who...don't want to have their ovaries removed....

Ms. I Genetic Counsellor

"... I think as geneticists we can say, you know, these are the percentages, we don't know... and it's your decision in the end, so I think in some ways we're not taking such a responsibility. I'm sure that surgeons must feel more uneasy than the geneticists."

Dr. D, Oncologist

In this study, all the health care professionals reported struggling with the difficult problem of how to convey uncertainty without undermining hope. It is likely that the lack of comprehensive answers allowed the health care professionals to be more comfortable with an "It's your decision in the end" position. One geneticist, reflecting the position of others, said he saw himself as part of the, evolving and exciting, new field of genetic medicine, but practicing at a point in time when scientists had not yet been able to provide answers that they and their patients needed.

SUMMARY

Our interview data revealed themes that clarified how the health care professionals dealt with the uncertainty that was intrinsic to the information that they gave to their patients. We found a clustering of patterns that we call "Ownership of Uncertainty" -- sole, shared, diffused, normalized and transferred.

The health care professionals who leaned toward a "sole ownership of uncertainty" position referred to their experience with bad clinical outcomes when their patient refused to take their professional advice. Those who believed in the shared ownership position focused on informing and educating their patients. Those who diffused ownership of uncertainty were adherents of the team approach between surgical expertise and risk estimation expertise. Some also tried to normalize the high degree of uncertainty in their work with women from

HBOC families with inconclusive *BRCA1/2* genetic test results. They said that the uncertainty they faced, compared with other areas of genetic medicine, was only a matter of degree not of kind. This probably made them feel part of the larger clinical genetics field, rather than feeling isolated in an extreme area of uncertainty.

DISCUSSION

Based on the findings in this study, we propose use of a novel concept that we call “Ownership of Uncertainty” to advance the understanding of how health care professionals counsel and care for women who receive an inconclusive *BRCA1/2* genetic test result. This concept fits several of the conditions descriptive of a core category, or theory, as described by Glaser (1998): it suits the situation (inconclusive genetic test results), helps individuals make sense of their situation (health care professionals concern about informing patients about the meaning of inconclusive results and their own concerns about the uncertainty involved) and links different aspects of the situations (Ownership of Uncertainty and the five subcategories: sole ownership, shared ownership, diffused ownership, normalisation of uncertainty and transfer of uncertainty).

While this qualitative study cannot be generalized, it does shed light on how a segment of professionals in the genetics community counsel and care for patients from HBOC families. There is a serious need to take this information into account because the future may alter if testing becomes available for common low penetrance genes that may refine risk for unaffected women (Weber, 2000; Campeau, Foulkes, Tischkowitz, 2008). Despite these recent advances, most of the familial risk of breast/ovarian cancers has yet to be explained (Turnbull, Rahman, 2008). Furthermore, these advances will bring with them additional uncertainties.

The social context in which genetic medicine is practiced today has drastically changed. These social changes together with technological advances affect how patients evaluate risk (Beck-Gersheim, 2000). It is characterized by interaction between increasingly sophisticated diagnostic tools, development of new medical management techniques, rapid advances in genome wide association studies (GWAS) and new social norms.

In the mid 20th century when the norm for physicians was paternalism, (Elwyn et al.2000), there were far fewer bio-technological advances, the Human Genome Project was a futuristic idea, *BRCA1/2* genetic testing for women at increased risk for breast/ovarian cancer did not exist so health care professionals did not have to face the number and kind of uncertainties present in a genetic risk clinic today. Furthermore, at that time, rigorous enforcement of women’s rights and bioethical standards had not yet been achieved. Tomes (2007) asserts that is impossible to return to the model of paternalism. Instead she advocates the improvement of collaboration between patient and physician that has been developing for the past two decades.

Patients now use alternate sources of information ranging from experiences of friends, relatives and the internet about their future risks of developing breast/ovarian cancer and their choices of medical management options (Kenen et al.2007). While the health care professional is still considered to be an important resource by most of the women from HBOC families, they often expect more certainty than the health professionals are able to provide. Several of the professionals blamed the media’s black and white presentation of genetic testing for the women’s erroneous expectations (Petersen, 2001; Bubela and Caulfield, 2004). They needed to explain to the women that despite the enormous advances in the field, there was still a gap between scientific, technical possibilities and their clinical

meaning. This comprised complicated information that the health care professionals were not always sure that the women completely understood.

Some research has reported that women deciding on *BRCA1/2* testing frequently wanted to know the opinions of their primary care, as well as their cancer genetics care doctors regarding their options (Armstrong, et al. 2002). The researchers found that over three quarters of women who went for *BRCA1/2* genetic testing wanted to know the opinion of their cancer genetics doctors and more than half wanted to know their primary care doctors' opinions as to what they should do. In our conceptual terms, these women seemed to want to "share the ownership of uncertainty" with their health care professionals by factoring into their own decision-making how the practitioners viewed the uncertainty. We can interpret this in two ways; one, that the women wanted to incorporate this information into their repertoire of knowledge and preferred to make a completely autonomous decision, in effect having their health care professionals transfer ownership of uncertainty to them. In other words, the women wanted to share information, but not responsibility. Secondly, the women wanted this information as part of a shared ownership of uncertainty with their health care professionals contributing both information and responsibility. Both these interpretations indicate that women do not want to return to the paternalistic model. However, sharing uncertainties about the outcome of medical processes between health care professional and patient can result in an increase in anxiety for both partners (Elwyn, et al. 2000).

Our data also showed that within our sample, most of the health care professionals did not want to revert to a paternalistic model. A decade ago Angela Coulter, writing in the British Medical Journal, claimed that paternalism on the part of the health professional led to "an unhealthy dependency which is out of step with other currents in society" (1999, p. 719). She further asserted that successful partnerships between patients and health care professionals should not be hierarchical and that the professionals need to value the patients' expertise which is of a different type but equally important. A non hierarchical perspective regarding women's knowledge acknowledges their autonomy, and autonomy holds contemporary dominance over other western principles of medical ethics (J. et al. 2000). Autonomy can lead to a desire for empowerment. McAllister et al. (2008) have developed a model of empowerment that evaluates patient benefits from utilizing genetic services. Perceived benefits, however, may not include possible latent negative consequences associated with increased knowledge and use of the latest technological options in the field of clinical genetics.

Currently, the high degree of uncertainty endemic in cutting edge hereditary breast/ovarian cancer genetics combined with changes in the way society views human rights in general, might be one reason why few health care professionals in this study chose a sole ownership of uncertainty model as their practice modality and tended to use the shared or transference of uncertainty models instead.

In 2000, Beck-Gersheim wrote presciently that genome analysis will lead to a redefinition of both health and responsibility. Health will be viewed as an end product, or just the promise of health will become a deeply held value, even when experts in the field debate both efficacy and ethics. Thus, both health care professionals and patients are likely to adhere to new social norms regarding a technological model of preventive health care despite the amount of uncertainty involved. The health care professionals stress new genetic screening and testing options and new surgical and biochemical methods of purported risk reduction. Women want to have this knowledge, yet paradoxically a large number of choices may reduce a woman's control of her future well being, if the uncertainties and unknown risks of some of them are too high.

In concert with technologically driven changes in health care, the concept of responsibility has become an increasingly important value in the modern era. For example, genetic testing is voluntary, but there may be subtle pressure to have a test. Irresponsibility and blame may be attached to naysayers. For many physicians and women, use of modern genetic technology with all its downsides seems to provide a better handle on uncertainty and reduction of risk as well as reducing self blame and feelings of irresponsibility (Beck-Gernsheim, 2000). “Anticipated regret”, the result of not taking advantage of the latest genetic tests and clinical advances is a potent driver of possible unwarranted or overuse of cutting edge technology. This regret is sometimes fuelled by social pressure (Aronowitz, 2007; 2009). This social pressure probably reflects some of the “other currents in society” that Coulter mentioned but did not specify (1999).

The health care professionals daily traversed a minefield of uncertainty intrinsic to their practice. At times, they seemed caught between two creeds of sound and ethical medical practice – beneficence (doing good) and avoiding maleficence (doing no harm). The providers expressed hope that their dilemmas would be solved with better solutions in the relatively near future. They just did not know when, and however frustrating they currently found translating uncertainty laden information into effective risk communication, they expressed the belief that there was “light at the end of the tunnel” in providing comprehensive answers. They, however, did not appear to adhere to Becks’ (1992) assertion that in a risk society the growing complexity of modern knowledge systematically produces “non-knowledge” which allows risks and dangers to develop, and that this exists at every higher level of new knowledge. Practicing clinical genetics during an era dominated by a plethora of new genetic discoveries is a daunting endeavour, whether the perspective of the health care professional emphasises the advances in medical understanding and treatment or the uncertainties that are endemic in a risk oriented society.

LIMITATIONS

The study was conducted at only one major cancer centre in the UK that has a National Health Care System. The health care professionals at this site may not be typical of those working with women from HBOC families in general UK hospitals or in hospitals located in another country with privatized health care. The patients coming to this institution tended to be white, educated and knowledgeable. Other sites are likely to have more varied patient populations that might influence the health care professionals approach regarding decision-making.

Future Research

This paper highlights the uncertainties expressed by the physicians, surgeons and nurse genetic counsellors in our study. Two broad questions particularly require further research:

1. How do health care professionals resolve the tension between their understanding that advances in technology bring new uncertainties with their desire to reduce uncertainty by finding answers for themselves and their patients in a clinical setting?
2. How do cultural differences of both health care professionals and patients influence the usefulness of the five subcategories of the Ownership of Uncertainty (sole, shared, diffused, normalised and transferred) in communicating inconclusive genetic information to members of ethnic groups holding varying perspectives toward privacy?

The dearth of knowledge in this area would make an inductive qualitative approach appropriate. After qualitative analyses have been completed, it would be useful to carry out

cross cultural surveys in order to determine the robustness and generalisability of these findings and whether they are specified by demographic variables e.g., age, gender, ethnicity of health care provider and patient clientele, type of professional education related to genetic risk and social and institutional context.

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