



uOttawa

L'Université canadienne
Canada's university

FACULTÉ DES ÉTUDES SUPÉRIEURES
ET POSTDOCTORALES



FACULTY OF GRADUATE AND
POSTDOCTORAL STUDIES

Lynne Jolicoeur

AUTEUR DE LA THÈSE / AUTHOR OF THESIS

M.Sc. (Nursing)

GRADE / DEGREE

School of Nursing

FACULTE, ÉCOLE, DÉPARTEMENT / FACULTY, SCHOOL, DEPARTMENT

Women's Decision Making Needs Related To Recurrent Ovarian Cancer: A Pilot Study

TITRE DE LA THÈSE / TITLE OF THESIS

Dr. Annette O'Connor

DIRECTEUR (DIRECTRICE) DE LA THÈSE / THESIS SUPERVISOR

CO-DIRECTEUR (CO-DIRECTRICE) DE LA THÈSE / THESIS CO-SUPERVISOR

EXAMINATEURS (EXAMINATRICES) DE LA THÈSE / THESIS EXAMINERS

Kathryn A.S. Higuchi

A. Kirsten Woodend

Gary W. Slater

Le Doyen de la Faculté des études supérieures et postdoctorales / Dean of the Faculty of Graduate and Postdoctoral Studies

**Women's Decision Making Needs Related to Treatment for Recurrent
Ovarian Cancer: A pilot study**

Lynne J.A. Jolicoeur, RN

Thesis submitted to the School of Graduate Studies & Research
in part time fulfillment of the requirements for
the degree of Masters of Science of Nursing

University of Ottawa
April, 2006



Library and
Archives Canada

Bibliothèque et
Archives Canada

Published Heritage
Branch

Direction du
Patrimoine de l'édition

395 Wellington Street
Ottawa ON K1A 0N4
Canada

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file *Votre référence*
ISBN: 978-0-494-18430-1
Our file *Notre référence*
ISBN: 978-0-494-18430-1

NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.


Canada

Acknowledgements

A research study such as this cannot be completed without the assistance of many people. I would like to thank Dr Annette O'Connor, my thesis advisor for sharing her expertise in patient decision making, and for giving me the necessary guidance and support to conduct this study, and to develop my skills as a nurse researcher. This thesis would not have been possible without the support of the other members of my thesis committee, Dr Ian Graham and Dr Laura Hopkins, who provided me with their expertise in qualitative research methodology and of gynecologic oncology respectively. Thanks are extended also to Liz Drake for her great editorial skills.

Thank you to all my colleagues in the gynecologic-oncology program who encouraged and assisted me during this study. Thanks to Monique for providing her expertise in this study and for sharing her perspective on the concept of hope. Thanks also to the primary nurses of the day care unit for their encouragement and assistance with subject recruitment. Without all of you this study would not have been possible.

I would like to take this opportunity to thank the Nursing Professional Practice Department of the Ottawa Hospital and more specifically, the selection committee for the Karen Taylor Nursing Bursary, for the financial support I received throughout my Masters education.

And finally, I would like to thank the many people who supported and encouraged me during my graduate studies. Thank you to my husband Alain for taking on more than 50% of the responsibility of running a home and caring for our son Samuel. Thank you to my family and friends for caring for Samuel for a day or a weekend to give me time to work. And last but not least, thanks to Samuel and my baby Marjorie for simply being there.

Abstract

Context: Ovarian cancer is the 5th leading cause of cancer death among women in Canada (National Cancer Institute of Canada, 2005). It is estimated that 2,400 women were diagnosed in Canada in 2005. Unfortunately mortality for ovarian cancer is high; in 2005 approximately 1,550 Canadian women died of the disease (National Cancer Institute of Canada, 2005). Despite response rates to primary treatment of between 70 and 80%, 70% of cancers will recur within 24 months (McGuire, 2002).

Due to an increasing number of chemotherapy options available for recurrent ovarian cancer, its management has shifted from a palliative approach to that of a chronic disease approach (Fitch & Turner, 2003b). Randomized controlled trials have failed to demonstrate clear evidence that any one treatment provides superior long-term survival, response rates, or better quality of life (Fung Kee Fung, Elit, Hirte, Rosen, & Members of the Gynecologic Oncology Disease Site Group, 2003). It has been suggested that, in the absence of such evidence, treatment decisions should be based on patient preference (O'Connor et al., 2004).

Objectives: The purpose of this pilot study was to describe the decision making needs of women considering treatments for recurrent ovarian cancer.

Design: A retrospective, cross-sectional needs assessment was conducted to describe the treatment decision making needs of women with recurrent ovarian cancer. Data were collected from women using face-to-face interviews. A semi-structured interview guide was developed based on the Ottawa Decision Support Framework and a standard template developed by Jacobsen and O'Connor (1998). The data were analyzed using Silverman's (2001) approach to content analysis.

Setting: The Regional Gynecologic-Oncology Program of the participating center.

Participants: Thirteen women with recurrent ovarian cancer who had made treatment decisions within the past 3 months were recruited from the outpatient day care unit.

Outcome measures: Participants' views of their needs when considering treatment decisions for recurrent ovarian cancer. The interview guide elicited: perceptions of the decision including decisional conflict; perceptions of others involved in the decision; resources to make the decision; and individual characteristics. The Control Preference Scale was used to measure role preference (Degner & Sloan, 1992). Additional questions were asked about the extent to which hope influenced decisions.

Results: Only five of 13 women perceived that they had options, only two of 13 had manifestations of decisional conflict. All women understood the poor prognosis associated with ovarian cancer. Seven of 13 women had played a passive role in the treatment decision. When considering future decisions, 9 of 13 women stated that they would prefer a shared or autonomous role. Moreover, 7 of 13 women wanted to be presented with options. Participants valued the role of nurses in providing information. In addition, the women identified hope as an important element in their lives.

Conclusions: This pilot study provides preliminary information on women's decision making needs related to treatment for recurrent ovarian cancer. The findings need to be replicated in a study with a larger sample and in multiple centers before recommendations can be made. The findings also 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.

Table of content

Abstract	3
List of Figures	7
List of Tables.....	8
Chapter One.....	9
1.1 Introduction	9
1.2 Research problem.....	9
1.3 Purpose of the study	12
Chapter Two.....	13
2.1 The Ottawa Decision Support Framework (ODSF).....	13
2.2 The additional construct of hope.....	15
2.3 Rationale for use of the framework.....	16
2.4 Search method.....	17
2.5 Perception of the decision	18
2.5.1 Knowledge of ovarian cancer.....	18
2.5.2 Stage of decision making	19
2.6 Perception of others: roles, support and pressure.....	19
2.7 Resources: Informational needs	21
2.8 Client characteristics	23
2.9 Hope.....	23
2.10 Summary	24
Chapter Three.....	26
3.1 Research design.....	26
3.2 Sample.....	26
3.3 Sample size.....	26
3.4 Inclusion criteria.....	27
3.5 Exclusion criteria.....	27
3.6 Setting.....	28
3.7 Data collection method.....	28
3.8 Interview guide development	29
3.8.1 Specific needs assessment questions in the interview guide.....	29
3.8.2 Validity of the interview guide.....	32
3.8.3 Pilot testing.....	33
3.9 Data collection procedures	33
3.9.1 Recruitment.....	33
3.9.2 Interview.....	33
3.10 Protection of human rights	34
3.11 Data analysis	35
3.12 Procedures to ensure data quality.....	35
3.12.1 Quality of the interviewer's interpretation of participants' responses at the time of the interview	36
3.12.2 Quality of the transcription	36
3.12.3 Quality of the analysis.....	36

Chapter Four: Results.....	38
4.1 Participant recruitment and interviews.....	38
4.2 Decision making needs.....	39
4.2.1 Participants' demographic and clinical characteristics	39
4.2.2 Perceptions of the decision.....	40
4.2.3 Perception of others.....	44
4.2.4 Resources to make the decision	48
4.2.5 Practitioner's characteristics	50
4.2.6 Hope	51
4.2.7 Anticipated needs regarding future decisions	53
Chapter Five: Discussion	58
5.1 Sample characteristics	58
5.2 Perception of the decision	59
5.3 Perception of others.....	62
5.4 Preferences for future decisions	64
5.5 Hope	66
5.6 Limitations	68
5.7 Implications for future research	70
5.8 Implications for practice.....	70
5.8.1 Implications for advance practice nurses	71
5.9 Implications for theory	72
5.10 Conclusion.....	72
Appendix A: The Evidence	80
Appendix B: Data collection Sheet	91
Appendix C: Interview Guides.....	92
Appendix D: Control Preference Scales.....	108
Appendix E: REB approval letters	113
Appendix F: Letters of information/Consent Forms	116

List of Figures

Figure 1.1: Summary of chemotherapy options.....	11
Figure 2.1: Ottawa Decision Support Framework.....	14
Figure 4.1: Accrued and interviewed participants.....	38
Figure 4.2 Practitioners involved in the decision or in information provision.....	47
Figure 4.3 Helpful resources.....	49

List of Tables

Table 2.1: Definitions of Determinants of Decisions from the ODSF.....	15
Table 4.1: Demographic/characteristic of participants.....	39
Table 4.2: Treatment history of participants and non participants.....	40
Table 4.3: Options.....	41
Table 4.4: Women’s reported versus preferred role in decision making.....	44
Table 4.5 Help received from Practitioners regarding decision making.....	47
Table 4.6: other resources.....	50
Table 4.7 number of options preferred.....	53
Table 4.8: Preferred source of information.....	54
Table 4.9: preferred counsellor to provide information.....	55
Table 4.10: content of information.....	56
Table 4.11 Values for treatment characteristics.....	57

Chapter One

1.1 Introduction

Little is known about how women make treatment decisions when faced with recurrent ovarian cancer. The current pilot study describes women's decision making needs related to the treatment for recurrent ovarian cancer.

1.2 Research problem

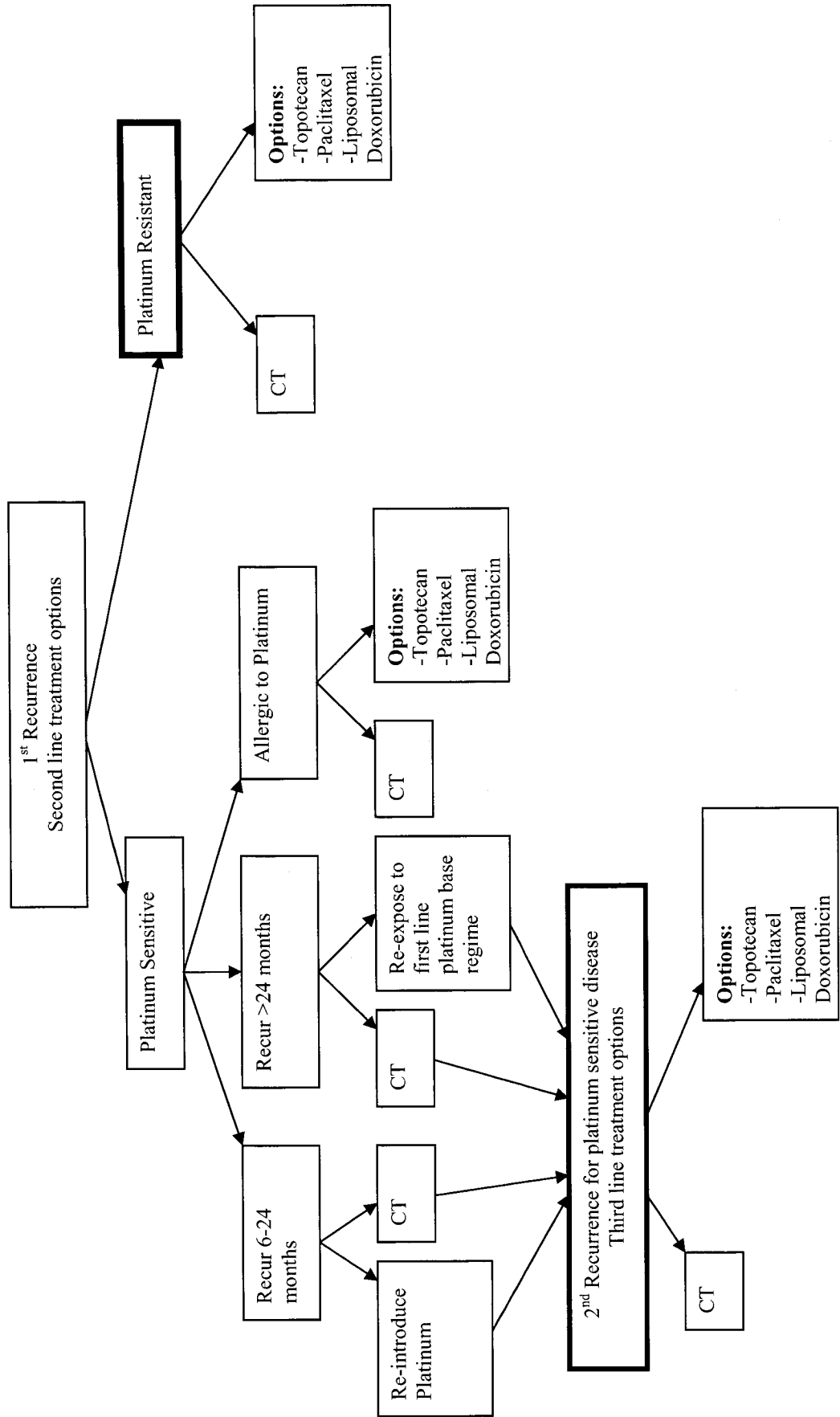
Ovarian cancer is the fifth leading cause of cancer death among women in Canada (National Cancer Institute of Canada, 2005). It is estimated that 2,400 women were diagnosed with ovarian cancer in Canada in 2005 and 1,550 women died from the disease. Seventy percent of women with ovarian cancer are diagnosed with advanced stage disease (stage 3 or 4) which carries a five year survival rate of 20% (Howell, 1998). Response rates to primary treatment range between 70 and 80%; however, ovarian cancer will recur in 70% of women within 24 months (McGuire, 2002). Response to second-line treatment is based on whether individuals have platinum-sensitive or platinum-resistant tumors. Patients who relapse within six months are considered to have platinum-resistant disease; and those who do not relapse for a period of at least six months, are said to have platinum-sensitive disease (Fung Kee Fung et al., 2003).

The mean response rates to second line therapy for platinum-sensitive disease range from 20% to 58%. For platinum-resistant disease, response rates are poorer, ranging from 6% to 54%. Time to progression following second line therapy, defined as the time from completion of treatment to disease recurrence or disease progression, ranges from 15 to 76 weeks in platinum sensitive disease and 7 to 40 weeks in platinum resistant disease (Fung Kee Fung et al., 2003). Due to an increasing number of options available for subsequent lines of treatment, the

management of advanced ovarian cancer is shifting from a purely palliative approach to that of the management of a chronic disease (Fitch et al., 2003b). When cancer recurs we now have more than one treatment option, for some this may mean several treatment lines for recurrent cancer before death.

For patients with recurrent ovarian cancer, the goal of chemotherapy is to slow the progression of the disease and to control its associated symptoms. Figure 1.1 summarizes the treatment guideline for recurrent ovarian cancer (Fung Kee Fung et al., 2003). Randomized controlled trials have failed to provide clear evidence that any single treatment option provides superior long-term survival, response rates, or better quality of life (Fung Kee Fung et al., 2003). It has been suggested that in the absence of such evidence, treatment decisions should be based on patient preferences (O'Connor et al., 2004).

Figure 1.1: Summary of chemotherapy options for recurrent epithelial ovarian cancer previously treated with platinum



Bolded squares represent the population of interest.

CT: Clinical Trials
(Fung Kee Fung et al., 2003)

It is not currently standard practice to share treatment decision making with patients with recurrent ovarian cancer. This is due to the complexity of the available treatments and the time required of practitioners to present all of the options. In addition, little is known about how women with recurrent ovarian cancer make treatment-related decisions. Most of the literature published about decision making in women with ovarian cancer focuses on decisions related to genetic testing, prophylactic oophorectomy, or screening for ovarian cancer. There are few studies on patient decision making post-diagnosis of ovarian cancer (Elit et al., 2003; Elit et al., 1996; Fitch, Deane, & Howell, 2003a; Stewart et al., 2000). Only one study was found that examined patient decision making in the setting of recurrent disease (Donovan, Greene, Shuster, Partridge, & Tucker, 2002). In this study of healthy women and those receiving first line treatment for recently diagnosed ovarian cancer, a decision board was used to elicit their hypothetical preferences between palliative care and salvage chemotherapy in the event of a recurrence. Compared to the healthy women, those with ovarian cancer were more likely to choose staying on the chemotherapy longer before switching to palliative care. In this study, patient participants did not actually have recurrent disease. Therefore, research is required to better understand how to support women making decisions about recurrent ovarian cancer.

1.3 Purpose of the study

The purpose of this pilot study is to describe the treatment decision making needs of women with recurrent ovarian cancer. The study findings may lead to improved patient education and the development of evidence-based decision support interventions.

Chapter Two

In this chapter, we present the conceptual framework which guided the current study. The literature search methodology is described and the empirical evidence around the determinants of treatment decision making in women with ovarian cancer is discussed. This chapter concludes by clarifying the study objective.

2.1 The Ottawa Decision Support Framework (ODSF)

The Ottawa Decision Support Framework (O'Connor & Jacobsen, 2001) is based on the theoretical constructs of decisional conflict (Hiltunen, 1989; Janis & Mann, 1977), decision analysis (Keeney & Raiffa, 1976), decision making (Feather, 1980), social psychology (Ajzen & Fishbein, 1980; Tversky & Kahneman, 1981), self-care (Orem, 1995), and social support (Norbeck, 1988).

The ODSF is divided into three components or processes: (1) assessing needs, which are the determinants of decisions that may be sub-optimal; (2) providing decision support that is tailored to the needs, and (3) evaluating the decision making process and the outcomes of the decision (Figure 2.1).

According to the framework, several determinants may be sub-optimal and lead to poor decision making. For example, a patient's decision may be based on inadequate knowledge, unrealistic expectations, unclear values, high decisional conflict, inadequate support, pressure, or the inability to play the role that they prefer in the decision. Patients may have inadequate access to resources such as information or advice. Demographic characteristics and clinical functioning may also affect capacities for decision making. Decision support interventions can address these deficits by providing information, realigning expectations, clarifying values, and providing

guidance and coaching in decision making. As a consequence, indicators of the quality of decision making and decision outcomes may improve.

This study focuses on the first component: assessing needs. These needs include: the perception of the decision; the perception of others' opinion; personal and external resources to make the decision; and individual and practitioner characteristics. Each of the needs identified in the ODSF are defined in Table 2.1.

Figure 2.1: Ottawa Decision Support Framework

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

Table 2.1: Definitions of needs in the Ottawa Decision Support Framework

Participants' Perceptions of the Decision	
Knowledge	Cognizance of the health problem or situation, opinion and outcomes
Expectations of outcomes	Perceived likelihood or probability of outcomes of each option
Values for outcomes	Desirability or personal importance of outcomes of options
Decisional conflict	Uncertainty about course of action to take
Stage of decision making	Phase of decision making in the context of stages of change: pre-contemplation (not thinking about change or choices); contemplation (considering options); preparation (taking steps towards change, may be considering options); action (change for less than 6 months); maintenance (change for at least 6 months)
Predisposition	Degree to which a person is leaning strongly towards choosing an option or is uncertain
Participants' perception of others involved in Decision Making	
Perception of others' opinion and practices	Perceptions of what others decide or what others think is the appropriate choice. For the client, important others may include their spouse, family, peers, and practitioner(s). For the practitioner, it may include the client, professional peers, and personal network.
Support	Informational, emotional, and tangible help from important others to bolster and sustain decision making.
Pressure	Perception of persuasion, influence, coercion from important others to select one alternative
Role in decision making	The way a participant is or wants to be involved in decision making with others; do they wish to make the choice themselves after considering others opinions, do they want to share decision making with someone else, do they want others to make the decision for after considering their opinion.
Participants' Resources for Decision Making	
Personal	
Previous Experience	Previous exposure to the situation, options, outcomes, decision making process
Self-confidence	Belief in one's abilities in decision making, including shared decision making
Motivation	Readiness and interest in decision making, including shared decision making
Skill	Ability in making and implementing a decision
External	
Type	Available and access to information, advice, emotional support, instrumental help, financial assistance, and health & social services
Source	social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors
Participants' Characteristics	
Client/Patient	Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social)
Practitioner	Age, gender, ethnicity, clinical education and specialty, practice locale, years of experience, counselling style

2.2 The additional construct of hope

Authors have suggested that hope may influence patient decision making (Donovan et al., 2002; Ehrenberger, Allgood, Thomas, Wallace, & Licovoli, 2002; Murray, 2001; Olver, Elliot, & Blake-Mortimer, 2002). Hope is defined as “a multidimensional dynamic life force

characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant. Hope has implication for action” (Dufault & Martocchio, 1985). It has been suggested that in order to maintain hope at the time of palliation, patients prefer to avoid certain information, leaving the decision making up to their practitioners (de Hays & Koedoot, 2003).

The term ‘hope’ is not used in the Ottawa Decision Support Framework. However, the construct has some conceptual similarity to ‘expectations’. In this thesis, the construct was considered separately from the framework.

2.3 Rationale for use of the framework

Quality decisions have been defined as those that reflect the considered needs, values and expressed preferences of a well informed patient and are implemented (Sepucha, Fowler, & Muller, 2004). In a prior concept analysis of patient decision making (Jolicoeur, 2002) the ODSF (O'Connor et al., 2001) was identified as the theoretical framework that best guides the assessment of individual information needs (about the problem, the available options, and expectations), individual values (what is personally important), and interventions required to address these identified needs. The ODSF has been used to guide previous needs assessments of both individual and population decision making (DeGrasse, 1995; Murray, 2001; Wood, 1995). It has also been used in other advanced cancer care settings (Fiset et al., 2000; Murray, 2001) and with other populations of women diagnosed with cancer (Murray, 2001; Stacey, O'Connor, DeGrasse, & Verma, 2003).

The ODSF framework was developed for health decisions that: (1) are stimulated by new circumstances, diagnoses, or developmental transitions; (2) require careful deliberation and/or assessment of the advantages and disadvantages based on personal values; and (3) need more

effort in the deliberation phase than in the implementation or action phase (O'Connor et al., 2001). The decision about treatment for recurrent ovarian cancer clearly meets these criteria.

2.4 *Search method*

Literature cited in this review was identified through a search of Medline, PsycINFO, HealthStar, Cancerlit and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. Publications from 1996 to 2004 were included in the search strategy. Search terms included: decision making, patient decision making, choice behaviour, patient satisfaction, patient participation, informed consent, decision support techniques, patient preference, patient education, and information seeking behaviour. These search terms were then combined with the term ovarian neoplasm resulting in a total of 193 citations. One hundred and seventy four (174) publications related to physician decision making and women's decision making about screening and early detection of ovarian cancer were excluded from the review. Nineteen publications were retained for closer perusal. Eight of these were excluded because they did not reflect the patients' perspective; 11 articles were retained and included in the literature review. Literature summary tables are found in appendix A.

Research on 'hope' was explored in a separate search. The PsychInfo and CINAHL databases were searched using the term 'hope' combined with 'neoplasm' and decision making. This search generated an additional 10 publications: six publications were incorporated into the literature review and four were excluded because they were not directly relevant.

The research studies on decision making needs are organized according to the ODSF; research on hope is presented separately.

2.5 *Perception of the decision*

2.5.1 *Knowledge of ovarian cancer*

Very little research has been conducted on women's knowledge of ovarian cancer.

Women's knowledge of ovarian cancer and its treatment options in first line therapy was measured in a study by Elit et al. (1996). Twelve women were asked to complete a 10-item true/false questionnaire to measure understanding of information presented during a decision support intervention. The questionnaire was completed by patients after they were presented with the decision support intervention. Ninety-two percent of the participants answered the comprehension questions correctly. It would have been interesting to see whether these knowledge scores persisted one week following the decision support intervention. It has been the researcher's experience that oncology patients have difficulty remembering information discussed during consultation visits. It is not clear, if the women in this study had access to print material after the decision support intervention for review at home with their family.

In a national mail survey of women with ovarian cancer, 55% of women (out of 315) reported having received information about staging, most (85%) felt they knew the stage of their ovarian cancer when this information was provided to them. (Fitch, Gray, DePetrillo, Franssen, & Howell, 1999).

Women who participated in a qualitative study (n=18) of their experience of ovarian cancer, reported not feeling knowledgeable enough to participate in decisions about primary treatment (Fitch et al., 2003a). However, women reported that their understanding of the disease increased over time and that they felt better prepared to participate in decision making at the time of recurrence (Howell, Fitch, & Deane, 2003). Similar findings were reported in a qualitative study conducted by Elit et al. (2003) in which women's perception of the decision they made about first line treatment for ovarian cancer was described. Participants spoke about feeling

uncomfortable making decisions about treatment at the time of diagnosis and were more able to articulate the risks of treatment than the benefits. A quarter of the women in this study (5/21) over-estimated the potential benefits of treatment (Elit et al., 2003). In addition, 35% of women could not report the number of chemotherapy agents they were receiving. These findings may be due to lack of understanding, lack of recall of the discussion with the health care team, or perhaps due to other factors such as hope.

In summary, there is limited empiric evidence about what women understand about ovarian cancer and its treatment.

2.5.2 Stage of decision making

It has been demonstrated that factors relating to timing appear to have an impact on women's ability to make decisions. These factors include: the readiness to make the decision (Elit et al., 2003; Fitch et al., 2003a), urgency to get treatment underway (Ekwall, Ternstedt, & Sorbe, 2003), and the diagnosis coinciding with other life events (Elit et al., 2003). Women also described feeling pressured to decide (Ekwall et al., 2003; Elit et al., 2003; Fitch et al., 2003a; Howell et al., 2003)

2.6 Perception of others: roles, support and pressure

Role and participation in decision making. Twelve of 21 women (57%) with ovarian cancer who participated in a telephone interview about their decision making experience at the time of diagnosis, reported that they made the decision about their treatment (Elit et al., 2003). However, only four (19%) perceived that they had been presented with treatment options. Three of the four women who reported not wanting any chemotherapy initially, received chemotherapy in the end. It is not clear how this happened. Only one woman described a shared decision making process (Elit et al., 2003). Although more than half of the women reported participating

in making the decision about treatment, evidence of shared decision making as defined by the 'McMaster Shared Decision Making Model' was not apparent.

The reason for the small proportion of women who perceived that they had options may be due to the nature of first line treatments. It is well established that a combination of Carboplatinum and Taxol is the treatment of choice (Covens, Bryson, Verma, Fung Kee Fung, & Members of the Gynecologic Disease Site Group, 2004). A single drug regimen would usually only be considered in women with lower performance status (spending more than 50% of time in bed and needing assistance to perform activities of daily living). The majority of the women in the Elit study (2003) would only have been offered the combination treatment.

Two publications arising from the same qualitative study of 18 women with ovarian cancer (Fitch et al., 2003a; Howell et al., 2003), reported on the role women played in decision making about their treatment. However, decision making in ovarian cancer was not the primary focus of this study. Women described passive roles at the time of primary therapy (Fitch et al., 2003a) and an increased need for involvement and control over decisions at the time of recurrence (Howell et al., 2003). It is not clear whether women actually had a more active role when their cancer recurred nor is it clear how many of the 18 women experienced a recurrence.

The need for increased involvement in decision making was also expressed by ovarian cancer survivors during the 1999 Forum on Ovarian Cancer. Survivors expressed the need for empowerment training in order to enhance their ability to participate in decision making (National Ovarian Cancer Association, 1999).

Stewart et al. (2000) surveyed 105 women with ovarian cancer to assess their information needs and decision preferences. They measured role preference using the Decision Preference Scale (Degner et al., 1997). Results indicated that 62% of women desired a shared decision making approach, 15% preferred an autonomous role and 22% preferred a passive role. Role

preference was influenced by women's perception of their illness ($p=0.001$). Women, who perceived their cancer to be very serious or had metastatic disease, tended to prefer a shared decision making role. This is the only trial that has examined role preference using a valid and reliable tool in women with ovarian cancer.

The evidence suggests that women appear to play a more passive role in decision making in the first line setting but prefer a more active role when considering subsequent lines of treatment.

Support and Pressure. Fitch et al (2003a) and Howell et al (2003) also reported on women's perceptions of support and pressure related to decision making. Participants reported that positive and negative comments from their personal support network or their health care team had an impact on their decision making (Fitch et al., 2003a; Howell et al., 2003).

2.7 Resources: Informational needs

Only one study has specifically explored the information needs of women with ovarian cancer (Stewart et al., 2000). Results indicated that 82 to 90% of women wanted detailed information about their treatment options. Participants in this study favoured information about their cancer and its treatment over psychosocial information, which is consistent with findings from other studies (Feldman-Stewart, Chammas, Hayter, Pater, & Mackillop, 1996; Fitch et al., 1999; Stewart et al., 2000) that examined issues other than active decision making needs. The amount, type, and focus of information did not vary across the cancer trajectory; however, education, age, and psychological functioning (measured by the Rand Mental Health Inventory) influenced women's preference for information. Well-educated women wanted more detailed information. Older women, who had high levels of psychological functioning, tended to want only information about the physical aspects of their cancer and its treatment. Women under 60,

who had higher levels of depression, were significantly more likely to be concerned with information on coping techniques. Women who had lower levels of depression wanted information on “the best possible” outcomes.

In the national survey of 315 women with ovarian cancer that examined their overall needs; 81% felt that being given information about treatment choices was important and 66% were satisfied with the amount of information they received (Fitch et al., 1999). Findings also showed no statistically significant differences between women with or without recurrence in their level of satisfaction with information provided (Fitch, Gray, & Franssen E., 2000). Despite feeling overwhelmed, women described searching for information on their own to meet their learning needs (Fitch et al., 2003a). Women with recurrent disease reported greater difficulty in accessing information about treatment options. In addition, some of the women expressed the need to be their own advocate; some even requested a second opinion (Howell et al., 2003).

Findings from this study were presented during the 1999 Forum on Ovarian Cancer during which women questioned whether all options were being presented to them, and whether there was consistency in the availability of options across the country (National Ovarian Cancer Association, 1999). Since that time, practice guidelines have been developed to standardize the management of recurrent ovarian cancer (Fung Kee Fung et al., 2003) which should enhance the consistency of treatment options offered to women. Moreover, informational resources provided by the National Ovarian Cancer Association (NOCA) and support groups are now available to women living with this disease.

One of the recommendations of the 1999 Ovarian Cancer Forum was that decision support interventions such as decision aids should be made available to women facing decisions about ovarian cancer treatment (National Ovarian Cancer Association, 1999). Despite increased resources in cancer care, no such decision aids are available.

Decision aid developers should be aware that research indicates that women prefer to receive information from their oncologist or other health care provider (Fitch et al., 1999; Stewart et al., 2000). However, these women also want access to printed material and up to 50% report they would consider using CD-ROMS or the Internet (Stewart et al., 2000). Women also obtained information from other resources such as support groups. More women with recurrent ovarian cancer (27%) than women in first-line treatment (19%) reported using support groups to access information. However, less than 20% of women had the opportunity to participate in such groups (Fitch et al., 2000).

Overall, the available evidence suggests that women want information about their cancer and its treatment, and that multiple sources of information are required to meet their needs.

2.8 *Client characteristics*

Women have described that decreased physical (Elit et al., 2003; Fitch et al., 2003a; Howell et al., 2003) and psychosocial health (Elit et al., 2003; Howell et al., 2003), due to the cancer or its treatment, prevented them from participating in decision making to the degree they desire. In addition, women who had had difficulty with previous chemotherapy, initially tended to opt for palliative care over salvage therapy (Donovan et al., 2002).

2.9 *Hope*

Participants (n=23) in a face-to-face interview reported that if they had any hope of survival, they would not opt for a “do not resuscitate” (DNR) order; they would wait until their physician indicated there was “no hope.” Hope, in this study influenced the choice of agreeing to a DNR order (Olver et al., 2002). Contrary to these findings, Ehrenberger and colleagues (2002) did not find that the level of hope, measured by the Herth Hope Index, influenced the decision of women newly diagnosed with cancer (n=40) to participate in a clinical trial. Elliott and Olver

(2002) recommended that when studying hope, researchers should seek to understand its meaning qualitatively rather than quantitatively.

The importance of hope for women with ovarian cancer has been documented in the literature (Bowes, Tamlyn, & Butler, 2002; Donovan et al., 2002). Bowes et al. (2002) interviewed nine women with ovarian cancer and explored the emotion of anger and “dealing with an early death.” Hope was identified as a necessary condition for women to find meaning and perspective in their lives after diagnosis. Another study, which included 81 women with ovarian cancer, examined the preference for palliative care or salvage therapy (chemotherapy given with aim of controlling symptoms and slowing disease progression) or palliative care at the time of recurrence (Donovan et al., 2002). The conclusion of the authors was that hope may outweigh all other psychological constructs when looking at treatment preference in recurrent ovarian cancer.

2.10 Summary

In summary, there is evidence that women want more information related to ovarian cancer (Fitch et al, 2003; Howell et al, 2003; Fitch et al, 1999; Stewart et al, 2000). 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. Only one study reported on the types of resources and decision support interventions women with ovarian cancer would prefer. There is a dearth of literature in relation to the decision making needs of women using a comprehensive model/framework in decision making.

Research findings show that more than half of women with ovarian cancer want to play an active role in decision making. However, it is not clear what role women have actually had in

decision making and whether hope is a determinant in their decision making. Empirical evidence justifies the need to further investigate hope as a determinant of the decision in this population.

Based on findings from the literature and the researcher's clinical expertise further research seemed warranted. The purpose of this pilot study was to describe the decision making needs of women with ovarian cancer related to treatment of recurrent disease. More specifically, this pilot needs assessment study using the Ottawa Decision Support Framework (ODSF) (O'Connor et al., 2001) aimed at describing the following needs: women's knowledge of ovarian cancer and of options for treating recurrent disease; their expectations of outcomes for each options and associated side effects; their values for outcomes (that is the benefits, harms and side effects important to women in making treatment decisions); their actual role in decision making as well as their preferred role; and finally the resources that were available to make the decision.

Chapter Three

This chapter describes the research design, sample, setting, data collection method, interview guide development, data collection procedures, protection of human rights, and data analysis. The chapter concludes with an overview of the procedures used to ensure quality.

3.1 *Research design*

This pilot study used a retrospective cross-sectional design to describe the needs of women who had made a recent treatment decision and was based on needs assessment principles (Polit & Beck, 2004; Witkin & Altschuld, 1995). A need was defined as a gap between the current state and the desired state of affairs (Witkin et al., 1995). “A needs assessment is a set of procedures undertaken to set priorities and making decisions about program and organizational improvement and allocation of resources” (Witkin et al., 1995). The decision making needs of women with recurrent ovarian cancer was assessed.

3.2 *Sample*

The study employed a convenience sample of patients of the Ottawa Hospital who had recently made a treatment decision for recurrent ovarian cancer.

3.3 *Sample size*

For this pilot study, a sample size of 20 consecutive patients was planned. A sample size of ten to 20 is sufficient for a pilot study (Frank-Stromborg & Olson, 2004). In the fiscal year 2004-2005, 175 women received care for ovarian cancer in the hospital’s outpatient clinic (The Ottawa Hospital, 2004). It was estimated that 75% (131) of these outpatients were admitted for chemotherapy for ovarian cancer and 66% (86) of these would be treated for a recurrence of their ovarian cancer and would meet the inclusion criteria for this study. Therefore, the recruitment of

20 participants (or one quarter of a possible 86 patients) was considered feasible in the planned three month recruitment period.

3.4 *Inclusion criteria*

Women eligible for this study:

- Were eighteen years of age or older;
- Were able to speak English or French;
- Had been diagnosed with recurrent ovarian cancer within the past 3 months as identified by a gynecologic-oncology physician or primary nurse, and documented in the progress notes;
- Had more than one treatment option available to them;
- Were offered chemotherapy;
- Had made their treatment decision a minimum of one week and maximum of three months prior to being approached to participate;
- Were able to participate based on their nurses' assessment of the women's symptoms and performance status; and
- Consented to participate.

The timing of when to approach patients making end-of-life decisions to participate in a study has been reported to significantly influence their participation (Hinds, 1998).

Approaching a patient within 72 hours of making a decision has been found to result in the highest refusal rate. This has been attributed to the emotional state of the patient resulting from having to make the decision. Agreement to participate has been demonstrated to be optimal between 4 to 6 weeks after the decision is made (Hinds, 1998). Therefore, women were approached between one week and 3 months after making the decision about treatment for recurrence of ovarian cancer.

3.5 *Exclusion criteria*

Women ineligible for this study were those:

- who only had one option (i.e. those with platinum-sensitive disease who recur after first line treatment: evidence clearly supports re-treatment with platinum-based chemotherapy);

- who received treatment in a satellite cancer center; and
- who had received care from the investigator/interviewer in another clinic.

3.6 *Setting*

Participants were recruited from the day care chemotherapy unit of the Regional Gynecologic-Oncology Program of the Ottawa Hospital. The four-bed outpatient day care unit specializes in gynecologic oncology systemic therapy and symptom management. It is staffed with four Primary Nurses who rotate in the treatment unit (to administer chemotherapy and provide supportive care), in the office (to triage patient needs and concerns over the telephone between visits), and in the follow-up clinic with the gynecologic-oncologists (to make treatment plans and monitor women's disease status).

3.7 *Data collection method*

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 and status. A data collection sheet (Appendix B) was developed based on the contributing factors to decision making identified in the literature review and the ODSF (participants' characteristics). This sheet was used to extract the following items during a review of the participants' medical records: (1) information pertaining to the diagnosis; (2) current treatment; (3) past treatment history; and (4) treatment options presented. The chart review was performed to obtain data about the stage of the patient's disease and the name and number of chemotherapy agents they had received. Previous work by Elit et al. (2003) had indicated that patients often cannot report these pieces of information accurately.

The decision to conduct face-to-face interviews with patients to elicit their decision making needs (in contrast to self-administered questionnaires) was made for the following reasons: (1) interviews provide the opportunity for participants to freely express their feelings and

attitudes about their experience; (2) the interviewer can probe for more information about determinants/contributing factors; (3) interviews provide an opportunity to observe non-verbal behaviour; and (4) interviews provide an environment that builds rapport between the participant and the interviewer. Finally, face-to-face interviews may be a more effective way to enlist cooperation of participants (Fowler, 1993a; Fowler, 1993b; Witkin et al., 1995).

3.8 Interview guide development

A semi-structured interview guide was developed to elicit information from the women about their treatment decision making needs. Participants were asked to reflect on their needs during their recent treatment decision and to consider what they might need for any future treatment decision.

The interview questions were adapted from a standard template for eliciting needs based on the Ottawa Decision Support Framework (ODSF) (Jacobsen & O'Connor, 1998). The template had been used previously to guide other decision making needs assessments, including one in which women considered options for location of care in the last weeks of life (Murray, 2001). The interview guide (Appendix C) was adapted to the current decision making context based on: the clinical expertise of the researcher; advice from a panel of experts in gynecologic-oncology and decision support; the review of the literature; and feedback from a survivor, who is also a nurse trained in providing decision support. The questions were open-ended but were followed by probes with structured response categories.

3.8.1 Specific needs assessment questions in the interview guide

The specific components of the interview guide are described below, beginning with the elements from the ODSF.

ODSF: Perception of the decision. In the first section of the interview guide, participants were asked questions pertaining to: finding out about the recurrence; the treatment options they were offered; their feelings about the making the decision, including probes regarding the behavioural manifestations of decisional conflict; factors contributing to decisional difficulty, with probes regarding factors contributing to decisional conflict. Participants were asked about how knowledgeable they felt when making the treatment decision, as well as their recall of treatment response rates. They were also asked about their perceptions of the likely advantages and disadvantages of options (expectations).

ODSF: Perception of others. Participants were asked about actual and preferred roles in decision making in relation to others such as family, friends and health care providers. The women's preferred role in making treatment decisions was measured using Degner's Control Preference Scale (CPS) (Degner & Sloan, 1992)(Appendix D). The CPS consists of five statements that describe different roles patients can assume in making treatment-related decisions. The reliability of the CPS was established in a sample of 436 cancer patients and 482 members of the general public (Degner et al., 1992). Content validity of the tool was based on previous research findings from a four year field study of factors that influence treatment decisions (Degner & Beaton, 1987).

The statements from the CPS were translated from English to French by a bilingual research psychologist. Following this, the French statements were translated back into English by a bilingual nurse who had experience in tool translation. The translated English version was then sent to the original author (Degner), to ensure that the meaning was consistent with the original tool. The original author felt that the back-translation of two of the five role statements did not accurately reflect their original intent. However, upon further review, it was found that this was due to the wording of the back-translation from French to English and not the translation from

English to French. No corrections were made to the French statements. See Appendix D for a copy of the translated tool.

Each of the five statements was written on individual cards and the participants were asked to choose the card that best described the role they preferred when making health-related decisions. Women who chose statement A (I prefer to make the final selection about which treatment I will receive) or B (I prefer to make the final selection of my treatment after seriously considering my doctor's opinion), were classified as preferring a more active role in decision making; those who chose D (I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion) or E (I prefer to leave all decisions regarding my treatment to my doctor) were classified as preferring a more passive role; and those who chose C (I prefer that my doctor and I share responsibility for deciding which treatment is best for me), were classified as preferring a collaborative or shared approach.

To obtain information about the actual role the participants had when making their decisions about treatment for recurrent ovarian cancer, a second set of cards (Appendix D) was developed by changing the verb from "I prefer to ..." to the past tense "I made the decision...." These cards were presented to the participants and they were asked to choose the card that best described the role they had in making their recent decision about treatment for recurrent ovarian cancer.

Participants were also asked who else was involved in the decision and how they were involved.

ODSF: Resources. Participants were asked about what personal and external resources helped in making their decision. The interviewer provided a list of potential resources to the participants for consistency. Another question focused on the amount of time the participant had

to make the decision. They were also asked to identify what hindered them in making the decision, as well as what additional resources would have been beneficial.

ODSF: Participants' characteristics. Participating women were asked to provide their age and level of education at the end of the interview.

Hope. The concept of hope was explored with participants by asking them about their level of hope and its impact on their decision.

Needs related to future decisions. Participants were asked about their preferences and needs for future decisions. These included: whether they would want all options presented; who should narrow down the options; and the features of treatments that mattered most to them. They were also asked about what was needed to facilitate their treatment decision making.

At the end of each interview participants were asked to summarize their needs related to decision making about treatment for recurrent ovarian cancer.

3.8.2 *Validity of the interview guide*

As described earlier, the ODSF served as the framework for the development of the interview guide which contributed to its content validity. Face and content validity of the interview guide was established by a panel of experts. The panel was composed of two researchers with expertise in patient decision making and the ODSF, two clinical experts in gynaecologic-oncology, a gynaecologic-oncology psychologist and an ovarian cancer survivor who is also a nurse with training to support clients using the ODSF. Earlier drafts of the interview guide were reviewed for content and clarity by the panel and changes were made prior to pilot testing the interview guide.

3.8.3 *Pilot testing*

A purposeful sample of two women was selected to pilot test the interview guide. The purpose of the pilot test was to determine the clarity and appropriateness of the questions, time required to complete the interview, perceived and actual burden of participating, and utility of the data collection methods. Participants' comments and the interviewer's experience were used to make minor changes to the interview guide, including the order of the questions. As participants were reflecting on future treatments, they were asked to comment on how various features of the treatment were important to them, rather than rating their importance on a scale from one to five.

3.9 *Data collection procedures*

3.9.1 *Recruitment*

The gynecologic-oncology primary nurses approached eligible participants during a visit to the cancer center or over the telephone. The researcher contacted women who had expressed interest in participating at which time they received further information and read and signed the study consent form.

3.9.2 *Interview*

The Witkin and Altschul (1995) guidelines for interviews were followed. Interviews were scheduled at a mutually convenient time and took place either in the participants' homes or the researcher's office at the hospital. A copy of the interview guide was not provided to the participants. All interviews were audio-taped to enable the interviewer to focus on listening to the participant rather than on data collection. The researcher conducted the interviews to reduce the cost of the study. The interviews were conducted in English or French according to the participant's preference; all but two interviews were conducted in English. At the end of their interview participants were offered a follow-up telephone call to answer any questions and/or

provide support. None of the participants requested a follow-up call. In addition, all participants were asked if they would agree to a second interview by telephone to verify findings from the content analysis. All participants agreed to a second call, however, no follow-up interviews were required.

3.10 Protection of human rights

The study was conducted in accordance with the Guidelines of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Interagency Advisory Panel on Research Ethics, 2003). Verbal and written approvals for the study were obtained from the Director of Obstetric/Gynecology/Women's Health and Newborn Care and from the Head of the Gynecologic Oncology Program of the hospital. Following this, the study proposal was approved by Research Ethics Board of the hospital and the University of Ottawa (Appendix E).

Women who agreed to take part in the study received a letter of information/consent form (Appendix F) from one of the primary nurses of the day care unit. The letter of information/consent form described the study objectives, the confidentiality of the answers, as well as what was being requested of the participants in this study. The researcher discussed the voluntary nature of their participation in the study and informed them that they could withdraw at any time during the study. In addition, participants were informed that they could choose not to answer questions that made them uncomfortable. Participants were also informed that the interviews would be audio-taped and transcribed by experienced research assistants hired by the researcher, that a code would be assigned to all transcripts and to chart audit information, and that any identifying information provided during the interview would be removed from the transcripts. They were also informed that the study enrollment record would be accessible only to the researcher and would be kept in a different location from the transcripts and tapes. All audio-

tapes were kept in a locked filing cabinet in the researcher's office in accordance with the REB guidelines. Finally, participants were told that the audio-tapes would be destroyed after the researcher's thesis defense and publication of the findings.

3.11 Data analysis

For chart data and interview questions with pre-coded responses, descriptive statistics (frequencies and percentages) were used to summarize the results. The responses to open-ended questions were subjected to a content analysis. This content analysis was conducted using the principles described by Silverman (2001) in which the categories (deductive codes) are established and then a count is taken of each occurrence of a category in the transcript. The needs identified in the ODSF served as the categories (deductive codes) in analysing the transcripts. The a priori codebook definitions were taken from the ODSF (See Table 2.1). The transcripts were read line by line and deductive codes were attributed to the participants' answers. Inductive codes were developed from the emergent topics when participants' answers were not identified in the a priori codebook. The researcher and a member of the thesis committee with expertise in decision support reviewed the participant's answers when an inductive code emerged.

3.12 Procedures to ensure data quality

Several procedures were put in place to ensure the quality of the data in this pilot study. The procedures taken to ensure the reliability and validity of the transcripts, the instrument, the analysis, and the findings are described below. Validity of the instrument was described earlier in section 3.8.2.

3.12.1 *Quality of the interviewer's interpretation of participants' responses at the time of the interview*

Member checking was used to ensure the interviewer/researcher correctly interpreted the information provided by the participants during the interview. At the end of the interview the interviewer/researcher summarized the information provided by the participants and provided them with the opportunity to clarify the interpretation.

3.12.2 *Quality of the transcription*

The quality of the transcripts was determined by listening to a random sample of three of the 13 audiotapes and simultaneously reviewing the content of the transcripts. Word for word transcription was obtained except when there was noise interruption or when the words used by the participants were unclear to the transcriber. In all cases, a notation was made in the transcript prompting the researcher to refer to the audiotape. The remaining 10 audiotapes were reviewed as required.

3.12.3 *Quality of the analysis*

Reliability: Reliability was ensured by measuring reproducibility or inter-coder reliability. This refers to the extent to which the content classification produces the same results when more than one coder codes the same text (Weber, 1985). This was ensured by randomly selecting five of 13 transcripts to verify the inductive and deductive coding. All of the researchers' codes for responses to the 15 open-ended questions were verified by the gynecologic-oncology psychologist who was a member of the expert panel. The coding was consistent between the two coders for seventy of the seventy-five coding opportunities. This represents 93% inter-coder agreement. The discrepancy (7%) was due to the psychologist's interpretation of responses from a psychological frame of reference versus the researcher's interpretation of responses from a

nursing frame of reference. Discrepancies were resolved by consensus. Two members of the expert panel also reviewed sample transcripts and data reduction documents.

Validity: Validity in this study was ensured by two methods: semantic and face validity. Semantic validity is ensured when words or coding units coded together have similar connotations. Difficulties in semantic validity arise when ambiguity exist in the definition of words or categories (Weber, 1985). In order to ensure that the coding categories (deductive codes) were clear, the determinants of decisions and their definitions as described in the ODSF served as the coding categories. The concept of hope was also defined (Dufault et al., 1985).

Face validity is ensured when the definition of a construct provided by the investigator correspond with the definition of the categories that it measures (Weber, 1985). The coding units that represented the concept of hope were reviewed by the researcher and two members of the thesis committee during the data analysis phase. 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 categorized.

Chapter Four: Results

This chapter describes the findings. The decision making needs identified by women with recurrent ovarian cancer are described in relation to the Ottawa Decision Support Framework (O'Connor et al., 2001).

4.1 Participant recruitment and interviews

The number of women who: (1) were receiving treatment for recurrent ovarian cancer during the study period and therefore potentially eligible to participate; (2) were approached; (3) consented; and (4) were interviewed are detailed in Figure 4.1. Women were approached to participate between October 15th, 2004 and February 28th, 2005. A total of 34 women met the eligibility criteria, but only 21 of these who were approached to participate in the study. The remainder were not approached because the nurses forgot or were too busy. Of the fifteen women approached to participate only 13 consented and were interviewed. The health of the two women who were not interviewed deteriorated after they had given consent, impairing their ability to participate in the study. After five months of recruitment, the study was closed due to slow recruitment.

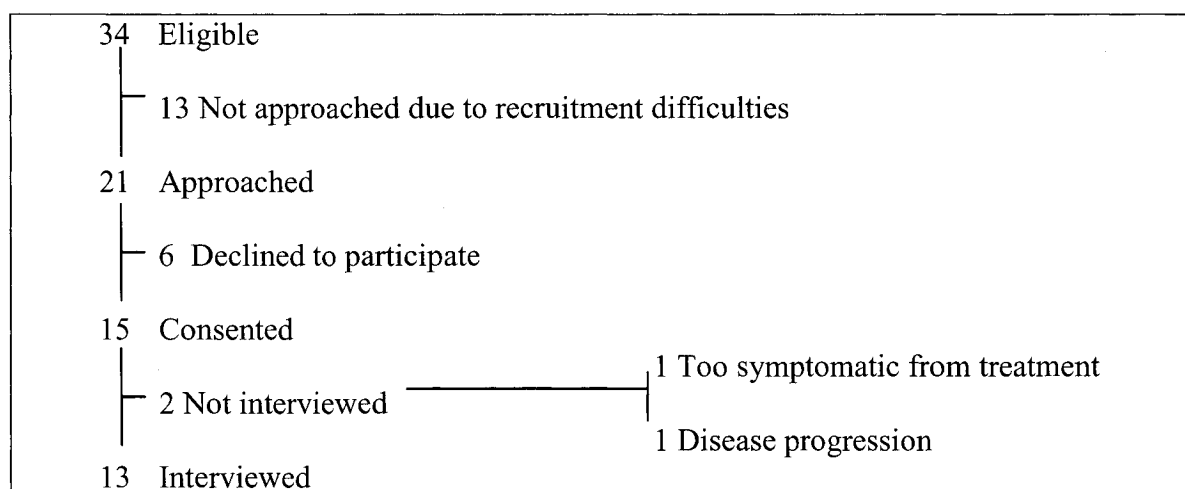


Figure 4.1: Accrued and interviewed participants

The interviews ranged in duration from 30 minutes to 75 minutes. Participants were interviewed in their homes or the investigator's office.

4.2 *Decision making needs*

4.2.1 *Participants' demographic and clinical characteristics*

Of the 13 participants, the typical participant was a 57 year old, Caucasian English-speaking woman, with a high school diploma (Table 4.1).

Table 4.1: 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

All participants were offered treatment and accepted it. As shown in Table 4.2 the modal participant was: diagnosed with advance stage ovarian cancer (stage 3 or 4); had platinum-sensitive disease after first line treatment; was receiving second line treatment; and had surgery and chemotherapy to treat her disease. When the characteristics of participants were compared to non-participants, the 95% confidence intervals overlapped in all cases. However, the sample of eligible patients was too small to rule out large differences in location of residency, stage at diagnosis and number of lines of treatment.

Table 4.2: Treatment history of participants and non-participants during the five month study period

	Participants n=13			Non-participants n=21		
	n	%	95% CI	n	%	95% CI
Location of residency						
Metro Ottawa	12	92%	66, 98	12	57%	36, 76
Ontario residents outside metro Ottawa	0	0%	0.2, 23	6	29%	14, 50
Outaouais, Quebec	1	8%	2, 34	3	14%	5, 35
Stage at diagnosis						
2	1	8%	2, 34	1	5%	1, 23
3	6	46%	23, 71	16	76%	55, 89
4	6	46%	23, 71	2	9.5%	3, 29
Unknown	0	0%	0.2, 23	2	9.5%	3, 29
Platinum status						
Sensitive	10	77%	49, 92	13	62%	41, 79
Resistant	2	15%	5, 43	4	19%	8, 40
Borderline	1	8%	2, 34	4	19%	8, 40
# of treatment lines						
2	5	38%	18, 65	3	14%	5, 35
3	3	23%	8, 51	8	38%	21, 59
4	4	31%	13, 58	7	33%	17, 55
5 or >	1	8%	2, 34	3	14%	5, 35
Prior treatment modalities						
Surgery	13	100%	77, 99	21	100%	85, 99
Chemotherapy	13	100%	77, 99	21	100%	85, 99
Radiation	3	23%	8, 51	4	19%	8, 40
Median age (range)	57 (46-77)			59 (45-75)		

4.2.2 Perceptions of the decision

Perceptions of the options. Five of 13 participants perceived that their doctor had presented treatment options to them (Table 4.3). In addition to these participants, another participant's husband, who was present during the interview, reported that his wife had been presented with options; however, his wife did not remember being presented with options. Three of the five women who perceived they had options, reported that one of the options was to do "nothing". The husband who had been present during his wife's interview reported that she was also presented with the option to do "nothing". Two participants reported that the word

“palliative” was used in describing their options, but neither understood what the term meant. For example, one participant said: *“I don’t understand what he/she (the physician) meant by palliative care, ’cause I’d figure, OK, well it’s another type of care”* (pt 3).

The participants’ perception that options were presented to them and whether or not this was documented in their charts is listed in Table 4.3. According to the chart review, seven women were presented with options; including four of the five who perceived they had options.

Table 4.3: Options

Participants #	Perceived that options were described	Documented that options were described
1		X
2	X	X
3		X
4	X	X
5		X
6		
7	X	X
8		
9	X	X
10	X	
11	(husband)	
12		
13		

Decisional conflict. When women were asked about how they felt when making their treatment decision, there was no evidence of decisional conflict in 11 of the 13 participants. One woman reported: *“...in some ways, I was relieved...I was afraid he was going to tell me there was nothing else he could do, so I was relieved that we were actually going to do something”* (pt 13).

Participants talked about not having control over the situation, but having to do something or try something to control the cancer. They, therefore, reported that nothing made the decision difficult. Five women talked about having “an option”, as described by one woman: *“I felt good, I had a choice to try, another means of treatment to try to attack this”* (pt 3).

One of the women who did experience decisional conflict reported that she did not have information about the pros and cons of the options that were offered; she felt she was expected to make the decision immediately. The options were presented by a member of the house staff (resident or fellow) and not her physician (a gynecologist-oncologist). She said: *"It was up to me to make the decision and I felt pushed to make a decision right then and there...I thought... what do I know about these treatments"* (pt 9).

The other patient who experienced decisional conflict attributed her difficulty to losing hope and courage, and to questioning the purpose of continuing with treatment. This woman described her conflict as follows: *"Well, I think that at certain point you lose hope and courage and you wonder... is it all worth it?"* (pt 6).

Some women also reported feelings about the cancer's recurrence or the options that were presented, rather than about the decision itself. Six of the 13 participants reported being upset at the news of the cancer recurrence. While they expected the cancer would recur, they had not expected it at that time. For example, one participant stated: *"Well I was upset but you don't have any alternative, you have to fight for it"* (pt 7).

One patient reported being upset because she was presented with the option of "nothing", she 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"* (pt 10).

Knowledge of ovarian cancer. 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. Six women provided information about what they understood about the expected response rate to their current treatment. Two of the six women were able to report potential response rates, however, one woman responded with three rates ranging from 20-25% to less than 50%. The other four women commented on the goal of the treatment: control the

symptoms of ovarian cancer, reduce the CA-125 level (ovarian cancer tumour marker), or put them in remission. An additional two women described how individuals respond differently to treatment.

Participants reported that they were less knowledgeable about the treatment options that were currently available to them than about the options that would be available to them with a subsequent recurrence. Two women wondered where their cancer was currently located; two women felt they lacked some understanding of how to interpret the significance of their CA-125. One participant wondered how physicians made decisions about treatment options. Four participants felt that they understood everything. Five women described their ambivalence about wanting information. The following statement represents one participant's feelings: *"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"* (pt 10).

One of the women described a helpful strategy used by a physician to ensure that she understood the information being conveyed. She reported: *"...one in particular has been exceedingly good and prefers to have me repeat what I understood...it's a very useful method to make sure the patient is understanding what the doctor is telling you, and not what you think you want to hear"* (pt 3).

Stage of decision making. 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. The reflection women made about their interaction with the physician is indicative of the contemplation stage of decision making, as described by one participant: *"I was prepared. I mean in my head I was prepared (for the news of recurrence)"* (pt 13).

Seven women reported that they were expected to make the decision during their visit.

One participant reported: *“I know doctors have other patients to see and often are late coming to see me but I often feel a bit rushed. Obviously to make a decision, I was going to make it quickly”* (pt 8).

However, women, who had expected to hear they needed more treatment, found the time was sufficient. As reported by this participant: *“You’re not given much time to think about it. I think if you go in and you’re expecting bad news you probably already got a decision made in your head”* (pt 5).

Both women who experienced decisional conflict requested not to start treatment immediately.

4.2.3 Perception of others

Women’s roles in decision making. As shown in table 4.4, 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.

Table 4.4: 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.

In addition to identifying the role they played using the modified control preference scale, participants also qualitatively described the role they had in deciding about treatment for their

recurrent ovarian cancer. One woman described having a passive role in decision making. She stated: *“I think sometimes the skill is knowing that it’s inevitable (need for more treatment) and the skill is knowing that your doctor is the right person to make the decision”* (pt 13).

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”* (pt 5).

In one case, the participant’s role revealed in the scale did not correspond to her comments about what happened. She perceived that she had played an autonomous role in decision making. She stated: *“The doctor came in and said this is the treatment, this is what you’re going to have to do and I said that’s fine”* (pt 13).

Four women described what patients need to do in order to participate in the decision. They described how women need to: access information about available treatment options; inform the practitioner that they want to have an active role in making the decision; and ask questions. The following are two women’s reports:

“...you have to be comfortable in asking questions for which you want answers...you need to be comfortable in getting information” (pt 12).

“...people have to be their own advocate and I think women need to be informed so that they can ask...you need to ask a few questions about the options” (pt 2).

Five women perceived that physicians could determine how they would respond to various treatments and therefore felt that the physicians were better able to decide on the best treatment for them.

Others’ roles. Seven of 13 women reported that their partner (husbands, common-law husbands or boyfriends) were involved in the decisions. Of these, the partners of five participants shared in the decision and two other partners provided support or information in order for the

women to make the decision. One woman reported: “...he listened, he asked questions, made sure we understood what the doctor said...we tried to do it (decide) together” (pt 3).

The other four women were alone at the time they made the decision. They reported that others were involved after they made the decision by providing support and supporting the decision they had made. This support was mostly provided by a family member, specifically a husband, sisters, a mother and children. One participant, who experienced decisional conflict, reported seeking advice from her family physician.

Two of the 13 women described taking others into consideration when deciding about the course of action to take. 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, they’re included in the decision I take” (pt 12).

Practitioners’ roles in decision making. Physicians were the only practitioners identified as being present during the actual time of the decision. Ten of 13 women reported that nurses had helped them make the decision; however, nurses participated either prior to or after the decision was made. Participants described how nurses helped them make future decisions over the telephone by explaining what options might be available in the event of a recurrence. Participants reported that both physicians and nurses helped them equally by providing information or helping with decision making (Figure 4.2).



Figure 4.2 Practitioners involved in information provision or decision making.

Both physicians and nurses provided information. Table 4.5 outlines the kind of help provided by practitioners. Seven women reported that physicians helped them make the decision by presenting them with the available options and six reported that the physicians provided further information about the options. Seven women reported that the nurses helped by providing them with additional information about the options. A few women also described the helpful support provided by the nurses including “acknowledging who I am”.

Table 4.5 Help received from Practitioners regarding decision making

Help Provided	n=13	Physicians	Nurses*
Presented Rx options		7	
Provided information		6	7
Presented pros and cons/side effects		2	4
Rx		1	4
Schedule of Rx			3
Answered questions		1	2
Cancer		1	1
Advice/recommendations		2	1
Told me what to do		2	1
Weight success rates of each options		1	
Emphasized QOL		1	1
Provided support			2
Acknowledge who I am			1
Role during Rx (positive past experience)			1

*was provided before or immediately after the decision was made or during treatment.

Participants described the help they received as follows:

“The first one (who helped) was certainly the doctor because he basically came in and said this is the treatment, this is what you’re going to have to do...the nurse came in and went through the steps, what the side effects were going to be, the type of treatment I can expect, how long I was going to have to go through it” (pt 13).

“They (doctors) only suggested Taxol...most of the information that I got was through (nurse’s name)” (pt 3).

“Well (MD) provided the options and weighed the success rates of each of those options and then it made it pretty easy to make the decision“(pt 10).

“...it makes it a lot easier knowing the part they (nurses) play during my chemotherapy, I mean I had such a good experience...I don’t worry about that ...I don’t have baggage to bring to this decision” (pt 2).

4.2.4 Resources to make the decision

Participants were asked which resources they found helpful in making the decision about treatment for recurrent ovarian cancer (Figure 4.3). Past experience with treatment and their physical health at the time of making the decision were most frequently reported.

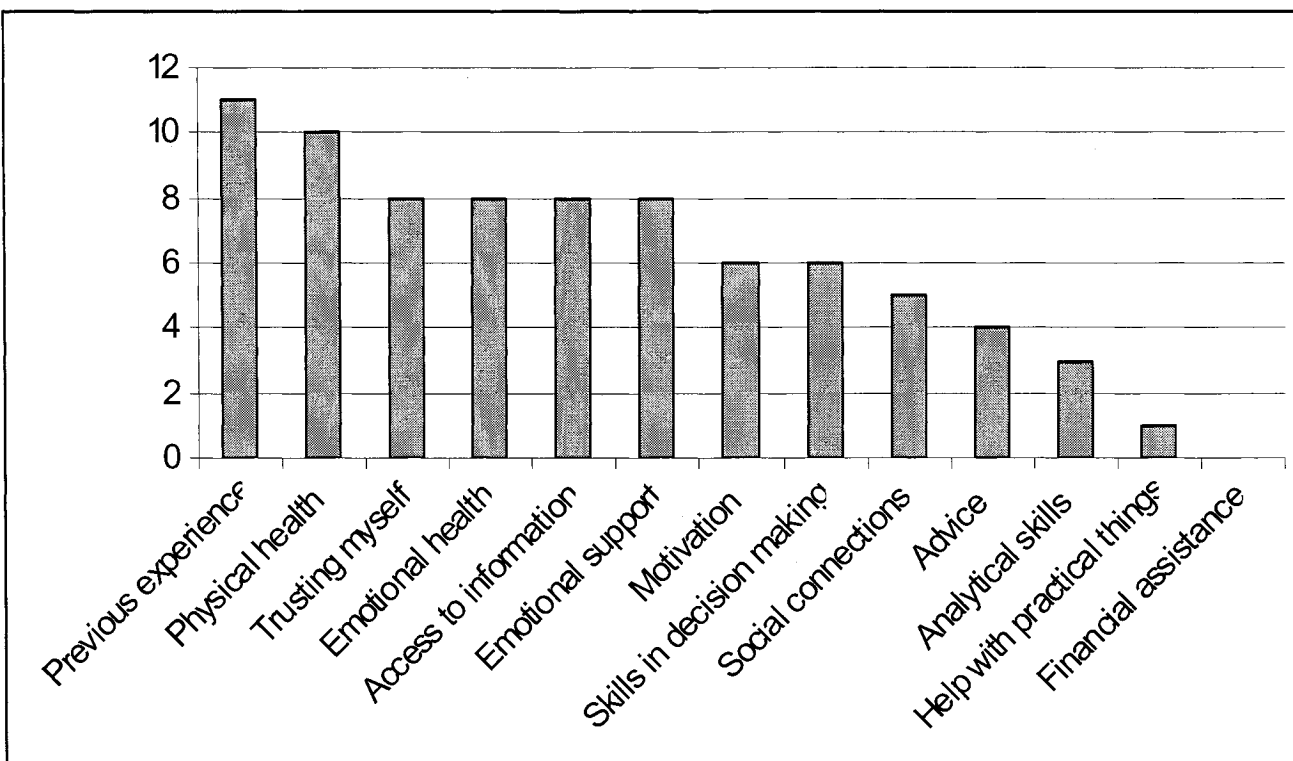


Figure 4.3 Helpful resources

The women described that their overall previous experience with chemotherapy was positive, which helped reduce their apprehension about having to receive further treatment. The following two statements are representative of participants' answers:

"I didn't have difficulty with the treatment the first time, I didn't get sick" (pt5).

"I've been fortunate on chemotherapy, other than fatigue, I've been lucky I have not been ill" (pt 10).

Regardless of women's current physical health, they wanted more treatment. They either felt well physically and able to endure treatment at this point in time or they felt symptomatic from their cancer and believed that treatment would help improve their physical wellbeing.

Other resources that facilitated the decisions that were identified by the participants are listed in Table 4.6. The most frequently cited resources were "trust in their physician and the other team members" and "the day care unit (other patients/nurses)". The day care unit provided

an informal support group atmosphere. Women received information directly from other patients and by listening to the nurses talking to other patients. In addition, participants reported that they did not feel alone because they were treated in a unit dedicated to gynaecological cancer.

Table 4.6: Other resources

Other resources	Frequency
Trust in physician and team	4
Day care unit (other patients/nurses)	3
Not being afraid of chemotherapy	1
Strategy used by the physician	1
Hope	1
Fear motivates	1
Knowing what questions to ask	1
Discussion that took place prior to being recommended further treatment	1
Knowing she needed to make a decision about treatment, prior to her visit	1

4.2.5 Practitioner's characteristics

A few participants described practitioners' characteristics which facilitated or hindered decision making. Four participants reported that physicians were not great communicators or that they were more clinical and less personable. One woman added that she found the physician more approachable over time. Women also described their physicians as experts in their field of medicine. Two women reported:

"Physicians are more insulated and calloused, not great communicators" (pt 5).

"Physicians are approachable. When you are first diagnosed you don't think so, but then they are approachable and they are human beings" (pt 4).

Nurses were described as being available, knowledgeable, comprehensive, sensitive, comforting and patient. Two women reported:

"They (nurses) will listen to me and they answer my questions, they acknowledge who I am, they are patient and give me comfort" (pt 8).

“...the nurses are wonderful, they are well organized, well informed, very encouraging and if we need information they provide it right away” (pt 6).

4.2.6 Hope

Eleven women spoke of the importance of hope in dealing with ovarian cancer. This woman’s statement is representative other patients’ comments about hope: *“...when you have hope everything is okay and it’s going to be okay, it’s kind of knowing that the unexpected can happen. If you don’t have hope, I think you’re pushing yourself further in the dark abyss” (pt 11).*

The remaining two women perceived that having hope was not being realistic or being in denial. They said that hope was not part of decision making. However, these women also described the importance of maintaining hope each. One of the participants reported: *“I’m realistic and I know I’m not going to live for ten years... I guess you always hope a little bit. No, I don’t have great hope at all” (pt 7).*

Uncertainty was considered a source of hope and women described what they hoped for: cure, remission, and new drugs. For example, one participant described: *“...if this doesn’t work there is going to be something else out there that’s going to and I’m going to go for it” (pt 3).*

As reported earlier, women understood the poor prognosis associated with ovarian cancer, they equated treatment with hope. For example three women said:

“...my fear was that there would be no hope so for him/her (physician) to even tell me there’s a fifteen to twenty percent (chance of response) that was better than what I had in my mind, if you come in and think that there is no hope (no more treatment) and then you’re offered something” (pt 13).

“...with each (line of) treatment they say the percentage of cure is less and less...I’ll go with anything that sounds like hope to me” (pt 1).

“...well for instance, one of the options was do nothing. I think anybody who’d make that decision would have no hope” (pt 9).

Women described factors that influenced their level of hope, such as the setting in which they received their chemotherapy and the information they were provided by practitioners. Women described how the day care unit provided them with a sense of hope. Participants indicated that they did not have much knowledge of ovarian cancer before being diagnosed and many did not know anyone with this diagnosis. However, once receiving treatment they were exposed to other women with the same diagnosis. One woman said: *“I started becoming more hopeful once I started treatment in the day care unit” (pt 2).*

Being reminded of the poor prognosis associated with ovarian cancer had a negative impact on hope. One woman reported: *“...one physician told me this(information) harshly ‘you know it will come back and we won’t give you treatment all your life’ (quoting physician) I was coming out of remission, I was still full of hope, I knew there was no cure...some physicians give you less confidence (in the outcome)” (pt 6).*

This participant compared that information to more hopeful information she had received from another physician earlier in her disease. She said: *“you’re responding well, here is where we are at, don’t quit...you got in remission, if it comes back there is something else’ (quoting physician)...he gave us hope” (pt 6).*

Another woman described how her hope was reduced because the information she received about her prognosis was too vague. She would have preferred to be given a more precise timeline even if this was short. In this instance, there was too much uncertainty and therefore the uncertainty did not provide hope. She reported: *“I don’t think it was a very compassionate way, especially when it (prognosis range 6 months to 4 years) was given in such a cavalier attitude...I want him/her to treat me like I’m the only patient...if he/she knew how hurt and the devastation*

he/she caused...I think his/her (physician) answer should have been: at this point we do not know... You know if you had said to me six or seven months or four or five years that's a little bit of a closer correlation in as far as time goes." (pt 10).

4.2.7 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.

4.2.7.1 Needs relevant to knowledge

Eleven of 13 women want to be presented with more than one treatment option. Four of 13 women preferred to have options narrowed to one or a few (Table 4.7) and wanted this to be done by the physician. It was not clear if participants wanted information about options in order to decide between options or if they wanted information about options in order to plan options over time.

Table 4.7 Number of options preferred

Number of options preferred	frequency
All the options	9
2-3 options	2
1 option	2

One woman, who wanted to be presented with only one option, stated: "*...they (physicians) should present the best option to you for your case, if you don't agree then you can delve into it...you have to accept what your doctor says" (pt 7).*

Women who wanted to be presented with multiple options stated:

"I think that women should be fully informed by her specialist as what her chances are and all the information about the various treatments and what option is the best one, because without that you can't make the proper decision" (pt 9).

“...if all the options are not presented, I would find that very paternalistic...” (pt 8).

Women who explained why they wanted to be presented with options said:

“I would like to know everything that is out there. Not that it may influence my decision making but it influences my comfort level” (pt5).

“I would want to hear them all because sooner or later I would find out about options not presented to me and I would regard that as failure on the management team” (pt 8).

“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)”(pt 10).

Preferred sources of information for future decisions. In future decisions, all the women said that they would prefer counselling (discussion) over other methods of receiving information about the treatment options (Table 4.8). Of the five women who reported that discussion groups would be a good method for receiving information about options, two would not attend personally. One of the two women who would access the internet for information about treatment options would only do so if the site was recommended by the treatment team.

Table 4.8: Preferred source of information

Preferred source of information	Frequency
Counselling	13
Discussion groups	5
Information materials	9
Booklets & pamphlets	8
Videos	1
CD-ROMs	1
Internet	2

Women reported that they would prefer to receive information/counselling from nurses because they were perceived to have more time, to have better skills in providing information, to know the patient better (Table 4.9).

Table 4.9: Preferred counsellor to provide information

Preferred counsellor	Frequency
Nurse	7
Physician, nurse or other practitioner	3
Physician	2
Not specified	1

For example, three women reported the following about why they would prefer to be counselled by a nurse:

“They (nurses) have more time...they’re the ones that talk the most to patients...just seem to have a better method of giving out information” (pt 13).

“I don’t think it has to be the doctor, I think it has to be one of the oncology nurses, certainly somebody from oncology who has contact and works with the doctor, we could have a nurse practitioner” (pt 3).

“They (nurses) deal with people one-on-one so many times for their chemotherapy and they get to know the person, whereas the doctor would see you for five-ten minutes at the most every three to six months, so they really don’t know the person’s feelings, so definitely the nurse” (pt 1).

Preferred content of information. The most frequently reported topics of information women wanted to receive when considering future decisions about treatment for recurrent ovarian cancer were: side effects of treatment, length of treatment/scheduling, prognosis/survival and how to manage side effects (self-care and symptom control) (Table 4.10).

Table 4.10: Content of information

Topics of information	Frequency
Side effects	6
Length of treatment/scheduling	5
Prognostic/ survival	4
Toxicity management (self, by team)	4
Pros and cons of treatment options	2
What the drug is going to do	3
Treatment options	2
Effectiveness of the drug	2
How to get to treatment area	1
How the treatment will affect me	1
Information about the drug	1
% of risk of the side effects	1
Information about ovarian cancer	1
Chronic nature of ovarian cancer	1
What make the MD decide about options	1
Euthanasia and end of life issues	1
Impact on my family	1
All characteristics of treatment	1
How will I be monitored	1
What will be done if the treatment does not work	1

Two women commented that the type and amount of information that practitioners provide would need to be considered judiciously. One woman reported: *“There is always a problem with giving out too much information because then the mind starts running with it so it’s very difficult. I certainly wouldn’t get into mortality rates or things like that, but going through the things that might happen to you”* (pt 4).

4.2.7.2 Needs relevant to values.

The question of whether the number of treatment options presented to a patient could be shortened based on her values for various treatment characteristics (e.g., benefit, risk, and frequency of visits) was considered. Women were asked about how important these characteristics would be to them in deciding between treatment options. As shown in table 4.11, 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 between women. While many women wanted

Table 4.11 Values for treatment characteristics

n=11	Important	Moderate	Not important
Efficacy of treatment (response rates)	11		
Control of symptoms	8		1
Living longer	7	3	
Quality of life	5	4	
Avoiding certain side effects	4	5	4
Frequency of visits	1	2	6
Controlling the cancer		1	
Participating in clinical trials		3	4
Oral treatment		6	4

to avoid nausea/vomiting and hair loss; there were others who considered these to be of little importance. Women had difficulty rating the importance of individual treatment characteristics as they understood that each treatment has various characteristics.

Chapter Five: Discussion

This chapter summarizes and discusses the results, and presents the study limitations, and the implications for research, practice and theory. Finally, a brief conclusion is presented.

Most of the women did not experience decisional conflict; however, only five women perceived they had options. Women perceived they either had a passive or shared role in the decision, as opposed to an autonomous role. Women also identified passive and shared roles as their preferred involvement in decision making. All women were knowledgeable about the poor prognosis and incurable nature of ovarian cancer. Past experience with ovarian cancer and chemotherapy, as well as their current physical health were most frequently reported to influence their decisions. Most women reported that hope was important to them in their cancer experience and in decision making.

When considering future decisions, most women want to be presented with all the options and the preferred method to receive information about the options was counseling. Nurses were identified as a preferred source of information.

5.1 Sample characteristics

No participants resided outside metro Ottawa. Although one cannot rule out this being a statistical artefact, another explanation may be the time involved in participating in an interview study. Women, who lived outside metro Ottawa, may have declined to participate in the study because it required more time to travel or they were trying to avoid additional trips to the hospital. In addition, the women may not have wanted to have the interviewer travel to their home. In subsequent studies, it would be important to include a rural population because their

decisions about other cancer treatments (breast cancer) have differed (Howe, Lehnerr, & Katterhagen, 1997; Stafford, Szczys R., Becker, Anderson, & Bushfield, 1998).

5.2 *Perception of the decision*

Perception of options. The observation that more than half of the women did not perceive they had options presented to them is consistent with two other studies (Elit et al., 2003; Howell et al., 2003). There may be at least three explanations for these findings. Firstly, some of the women may have not considered “doing nothing” or palliative care/best supportive care as an option. In four of the cases where women said there were no options, their spouse or their chart indicated that palliative care was an option. In prior studies, women have also failed to perceived “nothing”, best supportive care, or palliative care as an option, or felt it would be applicable a low percentage of the time (Charles, Redko, Whelan, Gafni, & Reyno, 1998; Elit et al., 2003; Penson et al., 2004).

Secondly, women may not have perceived they had options due to poor recall of their conversation with the physician at the time of their cancer recurrence. Women were eligible to participate if they had made the decision within the past three months and the passage of time this may have affected recall. Moreover, if they were informed of their recurrence during the visit in during which options were discussed, their recall may have been affected. Women may have not have been able to actively listen after hearing the bad news. It has been demonstrated that recall of options is improved with the use of decision aids (Whelan et al., 2003; Whelan et al., 2004; Whelan et al., 1995).

A third explanation may be that the way in which the information about options was provided may not have made sense to the participants and they therefore, did not recognize that they had options.

Decisional conflict. Generally, women did not express having any difficulty making the decision about treatment for recurrent ovarian cancer. 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 et al., 2003). There may be several reasons why these results differed from earlier studies. Firstly, in contrast to women in other studies, few women in this study perceived they had options. Secondly, other studies directly measured decisional conflict using the Decisional Conflict Scale. Thirdly, some women expected their cancer to recur and were prepared to discuss options. Some patients had already discussed potential options with their physicians when they completed their previous line of chemotherapy treatment. Therefore, some of the patients' decisional conflict may have been resolved at an earlier date. Finally, the low level of decisional conflict may also be attributed to the high level of acceptance of chemotherapy by women with ovarian cancer as reported in the literature (Donovan et al., 2002; Ekman, Bergbom, Ekman, Berthold, & Mahsneh, 2004; Penson et al., 2004; Sun et al., 2002).

Knowledge. All women were knowledgeable about the poor prognosis associated with their cancer; they expected their cancer to recur and anticipated the need for further chemotherapy. This is consistent with 85% of women reporting that they understood the stage of their cancer when it was presented to them (Fitch et al., 1999). Women in this study described learning about their cancer and its treatments from the physicians and nurses and also considered the day care unit as a supportive environment conducive to learning (e.g., hearing from other women with ovarian cancer about treatment options, did not feel alone in their battle against this cancer, observed what type of complications other women with ovarian experienced). Women with ovarian cancer have described using support groups to access such types of information

(Fitch et al., 1999). Therefore, the day care unit setting appears to have similar advantages to formal support groups.

Only half of the women in this study appeared to understand the benefits (response to treatment) and most described this using words rather than numbers. Similar findings were reported by Elit et al (2003) who reported that most women were unable to describe the benefits quantitatively. As described by Jalowiec et al (1984), some individuals have an evasive coping style which is demonstrated by avoidance behaviors. Therefore, women may selectively remember certain information or refrain from asking questions in order to not receive information they do not want to hear. This is consistent with women reporting they were ambivalent about wanting certain types of information.

The method of explanation may have affected women's perceptions about the expected response rates. In order to help patients understand response rates, health care providers tell patients that response rates represent what will happen to 100 individuals. Patients are told that there is no way of knowing whether they will be in the group who responds or the group who will not. This explanation not only explains the difficulty predicting outcomes at an individual level, but also provides patients with hope that they will be in the group that benefits. 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; Whelan et al., 1995). A decision aid may therefore be useful to better present information such as response rates.

Time to make the decision. The observation that half of the participants in this study perceived they had to make the decision during their visit is consistent with prior studies (Elit et al., 2003; Fitch et al., 2003a). Women with ovarian cancer may assume that there is an urgency to make a treatment decision in order to get treatment underway. Women with advanced cancer have an estimated 25% five year survival rate; however, if they had been diagnosed at stage 1, the

five year survival rate would be as high as 90%. Therefore, knowing that an earlier diagnosis (earlier stage) would have significantly improved their overall survival, women may believe that starting treatment for recurrent disease earlier may have an impact on their survival. Unless women are informed that early diagnosis and treatment only has an impact on survival in the first line setting, they may transpose this knowledge to the current setting.

An alternative explanation of the perceived urgency may be due to verbal and non-verbal messages provided by physicians and nurses. Women need to be told that they can take time to consider the options and discuss this with loved ones before making a final decision and starting treatment.

5.3 *Perception of others*

Women's roles. Half of the women reported playing a passive role in the decision. Women in previous studies 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., 2003a; Howell et al., 2003; National Ovarian Cancer Association, 1999; Stewart et al., 2000). There was no relationship found between role preference and time since diagnosis in a sample of 1012 women with breast cancer (Degner et al., 1997). However, none of the earlier studies 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). As reported in one case, the participant's comment did not correspond to the role she identified using the modified CPS. Therefore, the role women reported playing may not accurately reflect the role they assumed in the decision. Women's actual role in the decision may have been more accurately reported using a qualitative approach.

When asked what role they would prefer, four of 13 (31%) women stated they would like to have a passive role in making future decisions. This finding is inconsistent with previous research (Elit et al., 2003; Howell et al., 2003; National Ovarian Cancer Association, 1999; Stewart et al., 2000); including the study of Stewart et al (2000) in which the same scale was used (22% preferred a passive role). There may be one of three reasons for this difference. First this is most likely a random error due to sample size. The 95% confidence intervals of the true percentage for the preference for passive role in both studies the intervals overlap which indicates a random error. Second, it may be due to approach of measurement, in both studies participants were asked to identify their preferred role in decision making using Degner's CPS. Despite using the same tool, the women in this study were first asked about the role they actually played, following which they were asked about their preferred role. Perhaps women did not want to admit having regret for the role they played. It may have been preferred to ask them about their preferred role when they were asked to consider future decisions, the two role questions would therefore not have been asked back to back. And third, this may be due to practice difference. The physician group in this study has the reputation to administer more lines of therapy for recurrent ovarian cancer. Therefore patients may feel a lesser need to advocate for more therapy.

A few women also described what women need to do in order to participate in future decisions. They identified things such as needing to access information about treatment options, informing practitioners of their wish to play an active role in the decision making process, and asking questions. This is consistent with what women have reported in other studies (Fitch et al., 2003a; Howell et al., 2003). 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 options, and by clarifying their expectations. In addition, women should not need to seek out information on treatment options on their own. Providers should offer patients sufficient information so that they don't feel the need to seek out treatment options on their own.

5.4 *Preferences for future decisions*

Preferences about the presentation of options. Most women wanted to be presented with more than one treatment option, which is consistent with the role women wanted to play in 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. side effects, 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. Firstly, women may desire to participate in choosing among options. Once they realize that the survival rates are comparable, they may be willing to consider the negative aspects of treatment that differentiates each option (side effects of treatment and having to travel, blood work) (Donovan et al., 2002; Ekman et al., 2004; Penson et al., 2004). Secondly, some women may want information but may not desire to participate in decision making (Averill, 1973; Degner et al., 1987; Dennis, 1987). This would explain why some women may want to be presented with options; yet still want to play a passive role. Women may want information in order to help them cope or feel confident in the plan of care proposed by the oncologist. Or thirdly, women may want to be presented with treatment options in order to plan

treatment over time. Information would re-assure women that multiple options are available in the event the currently recommended treatment does not work.

Finally, 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 (cancer, coronary artery disease, renal failure). 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 selecting a treatment.

Preferred source of information. Women's preferred source of information for future decisions was counseling, followed by print materials. These results are consistent with findings reported in prior studies in which the preferred or most often accessed source of information was health care professionals, followed by print materials (Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Smith et al., 2004; Stewart et al., 2000; Wong et al., 2002). Interestingly, more women in the current study commented on the importance of the primary nurse in providing information. These findings are inconsistent with other studies in which physicians (oncologist, surgeons or general practitioners) were preferred as the primary source of information (Booth, Beaver, Kitchener, O'Neil, & Farrell, 2005; Rutten et al., 2005). The preference for nurses to provide information identified in this study can be explained by the models of nursing and medical care provided in gynecologic-oncology at the participating facility. In the outpatient oncology setting where this study took place, a small number of nurses are dedicated to one disease site group. All the nurses provide direct patient care in the day care unit, engage in telephone triage and

collaborate with the oncologists in the follow-up clinics. Each patient is assigned a primary nurse in order to promote individualized and continuous care. In addition, the gynecologic-oncologists have a team approach to patient care and share the responsibility to plan and monitor patient progress. In the participating facility, patients with other types of cancer have less contact with the same nurses than women with ovarian cancer where women have more opportunity to develop a therapeutic relationship with the nurses.

The participants' preference for nurses as a source of information may be that they viewed the issue of options in the context of chronic condition management, in which a team approach is more common than for single treatment decisions. Alternatively, women may have a preference for nurses due to the skills of nurses in promoting hope, as described below. A third explanation may be that social desirability came into play, as the participants knew the interviewer was a nurse.

5.5 *Hope*

Hope was identified by all women in this study as being part of their daily lives. All but one patient reported having a high level of hope, which is consistent with the literature on hope in individuals with advanced cancer (Felder, 2004). Most women reported that hope played a role in making decisions. However, women did not articulate the relationship between hope and decision making. The relationship between hope and decision making can be explained as follows. Active participation in decision making has been identified as a strategy to maintain hope (Dufault et al., 1985; Ersek, 1992). Despite hope not being identified as a determinant of decisions in the ODSF, hope could be classified under the determinant of individual characteristics, since hope is a mechanism used to cope (Felder, 2004) and how an individual copes is part of his or her character.

Hope has also been identified as a concept in other studies of women with ovarian cancer (Bowes et al., 2002; Donovan et al., 2002; Murray, 2001). In the current study, when hope was used as a noun, patients talked about hope as the availability of treatment to ensure a cure or to prolong life. Hope was up to the doctor to determine. However, when hope was used as a verb, it was linked to a possible outcome. Hope, as a verb was also expressed by participants in this study when describing what they hoped for. Findings from this study are consistent with research looking at hope in a sample of oncology patients questioned about DNR status (Elliott & Olver, 2002; Olver et al., 2002).

Interestingly, one participant described hoping for the unexpected to happen which is in consistent with the definition of hope provided by Dufault et al. (1985), who described hope as being something that is uncertain but realistically possible. For this participant, she is hoping for something which she is not expecting, or does not believe it to be possible.

Participants also described actions by health care providers that promoted hope and those that hindered hope. Felder (2004) recommended incorporating the following interventions to foster hope: presence, touch, active listening, values clarifications, reality surveillance, and providing information in an honest, respectful and compassionate manner. Such interventions were identified by participants in this study when describing the help they received from nurses in making treatment decisions. The following interventions have been identified as hope hindering interventions: uncontrolled symptoms, abandonment, isolation, devaluation of personhood, negative hospital experience, disrespectful or cold manner on the part of staff, trivializing the situation or giving discouraging facts without offering something to hold on to (Felder, 2004). Women reported experiencing similar hope-hindering interactions, when the physician emphasized the limitation of treatment without acknowledging that the patient had just

completed treatment and appeared to be in remission, or when another physician discussed the prognosis using too wide a range of survival (6 months to 4 years).

The day care unit was identified as a source of hope for women in the current study. Approximately 80% of the women who are treated in the unit carry a diagnosis of ovarian cancer. They have the opportunity to meet other women with a variety of experiences in ovarian cancer. Many patients here receive more than one line of chemotherapy and have lived with the disease for some time. They described this setting as providing them with the opportunity to connect to other women but also to observe what was involved in the disease process. Ferrell et al (2003) reported the theme of belonging to a sisterhood, in analyzing the correspondence of women with ovarian cancer who subscribed to a newsletter. Being connected to other women who had walked in their shoes offered them hope, even if all were at different stages of the disease trajectory.

5.6 *Limitations*

The sample size was too small to draw substantial conclusions about whether the participants were representative of the population of women treated at the center during the time period of the study. In addition, the small sample size and relatively homogenous characteristics of the participants limits the generalizability of the results. Women living outside the city and those of diverse cultural backgrounds may have different needs related to treatment decisions at the time of recurrence with ovarian cancer.

Participant bias may have been introduced in two important ways. Firstly, social desirability (individuals give answers they think the interviewer would approve of or would want to hear) may have influenced participants' answers (Polit et al, 2004). Despite not enrolling women who had been cared for by the interviewer, women may have recognized the investigator/interviewers' name as being a nurse and a member of the multidisciplinary team. However, attempts were made to reinforce that their responses and participation would be kept

confidential. Secondly, participants answers may have been influenced by self serving bias, which is a psychological defense mechanism in which individuals choose to see themselves as how they wish they were (MacDonald & Standing, 2002).

The timing of the interview may have resulted in poor recall of the discussion that the participants had with the gynecologic-oncologist at the time they made the decision about treatment for recurrent ovarian cancer. In order to best assess decisional conflict and women's needs it would have been ideal to interview women when they were actively considering options since this is when individuals experience higher levels of decisional conflict (O'Connor et al., 2001) and find decision support most helpful. Since most decisions are made during the visit when the discussion of options took 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. Family members could have been interviewed in order to have their perspective on how women make decisions, the role they played in supporting the women and their personal needs. The perspective of physicians could have provided more specific information related to the options that are available to women. By interviewing health care providers a better understanding of the changes in providing decision support to this patient population would have be obtained. The perspective of the nurses would have given insight into their role in providing patients with information needed to make treatment decisions, as well as their role as patient advocates.

5.7 *Implications for future research*

Questions emerge from the study findings that warrant further investigations, such as: (1) what are the complementary roles of nurses and physicians in discussions about treatment 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 or is it comparable to the typical “cross road” decision making seen in oncology?

The presence of hope in women living with ovarian cancer was reported earlier by Bowes et al. (2002); their findings suggest that hope is a necessary condition for women to find meaning in their illness. More research is needed to explore the concept of hope in women with ovarian cancer; specifically, what is the meaning of hope to women with ovarian cancer and what role does hope have in decision making.

5.8 *Implications for practice*

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 from the present study suggest that an intervention, based on the ODSF in which there is a multidisciplinary approach to decision support, is an appropriate next step. Such interventions have been incorporated into clinical pathways in counseling men with benign prostatic hyperplasia in several UK Urology practices in the National Health Service and in pre-operative counseling of women with breast cancer at the American Dartmouth Hitchcock Medical Center. It has been demonstrated that recall of options is improved with the use of decision aids (Whelan et al., 2003; Whelan et al., 2004; Whelan et al., 1995). 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; Whelan et al., 1995). A decision aid may therefore be useful to better present information such as response rates.

Once the decision making needs of women with recurrent ovarian cancer have been clearly defined, one of three designs of decision aids may be appropriate. If women want to participate in the choice between chemotherapy regimes, a decision aid describing the various options available to women with platinum-resistant disease should be developed. The options would be presented along with the expected outcomes, side effects and administration schedule for each option. The tool would also include a section to help women clarify their values for each option and identify the preferred role in decision making. If future studies involving health care providers demonstrate a greater need to ensure women understand the options of salvage chemotherapy now versus later (when they become are symptomatic) versus best supportive care, then a tool describing these options should be developed. If research demonstrates that women with ovarian cancer make treatment decision by plotting treatment over time, then a tool similar to the one available in “The Patient Active Guide to Living with Ovarian Cancer” (Berek & Redlin-Frazier, 2003) could be adapted to the Canadian setting.

5.8.1 Implications for advance practice nurses

As leaders and change agents, advance practice nurses (APNs) can advocate, with administrators and policy makers, for the role of nurses in the provision of decision support in this patient population. APNs with expertise in the decision support possess the required research skills to interpret the decision making literature and to understand patients’ views of treatments for ovarian cancer. Development of decision aids requires multidisciplinary perspectives; APNs have the skills to coordinate the development of a decision aid and its integration in clinical pathways. The APN also possesses the necessary skills in the domain of staff education and consultation to educate and mentor primary nurses and physicians in the provision of decision support using the ODSF. As project manager and researcher, the APN

could also lead the team in the implementation and evaluation of multidisciplinary decision support interventions and use of evidence based decisions aids.

5.9 Implications for theory

As found in other studies (Murray, 2001; Taylor-Clapp, 2001) the ODSF was a relevant framework on which to base the development of a decisional needs assessment tool. Further exploration of the concept of hope in this population should be pursued to provide new understanding of the meaning of hope to women with ovarian cancer. The role of hope in decision making and its relevance to the ODSF may be better elicited via using qualitative methodology. As previously identified by Donovan et al (2002), hope may explain the variations in decision making seen in this patient population.

5.10 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 center involved in the current study. The interview tool used in this study shows promise but needs to be tested in a larger sample. In addition, the findings need to be replicated in a study with a larger sample and in multiple centers.

References

- Ajzen, I. & Fishbein (1980). *Understanding Attitudes and Predicting Social Behaviors*. NJ: Prentice Hall.
- Averill, J. F. (1973). Personal control over aversive stimuli and its relationship to stress. *Psychological Bulletin*, 80, 286-303.
- Berek, J. & Redlin-Frazier, S. (2003). *The patient active guide to living with ovarian cancer*. Washington, DC: The Wellness Community-National.
- Booth, K., Beaver, K., Kitchener, H., O'Neil, J., & Farrell, C. (2005). Women's Experience of Information, Psychological Distress and Worry after Treatment for Gynecological Cancer. *Patient Education and Counseling*, 56, 225-232.
- Bowes, D. E., Tamlyn, D., & Butler, L. J. (2002). Women living with ovarian cancer: Dealing with an early death. *Health Care for Women International*, 23, 135-148.
- 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.
- Covens, A., Bryson, P., Verma, S., Fung Kee Fung, M., & and Members of the Gynecologic Disease Site Group (2004). First Line Chemotherapy for post-operative patients with stage II, III OR IV Epithelial Ovarian Cancer, Fallopian Tube Cancer or Primary Peritoneal Cancer. *Cancer Care Ontario*.
- de Hays, H. & Koedoot, N. (2003). Patient centered decision making in palliative cancer treatment: a world of paradoxes. *Patient Education and Counseling*, 50, 43-49.
- Degner, L. F. & Beaton, J. I. (1987). *Life-death decisions in health care*. New York: Hemisphere Publishing.
- Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J., Carriere, K. C., O'Neil, J. et al. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277, 1485-1492.
- Degner, L. F. & Sloan, J. A. (1992). Decision Making During Serous Illness: What Role do Patients Really Want to Play? *Journal of Clinical Epidemiology*, 45, 941-950.

- DeGrasse, C. (1995). *Women's breast cancer screening practices, knowledge, attitudes and decisional conflict*. Masters of Science in Nursing, University of Ottawa.
- Dennis, K. E. (1987). Dimensions of client control. *Nursing Research*, 36, 151-156.
- 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.
- Dufault, K. & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.
- Ehrenberger, H. E., Alligood, M. R., Thomas, S. P., Wallace, S. P., & Licovoli, C. M. (2002). Testing a theory of decision-making derived from King's systems framework in women eligible for a cancer clinical trial. *Nursing Science Quarterly*, 15, 156-163.
- Ekman, I., Bergbom, I., Ekman, T., Berthold, H., & Mahsneh, S. M. (2004). Maintaining Normality and Support Are Central Issues When Receiving Chemotherapy for Ovarian Cancer. *Cancer Nursing*, 27, 177-182.
- Ekwall, E., Ternstedt, B. M., & Sorbe, B. (2003). Important aspects of health care of women with gynecologic cancer. *Oncology Nursing Forum*, 30, 313-319.
- Elliott, J. & Olver, I. N. (2002). The discursive properties of "hope": a qualitative analysis of cancer patients' speech. *Qualitative Health Research*, 12, 173-193.
- 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.
- Elit, L. M., Levine, M. N., Gafni, A., Whelan, T. J., Doig, G., Streiner, D. L. et al. (1996). Patients' preferences for therapy in advanced epithelial ovarian cancer: development, testing, and application of a bedside decision instrument. *Gynecologic Oncology*, 62, 329-335.
- Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. *Oncology Nursing Forum*, 19, 883-889.
- Feather, M. (1980). *Expectations and Actions: Expectancy, Values, Models in Psychology*. NJ: Hillsdale.
- Felder, B. E. (2004). Hope and coping in patients with cancer diagnoses. *Cancer Nursing*, 27, 320-324.

- Feldman-Stewart, D., Chammas, S., Hayter, C., Pater, J., & Mackillop, W. J. (1996). An empirical approach to informed consent in ovarian cancer. *Journal of Clinical Epidemiology*, *49*, 1259-1269.
- Ferrell, B. R., Smith, S. L., Ervin, K. S., Itano, J., & Melancon, C. (2003). A Qualitative Analysis of Social Concerns of Women with Ovarian Cancer. *Psycho-Oncology*, *12*, 647-663.
- 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. (2003a). Living with ovarian cancer: women's perspectives on treatment and treatment decision-making. *Canadian Oncology Nursing Journal*, *13*, 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.
- Fitch, M. I., Gray, R. E., & Franssen E. (2000). Women's Perspectives Regarding the Impact of Ovarian Cancer. *Cancer Nursing*, *23*, 359-366.
- Fitch, M. I. & Turner, F. (2003b). *Getting on with life In M. Fran Turner (ed), You are not alone*. Toronto: National Ovarian Cancer Association.
- Fowler, F. J. (1993a). *Survey Research Methods*. (second ed.) Newbury Park, California: Sage Publications.
- Fowler, F. J. Jr. (1993b). *Survey Research Methods*. (Second Edition ed.) Newbury Park, California: Sage Publications.
- Frank-Stromborg, M. & Olson, S. J. (2004). *Instruments for Clinical health-care Research*. (Third ed.) Sudbury, MA: Jones and Barlett Publishers.
- Fung Kee Fung, M., Elit, L., Hirte, H., Rosen, B., & Members of the Gynecologic Oncology Disease Site Group (2003). Chemotherapy for recurrent epithelial ovarian cancer previously treated with platinum. *Cancer Care Ontario*.
- Hiltunen, E. (1989). Nursing Diagnosis: Decisional Conflict (specify). In R.M.Carrol-Johnson (Ed.), *Classification of nursing diagnosis: Proceedings for their eight conference*. (Philadelphia: J.B. Lippincott.

- Hinds, P. (1998). Personal Communication in Ehrenberger et al,(2004). Testing a Theory of Decision-making derived from King's System Framework in Women Eligible for a Cancer Clinical Trial. *Nursing Science Quarterly*, 15, 156-163.
- Howe, H. L., Lehnherr, 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. (1998). *A comprehensive nursing guide to ovarian cancer*. (Interlink Community Cancer Nurses ed.) Toronto, ON.
- Howell, D., Fitch, M. I., & Deane, K. A. (2003). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, 26, 10-17.
- Interagency Advisory Panel on Research Ethics (2003). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. authors.
- Jacobsen, M. J. & O'Connor, A. M. (1998). *Population Needs Assessment: A workbook for assessing patients' and practitioners' decision making needs*. University of Ottawa.
- Jalowiec, A., Murphy, S., & Powers, M. (1984). Psychometric assessment of the Jalowiec Coping Scale. *Nursing Research*, 33, 157-161.
- Janis, I. & Mann, L. (1977). *Decision Making*. (Free Press ed.) New York, NY.
- Jolicoeur, L. (2002). *Concept analysis: patient decision making*. University of Ottawa, NSG 5220, Nursing in Tertiary Health Care.
- Keeney, R. & Raiffa, H. (1976). *Decisions with multiple objectives: preferences and value trade-offs*. New York, NY: J Wiley & Sons.
- MacDonald, D. J. & Standing, L. G. (2002). *Social Behavior and Personality*, 30, 625-630.
- 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*.

- 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*. Masters of Science in Nursing, University of Ottawa..
- National Cancer Institute of Canada (2005). *Canadian Cancer Statistics 2005*. Ottawa: Authors.
- National Ovarian Cancer Association (1999). *Order of the proceedings of the ovarian cancer forum*.
- Norbeck, J. (1988). Social Support. *Annual Review of Nursing Research*, 6, 85-109.
- O'Connor, A. M. & Jacobsen, M. (2001). *Decisional Conflict: Assessing and supporting patient experiencing uncertainty about decisions affecting their health*. Ottawa: University of Ottawa.
- 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, UK: John Wiley & Sons, Ltd.
- Olver, I. N., Elliot, J. A., & Blake-Mortimer, J. (2002). Cancer patients' perceptions of do not resuscitate orders. *Psycho-Oncology*, 11, 181-187.
- Orem, D. (1995). *Nursing Concepts of Practice*. (5th ed.) Toronto, ON: Mosby.
- 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.
- Polit, D. F. & Beck, C. T. (2004). *Nursing Research. Principals and methods*. (Seventh edition ed.) Philadelphia, PA: Lippincott Williams & Wilkins.
- 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.
- Sepucha, K. R., Fowler, F. J., & Muller, A. G. (2004). Policy Support For Patient-Centered Care: The Need For Measurable Improvements In Decision Quality. *Health Affairs (Web Exclusive)*, oct.
- Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. (Second ed.) London: Sage Publications.

- Smith, J., Kindo, C. C., Kurian, S., Whitaker, L. M., Burke, C., Wachel, B. et al. (2004). Evaluation of Patient Chemotherapy Education in Gynecology Oncology Center. *Support Care Cancer*, 12, 577-583.
- 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*, Mar; 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., Dancey, J., Meana, M., Cameron, J. I. et al. (2000). Information needs and decisional preferences among women with ovarian cancer. *Gynecologic Oncology*, 77, 357-361.
- Sun, C. C., Bodurka, D. C., Donato, M. L., Rubenstein, E. B., Borden, C. L., Basen-Engquist, K. et al. (2002). Patient preferences regarding side effects of chemotherapy for ovarian cancer: do they change over time? *Gynecologic Oncology*, 87, 118-128.
- Taylor-Clapp, S. (2001). *Parents' decision making needs regarding circumcision of male newborns*. Masters of Science in Nursing, University of Ottawa.
- The Ottawa Hospital (2004). *The Ottawa Hospital Utilization Report*. Ottawa, ON: author, The Ottawa Hospital.
- Tversky, A. & Kahneman, D. (1981). The framing of decisions and the psychology of choice. *Science*, 211, 453-458.
- Watt, S. (2000). Clinical decision-making in the context of chronic illness. *Health Expectations*, 3, 6-16.
- Weber, R. P. (1985). *Basic Content Analysis*. Beverly Hills: Sage Publishers.
- 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.

- Whelan, T. J., Levine, M. N., Gafni, A., Lukka, H., Mohide, E. A., Patel, M. et al. (1995). Breast irradiation postlumpectomy: development and evaluation of a decision instrument. *Journal of Clinical Oncology*, 13, 847-853.
- Witkin, B. R. & Altschuld, J. W. (1995). *Planning and Conducting Needs Assessments: A Practical Guide*. Thousand Oaks, California: Sage Publications.
- Wong, R. K. S., Franssen, E., Szumacher, E., Connelly, R., Evans, M., Page, B. et al. (2002). What do patients living with advanced cancer and their carers want to know?- A needs Assessment. *Support Care Cancer*, 10, 408-415.
- Wood, E. A. (1995). *Women's decisions and decisional conflict regarding long term hormone replacement therapy*. Masters in Science of Nursing, University of Ottawa.

Appendix A: The Evidence

Role preference

Authors	Methodology	Sample	Tools	Data source	Type of decision	Preferred/ actual role
Fitch, Deane & Howell (2003) Results related to treatment decision are published in this paper.	Phemenological study exploring the lived experience of women with ovarian cancer	18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview.	Description of decision making related to initial surgery & chemotherapy	Women described a passive role in decision making
Howell et al (2003) Results of recurrent ovarian cancer are published in this paper.	Phemenological study exploring the lived experience of women with ovarian cancer	Convenience sample of 18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview.	Description of women's needs at the time of recurrence	Women described an increase need for involvement in TX decisions that grew from first line TX to recurrence. More women requested a second opinion at the time of recurrence then at diagnosis.
Stewart et al 2000)	Needs assessment	Consecutive sampling, 105 women diagnosed with ovarian cancer consented. 61% were in follow-up and 39% were on active treatment	Degner Decision Preference Scale (Degner, 1992)	Self-report Questionnaires	Not specified	Shared decision making (62.9% at diagnosis, 59.6% during TX, 61.9% after TX) Passive role (22.9% at diagnosis, 23.1% during tx, 21.9% after TX). Autonomous role (14.3% at diagnosis, 17.3% at treatment, 15.2% after TX)
Eilt et al (2003)	Qualitative and exploratory study using in-depth, semi structured interviews. Based on the McMaster model of Shared Decision Making	21 women diagnosed with epithelial ovarian cancer.	Questionnaire	Face to face interviews in the patients homes. Interviews took place within 8 weeks of women starting chemotherapy.	Decision about first line chemotherapy. Options: carboplatin & paclitaxel, single agent carboplatin or no chemotherapy	Options: Most did not perceive that they had been given a TX choice. 4 women perceived they had an option, 1 woman reported being offered the option to receive one drug. Role: 4 did not want chemo (3 end-up receiving some), 12 clearly indicated they made the decision (only 1 woman described a shared decision making process) and 5 clearly indicated the MD made the decision.
NOCA (1999)	Conference proceeding from the '99 Ovarian Cancer Forum			Discussion from focus group and summary discussions		Need for improved communication between women and health care providers, improved shared decision making. Decision aids.

Information

Authors	Methodology	Sample	Tools	Data source	Amount	Type	Topic	Source	Satisfaction	Determinants
Fitch et al (2003) Results related to treatment decision are published in this paper.	Phemenological study exploring the lived experience of women with ovarian cancer	Convenience sample of 18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview.			Need to learn new terminology and strategies for treating cancer before feeling capable of participating.	Women researched for information on their own. Needed to be their own advocate, described researching options and presenting these to their oncologist and seeking second opinion		Felt overwhelmed.
Howell et al (2003) Results recurrent ovarian cancer are published in this paper.	Phemenological study exploring the lived experience of women with ovarian cancer	Convenience sample of 18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview.			Difficulty in getting information about TX options (> then at initial do).		Need to push for information.	
Fitch et al (2000)	A cross sectional survey of a convenience sample of Canadian women. Comparison needs between women with and without recurrent ov.ca.	263 (93 with recurrent ca, 170 without recurrence) from the original sample of 315.	Questionnaire	Self-report questionnaire distributed by health care team			The only statistical difference was with information on emotional reactions ($p < 0.005$).	26.9% women with recurrence compared to 18.8% without reported that a benefit of support groups was access to information about ovarian cancer and its treatment	No statistical differences between women with rec.ov.ca. and those without a rec. in satisfaction re: info on: medical condition, possible side effects of ca. treatment choices available, possible side effect of TX.	

Fitch, et al (1999)	A cross sectional survey of a convenience sample of Canadian women	315 women, mean age 59 (21-93), 68% married, 96% Caucasian or European. Education: 10% primary, 45% secondary, 41% college or university	Questionnaire	Questionnaire distributed by health care team		Topic most important: 87.9% medical condition (76.2% were satisfied with info), 82.9% Physical effects of the cancer (65.4 were satisfied), 81.3% treatment choices (66.4% were satisfied) and 79.1% Side effects of treatment (71.1% satisfied).	Source of information: 51% gyn-onc, 55%GP, gynecologist42% and Nurses 40%. 16% sought a second opinion, 50% of women relied on gyn-onc oncologist for TX of ovarian ca.		
Stewart et al (2000)	Needs assessment	Consecutive sampling, 105 women diagnosed with ovarian cancer consented. 61% were in follow-up and 39% were on active treatment, 85% Caucasian, Man age: 55.8 (range 21-87), 67% married living with partner, 55% well-educated, 116 physicians, 83 women with ovarian cancer, 92 surrogate Demographic of ov ca pts: Median age 55, 71 % married, 77% had children, 27% finished high school,	Questionnaire: Information format (preference 1-10), Information amount, type and focus preferences, Specific information needs	Details 83% at diagnosis, 90% at time of treatment, 82% post treatment Brief: 16.2 at diagnosis, 9.7% at treatment, 18.1% post tx None: 1% diagnosis, 0% tx, 0% post tx.	Most likely outcome (mean 43.6%) to best possible outcome (mean 43.6%). Only 8% wanted worse possible outcomes.	Focus of info: 67% want both physical and psychosocial info, 32.6% want mainly physical info and only 1% wanted mainly psychosocial info post treatment. Questions concerning cancer, treatment and self-care were frequently endorsed vs. physical appearance, sexuality, and financial (p<0.05).	Most preferred from MD or other health care provider. Younger women and better educated women were more likely to use the internet (p.0.05)	Education, age and psychological functioning, perception of seriousness of disease	Education accounted for 16.8% variance on question related to length of TX if more TX is needed. Parental status accounted for 21.5 % of variance to question about
Feldman-Stewart et al (1996)	Comparison study		Information preference Questionnaire (list of questions in Table 2)	57 item questionnaire, 10 different question order were created to minimize the order effect.		There was statistical agreement within the group of women however not enough to predict individual women's preference for topic of information			

<p>NOCA (1999)</p>	<p>Conference proceeding from the '99 Ovarian Cancer Forum</p>	<p>43% high school, 30% college of university, 68% had been on TX<1year ago,</p>					<p>more pt tailored information, women felt that few options were available for rec., some questioned whether all options were being presented. Focus on access to clinical I trials. Need for guidelines to ensure more consistency in options being presented are consistent nationally/provincially.</p>	<p>Discussion from focus group and summary discussions</p>		<p>risk of children for ov ca.</p>
------------------------	--	---	--	--	--	--	---	--	--	--

Knowledge

Authors	Methodology	Sample	Tools	Data source	Pt knowledge & expectations
Fitch et al (2003)	Phemenological study exploring the lived experience of women with ovarian cancer	18 pts (12 dx in past year, mode 5 months) with ovarian cancer, approached by team, consent obtained by study RN	Telephone interview. Results related to the experience of women related to treatment decision are published in this paper.	Telephone interview with open ended questions used to probe	Lack of knowledge of ca. this was a barrier identified by patients. They went along with what was proposed.
Howell et al (2003)	Phemenological study exploring the lived experience of women with ovarian cancer	Convenience sample of 18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview. Results related to the experience of women related to recurrent ovarian cancer are published in this paper.	Women had gained knowledge of ovarian cancer by the time of their recurrence.
Fitch et al (1999)	A cross sectional survey of a convenience sample of Canadian women	315 women, mean age 59 (21-93), 68% married, 96% Caucasian or European, Education: 10% primary, 45% secondary, 41% college or university	Questionnaire Pre and Post test Comprehension questionnaire 10 items (true or false), State portion of the State Trait Anxiety Inventory	Questionnaire distributed by health care team	55% had been informed about stage of their cancer and 85% of them understood the information.
Eilt et al (1996)	Pre-experimental design, instrument development and testing, McMaster model	n=12 women with ovarian cancer	Questionnaire	Questionnaire pre and post decision support using the decision board intervention	86% comprehension questions were answered correctly
Eilt et al (2003)	Qualitative and exploratory study using in-depth, semi structured interviews. Based on the McMaster model of Shared Decision Making	21 women diagnosed with epithelial ovarian cancer.	Questionnaire	Face to face interviews in the patients homes. Interviews took place within 8 weeks of women starting chemotherapy.	Patients had better knowledge of risk then benefits of TX. Patients appeared to have a good understanding of the goal of TX, 5/21 reported that TX could Kill the cancer cells or "My cure", which could indicated higher expectations of potential outcomes of TX. 62% knew they were receiving two drugs. Women reported that they don't ask questions or do not feel ready to ask questions

Other Determinants

Authors	Methodology	Sample	Tools	Data source	type of decision/ choice	Other determinants
Fitch et al (2003)	Phemenological study exploring the lived experience of women with ovarian cancer	18 pts (12 dx in past year, mode 5 months) with ovarian cancer, approached by team, consent obtained by study RN	Telephone interview. Results related to the experience of women related to treatment decision are published in this paper.	Telephone interview with open ended questions used to probe	Treatment related to initial surgery & chemotherapy	Physical health: symptoms of the cancer and surgery, need to start TX soon. No time to make the decision and plan. Emotional state: women were overwhelmed initially(chock, fear, feeling rushed trough treatment, not psychologically ready, trying to come to terms whit diagnosis) Felt carried along. Lack of support and understanding form health care team re need to learn
Howell et al (2003)	Phemenological study exploring the lived experience of women with ovarian cancer	Convenience sample of 18 women with ovarian cancer (12 diagnosed in past year, mode 5 months)	Questionnaire, with open ended questions used to guide the interview and probe as needed	Telephone interview. Results related to the experience of women related to recurrent ovarian cancer are published in this paper.		Psychosocial health: Challenge to maintain control of ca. devastated at the news of recurrence, one pt was not surprised Physical health: difficulty with side effects of progressive disease. Characteristics of providers: Change they felt about health care prof. attitude toward them perceived they were not being heard, this change in attitude was perceived that there was no hope. Other: Geographic location limiting access to TX.
Eilt et al (2003)	Qualitative study reference to article that describes the method is given. Objectives: 1) perception of pot that they had options, 2) understanding of risk and benefits, 3) preference to participate in TX decision, no theory	21 women diagnosed with epithelial ovarian cancer.	Questionnaire	Face to face interviews in the patients homes. Interviews took place within 8 weeks of women starting chemotherapy.	First line decision to have chemotherapy. Options presented by author: Carbo taxol, single agent chemo, or no chemo.	Readiness to make a decision: overwhelmed post-op medication post-op, unexpected diagnosis Psychosocial health: coping with losses (body image, deceased energy) frightened, pressured into decision. Some women saw beyond the current circumstance and Hope and instinct motivated them to make the decision. pl/MD relationship: positive aspect: Knowledge of oncologist, support form MD, knew outcome of TX Negative aspects: problems with other members of the health team, oncologist not personable, lack of continuity between oncologist and lack of communication between MDs, lack of explanation of disease by Medical staff. social support Positive aspects: family asked more questions, support network (spending time with them), encouragement, others experience with cancer system, Negative aspects: negative friends and family, change in attitude of others toward them, pressure to return to work, stories of people who had TX then died, life events made some postpone decision (family members wedding). Characteristic of provider: MD were biased toward medical model of evidence based proactive and did not offer less aggressive TX. Lack of evidence of MD exploring pt preference and values.

Donovan et al (2002)	Quantitative Cross sectional study, no theory	81 women with ovarian cancer and 75 noncancer controls, cross sectional from gyn-onc day unit and uro gyn clinic	Fact-o, Functional Assessment of Chronic Illness Therapy-Spiritual well-Being Scale, System of Belief Inventory-15R, Profile of Mood States, Satisfaction with Life Scale,	<p>Recurrence: Palliative care vs. salvage (no regime specified) Choice: women wanted aggressive treatment</p>	Choice was independent of age, number of children, QoL, spiritual well-being, Health status did not differ between pts who preferred salvage to palliation, Women who reported that chemotherapy was a somewhat difficult bit difficult. Difficulty with chemotherapy did not predict perceived quality of life during salvage TX. Need for hope seems to outweigh all other psychological constructs that may influence TX decision.
Sun et al (2002)	Prospective descriptive study, based on concept from decision analysis theories	40 women with stage 3 and 4 enrolled in a phase 2 study of high dose chemotherapy and peripheral stem cell support	Visual analog scale and Time Trade off	Post decision to participate in phase 2 trial. Preference for health states were assessed at T1(during mobilization chemotherapy) and T2 (high dose chemotherapy).	Number of prior cycles of chemotherapy.
Ekwall et al (2003)	Qualitative study exploring what women reported as important during interaction within the healthcare system	17 women with gynecological cancer (2 cervical cancer, 4 ovarian, 8 uterine)	Semi structure interviews conducted between 2-12 months post diagnosis	No specific decision	Time between initial dx and tx too short to participate, Good communication with health care staff helped women feel more confident and participate more, Women described that they have to put their lives in the hands of MD, they still wanted to participate in health care decisions. The desire to be cured overshadowed everything else.

Hope

Authors	Location/s setting	Key concept/ variables	Methodology (Design, Framework Theory)	Sample size/population/Method	Tools	Data source	Statistical tests	Findings	Recommendations/ conclusion	Strength	Weakness
De Haes & Koedoot (2003)	Review article	N/A	N/A	N/A	N/A	literature	N/A	The author suggests that patients can avoid certain information if they leave the decision to the clinician. This is described as a mechanism to maintain hope . They describe a ' coalition of hope ' between the physician in patients in palliative cancer treatment, which reassures the patient and physician and allays anxiety.	N/A	Review of various determinant of decision in palliative cancer treatment which is an area will limit research.	Secondary data, literature search strategies not included.
Donovan, Green, et al (2002)	University Hospital the US	Spiritual well being, spiritual and religious practices, QoL, psychological distress, life satisfaction and Decision board	Quantitative Cross sectional study, no theory	81 women with ovarian cancer and 75 non cancer controls, cross sectional from gynec onc day unit and uro gyn clinic	Fact-o, Functional Assessment of Chronic Illness Therapy-Spiritual well-Being Scale, System of Belief Inventory-15R, Profile of Mood States, Satisfaction with Life Scale,			The need for hope may outweigh all other psychological constructs that influence tx decision.			

Oliver, Elliott & Blake-Mortimer (2002)	Australia	Pt perception of DNR orders	Qualitative Grounded Theory approach	23 patients from a cancer center	Interview questionnaire developed for the study	Face to Face interviews, analysis using NUD*IST	N/A	<p>Hope determined choice and outcomes. Hope was linked to treatment efficacy and the progression of the illness. Some respondents connected hope to miracles. Some attributed hope to other positives outcomes such as making informed decisions. Some did not want to initiate DNR discussion in the presence of hope. Hope is associated with desire and expectations.</p>	<p>Difference in patients and practitioner definition of hope was identified.</p>	<p>Qualitative methodology was respected. No evidence of researcher bias. Novel topic.</p>	<p>Most patients did not associate themselves with being at the stage when a DNR discussion should take place. The author identified the need to conduct the study with pts with more advanced disease.</p>
Elliott & Oliver (2002)	Australia	Hope	Qualitative Grounded Theory approach looking at pt perception of DNR orders, this article is a secondary analysis looking at the concept of hope.	23 patients from a cancer center of those 12 participants discussed the concept of hope.	Interview questionnaire developed for the study	Face to Face interviews, analysis using NUD*IST	N/A	<p>Summary table of previous papers on the elements of hope is presented in the literature review. Themes that emerged: Hope exists independently (it could be determined by the physician), Hope can vary in degree and resilience, Unrealistic or false hope, Hope is subjective, Hope is the active desiring of a possible future outcome, The consequence of hope, The discourse of will (hope and the progression of cancer).</p>	<p>Recommend focusing on determining the meaning of hope for each individual versus looking at measuring it with tools. Recognize that individuals may differ in their understating of hope.</p>	<p>Qualitative methodology was respected. No evidence of researcher bias. Novel topic.</p>	<p>Few quotes from participants which would help demonstrate the themes presented. The themes seem to be coming as much from the literature as the participants as there are a lot of references in the presentation of the findings. The authors seem to have merged the presentation of findings along with the discussion.</p>

Murray (2001)	In patient and outpatient in Ottawa	Decision making. Location of end of life care	Needs assessment, Ottawa Decision Support Framework	20 women with advance cancer, prognosis less than 9 months	Decisional conflict scale, Needs assessment survey (developed for this study)	Face to face interviews	Descriptive (frequency and mean)	No findings were reported that are directly related to the concept of hope. A dictionary definition of hope is provided: an expectation and a desire. The concept of hope is described based on the perspective of different culture and various religions as well as from an existential perspective. The concept of hope is then described from findings in the literature.	Author recommended that future studies should look at the concept of hope as it related to decision making in the palliative setting.	Based on well-defined framework, Introduced the concept of feminist view in decision making.	Qualitative data was not transcribed which may have been a barrier to identifying themes such as hope form the data provided by the participants. NO obvious link between the recommendation to look at hope and the data presented.
Cutcliffe & Herth (2002)	N/A	Hope	Review of the origins, background and definitions of hope	N/A	N/A	Literature	N/A	Hope is multidimensional, dynamic, central to life, future oriented, individualize4, some identify it as a process, goal setting and some associated the concept of hope to nursing.	Summary of some of the literature on hope.	Search strategy is not described.	
Bowes, Tamplin & Butler (2002)	Nova Scotia	Dealing with an early death	Qualitative Grounded Theory approach	nine women post first line therapy	N/A	face to face interviews	N/A	Themes that emerged are presented in a pictorial outline. Hope was identified as a necessary condition for women to find meaning and perspective in their lives. Hope was described as a dynamic feeling, which has fluctuating beliefs for the a future and attainment of life goals. Physical wellbeing fostered hope. Comments, "if you don't have hope you have nothing", "I don't not plan for the future I hope for the future"	The high mortality rate of ovarian cancer precipitates a unique terrifying response in women with the haunting fear of death in their immediate future.	Good balance between quotes and interpretation of data. The quotes are representative of the themes. Rigor in qualitative methodology was present	Sample was very homogenous, all participants had completed first line tx. Therefore the concepts may not be attributable to the recurrent setting.

<p>Ehrenberger, Alligood Thomas, Wallace & Licavoli (2002)</p>	<p>Four cancer care facilities in the USA.</p>	<p>to test the relationships among uncertainty, role functioning, and social support and emotional health (hope & mood state)</p>	<p>To test an exploratory theory of decision making derived from King's framework</p>	<p>40 women newly diagnosed with cancer</p>	<p>Mishel Uncertainty in Illness Scale-Community Form, Inventory of Functional Status Cancer, Medical Outcomes Study-Social Support Survey, Herth Hope Index and Profile of Mood State-Short form.</p>	<p>Survey</p>	<p>Spearman Rank order correlation Mann-Whitney U test</p>	<p>Uncertainty, role functioning and social support had a statistically significant relationship with hope However there were no significant difference in the level of hope and the decision. Most women reported hope without significant differences in mood disturbance in spite of the decision.</p>	<p>Hope is mediating variable and that mood state is the outcome variable.</p>
--	--	---	---	---	--	---------------	--	---	--

Appendix B: Data collection Sheet

(Source: Patient health Record)

Participant code: _____

Date: _____

Clinical profile:

1. Date of diagnosis: ___/___/___

2. Stage of disease at diagnosis: 1 2 3 4

3. Current chemotherapy regime: _____

4. Options presented during counselling sessions:

Option 1:
Option 2:
Option 3:
Option 4:
Options presented not documented in progress notes

5. Current line of treatment: 2nd line 3rd line

6. Prior therapy:

 Chemotherapy (regime) _____ Date of last tx ___/___/___

Chemotherapy (regime) _____ Date of last tx ___/___/___

Chemotherapy (regime) _____ Date of last tx ___/___/___

 Surgery (specify) _____ Date ___/___/___ Radiation (site) _____ Date of last tx ___/___/___Demographic information:

DOB ___/___/___

Age: _____

Appendix C: Interview Guides

Needs Assessment Interview guide Interview Questions for Women with Recurrent Ovarian Cancer

Thank you for agreeing to participate in this study. My name is Lynne Jolicoeur, I am a masters student in Nursing at the University of Ottawa.

I am conducting a study to learn more about the needs of women when they are making decisions about treatment for ovarian cancer that has come back. This information will be used to help plan ways to better support to women facing this decision.

All of the information collected will be kept confidential. I (We) expect it to take about 30-60 minutes. As we go through the interview, please let me know if you are feeling tired, unwell, or if you need a break. Please remember that this is a voluntary survey and if for any reason you wish to stop, please let me know and we will stop the interview immediately.

Examples of some common health decisions that women with ovarian cancer have to make about treatment when the cancer has come back are:

- Whether or not they want more chemotherapy,
- Watch and wait for symptoms or start treatment now (for biochemical recurrence)
- Which chemotherapy treatment protocol to choose when there is more than 1 choice and/or
- Whether or not to participate in research studies on newer chemotherapy drugs or newer ways to give the chemotherapy.

Today, I would like to talk to you about your experience in making these type of decisions. Do you have any questions before we start?

Start time of interview: ___:___

CHARACTERISTIQUES

When were you originally diagnosed with ovarian cancer? _____

Are you currently on treatment? Yes ___ No ___

If so, what are you currently receiving _____

PERCEPTION OF THE DECISION

1. Can you tell me about how you found out your cancer had come back/flared up (recurred/progressed)?

2. Thinking about the time when you were told your cancer had come back, what kind of treatment options were you given?

3. What options did the doctor discuss with you:

watch and wait clinical trial/drug study Topotecan Liposomal Doxorubicin Paclitaxel oral chemotherapy hormonal therapy Symptoms control Palliative care nothing other _____

4. How did you feel when making this decision?

[Probe: Did you feel: unsure about what to do worried what could go wrong distressed or upset constantly thinking about the decision wavering between choices or changing your mind delaying the decision questioning what is important to you feeling physically stressed (tense muscles, racing heartbeat, difficulty sleeping) Anxious unqualified to make the decision confused

5. **Sometimes there are certain things that make such a decision difficult. What things made this decision difficult for you?**

Probe: Were you : lacking information about options, pros and cons lacking information on the chances of benefits and harms unclear about what is important to you lacking information on what others decide feeling pressure from others lacking support from others lacking motivation or not feeling ready to make a decision lacking the skill or ability to make this type of decision other too distress to think straight too anxious putting others needs ahead of our own (not wanting to be a burden) wanting to choose on the basis of family needs/preferences

6. **How knowledgeable were you about ovarian cancer and its treatment at the time of making the decision?**

7. **What did you understand?**

8. **What did you not understand as well?**

9. **What have you been told about what you can expect as far as a response to treatment (chance of cure) for ovarian cancer?**

10. So at the time, you were considering the options. What was your understanding of the main pros (advantages) and cons (disadvantages) of those options? Let's start with the first option, what were the reasons for and against choosing that option?

Options	advantages		disadvantages	

PERCEPTION OF OTHERS

11. Women participate in decisions in different ways. There are 5 different ways in which women want to participate in decisions about their health. Please choose the way that best describes how the decision was made about the treatment for your ovarian cancer when it came back.

(Show control preference scale)

12. You have just described how you were involved in the decision. Is this how you prefer to make decisions?

☐ Yes ☐ No

If not, can you describe to me how you would have preferred to make the decision?

(Show control preference scale)

13. Who else was involved in making this decision? What was their opinion? How were they involved in making this choice?

Relationship	How were they involved?
	☐ making the decision for you, ☐ sharing the decision with you, ☐ providing support or advice to you to make the decision on your own
	☐ making the decision for you, ☐ sharing the decision with you, ☐ providing support or advice to you to make the decision on your own
	☐ making the decision for you, ☐ sharing the decision with you, ☐ providing support or advice to you to make the decision on your own

RESOURCES

14. Think back to when you were first told about the treatment options when your ovarian cancer came back. How did you go about making this decision?

Did you: get information on choices get information on how likely the choices are consider how important choices are, get information on how other patients decide or recommend find ways to handle pressure while deciding get support from others advice from loved ones follow MD's advise other

How much time did you have to make the Decision? _____

Was this sufficient for you? _____

15. What things really helped you make this decision?

Personal resources: previous experience with the situation Trusting yourself (self-confidence) Motivation Skill in decision making physical health general emotional health good analytic skills (cognitive health) good social connections (social health)

External resources: availability and access to information advice emotional support help with practical things financial assistance

Sources: social network professional network (specify: _____) support groups voluntary agencies formal health care system education social sector (Friends) employer

16. What things got in the way of (hindered you) making this decision?

Probe: other responsibilities emotional stability lack of confidence depression anxiety conflicting needs (ill husband/children) confusion/conflicting feelings other's needs

17. Is there something that could have helped to overcome some of the things that got in the way (hindered) of making this decision?

18. How did your health team (doctors, nurses, social worker, pharmacist, psychologist) help you decide about treatment for your ovarian cancer when it came back?

Describe who (their profession) helped and how?

Professional	Help provided
	<input type="checkbox"/> give you information on your cancer <input type="checkbox"/> give you information on choices <input type="checkbox"/> give information on how likely the choices are <input type="checkbox"/> provide you with information about the pros and cons of each options, <input type="checkbox"/> help you consider how important each choices are to you, <input type="checkbox"/> provide you with information on how others decide or what they decided <input type="checkbox"/> suggest ways to help handle pressure <input type="checkbox"/> provide you with support <input type="checkbox"/> support to loved ones <input type="checkbox"/> other:
	<input type="checkbox"/> give you information on your cancer <input type="checkbox"/> give you information on choices <input type="checkbox"/> give information on how likely the choices are <input type="checkbox"/> provide you with information about the pros and cons of each options, <input type="checkbox"/> help you consider how important each choices are to you, <input type="checkbox"/> provide you with information on how others decide or what they decided <input type="checkbox"/> suggest ways to help handle pressure <input type="checkbox"/> provide you with support <input type="checkbox"/> support to loved ones <input type="checkbox"/> other:
	<input type="checkbox"/> give you information on your cancer <input type="checkbox"/> give you information on choices <input type="checkbox"/> give information on how likely the choices are <input type="checkbox"/> provide you with information about the pros and cons of each options, <input type="checkbox"/> help you consider how important each choices are to you, <input type="checkbox"/> provide you with information on how others decide or what they decided <input type="checkbox"/> suggest ways to help handle pressure <input type="checkbox"/> provide you with support <input type="checkbox"/> support to loved ones <input type="checkbox"/> other:

19. How would you describe your level of hope? And what is the relation between hope and your decision?

20. Now thinking about future decisions that you may be faced with or about other women finding out that their ovarian cancer has come back, if multiple options are available, should all options be presented OR should only a few options be provided?

21. If not all options should be presented, who should narrow down the options? How should the options be narrowed down?

22. There are many treatments that a doctor can offer, in order to narrow the options, it helps to know what matters most to you. Can you tell me which features of treatment matter most? _____

Probe: how effective the treatment is (response rate) Quality of life (minimal treatment side effects) ability of the treatment to control the symptoms of ovarian cancer living longer frequency of visits (Specify) participating in a clinical trial (drug study) oral treatment that I can take at home avoiding certain side effects of treatment (specify: hair loss, neuropathy, hypersensitivity, pancytopenia, myalgia/arthritis, PPE, other _____)

23. What may help to improve the support for making these tough types of decisions? I will list possible ways to help people with decisions, which ones do you think may be useful to women with recurrent ovarian cancer?

Counseling from health practitioner, IF YES, what type of practitioner _____

Discussion groups of people facing the same decisions, IF YES, what type of organization or group _____

Information materials

If yes, type of medium----> booklets, pamphlets videos CD ROMS
 Internet other, specify _____

24. If yes, what type of information should be included?

25. Can you summarize the key points about your recent decision about treatment?

CHARACTERISTICS

How old are you: _____

What is your highest level of schooling _____

Follow-up call: Yes _____ No _____

In the event that I would need to clarify impression of our discussion today or from the overall findings, could I call you to do so? Yes _____ No _____

Would you like to receive information about the study findings once the study is complete?
Yes _____ No _____

Additional information requested by the participant:

Referral to multidisciplinary team member:

Thank you for your valuable contribution!

End of interview: _____:_____

Questionnaire d'évaluation des besoins
Question d'entrevue pour les femmes avec une récurrence d'un cancer ovarien

Merci d'accepter de participer à cette étude. Mon nom est Lynne Jolicoeur, je complète ma maîtrise en soins infirmiers à l'Université d'Ottawa.

J'entreprends une étude pour mieux comprendre les besoins des femmes quand elles prennent des décisions au sujet des traitements pour une récurrence d'un cancer ovarien. Cette information sera employée dans la planification d'interventions visant à mieux soutenir/aider les femmes faisant face à cette décision.

Je prévois que l'entretien durera environ 30-60 minutes. Pendant cet entretien, SVP dites-moi si vous vous sentez fatigué, vous n'êtes pas bien, ou si vous avez besoin d'une pause. Veuillez vous rappeler que votre participation est volontaire et que si pour n'importe quelle raison, vous souhaitez arrêter l'entretien, avertissez-moi et nous arrêterons l'entrevue immédiatement. Toute l'information que nous rassemblerons sera confidentielle.

Voici quelques exemples de décisions de santé que les femmes avec le cancer ovarien doivent prendre au sujet du traitement quand le cancer a récidivé:

- Si elles désirent d'autres traitements de chimiothérapie
- Quel protocole de chimiothérapie choisir quand il y a plus de 1 choix
- Si vous participeriez à une étude sur des nouveaux agents de chimiothérapie ou sur des nouvelles façons de donner la chimiothérapie.

Aujourd'hui, je voudrais vous parler de votre expérience face à ces types de décision. Avez-vous des questions avant que nous commençons ?

Début de l'entrevue : ____ : ____

CARACTÉRISTIQUES

Quand avez-vous été originalement diagnostiqué avec un cancer ovarien? _____

Êtes-vous présentement en traitement? Oui ___ Non ___

Si oui, que recevez-vous? _____

PERCEPTION DE LA DÉCISION

1. Pouvez-vous me dire comment vous avez su que votre cancer était revenu (récidiver/progresser) ?

2. Pensant au moment où on vous a dit que votre cancer était revenu, quel genre d'options de traitement vous a-t-on donné?

3. Quelles options le médecin vous a-t-il (elle) discuter avec vous?

Sonde : suivi et attendre étude clinique/étude de médicament Topotecan Doxorubicin liposomique Paclitaxel chimiothérapie orale thérapie hormonale contrôle des symptômes soins palliatif rien autre _____

4. Comment vous êtes vous senti en prenant cette décision ?

[sonde : Vous êtes vous senti : incertain face à quoi faire inquieté que quelque chose n'irait pas bien affligé ou dérangé penser constamment à la décision hésitant entre les choix ou changeant d'avis retarder la prise de décision vous questionnez sur ce qui est important pour vous sentiment physiquement de stress (muscles tendus, emballant le battement de coeur, la difficulté dormant) Anxieuse sentiment de ne pas être compétente pour prendre la décision confuse

5. Parfois, il y a certaines choses qui rendent une telle décision difficile. Quelles sont les choses qui ont rendu cette décision difficile pour vous ?

[sonde : Aviez-vous : | _ | un manque d'informations sur des options, les pous et les contres | _ | un manque d'information sur les possibilités des avantages et inconvénients | _ | de l'incertitude face à ce qui est important pour vous | _ | un manque d'information sur ce que d'autres décident | _ | un sentiment de pression exercées par d'autres | _ | un manque de soutien de la part des autres | _ | un manque de motivation ou ne pas se sentir prête à prendre la décision | _ | un manque de technique ou d'aptitudes pour prendre ce type de décision | _ | trop perturbé pour pouvoir bien réfléchir | _ | trop anxieuse | _ | mettre les besoins des autres avant les votre (ne pas vouloir être un fardeau) | _ | vouloir choisir en fonction des besoins de la famille/de leur préférence | _ | autre

6. Quelles étaient vos connaissances au sujet du cancer ovarien et son traitement quand vous avez dû prendre la décision ?

7. Qu'est ce que vous compreniez bien?

8. Qu'est ce que vous ne compreniez pas aussi bien?

9. Que vous a-t-on dit sur ce que vous pouvez vous attendre face à la réponse au traitement (chance de guérison) pour un cancer ovarien ?

10. Au moment où vous considérez les options, quelle était votre compréhension des avantages principaux et des inconvénients de ces options ? Commençons par la première option, qu'elles étaient les raisons de choisir ou ne pas choisir cette option ?

Options	Avantages		Désavantages	

PERCEPTION DES AUTRES

11. Les femmes prennent des décisions de différentes façons. Il y a 5 façons différentes que les femmes utilisent pour participer aux décisions au sujet de leur santé.

Veillez choisir la façon qui décrit mieux comment la décision a été prise au sujet du traitement pour votre cancer ovarien quand il est revenu.

(montrez l'échelle de préférence du contrôle)

12. Vous venez de décrire comment vous avez été impliqué dans la décision. Pouvez-vous maintenant me décrire comment vous préférez prendre des décisions

(montrez l'échelle de préférence du contrôle)

13. Qui d'autres que vous sont impliqués en prenant cette décision ? Quel(s) était(ent) leur(s) opinion(s)? Comment était-il (étaient-ils) impliqué(s) en faisant ce choix ?

Lien	Comment était-il (étaient-ils) impliqué(s)?
	_ prenant la décision pour vous, _ partageant la décision avec vous, _ vous fournissant de l'appui ou des conseils pour prendre votre propre décision
	_ prenant la décision pour vous, _ partageant la décision avec vous, _ vous fournissant de l'appui ou des conseils pour prendre votre propre décision
	_ prenant la décision pour vous, _ partageant la décision avec vous, _ vous fournissant de l'appui ou des conseils pour prendre votre propre décision
	_ prenant la décision pour vous, _ partageant la décision avec vous, _ vous fournissant de l'appui ou des conseils pour prendre votre propre décision

RESSOURCES

14. En revenant en arrière au moment où vous avez été informé sur les options de traitement quand votre cancer ovarien est revenu, comment avez-vous abordé cette décision ?

[sonde : Avez-vous: | _ | obtenue de l'information sur des choix | _ | obtenue de l'information sur la probabilités des choix sont | _ | considéré l'importances des choix | _ | obtenue de l'information sur la façon dont d'autres ont décidé ou leurs recommandations | _ | trouvez des manières pour faire face aux pressions | _ | obtenue de l'appui de d'autres | _ | l'avis de vos proches | _ | suivi les conseil du médecin | _ | autre

Combien de temps avez-vous eu pour prendre la décision? _____

Est-ce que cela était suffisant pour vous? _____

15. Quels éléments vous ont vraiment aidés à prendre cette décision ?

[sonde : **Ressources personnelles** : | _ | une expérience précédente avec cette situation | _ | confiance en soi | _ | motivation | _ | compétence dans la prise de décision | _ | santé physique | _ | santé émotionnelle | _ | santé cognitive | _ | santé sociale

Ressources externes : | _ | disponibilité et accès à l'information | _ | conseil | _ | appui émotif | _ | aide avec des choses pratiques | _ | aide financière | _ |

Sources: | _ | réseau social | _ | réseau professionnel (spécifier _____) | _ | groupes de soutien | _ | agences volontaires | _ | réseau de santé formelle | _ | éducation | _ | secteur social (amis) | _ | employeur

16. Qu'est ce qui vous a empêché (obstacles) de prendre cette décision ?

Sonde : | _ | d'autres responsabilités | _ | stabilité émotionnelle | _ | manque de confiance | _ | dépression | _ | inquiétude | _ | des besoins conflictuels (époux/enfant malade) | _ | des sentiments de confusion/conflict | _ | autres besoins

17. Y a-t-il quelque chose qui aurait pu vous aidez à surmonter ce qui vous a empêché (obstacles) à prendre cette décision ?

18. Comment est-ce que votre équipe de santé (médecins, infirmières, travailleur(se) social, pharmacien(ne), psychologue) vous a aidé à prendre une décision au sujet du traitement pour votre cancer ovarien quand il est revenu ? Dites-moi qui (leur profession) vous a aidé et comment ?

Profession	Aide donné
	_ donné de l'information sur votre cancer _ donné de l'information sur les choix _ donné de l'information sur la probabilité des choix _ fournit de l'information sur les pour et les contres de chaque option, _ aider à considérez l'importance des choix pour vous, _ fournis de l'information sur la façon dont d'autres ont décidé et ce qu'ils ont décidé _ suggérez des manières pour géré la pression _ de l'appui _ Appui à votre famille _ autre :
	_ donné de l'information sur votre cancer _ donné de l'information sur les choix _ donné de l'information sur la probabilité des choix _ fournit de l'information sur les pour et les contres de chaque option, _ aider à considérez l'importance des choix pour vous, _ fournis de l'information sur la façon dont d'autres ont décidé et ce qu'ils ont décidé _ suggérez des manières pour géré la pression _ de l'appui _ Appui à votre famille _ autre :
	_ donné de l'information sur votre cancer _ donné de l'information sur les choix _ donné de l'information sur la probabilité des choix _ fournit de l'information sur les pour et les contres de chaque option, _ aider à considérez l'importance des choix pour vous, _ fournis de l'information sur la façon dont d'autres ont décidé et ce qu'ils ont décidé _ suggérez des manières pour géré la pression _ de l'appui _ Appui à votre famille _ autre :

19. Parlons quelques minutes de « l'espoir », comment décrireriez vous votre niveau d' « espoir » Est- ce –que « l'espoir » a eu un impact sur votre décision?.

20. Pensez maintenant à d'autres femmes qui apprennent que leur cancer a récidivé (est revenue). Si de multiples options sont disponibles, toutes les options devraient-elles être présentées ou seulement quelques-unes d'entre elles?

21. Si toutes les options ne devraient pas être présentées, qui devrait diminuer le nombre d'options? Et comment devrait-on éliminer des options?

22. Il y a plusieurs options qu'un médecin peut offrir, afin de diminuer le nombre d'options, il est utile de savoir qu'est ce qui est le plus important pour vous. Pouvez-vous me dire quel aspects des traitements son le plus important pour vous?

Sonde : comment efficace est le traitement (taux de réponse) Qualité de vie (effets secondaires minimum aux traitements) capacité du traitement a contrôler les symptômes du cancer des ovaires vivre plus longtemps fréquence des visites (spécifier) Participer à une étude clinique (étude sur les médicaments) traitement que je peux prendre par la bouche à la maison éviter certains effets secondaires des traitements (spécifier : p) d'autres responsabilités stabilité émotionnelle manque de confiance dépression inquiétude des besoins conflictuels (époux/enfant malade de cheveux, neuropathie, hypersensibilité, pancytopenie, myalgie/arthralgie, PPE, autre _____)

23. Qu'est ce qui peut aider à améliorer le soutien pour prendre ce types de décisions difficiles? J'énumérerai des façons possibles d'aider les personnes avec une décision. Lesquelles pensez-vous seraient utiles aux femmes avec une récurrence d'un cancer ovarien?

Counseling d'un professionnel de la santé, SI OUI, quel type de professionnel? _____

Groupes de discussion de personnes confrontés avec les mêmes décisions
SI OUI, quel type d'organisation ou de groupe? _____

Documents et matériels d'Informations

Quel type de média?

livrets, brochures vidéos CD ROM Internet autre, Spécifier

24. Si oui, quel type d'information devrait être inclus?

25. Pouvez-vous me résumer les point clés au sujet de la décision que vous avez prise récemment concernant les traitements?

CARACTÉRISTIQUES

Quel âge avez-vous? _____

Quelle est votre plus haut niveau d'éducation ? _____

Appel de retour désirer? Oui _____ Non _____

Dans l'éventualité où j'aurais besoin de clarifier certaines des informations que vous m'avez donner aujourd'hui ou face aux données obtenues pendant l'étude, puis-je vous téléphone?

Oui _____ Non _____

Voulez-vous recevoir de l'information au sujet des résultats de cette étude une fois quel sera terminer? Oui _____ Non _____

Information additionnelle demander par la participante :

Référez à un membre de l'équipe multidisciplinaire :

Merci de votre précieuse collaboration!

Fin de l'entrevue : _____ : _____



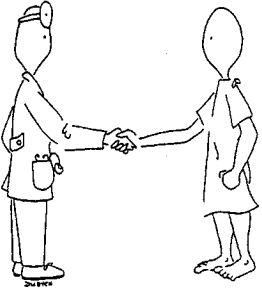


Appendix D: Control Preference Scales

D1: Control Preference Scale: Preferred role (English)



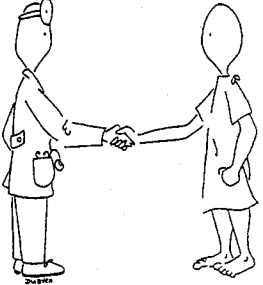
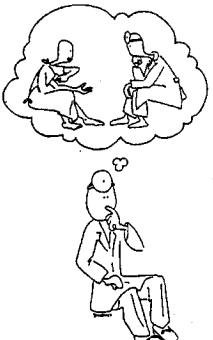
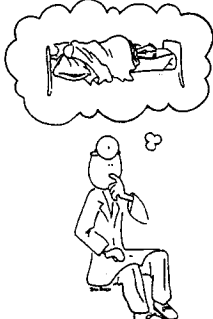
D2: Control Preference Scale: Preferred role (French)

D3: Control Preference Scale: Actual role (English)



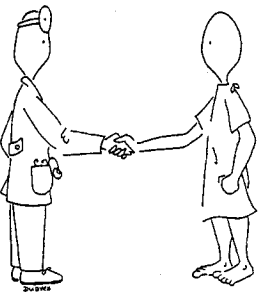

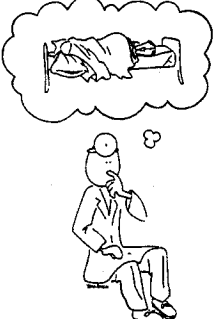
D4: Control Preference Scale: Actual role (French)



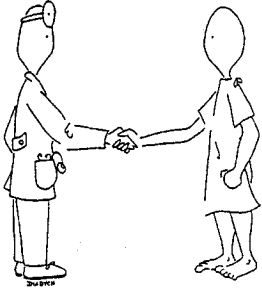

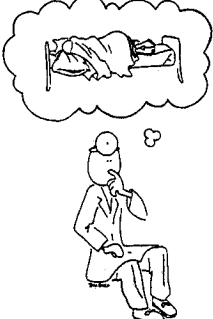
D1: Control Preference Scale (Degner et al, 1992): Preferred Role –English	
	<p>I prefer to make the final selection about which treatment I will receive.</p>
	<p>I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.</p>
	<p>I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</p>
	<p>I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.</p>
	<p>I prefer to leave all decisions regarding my treatment to my doctor.</p>

D2: Control Preference Scale (Degner et al, 1992): Preferred Role –French

	<p>Je préfère faire le choix final quant à quel traitement je vais recevoir.</p>
	<p>Je préfère faire le choix final quant à mon traitement après avoir sérieusement considéré l'opinion de mon médecin.</p>
	<p>Je préfère que mon médecin et moi partagions la responsabilité de décider quel traitement est le meilleur pour moi.</p>
	<p>Je préfère que mon médecin prenne la décision finale quant à quel traitement qui sera utilisé, mais qu'il/elle considère sérieusement mon opinion.</p>
	<p>Je préfère laisser toutes les décisions concernant mon traitement à mon médecin.</p>

D3: Control Preference Scale (Degner et al, 1992): Actual Role –English

	<p>I made the final selection about which treatment I am receiving.</p>
	<p>I made the final selection of my treatment after seriously considering my doctor's opinion.</p>
	<p>My doctor and I shared responsibility for deciding which treatment is best for me.</p>
	<p>My doctor made the final decision about which treatment is to be used, but seriously considered my opinion.</p>
	<p>My doctor made all decisions regarding my treatment.</p>

D4: Control Preference Scale (Degner et al, 1992): Actual Role –French	
	<p>J'ai fait le choix final quant à quel traitement je reçois.</p>
	<p>J'ai fait le choix final quant à mon traitement après avoir sérieusement considéré l'opinion de mon médecin.</p>
	<p>Mon médecin et moi avons partagé la responsabilité de décider quel traitement est le meilleur pour moi.</p>
	<p>Mon médecin a pris la décision finale quant à quel traitement qui est utilisé, mais qu'il/elle a sérieusement considéré mon opinion.</p>
	<p>Mon médecin a pris toutes les décisions concernant mon traitement.</p>

Appendix E: REB approval letters

Friday, August 06, 2004

Ms. Lynne Jolicoeur
Ottawa Hospital - General Campus
OBS/Gyn/Newborn Care & Women's Health
Chemotherapy Day Care Unit
501 Smyth Road
Ottawa, ON K1H 8L6

Dear Ms. Jolicoeur:

Re: Protocol # 2004429-01H Women's Decision Making Needs Related to Treatment for Recurrent Ovarian Cancer

Protocol approval valid until - Friday, August 05, 2005

I am pleased to inform you that your study (listed above), the French and English Needs Assessment Questionnaires, and the French and English Information Sheet and Consent Forms were given expedited review by the Ottawa Hospital Research Ethics Board (OHREB) and are approved. No changes, amendments or addenda may be made in the protocol without the OHREB review and approval.

The validation dated should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately two months prior to the expiration date listed above, a single renewal form should be sent to the OHREB office.

The Tri-Council Policy Statement requires a greater involvement of the OHREB in studies over the course of their execution. You must inform the Board of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Board review, either of which may impinge on the ethics of continuing the study. The OHREB will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,



Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

Encl.



Université d'Ottawa · University of Ottawa

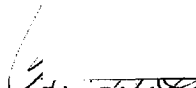
Cabinet du vice-recteur
à la recherche

Office of the Vice-Rector,
Research

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval for the research project entitled **Women's Decision Making Needs Related to Treatment for Recurrent Ovarian Cancer (file H 07-04-01)** submitted by Lynne Jolicoeur who is supervised by Dr. Annette O'Connor, both of the Faculty of Health Sciences. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid for one year from the date indicated below.



Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the
Health Sciences and Science REB

September 7, 2004
Date

COPY

Appendix F: Letters of information/Consent Forms

**Information Sheet and Consent Form
Women's Decision Making Needs
Related to Treatment for Recurrent Ovarian Cancer**

Background of Study

Very few studies have been done to look at how women with ovarian cancer participate in decision making about treatment. No studies have been done to look how women make decisions about the choice of treatment when their cancer has recurred (come back).

Purpose and Design

This study is being conducted with 20 women who have recently made decisions related to treatment for a recurrence of ovarian cancer. Women who are being followed by the Regional Gynecologic-Oncology Program of The Ottawa Hospital will be approached to take part in this study. The study will explore how women go about making the decision about treatment for a recurrence of ovarian cancer and to look at what has (or might have) been helpful when they made the decision. The summary of the results will be used to make recommendations and/or to develop interventions in order to better support women who are making such decisions.

Study Procedures

You are being asked to participate in this study because your ovarian cancer has come back and you are being cared for by the Regional Gynecologic-Oncology Program of The Ottawa Hospital. If you agree to participate in this study, you will be interviewed about the decision you have recently made about treatment for recurrent ovarian cancer. You will be asked questions about the information that was important to you about ovarian cancer and its treatment, how you made the decision and what support you received to make this decision.

The interview will last about one hour and will take place in a quiet office at The Ottawa Hospital or in your home. You may take a break at any time during the interview or choose not to answer particular questions. The interview will be tape recorded and the researcher may also take notes to ensure we review your answers accurately. The audio tape may be transcribed to ensure your answers are accurately interpreted.

Information will also be collected from your medical chart about the type ovarian cancer, the stage of your disease, the type treatment you are presently on as well as the type of past treatments you have received for ovarian cancer.

Your answers and information obtained from your chart will be summarized along with other participants answers.

Benefits of the Study

There is no benefit from participating in this study, although participating will allow you to think about and to express your decision making needs. The anonymous information you and others provide may help the health care team plan future programs to support women's decision making.

Inconvenience/ Risks of the study

There are no known physical or psychological risks associated with participating in this study. You may choose not to answer any question that you would rather not answer. If you have concerns about some of the issues that were raised in the interview, the researcher or your

primary nurse will provide you with some support or answer any questions you may have and refer you to another team member as needed after obtaining your consent to do so.

Right to Confidentiality

The transcript, the notes from the interview and the data collected during the review of your medical chart, will be identified by a study number; in no way will the data be linked to your name. Information, such as your name, the name of family members, your doctor or nurse's name that is provided during the interview will be removed in the transcript to ensure your answers can not be linked to you. You will not be identified in any publications or presentations resulting from this study.

All information you provide will be kept confidential, only the researcher and members of the research team will have access to the data. The transcripts and the tape recordings will be kept in a locked filing cabinet in the researcher's office. Once the study is completed the tape recordings will be destroyed. The coded transcripts (without identifying information) will be kept for a period of fifteen (15) years.

Right to information and to withdrawal from the Study

If you need more information on this study you can call me (Lynne Jolicoeur) at 737-8899 ext. 72616 or my thesis supervisor (Dr. Annette O'Connor) at 798-5555 ext. 17582. At the end of the study, a summary of the results will be posted outside the Chemotherapy Day Care Unit (the Ottawa Hospital, General Campus, 8th floor room 8212) and will be available for all participants upon request.

You are under no obligation to participate in the study; you may choose not to participate in the study or to withdraw from the study at any time. If you decide not to participate or to withdraw from the study, the care you receive by the Regional Gynecologic-Oncology Program of The Ottawa Hospital will not be affected in any way. You may choose not to answer some questions during the interview.

You may contact the Chairperson of the Ottawa Hospital Research Ethics Board, for information regarding person's rights as a research subject at (613) 798-5555, extension 14902.

Consent

"I have read this Patient Information Sheet/Consent Form (or have had this document read to me), and have had an opportunity to ask the researcher any questions I had about the study.

My questions and/or concerns have been answered to my satisfaction and I agree to participate in this study. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

A copy of this Information Sheet/Consent Form will be provided to me should I want to review the information at a later date, if I need to contact someone about the study or my participation in the study, or simply for my records.

Signatures

Participant's Name

Participant's Signature

____/____/____
Date

Investigator/delegate's Name

Investigator/delegate's Signature

____/____/____
Date

Lettre d'information et Formulaire de Consentement

Besoins des femmes face à la prise de décision

liés au traitement pour une récurrence d'un cancer ovarien

Contexte de l'étude

Très peu d'études ont été faites pour regarder comment les femmes avec un cancer ovarien participent à la prise de décision au sujet des traitements. Aucune étude n'a été faite pour étudier comment les femmes prennent des décisions au sujet du choix des traitements quand leur cancer a récidivé (est revenu).

But de l'étude

Cette étude est entreprise auprès de 20 femmes qui ont récemment pris des décisions liées au traitement pour une récurrence d'un cancer ovarien. Les femmes qui sont suivies du programme régional d'oncologie gynécologique de l'Hôpital d'Ottawa seront approchées pour participer à cette étude. L'étude explorera comment les femmes abordent la décision au sujet du traitement pour une récurrence d'un cancer ovarien et explorera ce qui a été (ou aurait pu être) utile quand elles ont pris la décision. Les résultats seront employés pour faire des recommandations et/ou développer des interventions afin d'améliorer le soutien aux femmes qui prennent de telles décisions.

Description de l'étude

Vous êtes invité à participer à cette étude parce que votre cancer ovarien a récidivé (est revenu) et vous êtes soigné par le programme régional d'oncologie gynécologique de l'Hôpital d'Ottawa. Si vous acceptez de participer à cette étude, vous serez interviewé au sujet de la décision que vous avez récemment prise au sujet du traitement pour une récurrence du cancer ovarien. Vous serez questionnée au sujet de l'information qui était importante pour vous au sujet du cancer ovarien et son traitement, de la façon dont vous avez pris la décision et quel appui vous avez reçu pour prendre cette décision.

L'entrevue durera environ une heure et aura lieu à un bureau à l'Hôpital d'Ottawa ou dans votre domicile. Vous pouvez prendre une pause à tout moment pendant l'entrevue ou choisir de ne pas répondre à des questions particulières. L'entrevue sera enregistrée sur bande audio et le chercheur pourrait également prendre des notes pour assurer que vos réponses soient correctement interprétées. La bande audio pourrait être retranscrite afin de s'assurer que vos réponses soient interprétées correctement. De l'information sera également relevé de votre dossier médical au sujet du type de cancer ovarien que vous avez, le stage (l'étendue) de votre maladie, le type de traitement que vous recevez actuellement ainsi que le type de traitements antérieurs que vous avez reçu pour le cancer ovarien.

Vos réponses et l'information obtenues de votre dossier médical seront résumées avec les réponses des autres participantes.

Avantages de l'étude

Il n'y a aucun avantage à participer à cette étude, bien que votre participation vous permet de penser et d'exprimer vos besoins face à la prise de décision. L'information anonyme que vous et d'autres fournissez pourrait aider l'équipe de soins à planifier des programmes pour mieux soutenir les femmes dans la prise de décision.

Inconvénients/Risques de l'étude

Il n'y a aucun risque physique ou psychologique connu en participant à cette étude. Vous pouvez choisir de ne pas répondre à n'importe quelle question que vous désirez ne pas répondre. Si vous avez des soucis concernant certaines choses qui ont été abordées dans

l'entrevue, le chercheur ou votre infirmière primaire vous fournira de l'appui ou répondra aux questions que vous avez et vous réfèrera avec un autre membre de l'équipe au besoin après avoir obtenu votre consentement.

Droit à l'anonymat et à la confidentialité

Les transcriptions, les notes d'entrevue et les données rassemblées pendant l'examen de votre dossier médical seront identifiées par un numéro d'étude; les données ne seront jamais liées à votre nom. L'information (telle que votre nom, le nom des membres de votre famille, votre docteur ou votre infirmière) qui est fournie pendant l'entrevue sera enlevée lors de la retranscription afin d'assurer que vos réponses ne puissent pas être liées à vous. Vous ne serez pas identifiée dans aucune publication ou présentation résultant de cette étude. Toutes les informations que vous fournissez seront confidentielles; seulement le chercheur et les membres de l'équipe de recherche auront accès aux données. Les retranscriptions et les enregistrements de bande audio seront maintenus dans un coffret verrouillé dans le bureau du chercheur. Une fois que l'étude sera achevée, les enregistrements de bande audio seront détruits. Les retranscriptions codées (sans informations pouvant vous identifier) seront gardées pendant une période de quinze (15) ans.

Droit à l'information et au retrait de l'étude

Si vous avez besoin de plus d'information sur cette étude, vous pouvez m'appeler (Lynne Jolicoeur) au 737-8899 ext. 72616 ou ma surveillante de thèse (Dr. Annette O'Connor) au 798-5555 ext. 17582. À la fin de l'étude, un sommaire des résultats sera affiché en dehors de l'unité de chimiothérapie de soins de jour (l'Hôpital d'Ottawa, campus Général, 8ème étage pièce 8212) et sera disponible pour toutes les participantes sur demande. Vous n'êtes sous aucune obligation de participer à l'étude ; vous pouvez choisir de ne pas participer à l'étude ou de vous retirer de l'étude à tout moment. Si vous décidez de ne pas participer ou de vous retirez de l'étude, les soins que vous recevrez par le programme régional d'oncologie gynécologique de l'Hôpital d'Ottawa ne seront pas affectés de quelque façon. Vous pouvez choisir de ne pas répondre à quelques questions pendant l'entrevue. Pour de l'information concernant les droits de la personne comme sujet de recherche, vous pouvez contacter le président du Conseil d'éthique en recherches de l'Hôpital d'Ottawa au (613) à 798-5555 ext. 14902.

Consentement

"J'ai lu ce formulaire d'information\feuille de consentement (ou ce document m'a été lu), et j'ai eu l'occasion de poser toutes les questions que j'ai eu au sujet de l'étude au chercheur. Mes questions ont été répondues à ma satisfaction et j'accepte de participer à cette étude. Si je décide ultérieurement dans l'étude que je voudrais retirer mon consentement, je peux le faire à tout moment. Une copie de ce formulaire me sera fournie afin de pouvoir revoir l'information à une date ultérieure, de pouvoir contacter quelqu'un au sujet de l'étude ou de ma participation à l'étude, ou simplement pour ma documentation personnelle.

Signatures

Nom de la participante (imprimer)

Signature de la participante

/ /
Date

Nom du Chercheur/Délégué(e) (imprimer)

Signature du Chercheur/Délégué(e)

/ /
Date