Women's decision-making needs related to treatment for recurrent ovarian cancer: A pilot study

by Lynne J.A. Jolicoeur, Annette M. O'Connor,
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Abstract

The purpose of this pilot study was to describe the decision-making needs of women with ovarian cancer related to treatment of recurrent disease.

Design: A retrospective, cross-sectional needs assessment was conducted. Data were collected using face-to-face interviews and analyzed using content analysis.

Results: Thirteen women were recruited. Eleven women did not report difficulty in making the decision. Five women perceived that they had options. Seven had a passive role in the decision. When considering future decisions, nine women preferred a shared or autonomous role; seven wanted to be presented with options. The role of nurses in providing information was emphasized.

Conclusions: The findings provide some beginning direction for an inter-professional decision support approach, as well as implications for future research.

Ovarian cancer is the fifth-leading cause of cancer death for women in Canada (National Cancer Institute of Canada, 2008). Response rates to primary treatment for ovarian cancer range between 70% and 80%. However, recurrence occurs in 70% of women within 24 months (McGuire, 2002). When cancer recurs, there are several treatment options. The goal is to slow disease progression and manage associated symptoms. Randomized controlled trials have failed to provide clear evidence that any single treatment option provides superior long-term

survival, response rates, or improved quality of life (Fung Kee Fung, Elit, Hirte, Rosen & Members of the Gynecologic Oncology Disease Site Group, 2006). Given the lack of one superior treatment, decisions should be based on patient preferences (O'Connor et al., 2004).

There is evidence that women want more information related to ovarian cancer (Stewart et al., 2000). In one qualitative study, women reported not feeling knowledgeable enough to participate in decisions about primary treatment (Fitch, Deane & Howell, 2003). However, they felt better prepared to participate at the time of recurrence (Howell, Fitch & Deane, 2003). A decision aid may be able to address women's informational needs related to treatment options. However, it is not clear what information women with ovarian cancer value (find important to consider) in making treatment-related decisions (Fitch, Gray, DePetrillo, Franssen & Howell, 1999; Stewart et al., 2000). Only one study has reported on the types of resources and decision support interventions women with ovarian cancer prefer (Stewart et al., 2000). However, research findings show that more than half of women with ovarian cancer want to play an active role in decision-making (Howell et al., 2003; Stewart et al., 2000). Thus far, it is not clear what role women with ovarian cancer have actually had in decision-making (Elit et al., 2003; Fitch et al., 2003; Howell et al., 2003).

Purpose

The purpose of this pilot study was to describe the decision-making needs of women with ovarian cancer related to treatment of recurrent disease. The Ottawa Decision Support Framework (ODSF) (O'Connor & Jacobsen, 2007) was the conceptual framework guiding the study. The ODSF is divided into three components or processes: (1) assessing needs, which are the determinants of decisions that may be suboptimal and lead to poor decision-making; (2) providing decision support that is tailored to the needs, and (3) evaluating the decision-making process and the outcomes of the decision (Figure One).

Methodology

A pilot study was conducted in order to test the recruitment process and the interview tool. We used a retrospective cross-sectional design to describe the needs of women who had made a treatment decision and it was based on needs assessment principles (Witkin & Altschuld, 1995).

Les besoins des femmes en matière de prise de décision thérapeutique liée au cancer de l'ovaire récurrent : une étude pilote

Abrégé

Le but de cette étude pilote était de décrire les besoins des femmes en matière de prise de décision thérapeutique liée au cancer de l'ovaire récurrent.

Conception : Nous avons réalisé une évaluation rétrospective et transversale des besoins de ces femmes. Les données ont été recueillies dans le cadre d'entrevues en personne et ont fait l'objet d'analyses du contenu.

Résultats : Treize femmes ont été recrutées. Onze d'entre elles n'ont pas signalé de difficultés à prendre une décision thérapeutique. Cinq d'entre elles avaient l'impression d'avoir des options. Sept ont joué un rôle passif dans la décision. Lorsqu'elles considéraient de futures décisions, neuf des femmes ont indiqué qu'elles préféreraient jouer un rôle partagé ou autonome; sept femmes souhaitaient avoir des options. Elles ont mis l'accent sur le rôle des infirmières dans la fourniture d'information.

Conclusions : Les résultats fournissent des idées préliminaires pour un modèle interprofessionnel de soutien à la prise de décision ainsi que des implications pour la recherche future.

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The study was conducted in 2004 and employed a convenience sample of patients at one centre who had made a treatment decision for recurrent ovarian cancer between one week and three months prior to the study.

Data collection methods consisted of a review of the patient's health record and a face-to-face interview. The chart review was conducted to extract data about the women's clinical history identified as contributing factors to the decision according to the ODSF. A semi-structured interview guide was adapted from a standard needs assessment template based on the ODSF. Women were asked for their perceptions about and experience of such things as their perception of the options, their difficulty in making the decision and role in making the decision. The standard template has been validated in several clinical contexts including women with cancer at the end of life (Murray, 2001). The women's preferred role in making decisions was measured using Degner's Control Preference Scale (CPS) (Degner & Sloan, 1992). To obtain information about the actual role the participants had, a second set of cards was developed by changing the verb from "I prefer to..." to the past tense "I made the decision..." Validity for this set of cards has not been determined.

The study proposal was approved by the research ethics boards of the hospital and the university. Women were approached to participate by nurses in the day care unit. The researcher then contacted the women who were interested in participating in the study and obtained informed consent prior to conducting the interviews. Participants were informed that the interviews would be audiotaped and transcribed verbatim.

Analysis

Descriptive statistics were used to summarize chart data and interview questions with pre-coded responses. The responses to open-

ended questions were subjected to a content analysis using the principles described by Silverman (2001) in which deductive codes were established and then a count was taken of each occurrence of a code in the transcript. The determinants and respective definitions identified in the ODSF served as the deductive codes. These determinants are listed in the first column of Figure One.

Reliability was ensured by measuring inter-coder reliability to verify the inductive and deductive coding. Inter-coder agreement was established at 93%; discrepancies were resolved by consensus. Two members of the expert panel (gynecologic-oncologist, psychologist and author of ODSF) also reviewed sample transcripts and data reduction documents. Semantic validity (coding units with similar connotations together) was ensured by using the determinants of decisions and their definitions, as described in the ODSF, as the deductive codes. In addition, sections of the transcripts were verified with the author of the ODSF and expert in decision-making to ensure the coding units were correctly coded.

Results

During the five months of the study period, 34 women met the eligibility criteria, and 21 were approached to participate. Fifteen women consented. The health of two women deteriorated impairing their ability to participate. The interviews ranged in duration from 30 to 75 minutes. Of the 13 participants, the typical participant was a 57-year-old, Caucasian English-speaking woman, with a high school diploma (Table One). All participants were offered treatment and accepted it. The model participant was: diagnosed with advance stage ovarian cancer (stage 3 or 4); had platinum-sensitive disease after first-line treatment and was receiving second-line treatment.

Figure One. Ottawa Decision Support Framework

Assess needs (determinants of decisions which are sub-optimal for decision-making)	Provide decision support	Evaluate
Perception of decision Knowledge Expectations Values Decisional conflict Stage of decision-making Predisposition Perceptions of others Perceptions of others' opinion & practices Support Pressures Roles in decision-making Resources to make decision <i>Personal</i> Previous experience Self-Confidence Motivation Skill in decision-making <i>External</i> Support (information, advice, emotional, instrumental, financial, professional help) from social networks and agencies Characteristics <i>Client:</i> age, sex, marital status, education, occupation, culture, locale, medical diagnosis & duration, health status <i>Practitioner:</i> age, sex, education, specialty, culture, practice locale, experience, counselling style	Provide access to information Health situation Options Outcomes Other's opinion and choices Re-align expectations of outcomes Clarify personal values for outcomes Provide guidance/coaching in: Steps in decision-making Communication with others Handling pressure Accessing support & resources	Decision-making Reduced decisional conflict Improved knowledge Realistic expectations & norms Clear values Agreement between values & choice Implementation of chosen option Satisfaction with decision-making Outcomes of decision Persistence with choice Improved quality of life Reduced distress Reduced regret Informed use of resources

(O'Connor & Jacobsen, 2007)

Perceptions of the decision

Five of 13 participants perceived that their doctor had presented them with treatment options. Three of the five women reported that one of the options was to do “nothing”. According to the chart review, seven women were presented with options, including four of the five who perceived they had options. One patient reported being upset because she was presented with the option of “nothing,” stated: “I was a bit discouraged by that, because you know, you only expect to hear that kind of thing after you’ve exhausted every possible option that’s available”.

Another participant reported: “I don’t think we are given many options, I think you either take treatment or you die and you’re not told why you’re given certain drugs and that might be a little bit reassuring to people that we’re giving you the best and we’re not placating you.”

When women were asked about how they felt when making the decision, there was no report of difficulty in making the decision in 11 of the 13 participants. Participants talked about not having control over the situation, but having to do something or try something to control the cancer. Five women talked about having “an option”. One of the women who did experience difficulty making a decision reported that she did not have information about the pros and cons of the options that were offered and felt she was expected to make the decision immediately. The other patient attributed her difficulty to losing hope and courage, and to questioning the purpose of continuing with treatment.

All participants reported that they understood the poor prognosis associated with ovarian cancer. They knew their cancer could not be cured and they expected a recurrence. Five women described their ambivalence about wanting information. The following statement represents this feeling: “I guess you ask yourself how ovarian cancer works, but on the other hand, you don’t want to deal with the negative aspects of things”. Seven women described how they thought or knew that their cancer had recurred. They described how they had initiated the decision-making process prior to their appointment by reflecting on what they would decide if they were offered further treatment.

Table One. Demographic/characteristic of participants	
Median Age (Range)	57 (46–77)
Education	
High school	5
College	2
University	4
Graduate	2
Race	
Caucasian	13
Language	
English	11
French	2

Table Two. Women’s reported versus preferred role in decision-making				
Reported Role	Preferred Role			
		Passive	Shared	Autonomous
	Passive	1, 2, 6, 7	5, 8, 11	
	Shared		3, 4, 10, 12	
	Autonomous			9, 13
Note: The numbers correspond to the case number; the bolded numbers represent those perceiving they had been given options.				

Perception of individuals involved in the decision

As shown in Table Two, seven of 13 participants reported playing a passive role in decision-making. Of these, three would have preferred a shared role. Most women (10 of 13) reported that the role they had was the role they preferred. There appeared to be no relationship between perceiving that they had been offered options and the roles that they had or preferred.

Four women described what patients need to do in order to participate in the decision. They described how women need to: access information about treatment options; inform the practitioner that they want an active role in making the decision; and ask questions. Five women perceived that physicians could determine how the patient themselves would respond to various treatments and, therefore, felt the physicians were better able to decide on the best treatment for them.

Seven of 13 women reported that their partner was involved in the decisions; partners either shared in the decision or they provided support or information in order for the women to make the decision. Four women were alone when they made the decision, but others provided support and supported the decision they had made. Two women described taking others into consideration. For example, one woman said: “Well, my children. I always consider them in my decisions. I am a single mother... I make my decisions based on them.”

Physicians were the only practitioners identified as being present during the actual time of the decision. However, women reported as often that nurses had helped them make the decision. Nurses participated before or after the decisions were made. Participants described how nurses helped them by explaining what options might be available in the event of a recurrence. Women also described how supported they were by the nurses during chemotherapy, including “acknowledging who I am.”

Resources to make the decision

Participants were asked to describe which resources they found most helpful when making their decision. They reported that their past experience with treatment and their physical health at the time of making the decision were most important. Overall, women’s previous experience with chemotherapy was positive, which helped reduce their apprehension about having to receive further treatment. Regardless of women’s current physical health, they wanted more treatment. They either felt well physically and able to endure treatment or they felt symptomatic and believed that treatment would help improve their physical wellbeing.

Anticipated needs regarding future decisions

Women were asked to make recommendations about how practitioners in the future could best help them or other women make decisions about treatment for recurrent ovarian cancer. Eleven of 13 women wanted to be presented with more than one treatment option. Four women preferred to have options narrowed to one or a few and wanted this to be done by the physician. It was not clear why participants wanted information about options. One woman said: “I would basically follow (the recommendation)... I would like to know if we try this next type of chemotherapy and we’re not successful, then we have many tricks in our bag (other options)” (quoting physician)."

In future decisions, all the women said that they would prefer counselling (discussion) to other methods of receiving information about treatment options. They would prefer to receive this from nurses because they were perceived to have more time, to have better skills in providing information, and to know the patient better.

Participants were asked whether the number of treatment options presented to them could be shortened based on how important various treatment characteristics (e.g., benefit, side effects, and frequency of visits) were to them. Women valued treatment efficacy more than any other aspects of treatment. They perceived the negative aspects of treatment, such as side effects, frequency of visits and decreased

quality of life during treatment, to be temporary. The importance of avoiding certain side effects and the side effects that participants wanted to avoid varied among women.

Discussion

Perception of the decision

The observation that more than half of the women did not perceive they had options presented to them is consistent with other studies (Elit et al., 2003; Howell et al., 2003). Some of the women may have not considered “doing nothing” or best supportive care as an option. In prior studies, women have also failed to perceive best supportive care as an option, or felt it would be applicable a low percentage of the time (Charles, Redko, Whelan, Gafni & Reyno, 1998; Penson et al., 2004). Women may also have not perceived they had options due to poor recall of their conversation with the physician. Moreover, if they were informed of their recurrence during the visit in which options were discussed, their recall may have been affected. It has been demonstrated that recall of options is improved with the use of decision aids (Whelan et al., 2003; Whelan et al., 2004).

Generally, women did not express difficulty making the decision. This is not consistent with other studies in which decisional conflict was reported by 43% to 63% of individuals who were making cancer-/terminal illness-related decisions (Fiset et al., 2000; Murray, 2001; Stacey, O'Connor, DeGrasse & Verma, 2003). In contrast, few women in this study perceived they had options. Secondly, these studies directly measured decisional conflict using the Decisional Conflict Scale; while women in this study qualitatively described how they felt at the time they made the decision. Finally, the low report of difficulty in making the decision may well be attributed to the high level of acceptance of chemotherapy by women with ovarian cancer (Donovan, Greene, Shuster, Partridge & Tucker, 2002; Penson et al., 2004).

Perception of individuals involved in the decision

In previous studies, women with ovarian cancer have reported the desire to take a more active role in decision-making at the time of recurrence (Elit et al., 2003; Fitch et al., 2003; Howell et al., 2003; Stewart et al., 2000). However, none measured the actual role at the time of recurrence. If women do not perceive that there are options, they cannot actively participate in the decision-making process. Nevertheless, the perception that there are options did not appear to be related to the role that women reported they played. The findings may also be due to how the role women played in the decision was measured (using a modified CPS). Women's actual role may have been more accurately reported using a qualitative approach.

When asked what role they would prefer, 31% of women stated they would like a passive role in future decisions. Fewer women in previous research wanted a passive role (Elit et al., 2003; Howell et al., 2003; Stewart et al., 2000). This is most likely a random error due to sample size, or it may be due to how women were asked about role preference. It may have been preferable not to ask them about their actual role and preferred role back to back. Perhaps women did not want to admit having regret for the role they played.

A few women also described what women need to do in order to participate in future decisions. This would suggest that despite an increased acceptance of patient's participation in decision-making, more effort on the part of health care providers is needed to facilitate patient participation. Physicians and nurses should go beyond providing patients with the opportunity to ask questions, by inquiring about their preferred role in decision-making, exploring their values for each treatment option, and by clarifying their expectations. In addition, providers should offer patients sufficient information so that they don't feel the need to seek out treatment options on their own.

Preferences for future decisions

Treatments available for women with platinum-resistant recurrent ovarian cancer offer similar response rates and overall survival, and

vary only by their treatment characteristics. However, when questioned about what treatment characteristics they valued (e.g., toxicities, response rates, quality of life, survival rates, frequency of visits, route of administration), women assigned a high importance to response and survival rates, but did not put much value on the other characteristics (e.g., side effects, frequency of visits, route of administration) that would differentiate one treatment over another.

The finding that women wanted to be presented with more than one treatment option can be interpreted in several ways. Once women realize that the survival rates are comparable, they may be willing to consider the aspects of treatment that differentiates each option. Some women may want information, but may not want to participate in decision-making (Degner & Beaton, 1987). This would explain why some women may want to be presented with options; yet still want to play a passive role. The decision-making process used by women with recurrent ovarian cancer may be more in line with how patients with chronic illness (hypertension, diabetes) make decisions than with how patients make decisions in acute illness (stroke, pregnancy). Watt (2000) described the similarities and differences between decision-making in acute and chronic illness. As with chronic illness, treatment decisions for recurrent ovarian cancer focus on symptom reduction, not cure; individuals are required to make multiple and recurrent decisions. In addition, the evidence considered by patients with chronic illness is focused on the illness and the individual's lifestyle. The decision-making process is focused on the goal of symptom management, as opposed to treatment selection.

Women's preferred source of information for future decisions was counselling, followed by print materials. These results are consistent with findings reported in previous studies (Rutten, Arora, Bakos, Aziz & Rowland, 2005; Stewart et al., 2000). Interestingly, more women commented on the importance of nurses in providing information. These findings are inconsistent with other studies in which physicians were preferred as the primary source of information (Rutten et al., 2005). The preference for nurses can be explained by the model of nursing care provided in gynecologic-oncology at the participating facility. A small number of primary nurses are dedicated to this disease site group. All the nurses provide direct patient care in the day care unit, engage in telenursing and collaborate with the oncologists in the follow-up clinics.

Limitations

No participants resided outside the metro area and all participants were Caucasian. Although one cannot rule out this being a statistical artifact, another explanation may be the time involved in participating in an interview study. In subsequent studies, it would be important to include a rural population because women with breast cancer from rural areas made different decisions about treatment compared to women living in urban areas (Howe, Lehnher & Katterhagen, 1997; Stafford, Szczys, Becker, Anderson & Bushfield, 1998).

The timing of the interview may have resulted in poor recall of the discussion. In order to best assess decisional conflict and women's needs, it would have been ideal to administer the Decisional Conflict Scale and to interview women when they were actively considering options. Individuals experience higher levels of decisional conflict (O'Connor et al., 2004) and find decision support most helpful during active decision-making. Since most decisions regarding recurrent ovarian cancer are made during the visit when the discussion of options takes place, changes in practice would have been required in order to interview women between the discussion of options and making the final decision.

Due to time constraints, only the perspective of women was explored in this study. This limits the holistic understanding of the decision regarding treatment in recurrent ovarian cancer. Inclusion of family members, physicians and nurses would have given a broader perspective of the question under study.

Implications

Questions emerged that warrant further investigations: (1) what are the complementary roles of nurses and physicians in discussions about options for recurrent ovarian cancer?; and (2) is the decision-making approach in ovarian cancer more in line with the approach to decision-making in chronic illness (repetitive decisions, focused on symptom control) or is it more comparable to the typical decision-making seen in oncology (discrete decision focused on cancer treatment options such as surgery options or chemotherapy approaches)?

If the results from this study are replicated in larger studies, there may be general implications for practice. Clearly, nurses have an important role in providing patient education and support. The findings suggest that an intervention, based on the ODSF with a multidisciplinary approach to decision support, is an appropriate next step. It has been demonstrated that recall of options is improved with the use of decision aids (Whelan et al., 2003; Whelan et al., 2004). Patients have inaccurate perceptions of probabilities of outcomes

unless decision aids are used (Fiset et al., 2000; McCormack et al., 2003; Whelan et al., 2004). A decision aid may, therefore, be useful to better present information such as response rates and characteristics of treatment. It would be important to include information about best supportive care. Women in this study did not have a good understanding of this concept. A decision aid and decision support in recurrent ovarian cancer should not only address treatment options but perhaps, more importantly, when to opt for chemotherapy (now, later or perhaps not at all).

Conclusion

Despite the limitations of this study, these results provide a preliminary view of women's decision-making needs related to treatment for recurrent ovarian cancer. The findings provide some direction for the design of a multidisciplinary decision-making approach. Such an intervention would fit well in Cancer Care Ontario's strategy to improve the flow of care by developing care pathways, particularly for the centre involved in the current study. 🍀

References

- Charles, C., Redko, C., Whelan, T., Gafni, A., & Reyno, L. (1998). Doing nothing is no choice: Lay construction of treatment decision-making among women with early-stage breast cancer. *Sociol. Health Illness*, **20**, 71–95.
- Degner, L.F., & Beaton, J.I. (1987). *Life-death decisions in health care*. New York: Hemisphere Publishing.
- Degner, L.F., & Sloan, J.A. (1992). Decision-making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology*, **45**, 941–950.
- Donovan, K.A., Greene, P.G., Shuster, J.L., Partridge, E.E., & Tucker, D.C. (2002). Treatment preferences in recurrent ovarian cancer. *Gynecologic Oncology*, **86**, 200–211.
- Elit, L., Charles, C., Gold, I., Gafni, A., Farrell, S., Tedford, S., et al. (2003). Women's perceptions about treatment decision-making for ovarian cancer. *Gynecologic Oncology*, **88**, 89–95.
- Fiset, V., O'Connor, A.M., Evans, W., Graham, I., DeGrasse, C., & Logan, J. (2000). Development and evaluation of a decision aid for patients with stage IV non-small cell lung cancer. *Health Expectations*, **3**, 125–136.
- Fitch, M.I., Deane, K., & Howell, D. (2003). Living with ovarian cancer: Women's perspectives on treatment and treatment decision-making. *Canadian Oncology Nursing Journal*, **13**(1), 8–20.
- Fitch, M.I., Gray, R.E., DePetrillo, D., Franssen, E., & Howell, D. (1999). Canadian women's perspectives on ovarian cancer. *Cancer Prevention & Control*, **3**, 52–60.
- Fung Kee Fung, M., Elit, L., Hirte, H., Rosen, B., & Members of the Gynecologic Oncology Disease Site Group. (2006). *Chemotherapy for recurrent epithelial ovarian cancer previously treated with platinum*. Cancer Care Ontario.
- Howe, H.L., Lehnher, M., & Katterhagen, J.G. (1997). Effects of physician outreach programs on rural-urban differences in breast cancer management. *Journal of Rural Health*, **13**, 109–117.
- Howell, D., Fitch, M.I., & Deane, K.A. (2003). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, **26**, 10–17.
- McCormack, J.P., Dolovich, L., Levine, M., Burns, S., Nair, K., Cassels, A., et al. (2003). Providing evidence-based information to patients in general practice and pharmacies: What is the acceptability, usefulness and impact on drug use? *Health Expectations*, **6**, 281–289.
- McGuire, W.P. (2002). *Patient active guide to living with ovarian cancer*. Ref type: Slide.
- Murray, M.A. (2001). *Women's decision-making needs regarding location of care in the last weeks of life for a terminal illness: A pilot study*. Master's of Science in Nursing, University of Ottawa.
- National Cancer Institute of Canada. (2008). *Canadian Cancer Statistics 2008*. Retrieved from www.cancer.ca
- O'Connor, A.M., & Jacobsen, M.J. (2007). *Decisional conflict: Supporting people experiencing uncertainty about options affecting their health* [PDF monograph on the Internet]. Ottawa: Ottawa Health Decision Centre.
- O'Connor, A.M., Stacey, D., Entwistle, V., Llewellyn-Thomas, H., Rovner, D., Holmes-Rovner, M., et al. (2004). *Decision aids for people facing health treatment or screening decisions* (Cochrane Review). The Cochrane Library, Chichester, U.K.: John Wiley & Sons, Ltd.
- Penson, R.T., Digman, F., Seiden, M.V., Lee, H., Gallagher, C.J., Matulonis, U.A., et al. (2004). Attitudes to chemotherapy in patients with ovarian cancer. *Gynecologic Oncology*, **94**, 427–435.
- Rutten, L.J., Arora, N.K., Bakos, A.D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: A systematic review of research. *Patient Education and Counseling*, **57**, 250–261.
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analyzing talk, text and interaction* (2nd ed.). London: Sage Publications.
- Stacey, D., O'Connor, A. M., DeGrasse, C., & Verma, S. (2003). Development and evaluation of a breast cancer prevention decision aid for higher-risk women. *Health Expectations*, **6**, 3–18.
- Stafford, D., Szczys, R., Becker, R., Anderson, J., & Bushfield, S. (1998). How breast cancer treatment decisions are made by women in North Dakota. *American Journal of Surgery*, **176**, 515–519.
- Stewart, D.E., Wong, F., Cheung, A.M., Dancy, J., Meana, M., Cameron, J.I., et al. (2000). Information needs and decisional preferences among women with ovarian cancer. *Gynecologic Oncology*, **77**, 357–361.
- Watt, S. (2000). Clinical decision-making in the context of chronic illness. *Health Expectations*, **3**, 6–16.
- Whelan, T., Levine, M., Willan, A., Gafni, A., Sanders, K., Mirsky, D., et al. (2004). Effect of a decision aid on knowledge and treatment decision-making for breast cancer surgery: A randomized trial [see comment]. *JAMA*, **292**, 435–441.
- Whelan, T., Sawka, C., Levine, M., Gafni, A., Reyno, L., Willan, A., et al. (2003). Helping patients make informed choices: A randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer [see comment]. *Journal of the National Cancer Institute*, **95**, 581–587.
- Witkin, B.R., & Altschuld, J.W. (1995). *Planning and conducting needs assessments: A practical guide*. Thousand Oaks, CA: Sage Publications.