What Women Want: Communication and information needs of women diagnosed with ovarian cancer regarding treatment-focused genetic testing

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Short title: Treatment-focused genetic testing in ovarian cancer

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ABSTRACT

Purpose: The objective of this study was to identify women’s information and communication preferences about treatment-focused genetic testing (TFGT) in the ovarian cancer context.

Approach: A qualitative interview study.

Setting: Two familial cancer services, and a gynecological oncology clinic in a major teaching hospital, in Australia.

Participants: Twenty two women diagnosed with ovarian cancer who had either (i) advanced disease and had previously undergone TFGT ($n=12$), or (ii) had been diagnosed recently with ovarian cancer and had not undergone TFGT ($n=10$).

Methodologic Approach: Participants were interviewed individually about actual and hypothetical views of TFGT. The interviews were transcribed and organised into themes using NVivo8 qualitative analysis software.

Findings: Most women wanted to be informed about TFGT prior to their surgery for ovarian cancer. The majority preferred to receive the information verbally; slightly more women preferred their medical oncologist to deliver the information, compared to a genetics specialist or oncology nurse. Women preferred the focus of pre-test information to be on them and their treatment.

Conclusions: Women diagnosed with ovarian cancer want information about genetic testing early with the focus on the potential benefits of genetic testing for their treatment plan.

Implications for Nursing: The findings of this study provide much needed guidance to oncology nurses and other oncology health professionals about when, what and how information about TFGT should be delivered to patients diagnosed with ovarian cancer. Supportive patient education materials now need to be developed to assist these women to make informed decisions about genetic testing.
Keywords: Ovarian cancer, BRCA1, BRCA2, genetic testing, treatment
INTRODUCTION

For women with an ovarian cancer diagnosis, genetic testing for mutations in *BRCA1* and *BRCA2* has traditionally been limited to those with a significant family history, after completion of surgery and adjuvant therapy. Arguably, the greatest benefit of this process has been for unaffected family members, particularly with regard to breast cancer screening and prevention, and bilateral risk-reducing salpingo-oophorectomy (RRSO), which has been shown to reduce the risk of ovarian cancer by approximately 95% (Kauff et al., 2002; Rebbeck et al., 2002). There is, however, growing evidence to support a change in current practice, by determining a woman’s mutation status at the time of her ovarian cancer diagnosis, in order to inform her treatment plan. Hereafter, genetic testing offered shortly after diagnosis while a woman’s treatment plan is being considered is referred to as ‘treatment-focused genetic testing’ (TFGT).

Support for TFGT stems from preliminary findings that the presence of a germline *BRCA* mutation defines a genotypic subgroup of epithelial ovarian cancers (EOC) that have a distinct biological and clinical behaviour (Trainer et al., 2010), with the potential to directly impact treatment and maintenance of ovarian tumors. Importantly, the presence of a *BRCA* mutation is associated with a better prognosis compared to non-*BRCA*-related EOC of similar stage and histological subtype (Bolton et al., 2012). *BRCA*-related EOC are reported to have higher response rates to platinum-based chemotherapy (Chetrit et al., 2008; Tan et al., 2008) and may be less responsive to taxanes than non-hereditary EOC (Foulkes, 2006; Quinn et al., 2007). Furthermore, results of phase 1 and 2 studies using poly (ADP-ribose) polymerase (PARP) inhibitors (i.e. novel agents that target *BRCA*-related tumours), in women with advanced *BRCA*-associated ovarian cancer are promising (Chionh, Mitchell, Lindeman, Friedlander, & Scott, 2011), suggesting that these agents may shortly be incorporated into first-line treatment, either in combination with chemotherapy or as maintenance treatment (Fong et al., 2009; Fong et al., 2010).

The possibility of targeted therapy suggests that widespread clinical use of TFGT for women newly diagnosed with ovarian cancer may be imminent. Data, however, about the psychosocial implications and acceptability of TFGT in the ovarian cancer setting are scant, with the focus to date being on its use in determining management of breast cancer. Concerns regarding TFGT stem from it requiring a woman to consider wider issues regarding her own treatment and future cancer risk, in addition to a potential risk for family, at a vulnerable time (Ardern-Jones, Kenen, & Eeles, 2005; Vadaparampil et al., 2009). In addition, results of studies assessing the
psychological impact of traditional genetic testing indicate that women diagnosed with breast cancer less than a year previously tend to report greater reductions in well-being after genetic testing than those tested more than 12 months after their cancer diagnosis (Bonadona et al., 2002; van Roosmalen et al., 2004). Despite this, data suggest few adverse psychological effects of TFGT in the breast cancer setting, and that breast cancer patients can be approached shortly after surgery without additional psychological burden (Schlich-Bakker et al., 2008; Schwartz et al., 2004).

While it is tempting to extrapolate these findings from TFGT in breast cancer to the ovarian cancer setting, it is important to acknowledge the significant differences between the two cancers. Prognosis for ovarian cancer, especially for non-BRCA-related EOC, is poor, with disease most often diagnosed at an advanced stage (Lacour et al., 2008). Recurrence rates are high in ovarian cancer, and treatments for recurrent disease usually have low response rates (Elit et al., 2010). Prevalence of BRCA mutations is higher in ovarian cancer than breast cancer, with approximately 13% of all invasive ovarian cancers being attributable to a BRCA1 or BRCA2 mutation (Risch et al., 2001). The prevalence of BRCA mutations is substantially higher among some affected women including individuals of Ashkenazi Jewish heritage, ranging from 16.2% for affected women without a relevant family history of breast and/or EOC to 58% for affected women with more than one close relative diagnosed with EOC (Myriad Genetic Laboratories, 2012). Currently, the key purpose of TFGT for breast cancer stems from the potential to surgically address a possible risk of further breast cancer (Schwartz et al., 2005) whereas in the ovarian cancer setting, its purpose would be to offer targeted treatment for current cancer. These fundamental differences between breast and ovarian cancer may, understandably, lead to higher acceptance of TFGT in the ovarian cancer setting (Lacour et al., 2008). The potential benefit of TFGT, which is shared by women diagnosed with either ovarian cancer or breast cancer, is the genetic risk information available to family members, including personal (or individualised) risk and information about other BRCA-related cancers including prostate cancer.

Data specific to the use of TFGT in the ovarian cancer setting, therefore, is urgently required if guidelines are to be developed which accommodate this potential shift in clinical practice. TFGT will require a multidisciplinary approach, meaning health professionals within the oncology setting are likely to need guidance from evidence-based research on how best to offer TFGT to cohorts of women with ovarian cancer in the near future. This paper reports on the results of a study to qualitatively identify women’s information and communication
preferences about TFGT, with regard to the timing, mode of delivery and format of information. The purpose of this study was to explore the range of information needs and preferences in order to provide the basis for the development of educational materials for women diagnosed with ovarian cancer considering TFGT. Results regarding women’s attitudes towards and acceptance of TFGT are reported elsewhere (Meiser et al., 2012).

METHODOLOGIC APPROACH

Participants

Purposive sampling, which is targeted sampling for heterogeneity to allow the determination of the full range of information needs and preferences from as many different perspectives as possible, was used to select potential participants (Patton, 1980). Two groups of women were recruited into the study. Group A comprised women with advanced ovarian cancer, who had already undergone TFGT at a genetics service under a research protocol to determine eligibility for participation in a PARP inhibitor trial (Group A denotes Actual decision-making about TFGT). The interval between genetic testing and recruitment to the study was 1-14 years. Both carriers and those who received inconclusive \texttt{BRCA1} or \texttt{BRCA2} mutation results were included in this group. Group H comprised women recently diagnosed with invasive ovarian cancer, who were unselected for family history and had never undergone genetic counseling or testing (Group H denotes Hypothetical decision-making about TFGT). Also for Group H, to avoid undue participant burden, women invited had not relapsed and were between 6 and 20 weeks post diagnosis. We elected to include women diagnosed with ovarian cancer who were unselected for family history because in the near future, all women diagnosed with non-mucinous epithelial ovarian cancer aged less than 60 are likely to be offered TFGT given the high rate of \texttt{BRCA} mutations in this tumor group (Alsop et al., 2012). Exclusion criteria were age under 18 years, insufficient English language to complete the interview unaided, and for Group H, women with germ cell and borderline ovarian cancer.

Group A was recruited through two major genetics services in Sydney and Melbourne, with a letter of invitation sent by their treating clinician. Group H was recruited through a gynecological oncology department at a major teaching hospital in Sydney; verbal permission was obtained from interested women by the Clinical Nurse Consultant, before a letter of invitation was mailed out by the research team. Twelve of 23 women meeting eligibility criteria for Group A participated and all 10 women eligible for Group H who gave verbal permission for contact by the researcher agreed to participate. For Group A, an opt-in method was required for women recruited through the genetics service in Sydney and an opt-out method was used for women recruited through
the genetics service in Melbourne because of differences in the ethical requirements of the two Institutional Review Boards which provided approval for the research. Hence, no reason for decline was available for the eight women from Sydney who were approached for Group A and who did not respond to the letter of invitation. Of the three women in Melbourne who opted out or who were unavailable, the reasons were that one woman was too busy, one woman did not return the call of the researcher to schedule an interview, and the third woman was already deceased. Prior to interview, women in both groups were mailed a consent form, a one-page information sheet about TFGT, and a decision aid as an example of an educational resource. All individuals gave their informed consent prior to their participation in the study.

Data collection

A qualitative data collection method is useful in exploring issues that have not yet been researched extensively (Denzin and Lincoln, 1994). Semi-structured interviews were conducted with women on an individual basis. A guide was used to conduct each interview including questions covering the following topics: (i) the preferred timing of information about TFGT; (ii) what type of information and what level of detail do women require about TFGT; (iii) how do women want the information about TFGT presented; (iv) which health professional(s) should deliver information about TFGT. Other topics explored included women’s acceptance and experiences of TFGT which are not reported here. Details of the interview guide are provided in Appendix 1. The interviews were semi-structured because the wording and sequencing of the questions was left open, with probes used to elicit more information, as appropriate. All interviews were conducted by MG, who has extensive experience as both a cancer genetic counsellor and an oncology nurse. All women opted for a telephone interview. Interviews lasted an average of 70 minutes, and were audiotaped and transcribed verbatim. Results from each interview were used to suggest additional lines of questioning in subsequent interviews to ensure that divergent points of view would be expressed. Interviewing was discontinued when data saturation was reached (i.e. when no additional information appeared to be forthcoming (Denzin & Lincoln, 1994).

Data Analysis

The framework of Miles and Huberman (1994) was used to guide data analysis. Transcripts were analysed for emergent themes using a standardised qualitative methodology described by Miles and Huberman (1994) which they identify as ‘transcendental realism’. Their approach is one of the most comprehensive frameworks with regard to data analysis and techniques which protects against threats to validity (Pitman & Maxwell, 1992). Each
transcript was reviewed line by line for concepts and themes from which the preliminary coding scheme was constructed. The qualitative data analysis software QSR NVivo 8.0 was used to organise the codes into hierarchical categories and to develop a structured coding tree (Coffey & Atkinson, 1996; Patton, 2002). MG identified the initial themes and categories and coded all transcripts. After MG had coded several transcripts, the thematic coding scheme was reviewed by experts within the research team before the remaining transcripts were coded. To ensure coding consistency, two early and two mid-way interviews were then coded independently, using the developed categories by a second member of the research team (NK). If discrepancies occurred with respect to specific categories, discussions took place within the research team until consensus was achieved. The query function in QSR NVivo 8.0 was used to cross-tabulate emergent themes and to facilitate comparisons by group (Group A versus Group H).

FINDINGS

The demographic characteristics of participants are summarised in Table 1. Quotations are followed by either (A) denoting Group A or (H) denoting Group H.

Timing of delivery of TFGT information

Participants were asked at what time point they would prefer to first receive information about TFGT. All participants wanted to receive the information early, with the majority of women preferring to be given the information prior to surgery. Some women wanted to receive the information post surgery, prior to chemotherapy. While women in Group A were almost even in their preference for receiving information either pre- or post-surgery, all but one participant from Group H preferred to receive the information pre-surgery. The factor most frequently cited as influencing women’s preference was whether they believed they were more clear-minded pre- or post-surgery.

….once you wake up from the surgery and for the two weeks after the surgery your head's in such a spin that I'm not sure you could even digest that information. (A)

I would be thinking after the surgery...because it’s a real minefield just to get through the surgery and the diagnosis...after the surgery you’re actually thinking, "Okay, I’m on the other side now, where am I going? ” (H)
Several women were happy to receive the information even if a clear diagnosis of ovarian cancer had not yet been established.

*This is probably ovarian cancer. I think at that point when they say that.* (H)

Two participants commented, however, on the importance of not giving the information about TFGT at the same time a woman receives her diagnosis, because of the shock experienced at this time. Although women did acknowledge the peri-diagnostic period as being very stressful and overwhelming, they did not believe that receiving information about TFGT would exacerbate this because ‘nothing could make this period any worse’.

*You’re going through the shock of everything then anyway, so you might as well, one more little shock and one more little test isn’t going to be as traumatic or stressful to you.* (H)

**Preferences for information content and level of detail**

The majority of women reported wanting information on the implications of TFGT for their family; the success rate of the new drug and its relevance to their treatment and survival; the potential for an increased risk of breast cancer in carriers; and the purpose of the test. A small number of women also reported wanting information on the chance of mutation detection, in the general population and/or for themselves specifically; how TFGT is done; whether TFGT is painful; the disadvantages of TFGT; the doctor’s opinion of TFGT; and the timeframe for results. What is important, however, is the level of detail of information that women wanted on each issue. Half of the women reported that they wanted the focus of the discussion regarding TFGT to be on them and the treatment of their cancer right now; several of these women, reported treatment implications for them as being the only information they would need to make a decision regarding TFGT

*I think at that time when I’m diagnosed I just want to know what it means for me.* (H)

Many women supported a one-step-at-a-time model of information delivery, whereby the specifics of other non-treatment-related information are not given until the results of TFGT are known. While most women said that they wanted to be informed about the family implications of TFGT, all participants said they only wanted details about these implications if a mutation was detected and not until their treatment had been organised.
I think it’s too much too soon … because … it’s enough to cope with your own diagnosis let alone also worry about the implications for other family members. (A)

Similarly, just over half of women reported wanting brief information only on the increased risk of breast cancer for mutation positive women, with none wanting statistics. These women believed that the risk of further cancers could be covered in greater detail at a later stage by the genetics team, if a mutation was detected. By contrast, some women (predominantly from Group A) felt strongly that they did not wish to know about the potential increased breast cancer risk around the time of their cancer diagnosis, as there was enough to worry about at this time, and it may not be relevant to them, in view of the advanced stage of their disease.

I don’t think that you need to be more worried about oh crap, now I’ve got ovarian I’m going to have breast. Yeah, I think that would be too much information at that stage. (A)

Some participants, who reported it was important to be given brief information about the likelihood of a mutation being detected, suggested it would both moderate women’s anxiety levels about their chance of being a mutation carrier and avoid disappointment potentially caused by unrealistically raising women’s hopes regarding their eligibility for targeted drugs.

Women also stressed the importance of including positive, hope-giving information. This included emphasizing: i) there are things that can be done to address the increased risk of breast cancer; ii) the potential benefits of the new drug in treating ovarian cancer; and iii) there may be other treatment drugs available if a patient is not eligible for PARP.

But I guess at the time that was all I wanted to know, there was hope that something would give me better treatment than the other. And that’s what we’re looking for. (A)

Format of information delivery

The majority of women wanted to be given verbal information about TFGT in the first instance, because it provided the opportunity to ask questions directly and to seek clarification. Other reasons women gave for this preference was to allow any emotional issues to be addressed, and to foster trust and reassurance.
I just think that basically it’s got to be face-to-face first, because it’s all about communication and trust. (A)

The majority of women who expressed a preference for verbal information, also said they wished to receive written information to take home subsequently. Several women preferred audiovisual information in the form of a DVD to accompany verbal information. None of the participants liked the idea of accessing information about TFGT on a designated website, as they either did not feel confident with computers, or they were put off by the quantity of information potentially available via this method.

Which health professional should deliver TFGT information?

Participants in Group A preferred to receive information from a genetics specialist, closely followed by their medical oncologist. In contrast, the majority of women in Group H preferred to receive information from their medical oncologist or the gynecological oncology nurse. Overall, therefore, there was a preference for the medical oncologist, compared to a genetics specialist. The most common reason given by participants who preferred a medical oncologist was because he/she plans their treatment, and the information gained by TFGT is most relevant to him/her. Other arguments for the medical oncologist as the preferred deliverer included: i) there is too much going on in the post diagnosis / post surgery period to introduce another health professional (i.e. genetics specialist), and to attend yet another appointment; ii) a trust relationship has already been established with the oncologist and iii) it is more convenient to have things done all-in-one-go, by the same doctor.

The most common reason for a preference for a genetics specialist was because women liked the fact that they would be receiving the information from an “expert. For Group H, the argument in favour of the gynecological oncology nurse was the belief that the nurse is more familiar to them, more involved, and better understands what the individual patient is going through.

Preferences for format of educational materials

All participants, except one, preferred a brief 1-2 page leaflet about TFGT as opposed to a lengthier booklet. Compared to a booklet or decision aid, women reported a leaflet to be less overwhelming. Over half of all participants, stated that the TFGT information sheet provided to them as part of the study, would have provided enough detail for them to understand the meaning and purpose of TFGT, if it was also accompanied by a brief
I think in booklet form it can be a little bit off putting because you think, ‘Oh God, I’ve got to read through all this!’ (H) Suggestions provided by participants for the best way to present information about TFGT in a leaflet format included: using a question/answer format; simple language; reassuring/positive language; dot points; flow charts; giving direction; a contact telephone number for questions; and diagrams.

Don’t make the documents too much doom and gloom. Give it a very, confident, hope kind of thing. Otherwise if it’s too much of gloom and doom there’s, ‘Oh forget it!’ (A)

DISCUSSION

This study aimed to identify the information and communication preferences of women regarding TFGT. The results suggest that the majority of women diagnosed with ovarian cancer want information about TFGT early, and prefer to receive this information in a face-to-face consultation from their medical oncologist, with brief written information provided as supporting material. The results also indicate that women prefer a ‘one-step-at-a-time’ model of information delivery, with the focus of pre-test information on their treatment.

The preference expressed by the majority of women for receipt of information about TFGT prior to surgery complements the findings of the qualitative interview study by Meiser et al. which demonstrates that the current sample’s primary motivation for TFGT is to inform their treatment plan (2012). Based upon current turnaround times for rapid BRCA sequencing, the length of time between pre-test genetic counseling and receipt of test results in a post-test appointment is approximately two weeks, which is an appropriate time frame for the genetic test results to inform the first-line treatment plan. Preferences regarding timing of information delivery for TFGT in the current study contrast to those of a previous qualitative study conducted among young women with breast cancer who were known BRCA carriers (Ardern-Jones et al., 2005). In the latter study, which assessed women’s willingness to undergo hypothetical TFGT, the majority of women believed having genetic testing at approximately the same time as their cancer diagnosis would have been too overwhelming. The present study differs from this previous investigation in that: i) both actual and hypothetical preferences regarding TFGT were assessed, ii) participants had a diagnosis of ovarian, rather than breast, cancer, and iii) participants were unselected for age and older. Differences in preferences for the timing of genetic testing in the present study are likely to result from fundamental differences in the purpose of TFGT in the context of breast and ovarian cancer.
In particular, if offered around the time of ovarian cancer diagnosis, TFGT has the potential to offer targeted
treatment of a current cancer, while in breast cancer its primary purpose is the potential to surgically address a
possible risk of future breast cancer.

The majority of women in this study preferred to receive information about TFGT verbally, so that questions
could be posed and to foster trust. This is in keeping with previous findings from research into patients’ preferred
communication strategies, which consistently show that patients prefer to receive health-related information as
part of an individual consultation with an expert (Andrews et al., 2006; Meiser, Mitchell, McGirr, Van Herten, &
Schofield, 2005). The preferred ‘expert’ differed between the two groups: half of Group A preferred a genetics
specialist and Group H preferred a member of their medical oncology team or the gynaecological oncology
nurse. The Group A results concur with the findings of Arden-Jones et al (2005); in both studies, women had
seen a genetics specialist at a genetics service, and their preference may well reflect the good experience they
had. In addition, the majority of Group A participants reported a family history of breast and/or ovarian cancer
and had likely lost relatives to these cancers, which may have heightened their awareness of the potential
hereditary nature of their cancer and influenced their preference to receive information about TFGT from a
genetics specialist - the perceived ‘expert’. Regarding content of the information, some women, predominantly
from Group A, wanted balanced information about the chance of a mutation being detected to alleviate anxiety
and to provide hope. Women in Group A had relapsed and previous treatments had failed. In contrast, women in
Group H were at an earlier phase in their treatment where they still likely had hope that it would be effective.
Among Group A women, therefore, the delivery of information in a balanced, yet positive and hope-giving
manner appears particularly important. Both groups of women, however, converged in their clear preference to
receive information about TFGT at or around their diagnosis to potentially inform their treatment plan and/or to
benefit family members.

Currently, women diagnosed with ovarian cancer at high risk of carrying a BRCA mutation may be referred for
genetic testing too late for the patient to directly benefit from the result (Daniels, Urbauer, Stanley, Johnson, &
Lu, 2009). Given the potential for TFGT to influence first-line cancer treatment, there is an urgent need to
consider the potential roles of health professionals who are already part of the patient’s treatment team in the
delivery of TFGT, in particular medical oncologists and oncology nurses. In the present study, the preference for
a ‘one-step-at-a-time’ approach to information delivery lends itself to the model of the treating oncologist or
oncology nurse presenting the initial information about TFGT which is focused on the individual and her cancer management., and indeed, this potential option has been shown to be well supported by the women in this study, supported by brief educational materials.

TFGT research to date has focused primarily on its use in women with breast cancer. This study highlights the importance of acknowledging and addressing the unique needs of women with ovarian cancer at different treatment stages regarding TFGT, and makes a significant contribution to planning for its future use. Limitations of the current study need to be acknowledged, however. Views obtained from women in Group A were retrospective and recall bias may limit the interpretation of results. Further, the women with advanced ovarian cancer in Group A had undergone genetic testing because all their other treatment strategies had failed. Selection bias therefore, may have also operated in the study because the women eligible for Group A who failed to respond to the study invitation were likely too unwell to do so. It is possible, therefore, that among Group A the views of women who were less ill at invitation were over-represented. Further, as with all qualitative studies, causal relationships cannot be established.

**Conclusions**

Women diagnosed with ovarian cancer, irrespective of their family history of ovarian and/or breast cancer, want information about TFGT early in their diagnosis, if it has the potential to influence their treatment plan. The majority of women preferred the information to be delivered face-to-face by a medical oncologist, genetics specialist or oncology nurse together with brief supporting educational materials. Women preferred a ‘one-step-at-a-time’ model of information delivery with the focus being on their treatment options, and with a preference for details about non-treatment related issues to be delivered later.

**Implications for Nursing**

Widespread use of TFGT in the management of women newly diagnosed with ovarian cancer is likely imminent and will require a multidisciplinary approach. Gynaecological oncology nurses and medical oncologists, involved in the care of women diagnosed with ovarian cancer, are likely to be involved in the delivery of information about TFGT. The findings of this study provide much needed guidance to oncology nurses and their colleagues about when patients diagnosed with ovarian cancer should be informed about TFGT, what they want to know, and how the information could be delivered. The study findings may be used by oncology nurses
and other members of the multidisciplinary team to facilitate early discussions about TFGT with their patients.

Patient education materials also need to be developed, to adequately support women in making informed decisions about TFGT.
REFERENCES


Conflict of Interest

The authors declare that there are no financial or other conflicts of interest. The authors confirm that they have full control of all primary data pertaining to this research and they agree to allow the journal to review the data, if requested.
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We would like to thank all the women who participated in this research and generously shared their views. We gratefully acknowledge the support and endorsement of the Psycho-oncology Co-operative Research Group (PoCoG) for this project. This project was supported by a Cancer Institute NSW Career Development Fellowship to Bettina Meiser. Nadine Kasparian is supported by a Post-Doctoral Clinical Research Fellowship from the National Health and Medical Research Council (NH&MRC) of Australia (ID 510399).
Table 1: Participant demographics and clinical characteristics by group (N=22)

<table>
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<th>Variable</th>
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<th>Group H (n=10)</th>
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<td>Yes</td>
<td>1</td>
<td>0</td>
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<tr>
<td>No</td>
<td>11</td>
<td>10</td>
<td>21</td>
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</tbody>
</table>
Notes. Group A = Actual decision-making about TFGT. Group H = Hypothetical decision-making about TFGT. PARP = poly (ADP-ribose) polymerase inhibitor. *Breast cancer (n=2), and endometrial cancer (n=1). **If a deleterious gene mutation is not detected in BRCA1 or BRCA2, and the participant does not have a family history of breast and/or ovarian cancer, it is unlikely that her ovarian cancer is due to an inherited mutation in a breast cancer protection gene. However, as not all breast cancer protection genes have been discovered, if a participant does have a strong family history of breast and/or ovarian cancer, it is still possible that she carries a mutation in an as yet undiscovered predisposition gene. For this reason, the result is termed, ‘inconclusive’, and the participant and her family may still be at increased risk of breast and ovarian cancer. #Of the four participants who were carriers of a BRCA mutation, one met the eligibility criteria to proceed to a PARP clinical trial; the remaining three were ineligible for the trial due to either a previous drug regime or the fact that they had not relapsed from their ovarian cancer within the relevant time frame.
Table 2. Quotations illustrating participants’ communication and information needs regarding treatment-focused genetic testing

<table>
<thead>
<tr>
<th>Theme</th>
<th>Quotation</th>
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</thead>
<tbody>
<tr>
<td><strong>Timing and delivery of information about TFGT</strong></td>
<td>Preference for information early</td>
</tr>
<tr>
<td></td>
<td>I think when you’re diagnosed have it done because there’s a time factor and I suppose in that process you can do your surgery and when the results come out, if it’s negative it’s good, it it’s positive then you know which way to treat. (A)</td>
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<td></td>
<td>I think basically straight away. It’s all part of the whole diagnosis…and the treatment choice I think, you know, ASAP. Have the testing done, get the results back and then, you know, the best decision can be made. I would say immediately. (H)</td>
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<tr>
<td></td>
<td>Preference for information pre-surgery</td>
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<td></td>
<td>I think probably if you were going to do that you’re really going to have to maybe include an information sheet about the genetic testing prior to the surgery…Maybe to have a mention there because once you wake up from the surgery and for the two weeks after surgery your head’s in such a spin that I’m not sure you could even digest that information. (A)</td>
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<td>Theme</td>
<td>Quotation</td>
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<tr>
<td>Preference for information post-surgery</td>
<td>I would be thinking after the surgery...because it’s a real minefield just to get through the surgery I think and the diagnosis, and then after the surgery you’re actually thinking, “Okay, I’m on the other side now, where am I going?” (H)</td>
</tr>
<tr>
<td>TFGT will not create an added burden</td>
<td>You’re going through the shock of everything then anyway, so you might as well, one more little shock and one more little test isn’t going to be as traumatic or stressful to you. (H)</td>
</tr>
</tbody>
</table>
| Content and level of detail of information about TFGT | **Focus on what TFGT means for the patient**  
I think at that time when I’m diagnosed I just want to know what it means for me. (H)  

**One-step-at-a-time method of information delivery**  
I think it’s too much too soon... because... it’s enough to cope with your own diagnosis let alone also worry about the implications for other family members. (A)  

...you know just very concise information, just giving you sort of the relevant information so that you can make the decision and then you know sort of you can look at getting further information afterwards. (H) |
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<td>Preference for positive information</td>
<td>And the last thing on either form would have to be a message of hope like as in the fact that yes the best possible treatment will be given, for whether you find the gene or not...Because sometimes at that stage rather than focusing on the positive you only – you start to only hear the negative. (A)</td>
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**Format of delivery of information about TFGT**

| Preference for verbal information               | If my oncologist can’t talk to me about it directly, then I wouldn’t...be too happy to be receiving, I just think that basically it’s got to be face-to-face first, because it’s all about communication and trust... (A) |

<p>| Preference for supporting written educational materials | I’d like my doctor to tell me about it. To talk me through it but I also need to have something to take away to, to read or somewhere to read about it but not the whole thing. No the greater part of it. Just again, how is it going to help me? What does it mean to me in my treatment? And then something to read because often you know, when you’re told that you have ovarian cancer you don’t kind of remember everything else that gets said after that. (H) |</p>
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| **Who should deliver information about TFGT?** | *Preference for delivery by the medical oncologist*  
I actually think that the medical oncologist would be better offering the genetic testing...because I think the medical oncologist would have a direct...benefit from finding out whether there’s because he’s the one that’s going to plan your treatment. (A)                                                                                     |
| *Preference for delivery by a genetics specialist* | I think the genetic people. If you want to do the genetic testing, it would be the genetic people because that’s their field and whatever questions you need to ask, you’re asking the person with that authority. (A)                                                                                                             |
| **Preferred format of the educational materials** | *Brief information leaflet*  
...but it’s good to have something printed that you can actually pick up and re-read if you’re thinking about something and you think oh yes what was that, and so you can go, go back and refer to it again. (A)                                                                                                      |
|                                            | I think a leaflet is better than you know something that’s too overwhelming. (H)                                                                                                                                                                                                                                                                 |

Note: (A) denotes a participant from Group A and (H) denotes a participant from Group H.