

# Communication and Information Needs of Women Diagnosed With Ovarian Cancer Regarding Treatment-Focused Genetic Testing

Margaret Gleeson, BNurs, PDipGenCoun, Bettina Meiser, PhD, Kristine Barlow-Stewart, PhD, Alison H. Trainer, PhD, Kathy Tucker, MBBS, FRACP, Kaaren J. Watts, PhD, Michael Friedlander, PhD, and Nadine Kasparian, PhD

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 and only after completion of surgery and adjuvant therapy. The greatest benefit of the traditional process, arguably, has been for unaffected family members shown to be at increased risk of breast and ovarian cancer, particularly with regard to breast cancer screening and prevention, and bilateral risk-reducing salpingo-oophorectomy, which has been shown to reduce the risk of ovarian cancer by about 95% (Kauff et al., 2002; Rebbeck et al., 2002). However, new evidence suggests a change in current practice by determining a woman's mutation status at the time of her ovarian cancer diagnosis and using that information in her treatment plan (Trainer et al., 2010). This 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 (EOCs) that have distinct biologic and clinical behavior (Trainer et al., 2010). This behavior has 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 EOCs of similar stage and histologic subtype (Bolton et al., 2012). *BRCA*-related EOCs 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 nonhereditary EOCs (Foulkes, 2006; Quinn et al., 2007). In addition, results of phase 1 and phase 2 studies using poly (ADP-ribose) polymerase (PARP) inhibitors (i.e., novel agents that target *BRCA*-related tumors) in women with

**Purpose/Objectives:** To identify women's information and communication preferences about treatment-focused genetic testing (TFGT) in the ovarian cancer context.

**Research Approach:** A qualitative interview study.

**Setting:** Two familial cancer services and a gynecologic oncology clinic at a major teaching hospital in Australia.

**Participants:** 22 women diagnosed with ovarian cancer who had either advanced disease and had previously undergone TFGT ( $n = 12$ ) or had been diagnosed in the previous 6–20 weeks 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 organized into themes using 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 genetic specialist or oncology nurse. Women preferred the focus of pretest information to be on them and their treatment.

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

**Interpretation:** The findings of this study provide much-needed guidance to oncology nurses and other oncology healthcare 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 in making informed decisions about genetic testing.

**Knowledge Translation:** Knowing that women do want TFGT, how they want it presented and by whom, and the content and level of detail that women want means that TFGT can now be presented as an option to women newly diagnosed with ovarian cancer, which may influence first-line treatment. The findings also provide the knowledge required to prepare education tools to assist oncology nurses involved in frontline care.

advanced *BRCA*-associated ovarian cancer (Chionh, Mitchell, Lindeman, Friedlander, & Scott, 2011) suggest that those agents may be incorporated into firstline treatment, either in combination with chemotherapy or as maintenance treatment (Fong et al., 2009, 2010).

The possibility of targeted therapy suggests that widespread clinical use of TFGT for women newly diagnosed with ovarian cancer may be imminent. However, data about the psychosocial implications and acceptability of TFGT in the ovarian cancer setting are limited, with the focus being on its use in determining management of breast cancer. Concerns about TFGT stem from a woman having 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 indicated that women diagnosed with breast cancer less than a year previously tended 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 that, the data suggest few adverse psychological effects of TFGT in the breast cancer setting, and patients with breast cancer can be approached shortly after surgery without causing additional psychological burden (Schlich-Bakker et al., 2008; Schwartz et al., 2004).

Although extrapolating these findings from TFGT in the breast cancer setting to the ovarian cancer setting is tempting, acknowledging the significant differences between the two cancers is important. Prognosis for ovarian cancer, particularly for non*BRCA*-related EOCs, 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 about 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% for affected women without a relevant family history of breast and/or an EOC to 58% for affected women with more than one close relative diagnosed with an EOC (Myriad Genetic Laboratories, 2012). The key purpose of TFGT for breast cancer stems from the potential to surgically address a *possible* risk of additional breast cancer (Schwartz et al., 2005); however, in the ovarian cancer setting, its purpose would be to offer targeted treatment for *current* cancer. Those 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 individualized) risk and information about other *BRCA*-related cancers, including prostate cancer.

Data specific to the use of TFGT in the ovarian cancer setting, therefore, are urgently required to develop guidelines that accommodate this potential shift in clinical practice. TFGT will require a multidisciplinary approach. Health professionals in the oncology setting will likely need guidance from evidence-based research on how best to offer TFGT to cohorts of women with ovarian cancer in the near future. This article 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 to provide the basis for the development of educational materials for women diagnosed with ovarian cancer who are considering TFGT. Results detailing women's attitudes toward and acceptance of TFGT are reported elsewhere (Meiser et al., 2012).

## Methodologic Approach

### Participants

Purposive sampling, which is targeted sampling for heterogeneity to allow for the determination of the full range of information needs and preferences from as many different perspectives as possible (Patton, 1980), was used to select potential participants. Two groups of women were recruited for the study. Group A was comprised of 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 time lapse from genetic testing and recruitment to the study ranged from 1–14 years. Both carriers and those who received inconclusive *BRCA1* or *BRCA2* mutation results were included in this group. Group H was comprised of women diagnosed in the previous 6–20 weeks with invasive ovarian cancer, whose family history had not been collected and who had never undergone genetic counseling or testing (Group H denotes hypothetical decision making about TFGT). In addition, to avoid undue participant burden, women invited to Group H had not relapsed. The authors elected to include women diagnosed with ovarian cancer who were unselected for family history because, in the near future, all women diagnosed with nonmucinous EOC who are younger than age 60 are likely to be offered TFGT

given the high rate of *BRCA* mutations in this tumor group (Alsop et al., 2012). Exclusion criteria included being younger than age 18 and having insufficient English language knowledge to complete the interview unaided. In addition, for Group H, women with germ cell and borderline ovarian cancer were excluded.

Group A was recruited through two major genetics services in Sydney and Melbourne, Australia, with a letter of invitation sent by each woman's treating clinician. Group H was recruited through a gynecologic 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 that provided approval for the research. Therefore, no reason for decline was documented for the eight women from Sydney who were approached for Group A and 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 deceased. Prior to interview, the women 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 for exploring issues that have not been researched extensively (Denzin & Lincoln, 1994). Semistructured interviews were conducted with women on an individual basis. A guide was used to conduct each interview,

### Understanding of TFGT

- Had you heard of genetic testing for a faulty ovarian cancer gene before reading the information sheet and/or hearing about this study?
- Have you ever thought about looking into genetic testing for a faulty ovarian cancer gene?

### Acceptability of TFGT

- Would you have been interested in having a genetic test to determine whether you carry a faulty ovarian cancer gene if it would have helped direct your cancer therapy? Why or why not?
- If the results of genetic testing would not help direct your cancer therapy, would you be willing to have the genetic testing soon after the diagnosis solely for the purpose of helping your family? Why or why not?

*For women who have never undergone TFGT:*

- How well are your family members coping with your diagnosis and do you think you could discuss genetic testing with them just now?
- What information would you need to have before you would consider having TFGT?
- What do you think are the advantages and disadvantages of genetic testing for TFGT?
- How would you feel if you found out that you carried a faulty ovarian cancer gene?
- Who in your family would you tell if you were found to have the faulty gene?
- Do you think that, if you had genetic testing for a faulty ovarian cancer gene, the results would affect your family (i.e., spouse or children)?

### Information needs and preferences regarding TFGT

- At what time point would you prefer to receive TFGT information?
  - Prompt: What would be the perfect timing for receiving this type of information?
- Would you want to receive this information shortly after your diagnosis with ovarian cancer?

*Note.* Prompts have been included for the questions exploring women's information needs and preferences regarding TFGT because these issues are the focus of this article.

- Prompt: How soon after your diagnosis and before chemotherapy would you prefer to receive this type of information?

- How much information (if any) would you like to receive as part of an offer of TFGT? The options would be: (a) only receiving information about the possible implications for yourself and then discussing the family implications later after treatment is finished, or (b) receiving information about the implications for you and your family members from the beginning (remembering that 80% of women will not have a fault found and so there may not be implications for other family members).

- Prompt: What would you define as the "perfect" amount of information you would like to receive? Would it be easier to make a separate time to discuss the implications for your family?

- How would you like to receive information about TFGT?

- Prompts: Information leaflet, question prompt sheet, information video, consultation with expert, talks by experts, Internet

- At the moment, women receive all this information from a genetic specialist. Do you think it would be stressful to introduce another person (such as a genetic specialist) into your health care after your ovarian cancer diagnosis and surgery but before chemotherapy?

- Who would be your preferred health professional (if any) to receive information about TFGT from?

- Prompts: Medical oncologist, surgeon, nurse specializing in gynecologic cancers, genetic specialist, clinical geneticist

### Cost of TFGT

- Imagine that your doctor has recommended that you have genetic testing for a faulty ovarian cancer gene. Suppose that, to have genetic testing for a faulty ovarian cancer gene, you were asked to pay 20% of the cost (about \$600). Would you be interested in having genetic testing?
- Suppose that, to have genetic testing for a faulty ovarian cancer gene, you were asked to pay the full cost (about \$3,000). Would you be interested in having genetic testing?

**Figure 1. Abbreviated Semistructured Interview Guide for Treatment-Focused Genetic Testing (TFGT)**

**Table 1. Participant Demographics and Characteristics by Group (N = 22)**

	Group A (n = 12)			Group H (n = 10)		
Variable	$\bar{X}$	SD	Range	$\bar{X}$	SD	Range
Age at interview (years)	59	10	42–73	55	8	45–67
Age at diagnosis (years)	55	10	37–71	55	7	45–67
Variable	n			n		
<b>Age at diagnosis (years)</b>						
Younger than 40	1			–		
40–49	2			2		
50–59	5			6		
60 or older	4			2		
<b>Language spoken in home</b>						
English	11			10		
Other	1			–		
<b>Highest level of education</b>						
No post-school qualification	7			7		
Post-school qualification	5			3		
<b>Marital status</b>						
Married or de facto	9			7		
Not married	3			3		
<b>Previous cancer<sup>a</sup></b>	2			1		
<b>Family history of breast or ovarian cancer</b>						
Yes	9			2		
No	1			7		
Unknown (adopted)	2			1		
<b>Mutation status</b>						
BRCA carrier	4			–		
Inconclusive result <sup>b</sup>	8			–		
<b>On PARP trial</b>						
Yes	1			–		
No	11			10		

<sup>a</sup> Breast cancer (n = 2) and endometrial cancer (n = 1)

<sup>b</sup> If a participant has a strong family history of breast and/or ovarian cancer, and a deleterious gene mutation is not detected in *BRCA1* or *BRCA2*, she may still carry a mutation in an as-yet-unidentified predisposition gene. For that reason, the result is termed inconclusive. Of the four participants who were carriers of a *BRCA* mutation, three were ineligible for the PARP trial because of either a previous drug regimen or the fact that they had not relapsed from their ovarian cancer within the relevant time frame.

PARP—poly (ADP-ribose) polymerase

counselor and an oncology nurse. All women opted for a telephone interview. Interviews lasted an average of 70 minutes and were audio recorded 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 analyses. Transcripts were analyzed for emergent themes using a standardized qualitative methodology described by Miles and Huberman (1994) as transcendental realism. Their approach is one of the most comprehensive frameworks with regard to data analyses and techniques that protect 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®, version 8, was used to organize the codes into hierarchical categories and to develop a structured coding tree (Coffey & Atkinson, 1996; Patton, 2002). The first author of the current article identified the initial themes and categories and coded all transcripts. After she had coded several transcripts, the thematic coding scheme was reviewed by experts in the research team before the remaining transcripts were coded. To ensure coding consistency, two early and two mid-point interviews then were coded independently using the developed categories by a second member of the research team. If discrepancies occurred with respect to specific categories, discussions took place until consensus was achieved by the research team. The query function in QSR NVivo 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 summarized in Table 1. Quotations are followed by either (A), which denotes Group A, or (H), which denotes Group H.

### Timing of Delivery of Treatment-Focused Genetic Testing Information

Participants were asked at what time point they would prefer to first receive information about TFGT.

including questions regarding the following topics: (a) the preferred timing of information about TFGT, (b) what type of information and what level of detail women require about TFGT, (c) how women want the information about TFGT presented, and (d) which health professional(s) should deliver information about TFGT. Other topics explored included women's acceptance and experiences of TFGT, which are not reported. Details of the interview guide are provided in Figure 1. The interviews were semistructured because the wording and sequencing of the questions were left open, with probes used to elicit more information as appropriate. All interviews were conducted by an individual with extensive experience as both a cancer genetic



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 postsurgery, prior to chemotherapy. Although women in Group A were almost even in their preference for receiving information either pre- or postsurgery, all but one participant from Group H preferred to receive the information presurgery. The factor most frequently cited as influencing women's preference was whether they believed they were more clear-minded pre- or postsurgery.

Once you wake up from the surgery, and for the two weeks after the surgery, your head is 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. One participant from Group H, in response to being asked when TFGT should be introduced, said, "'This is probably ovarian cancer.' I think at that point when they [the doctors] say that." However, two participants commented on the importance of not giving the information about TFGT at the same time a woman receives her diagnosis because of the shock already experienced. Although women did acknowledge the peridiagnostic 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

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 or for themselves specifically), how TFGT is done, whether TFGT is painful, the disadvantages of TFGT, the doctor's opinion of TFGT, and the time frame for results. What is important, however, is the level of detailed 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 their treatment implications as the only information they would need to make a decision regarding TFGT. One woman from Group H said, "I think at that time when I'm diagnosed I just want to know what it means for me."

Many women supported a step-by-step model of information delivery, whereby the specifics of other nontreatment-related information are not given until the results of TFGT are known. Although most women said that they wanted to be informed about the family implications of TFGT, all participants said they only wanted details about those implications if a mutation was detected and not until their treatment had been organized.

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, 55% of the women reported wanting brief information only on the increased risk of breast cancer for mutation-positive women, with none wanting statistics. Those women believed that the risk of additional cancers could be covered in greater detail at a later stage by the genetics team if a mutation was detected. In 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 that 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)

Participants who believed getting brief information about the mutation's detection was important also suggested that it would moderate women's anxiety levels about their chance of being a mutation carrier as well as avoid the disappointment potentially caused by unrealistically raising women's hopes regarding their eligibility for targeted drugs. Women also stressed the importance of receiving positive, hope-giving information, which included emphasizing things that can be done to address the increased risk of breast cancer, the potential benefits of the new drug in treating ovarian cancer, and that other treatment drugs may be 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 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 that preference was to allow any emotional issues to be addressed and to foster trust and reassurance. One woman in Group A said, "I just think that basically it's got to be face-to-face first, because it's all about communication and trust."

The majority of women who expressed a preference for verbal information also said they wished to receive written information to take home. 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 Web site, as they either did not feel confident with computers or they were put off by the quantity of information potentially available via this method.

## Healthcare Professionals Delivering Treatment-Focused Genetic Testing

Participants in Group A preferred to receive information from a genetic 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 gynecologic oncology nurse. Overall, therefore, a preference was noted for the medical oncologist compared to a genetic specialist. The most common reason given by participants who preferred a medical oncologist was because he or she plans their treatment, and the information gained by TFGT is most relevant to him or her. Other arguments for the medical oncologist as the preferred deliverer included (a) too much going on in the postdiagnosis/postsurgery period to introduce another healthcare professional (i.e., genetic specialist) and to attend yet another appointment, (b) a trusting relationship has already been established with the oncologist, and (c) having things done all at once by the same doctor is more convenient.

The most common reason for a preference for a genetic specialist was because women liked the fact that they would be receiving the information from an expert. For Group H, the argument in favor of the gynecologic 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 one- or two-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. Sixty-four

percent 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 also was accompanied by a brief discussion from their doctor.

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 included using a question and answer format, simple language, reassuring and positive language, bullet points, and flow charts, as well as 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 model that delivers information step-by-step, with the focus of pretest 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. (2012), which demonstrates that the current sample's primary motivation for TFGT is to inform their treatment plan. Based on current turnaround times for rapid *BRCA* sequencing, the length of time between pretest genetic counseling and receipt of test results in a post-test appointment is about two weeks, which is an appropriate time frame for the genetic test results to inform the firstline 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 Ardern-Jones et al. (2005), which assessed women's willingness to undergo hypothetical TFGT, the majority of women believed having genetic testing at about the same time as their cancer diagnosis would have been too overwhelming. The current study differs from the previous investigation in that (a) both actual and hypothetical preferences regarding TFGT were assessed, (b) participants had a

diagnosis of ovarian cancer rather than breast cancer, and (c) participants were unselected for age and, on average, were older. Differences in preferences for the timing of genetic testing in the current 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 an ovarian cancer diagnosis, TFGT has the potential to provide targeted treatment of a current cancer; whereas, in breast cancer, its primary purpose is the potential to surgically address a possible risk of future breast cancer.

The majority of women in the current study preferred to receive information about TFGT verbally so that questions could be posed and to foster trust. That response 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 genetic specialist and a majority in Group H preferred a member of their medical oncology team or the gynecologic oncology nurse. The Group A results concurred with the findings of Arden-Jones et al. (2005); in both studies, women had seen a genetic specialist at a genetics service and their preference may 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 those 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 genetic 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 likely still 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. All participants, however, converged in their clear preference to receive information about TFGT at or around their diagnosis to potentially inform their treatment plan and to benefit family members.

Women diagnosed with ovarian cancer at high risk for carrying a *BRCA* mutation may be referred for genetic testing too late to directly benefit from the result (Daniels, Urbauer, Stanley, Johnson, & Lu, 2009). Given the potential for TFGT to influence firstline cancer treatment, a need exists to consider the potential roles

of healthcare professionals who are already part of the patient's treatment team in the delivery of TFGT, particularly medical oncologists and oncology nurses. In the current study, the preference for a step-by-step 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. That potential option, supported by brief educational materials, has been shown to be well supported by the women in the current study.

TFGT research to date has focused primarily on its use in women with breast cancer. The current 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

Views obtained from women in Group A were retrospective and recall bias may limit the interpretation of results. In addition, the women with advanced ovarian cancer in Group A had undergone genetic testing because all other treatment strategies had failed. Selection bias also may have 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. Therefore, the views of women who were less ill at invitation in Group A may have been overrepresented. In addition, as with all qualitative studies, causal relationships cannot be established.

## Conclusions

Women diagnosed with ovarian cancer, irrespective of their family history of ovarian 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, genetic specialist, or oncology nurse, together with brief supporting educational materials. Women preferred a step-by-step model of information delivery, with the focus being on their treatment options and with a preference for details about nontreatment-related issues to be delivered later.

## Implications for Nursing

Widespread use of TFGT in the management of women newly diagnosed with ovarian cancer may be imminent and will require a multidisciplinary approach. Gynecologic 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 from this study provide much-needed guidance to oncology nurses and other healthcare professionals 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.

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Margaret Gleeson, BNurs, PDipGenCoun, is a genetic counselor (cancer) at Hunter Family Cancer Service in Newcastle and a research officer in the Department of Medical Oncology at Prince of Wales Hospital in Sydney; Bettina Meiser, PhD, is

the head of the Psychosocial Research Group in the Department of Medical Oncology at Prince of Wales Hospital and a senior research fellow at the Prince of Wales Clinical School in the Faculty of Medicine at the University of New South Wales in Sydney; Kristine Barlow-Stewart, PhD, is the director of the Master of Genetic Counselling Program at the University of Sydney; Alison H. Trainer, PhD, is a clinical geneticist at the Peter MacCallum Cancer Centre in Melbourne, Victoria; Kathy Tucker, MBBS, FRACP, is the head of the Hereditary Cancer Clinic at Prince of Wales Hospital; Kaaren J. Watts, PhD, is a research officer in the Psychosocial Research Group and Michael Friedlander, PhD, is a medical oncologist, both in the Department of Medical Oncology and at the Prince of Wales Clinical School in the Faculty of Medicine at the University of New South Wales; and Nadine Kasparian, PhD, is a research fellow in the School of Women's and Children's Health at the University of New South Wales, all in Australia. Support for this project was provided by a Cancer Institute New South Wales Career Development Fellowship to Meiser and a post-doctoral clinical research fellowship from the National Health and Medical Research Council of Australia (No. 510399) to Kasparian. Meiser can be reached at b.meiser@unsw.edu.au, with copy to editor at ONFEditor@ons.org. (Submitted May 2012. Accepted for publication September 19, 2012.)

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