

# Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information

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Using data obtained during a retrospective interview study of 30 women who had undergone genetic testing—*BRCA1/2* mutation searching—this paper describes how women, previously diagnosed with breast/ovarian cancer, perceive their role in generating genetic information about themselves and their families. It observes that when describing their motivations for undergoing DNA testing and their experiences of disclosing genetic information within the family these women provide care based ethical justifications for their actions. Finally, it argues that generating genetic information and disclosing this information to kin raise different types of ethical issues. The implications of these findings for ethical debates about informed choice in the context of genetic testing are discussed.

Many commentators have noted that, in contrast to other types of medical information, which pertain primarily to individuals, the information derived from molecular genetic testing and/or pedigree analysis (hereafter referred to as genetic information) necessarily has implications for biologically related kin.<sup>1–3</sup> It is generally accepted that the familial nature of genetic information distinguishes it from other types of medical information. As many authors have noted, this observation raises questions about the adequacy of current informed consent procedures in the context of genetic testing and the legitimacy of the disclosure/non disclosure of genetic information to biological kin.<sup>1–4</sup>

## THE FAMILIAL NATURE OF GENETIC INFORMATION: IMPLICATIONS FOR INFORMED CONSENT

The model of informed consent used within clinical medicine is based upon the principle of respect for autonomy.<sup>5</sup> Informed consent procedures exist to protect the individual's right to self determination; more specifically, their right to make autonomous decisions about their health care—to voluntarily accept or refuse treatment and to be informed of the risks they may incur through medical procedures.

It has been noted that "... in recent years the primary justification advanced for requirements of informed consent has been the protection of autonomous choice ..."<sup>6</sup> For many clinical purposes this model of consent is perceived as acceptable, or at least workable, in practice. When it comes to genetic testing, however, basing consent upon a model of autonomous decision making can be seen as a little more problematic,<sup>1,2</sup> for it ignores the fact that the results of genetic tests have implications not only for the patient, but also for their biological kin. The extent to which the familial nature of genetic information creates an ethical problem for our current conceptions of informed consent is explored below.

Using data collected in a study of women who have undergone *BRCA1/2* mutation searching, this paper demonstrates that, when accounting for their role in the testing process and disclosing genetic information within the family, women draw upon discourses of self determination and responsibility. It observes that, while these women view their role in generating

genetic information for their relatives as less ethically contentious than disclosing this information to their kin, their accounts raise important questions about the adequacy of current conceptions of autonomous choice within the context of genetic testing. It argues that if we are to develop a rigorous ethical justification for informed choice in this context, then we need to acknowledge that the individuals who consent to this procedure conceive of themselves as selves in relation. As such, they regard themselves as under an obligation to undergo genetic testing to provide information which will advance other family members' autonomy, often at the expense of their own.

## HEREDITARY BREAST AND OVARIAN CANCER (HBOC) AND THE ORGANISATION OF *BRCA1/2* MUTATION TESTING IN THE UK

Between 5 and 10% of cases of breast/ovarian cancer are inherited, approximately 50% of these are caused by a mutation in one of two genes, *BRCA1* and *2*.<sup>7,8</sup> Mutation carriers have increased risks of developing these cancers, which may be as high as 80–85% in the case of breast cancer and 30–60% in the case of ovarian cancer.<sup>9,10</sup> The medical management of high risk women includes chemoprevention, breast/ovarian screening, lifestyle modification, or prophylactic breast/ovarian surgery.<sup>11,12</sup>

At the present time predictive genetic testing for HBOC is generally only available to at risk men<sup>13</sup> and women in the United Kingdom once it has been established that a *BRCA1/2* mutation is present within the family. At risk family members' access to predictive testing is usually dependent, therefore, on relatives who have already had breast/ovarian cancer undergoing mutation searching, because it is only after it is confirmed that an affected relative carries a *BRCA1/2* mutation, that predictive testing for family specific mutations can be offered to at risk relatives. Thus, individuals who have previously been diagnosed with cancer assume a pivotal role in generating genetic information for their biological kin. They can be seen as providing a gateway to genetic testing for others, for without their consent to this procedure, their relatives are prevented from establishing their carrier status. Furthermore, because the law of confidentiality in the UK effectively

prohibits clinicians from disclosing genetic test results to other interested parties, including other family members, the index case initially bears the responsibility for informing their relatives about the result.<sup>14–17</sup> Thus, for technological and legal reasons, affected women (and men) are positioned as responsible for both generating genetic information and disclosing it to their kin. The aim of the present study was to determine women's understanding of the ethical issues generated by mutation searching, so as to gain insight into their information and support needs.

Finally, it must be noted that affected individuals who are identified as mutation carriers have an increased risk of developing a second primary cancer.<sup>18</sup> Thus, affected women and men, like their at risk relatives, may need to make decisions about prophylactic surgery or surveillance, following confirmation of their carrier status.

## METHODS<sup>19</sup>

This study involved in depth interviews with 30 women who had previously been diagnosed with breast/ovarian cancer and subsequently undergone *BRCA1/2* mutation searching. Ten women had been identified as *BRCA1/2* mutation carriers (carrier group), 12 had not been found to carry a known *BRCA1/2* mutation, (inconclusive group), and eight were awaiting DNA test results (waiting group).

### Recruitment

Participants were recruited by a genetics nurse specialist when they attended the cancer genetics clinic or by letter from the consultant in charge. The project was carried out according to the principles of grounded theory research and thus, recruitment ceased once theoretical saturation was reached in the data set.<sup>20</sup>

### Sample characteristics

The median age of the sample at the time of interview was 54 years (range 39–71 years). Twenty seven women had previously been treated for breast cancer, two for ovarian cancer and one for an unspecified gynaecological cancer. Time since the most recent diagnosis of cancer ranged between six months and 31 years (median five years). Twenty three women had children. Twelve women were educated until the age of sixteen, six until they were eighteen years, four had further education or professional qualifications and ten had a graduate or postgraduate degree. Three women had worked in a medically related occupation at some time in their lives.

### Family history of cancer

Eighteen women had a maternal family history of breast and/or ovarian cancer, seven a paternal family history and in five cases it was not clear whether the (putative) mutation had been inherited via the paternal or maternal line. A total of 119 relatives were reported as affected with cancer (range 1–10, median four per family). Twenty six women had at least one first degree relative affected with either breast/ovarian/endometrial/prostate cancer.

### Data collection and analysis

In depth interviews (between one and two and a half hours) were carried out at a location of the participant's choice between November 2000 and June 2001. The interviews explored the following themes: diagnosis and treatment of cancer; family support during illness and testing; experience of DNA testing; decision making about testing; communication of results within the family, and the impact of genetic testing on their lives. All interviews were tape recorded with consent and transcribed. The transcripts were coded using the method of constant comparison.<sup>21</sup> The data were initially indexed on a case by case basis, which allowed patterns and

relationships between the codes to emerge within the data set, leading to the development of second order categories. Between interview comparisons were drawn and deviant cases were taken into consideration. The analysis revealed that there were no differences in the women's responses when stratified by either disease or prognosis. Any differences that were observed in the responses of women receiving different types of test results are discussed below.

## FINDINGS

When describing their experiences of mutation searching these women drew upon two potentially competing ethical discourses: one in which selves are seen as relational entities that exist within a network of relationships that carry with them obligations of care and another in which selves are seen as autonomous individuals—self governing agents. The women drew on these discourses in different ways when describing their role in generating and disclosing genetic information. Indeed, the following analysis suggests that these women experienced their role in generating and disclosing genetic information very differently.

### Generating genetic information for others

Most of the women in this study did not see mutation searching as having any direct health benefits for themselves, in terms of providing them with access to medical services. They were either already engaged in annual surveillance, or had previously undergone therapeutic/preventive surgery on their breasts and/or ovaries, or had decided to forgo preventive surgery for the present. That does not mean, however, that they failed to derive any personal benefits from mutation searching, for their accounts revealed that this was clearly not the case.

Carol<sup>22</sup>: "It [testing] made me feel as though, because I have had the experience (breast cancer), I am helping and perhaps saving a life. But that is important to me because if any of my sisters' girls had, or is about to have, breast cancer and they were not aware and didn't do anything to test themselves and didn't know anything about it, it would have been a waste, a complete waste of all I have gone through, at least I am doing something with it now which is helpful." (Carrier)

These women constructed mutation searching as primarily affording them the opportunity to help their relatives: their children, siblings, grandchildren, and other family members.

Interviewer: "You said that one of the reasons was . . . to find out information for your daughters, were there any other reasons that you decided to proceed with testing?"

Oona: "Oh no, really just to help my daughters and any further family. I mean to me it's immaterial now I know that I have got breast cancer, or had breast cancer." (Waiting)

Like the participants in a recent study of *BRCA1/2* predictive testing,<sup>23</sup> all the women in this study said they had undergone testing to obtain genetic information for others, indeed, for 90% of the sample this was reported as being the most important, or the only, reason for undergoing this procedure. Mutation searching was thus perceived as enabling one to demonstrably care for others—to act as a moral agent and fulfil one's obligations to care for other family members.

Jane: “. . . I asked if it was possible my sister might be at risk, because my cousin had died from cancer at the age of 38 [unclear]. So I was worried about my sister, because she’s not as strong willed as myself, and if I could prevent her going through the same kind of treatment, then I’d do anything for her, to help her, basically. So that’s how I got on to the genetic testing part of it.” (Inconclusive)

In constructing their role as generator of genetic information as acting responsibly, these women can be seen as drawing upon a care based ethic.<sup>24-26</sup> In justifying why their obligations of care were satisfied by generating this information, these women drew upon discourses that construct genetic information as empowering because it provides individuals with choices.<sup>27</sup> Accordingly, these women stressed that their relatives should have access to information that could affect their future health.

Verity: “Well, I think in lots of ways it’s nice to know because almost forewarned is forearmed isn’t it, at least now, um . . . the girls will be well watched . . . if they have any problems they’ll be given priority because this is known, if they have the gene”. (Carrier)

As far as these women were concerned, to be in receipt of genetic information which confirms one’s risk or carrier status is to be forewarned, and to be forewarned presents individuals with choices, most importantly, with the possibility of forarming oneself against disease. Thus, in addition to alleviating their relatives’ anxiety about their potential risks, the participants were concerned to provide their relatives with information that was deemed necessary for them to make informed risk management decisions.

Cherie: “I thought, oh, well, that [testing] would be good, because I’ll know whether I’ve got it or not, which then means that I will know whether my daughter has got it or not, and my nieces wouldn’t have this big axe hanging over their head—because that’s how you sort of view it really. That’s how I view it, more for them rather than how I viewed it for myself . . . We’d hoped they could find this gene, and then it could take the worry off their shoulders.” (Inconclusive)

Therefore, these women saw their role in generating genetic information for their relatives as not only a responsible thing to do, but also as the right thing to do.

Angela: “I’ve got two nieces and obviously I felt a responsibility to, towards them and to their parents. So I thought for them also it would be useful and that I should do my bit really.” (Waiting)

Thus, generating genetic information about themselves, and, as a consequence, producing information for other family members, enabled these women to act, or to be seen as acting, as a moral agent, as caring for their relatives.

In justifying their participation in mutation searching these women frequently cited the need to preserve others’ autonomy, often at the expense of their own, and as such, presented themselves as altruistic testers par excellence. This observation raises questions about the nature of their consent in this instance. As was noted above, the information gained from genetic testing pertains to families, groups of people who stand in both biological and social relationships with each other. This study suggests that those who undergo *BRCA1/2*

mutation searching are not only aware of other family members’ interests in the information derived from this procedure, but primarily undergo genetic testing with these interests in mind. As far as most of the women in this study were concerned, mutation searching was not egocentrically motivated, it was not about self determination, in the accepted sense, but was an altruistic act. Ultimately, they saw themselves as acting for the benefit of others; they were consenting to testing on the behalf of their kin. Thus, whilst all voluntarily agreed to undergo mutation searching one can question the limit of their autonomy. Although there was no evidence that testing was explicitly coerced by medical staff, or in most cases other family members, arguably their choices were implicitly constrained by their obligations to care for, or help, their kin. The women who took part in this study were acting as selves in relation, not as autonomous agents as such. As selves in relation they perceived themselves as having an obligation to other family members to undergo mutation searching so that they could provide their kin with the genetic information they needed to make informed decisions about their risk management. Thus, as far as most women were concerned, they did not make an explicit decision concerning whether they underwent mutation searching, because, in a fundamental sense, they felt they had no real choice. While, in theory, these women could have refused to undergo this procedure, thus, preserving their right not to know<sup>28</sup> their genetic status,<sup>4, 29</sup> in practice, they perceived their actions as constrained by their need to care for other family members. These observations lead us to question the adequacy of the concept of autonomous choice in the context of genetic testing.

#### Disclosing genetic information to others

While, however, these women did not necessarily see their role in generating information for others as ethically problematic, the disclosure of genetic information to others was described as raising unforeseen moral dilemmas,<sup>20, 30, 31</sup> particularly by those identified as mutation carriers. Although all the women conceived of themselves as having a moral obligation to inform their family members<sup>32</sup> of their carrier status, for after all this is why they had undergone genetic testing in the first place, many regarded the disclosure of genetic information to their relatives as (potentially) difficult or ethically burdensome. First, many women indicated that they had not really reflected on which members of their family they might need to tell if, and when, they received a result. While they were all prepared to disclose information to sisters and offspring, many had not considered that they might need to inform their brothers or other members of their family of origin, and commented that that had been, or would be, difficult.

Verity: “I didn’t think backwards I only thought forwards. I only thought about my offspring and their offspring. I really didn’t consider my brother or, no I didn’t . . . I didn’t give any thought to that really until I spoke to Dr X and they started explaining . . . and then suddenly I thought ‘oh crumbs’. That’s why I say it’s like throwing a stone into a pond and the circles start coming out.” (Carrier)

Second, some women said they were uncertain about how or when they should disclose information to their kin—for example, Isobel, who had been confirmed as a mutation carrier two years previously, talked about her feelings about informing her lateral kin, a task she had not yet undertaken. She said she felt “ a great burden,” when her doctor had told her that she would have to tell her cousins about their risk.

Third, many women acknowledged that disclosing genetic information to their family potentially conflicted with their obligation to care for their relatives, because the disclosure of this information could result in increasing their relatives' anxiety about developing cancer.

Natalie: "Well I think the important thing is how you deal with imparting it to the relatives and um as I say I don't really remember how I dealt with my daughters, it was very tricky. And especially when they are young you don't want to burden them with information, but then they have a right to know I think." (Carrier)

Consequently, some women no longer constructed themselves as the providers of information, which would necessarily foster others' autonomy, but reconstructed themselves as the bearers of "bad news".

Mary: "Other members of the family I haven't done anything with, because how do you approach them? Because [to] my mother, her sisters, and brothers "cancer" is a death word . . . the ones who are further away I haven't approached. One, because I don't see them very often. Two, how do I do it? This is the dilemma. Do you ring people up, write to the people, go and see them and say 'look there is this chance'? I think if it was me, I would want to know . . . because then you can do bits and pieces. But if you are the bearer of this news, I think you are torn. You don't know what to do for the best." (Inconclusive)

Thus, depending upon the test outcome, many of these women perceived themselves as potentially forced into a situation in which they would be responsible for causing others harm. In this sense, having genetic information to impart to their relatives generated an ethical dilemma for these women.

In articulating the ways in which they approached and negotiated this dilemma, many women questioned their previously stated assumptions about the status of genetic information. From being empowering in and of itself, they considered whether having access to genetic information was universally good. Thus, many questioned whether having genetic information about oneself necessarily promoted autonomy at all times and in all circumstances. Some women commented that it was more difficult to receive this type of information at particular points in the life course—for example, when young or already incapacitated by illness. Others described having access to genetic information about the family and oneself as potentially harmful, because it reminded one of the risks of cancer occurring in others or recurring in oneself, and they acknowledged that this was not necessarily a good thing.

Beth: ". . . you might be lucky and you haven't got it [a mutation] and you are free, but if you are unlucky you are sort of doomed to a life of check ups going on and on and on, and always worried that it's going to come out at any moment or the next year or the year after, and [thinking] would I have to plan for the future because you may not have one, and all this." (Carrier)

Many women also commented that giving their relatives genetic information meant that their kin would then have to make difficult risk management decisions—for example, decisions about prophylactic oophorectomy or mastectomy; decisions that could be avoided or postponed whilst uncertainty about their carrier status remained.

Interviewer: "Will your sister have testing if they find the mutation?"

Sally: "Yes, yes everybody will. And then that's when it becomes difficult I think, when it will become a big issue." (lvr: "Why?") "Because then people will have to make decisions as to what they are going to do about it." (Waiting)

Thus, when considering the implications of receiving genetic information about oneself, many women questioned whether, in some circumstances and for some individuals, ignorance may, indeed, be bliss.

Caroline: ". . . There must be quite a lot of people who are terrified of the whole topic [testing]. And to have to go further into it with no knowledge of whether you are doing a good thing, or it may be bad, you know people don't want to know that they have a gene or genes." (lvr: ". . . Why do you think that some people might not want to know that?") Well, a lot of people prefer to be ignorant about all sorts of things don't they? I mean if you know that there is something unpleasant in your, either you make up or in what's going to happen, it affects your whole personality and how you are going to behave." (Waiting)

#### Balancing responsibility and autonomy

These women are faced with an ethical dilemma. On the one hand, they do not wish to harm others by giving them genetic information which may negatively affect their lives, while on the other, they regard others as having a right to information which may facilitate their health management decisions. In an effort to uphold their obligations of care and yet preserve others' autonomy, these women adopted different rhetorical and behavioural strategies.

First, they invested in discourses of hope; namely, the view that we as a society are currently on the brink of a technological breakthrough in the treatment or prevention of cancer.

Isobel: "The odds are that even if, that even if the girls develop perhaps the cancer, by the time that they do, there may be means of zapping it before it starts being a problem or screening so precisely that you know the rogue cell will be sorted. I mean it's just moving towards all these things all the time." (Carrier)

Arguably, drawing upon discourses of scientific progress enabled them to justify transmitting what they regarded as potentially "bad news" to younger relatives. Second, many described how they waited until an appropriate time to tell their relatives, namely, a time when they perceived the news would cause them less anxiety or distress—for example, following the birth of a child rather than during a pregnancy. Third, they delegated the responsibility of disclosure to others, either unconnected third parties, such as solicitors, who held the information for family members to access at their convenience, or female married in kin, for example, daughters/sisters in law.

Other women, particularly those who were either awaiting a test result or had received an inconclusive result, reported that they had intentionally avoided causing their relatives worry by not telling them they had undergone mutation searching. These women reasoned that as they had no conclusive results at present, they did not feel a need to inform their kin. Indeed, some were of the opinion that telling their relatives that they had undergone genetic testing, prior to receiving a conclusive result, would cause them needless

worry about cancer risks; risks, which may, or may not, exist. Others, who had received inconclusive results, had informed their relatives about their involvement in mutation searching from the outset, because they felt they had an obligation to inform their relatives of the possibility of surveillance. They said they had experienced no problems in disclosing this information to their kin, as Cheryl put it: “no news is good news until it is bad”.

In summary, this study indicates that some individuals who undergo genetic testing experience the disclosure of test results to other family members as ethically contentious. Whilst, however, ethicolegal debates<sup>1 2 4 15</sup> frequently present the disclosure of genetic information within the family as a coerced choice—to tell or not to tell—in practice, there appears to be no such clear cut distinction. The data presented above suggest that the ethical dilemma faced by women in the present study was not whether they should disclose genetic information to their relatives—indeed, all the women felt that all implicated family members should receive this information—but how they should effect this in practice. Thus, while all the women intended to disclose the information they received from testing to relevant parties, they frequently expressed uncertainty about who they should disclose information to, how they should disclose it, and when disclosure should occur.<sup>26 31</sup> Thus, as far as these women were concerned, disclosure itself was not perceived as ethically contentious, but rather the practice of disclosing genetic information to particular individuals was experienced as generating particular moral dilemmas; dilemmas they had not considered prior to testing. Such observations raise questions about the type of information these women had received, or understood, prior to consenting to testing, and thus, the degree to which their consent was in fact “informed”.

## CONCLUSIONS

To summarise, when describing their experiences of mutation searching the women who took part in this study described their actions as motivated by their obligations to care for their relatives. At one and the same time, they saw themselves as having the responsibility of providing their kin with genetic information that would foster autonomous decision making about their health risk management and as having a responsibility to protect their relatives from the harms that this information might cause.<sup>32</sup> In an effort to uphold their obligations of care and yet preserve others’ autonomy, these women adopted different strategies. They invested in discourses of hope, they delegated the responsibility for disclosure to others or they postponed informing their kin about their risk status until either their relatives’ personal circumstances had changed or they had more conclusive information to give. By acting in this way these women constructed themselves as moral agents, as doing the right thing, even when, by their own admission, the right thing was not always easy to discern.

This study suggests that generating genetic information to give to others, and disclosing this information to others, raise different types of ethical issues. In this final section of the paper we briefly look at the implications of these empirical findings for ongoing ethical debates and clinical practice.

It was argued above that this study raises questions about the suitability of conceptualising consent in the context of genetic testing as involving autonomous and informed choices. Although we are not claiming that we can reach conclusions about what consent to genetic testing should be on the basis of these observations, these data suggest that the current model, which is based upon a conception of autonomous decision making, may be inadequate.

First, it necessary to distinguish between two ways in which the term “choice” is used in discussions of consent. In the first, “choice” is used to refer to the act of “choosing” between two or more options—that is, the exercise of choice, whilst in the

second, it is frequently used to mean the “options” that are available. Whilst these uses can be seen as distinct they are interdependent, in so far as the act of choosing presupposes the existence of viable choices. As far as the women in this study were concerned, the choices that were on offer: (a) undergoing testing to generate information that may increase family members’ health care options or (b) refusing testing and, as a consequence, limiting others’ options, were not morally neutral. Thus, while all voluntarily consented to mutation searching—that is, technically *chose* to undergo testing, many felt that, given their obligations to their kin, their actions were constrained by a lack of viable choices, and therefore, the act of choosing in this context can be seen as more chimerical than real.<sup>33</sup> This observation raises more general questions about the nature of consent in the context of genetic testing.

It has been argued that the freedom to choose medical treatment is not absolute, but subject to many different types of constraints, and thus, the best we can hope for is that treatment decisions are “substantially autonomous”—that is, that there is at least a “substantial degree” of freedom of choice or independence of decision making.<sup>34</sup> As Beauchamp and Childress note,<sup>35</sup> it is impossible to generalise about the amount of freedom of choice needed for a decision to be regarded as “substantially autonomous”, thus, autonomous choice can only be defined according to context specific criteria. While we agree that a fully autonomous choice is a theoretical ideal, we question whether “substantial autonomy” is achievable when consenting to genetic testing. Arguably, the familial nature of genetic information compromises the possibility of making an autonomous decision about genetic testing on two counts. First, an individual’s DNA test results have direct implications for biologically related kin and second, the persons who undergo testing have social obligations towards these kin. For these reasons we would argue that the decision to undergo testing cannot be entirely egocentric, but may be influenced not only by one’s awareness of others’ interests in obtaining genetic information, but also by one’s own interests in maintaining relationships with these interested parties.

Thus, whilst the current practice of obtaining informed consent from individual patients satisfies legal requirements, thereby allowing clinicians to circumvent an array of legal actions, it can be argued that it fails to acknowledge that those persons who undergo testing are relational entities in both the biological and the social sense. The findings presented above suggest that we need to ground consent upon an ethic that takes into account the social nature of human beings. Such an ethic would acknowledge that human beings are social beings whose actions and choices are constrained by virtue of the fact that they exist within a network of relationships. Human genetics is about relationships—biological and social relationships—and it can be argued that any rigorous ethical justification of informed consent to genetic testing needs to take this into account.

The finding that some women experienced the disclosure of genetic information as generating unforeseen ethical dilemmas suggests there was a lack of awareness of the familial implications of accessing this information in some instances. Thus, on a more practical level, this research suggests that if consent to genetic testing is to be seen as “informed”, then those persons who undergo genetic testing need to be made aware of the extent of their role in disseminating this information within their family. First, they need to understand that they will bear the initial responsibility for disclosing this information to their kin. Second, they need more information about which members of their kinship may be at risk of carrying a mutation. Third, they need advice about how and when to go about informing family members about the possibility that they may carry a genetic mutation. Finally, there may be individuals who refuse to disclose genetic information to other family members. Given the legal guidelines on patient confidentiality and the non directive nature of genetic

consultations, such instances raise ethical problems for practitioners. While explicitly encouraging disclosure to implicated family members would compromise the non-directive nature of genetic consultations, providing advice and information about the implications and (potential) problems of living with a test result that they do not, or cannot, share with their relatives can be seen as legitimate.

Finally, if we are to talk of informed decision making in the context of genetic testing for *BRCA1* and *2* we not only need to ensure that clinicians provide information about the implications of mutation searching, but also that those who seek testing are given time to reflect upon their actions. At the present time, predictive *BRCA1/2* testing protocols in the UK incorporate a “cool off” period allowing women (and men) to consider the implications of testing, for themselves, and their family before proceeding. Arguably, the introduction of a similar period for reflection prior to mutation searching can be seen as warranted.

In conclusion, this study suggests that generating and disclosing genetic information raise different types of ethical issues. Although the women who took part in this study may not have perceived their role in generating genetic information as particularly ethically contentious, their accounts suggest that whilst the decision to undergo genetic testing was not perceived as ethically problematic, it was not a morally neutral choice. If we are to develop a rigorous ethical justification for informed consent to genetic testing, we need to take into account not only individuals’ information needs, but also the relational constraints on their actions. We need to acknowledge that those who consent to genetic testing may be less interested in furthering their own autonomy, than in enabling others to make autonomous decisions.<sup>36</sup>

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- See reference 5: 123.
- See reference 5: 124.
- It must be borne in mind that this study only included women who had undergone DNA testing, whether those who decline testing perceive their choices as constrained is an empirical question.