Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence

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### Abstract

# **Title of Project:** Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence

## **Background**:

The lifetime risk of developing ovarian cancer (OC) is less than 2%, but ovarian cancer ranks fifth in cancer deaths for women and is the most lethal of the gynecologic malignancies. Stage IV ovarian cancer five-year survival rate is 17%, with most patients diagnosed at Stage III or IV. Approximately 80% of women diagnosed with advanced OC will experience recurrence after first line chemotherapy. Recurrent OC is treated as a chronic condition and few patients diagnosed with recurrence will ever be disease free again. With continued therapy, all patients become resistant to therapy and the duration of response diminishes with each treatment. Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or one of the FDA approved therapies. Each of the choices may have a different trajectory, side effect profile, and treatment schedule. Regardless of the option chosen, response rates are low, about 20-50%. Because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values, knowledge about treatment options, and her expectations for both treatment and quality of life play a major role in the decision.

**Specific Aims:** The overall goal of this program of research is to improve the shared decision making process for women diagnosed with an OC recurrence through 1) Exploring the experiences of women making decisions about treatment for recurrent ovarian cancer 2) Exploring healthcare providers' experiences of clinical decision making for recurrent ovarian cancer 3) To triangulate the findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of OC recurrence

**Study Design**: Design: A descriptive qualitative study with thematic analysis will be used to evaluate the process of decision making as experienced by women with OC recurrence and healthcare providers.

Patient inclusion criteria are: 1) diagnosis of OC recurrence within the past 4-6 weeks, 2) 18 or older, 3) English speaking, 4) Plans to receive treatment, 5) Either platinum sensitive or platinum resistant. Inclusion criteria for healthcare providers are: 1) provide care for patients with OC recurrence, 2) physician, nurse, or advanced practice nurse. A target for patient enrollment is 25 women, and 10 healthcare providers.

**Cancer Relevance:** Exploration of the treatment decision making process for key stakeholders in an outpatient cancer clinic will provide important foundational knowledge for intervention development to build and support shared decision making for complex treatment decisions such as OC recurrence.

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#### CHAPTER ONE

#### Introduction

Ovarian cancer has the highest mortality rate of all of the gynecologic malignancies, with the five-year survival rate at 45% (American Cancer Society, 2017). In the United States, stage IV ovarian cancer five-year survival rate is 18%, with most patients diagnosed at Stage III or IV (Vogel et al., 2013). Women diagnosed with ovarian cancer who complete chemotherapy may achieve a complete remission; however, it is usually a matter of time before the cancer recurs. While there are treatment options for recurrence, and growing with the advent of precision medicine, there has yet to be an effective treatment for progressive disease. Because recurrent ovarian cancer is not typically curable, the therapeutic goal is control of symptoms, prolonging life and maintaining quality of life (Rauh-Hain & Del Carmen, 2013). Women as patients do not disrupt their family's lives with a diagnosis, instead they still function as caretakers, supporters, employees, mothers. The meaning in their lives and the multitude of relationships they tend must be acknowledged and taken into consideration. Therefore, shared decision making involving a robust discussion of patient goals and values is necessary to align the meaning of patient quality of life with the effects of disease and treatment, as well as treatment burden.

The first manuscript presented is *Shared decision making in recurrent ovarian cancer: a concept analysis*. Walker and Avant's method of concept analysis is used to gain a deeper knowledge of the attributes of shared decision making (SDM). This paper also examines the antecedents contributing to SDM, as well as the consequences of successful and unsuccessful SDM. This exploration may lead to insights about how women can be better supported in SDM, and may provide ideas of interventions aimed at improving SDM.

The second manuscript is *Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence*. This manuscript describes results from a descriptive qualitative study with thematic analysis of 35 semi-structured interviews of both patients with ovarian cancer recurrence, and providers. Results revealed major themes of living with cancer and maintaining hope from the patient perspective, and the art of treatment management and maintaining hope from the provider perspective.

The third manuscript presented is *The Woman's Perspective- Treatment Decision Making in the Context of Ovarian Cancer Recurrence.* Results from the qualitative study using thematic analysis of semi structured interviews are explored through the perspective of relationship based decision making. Major themes of contributing, caretaking and delegating the responsibility of the treatment decision were revealed. Several subthemes emerged for each primary theme, which included staying strong and supporting others, and having an active role in the decision about treatment versus deferring the decision to the provider. This dissertation concludes with a discussion of shared decision-making in the context of ovarian cancer recurrence as well as directions for future research.

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# CHAPTER TWO

**Research Proposal** 

#### **Project Summary/Abstract**

The lifetime risk of developing ovarian cancer (OC) is less than 2%, but ovarian cancer ranks fifth in cancer deaths for women and is the most lethal of the gynecologic malignancies. Stage IV ovarian cancer five-year survival rate is 17%, with most patients diagnosed at Stage III or IV. Approximately 80% of women diagnosed with advanced OC will experience recurrence after first line chemotherapy. Recurrent OC is treated as a chronic condition and few patients diagnosed with recurrence will ever be disease free again. With continued therapy, all patients become resistant to therapy and the duration of response diminishes with each treatment. Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or one of the FDA approved therapies. Each of the choices may have a different trajectory, side effect profile, and treatment schedule. Regardless of the option chosen, response rates are low, about 20-50%. Because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values, knowledge about treatment options, and her expectations for both treatment and quality of life play a major role in the decision.

The overall goal of this program of research is to improve the shared decision making process for women diagnosed with an OC recurrence through1) Exploring the experiences of women making decisions about treatment for recurrent ovarian cancer 2) Exploring healthcare providers' experiences of clinical decision making for recurrent ovarian cancer 3) To triangulate the

findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of OC recurrence. A descriptive qualitative study, through semi-structured interviews, with thematic analysis will be used to evaluate the process of decision making as experienced by women with OC recurrence and healthcare providers. Data will be supplemented by field notes from the interview. Patient data will include diagnostic and treatment information from the medical record. A qualitative descriptive approach will be employed, using thematic analysis to inform this exploration of recurrent ovarian cancer treatment decision-making.

#### **Specific Aims**

Ovarian cancer (OC) has the highest mortality rate of all of the gynecologic malignancies, with the five-year survival rate at 46%. In the United States, stage IV ovarian cancer five-year survival rate is 17%, with most patients (70%) diagnosed at Stage III or IV (American Cancer Society, 2017). The risk of recurrence is 60-70%, depending on stage of disease and volume of disease after primary surgery (Teo, 2014). Recurrent OC is treated as a chronic condition and few patients diagnosed with recurrence will ever be disease free again (Thigpen, 2012).

When a recurrence is diagnosed, women are enlisted to make decisions about which of the available treatments she would like to initiate. For these women, decision making requires not only an understanding of various treatment options, but also an assessment of goals, a high level of trust in the treatment team, consultation with loved ones, and useful communication over an extended period of time. With the advent of targeted chemotherapy and numerous new biologics, many women will have numerous options ranging from standard treatments to experimental therapies to maintenance of comfort. A patient described the experience of finding that she had recurrent ovarian cancer and discussing treatment options with her care team: "I was given three consent forms for clinical trials and asked to make a decision. I didn't know what to do, so I went to another hospital where the doctor told me what treatment to receive" (patient communication).

Elit, Charles and Amiram (2010) found that women with recurrent OC were not satisfied with the amount of information about standard treatment choices provided at the time of recurrence and also felt that their options were limited.

Studies in related fields indicate that shared decision making can increase patient satisfaction with the decision and improve patient outcomes (Smith et al., 2011; O'Brien et al., 2009; Hollen et al., 2013). In a 2011 national survey of 1,134 adults, only 24%-38% reported a shared decision making process for cancer screening (Hoffman et al., 2014). Effective shared decision making involves a mutual understanding of treatment options, likely outcomes, and patient values and goals. Few studies have been done to evaluate shared decision making in the context of OC recurrence.

The overall goal of this program of research is to improve the shared decision making process for women diagnosed with an OC recurrence. Using the Ottawa Decision Support Framework (O'Connor et al., 1998) as a theoretical guide, the purpose of this study is to describe the landscape of the decision making process for both the women diagnosed with OC recurrence and gynecologic oncology healthcare providers, in an outpatient clinic setting. A descriptive qualitative approach will be used to achieve three specific aims:

1) To explore the experiences of women making decisions about treatment for recurrent ovarian cancer

2) To explore healthcare providers' (doctors and nurses) experiences of clinical decision making for recurrent ovarian cancer

3) To triangulate the findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of OC recurrence

**Significance of this study for healthcare.** Exploration of the treatment decision making process for key stakeholders in an outpatient cancer clinic will provide important foundational knowledge for intervention development to build and support shared decision making for complex treatment decisions such as OC recurrence.

### **Background and Significance**

Ovarian cancer is colloquially a term used for a heterogeneous variety of tumors that involve the ovary, fallopian tube, and peritoneum. (Kroeger & Drapkin, 2017). When most people use the term ovarian cancer, it is meant to include fallopian tube and primary peritoneal cancers, and was originally thought to arise in the ovary due to repeated ovulation. It is now believed that the majority (60%) of cancers arise in the fallopian tube (Kroeger & Drapkin, 2017). However, it remains that the diagnosis of ovarian cancer includes fallopian tube and primary peritoneal cancers.

The lifetime risk of developing ovarian cancer is less than 2%, but ovarian cancer ranks fifth in cancer deaths for women and is the most lethal of the gynecologic malignancies (Oronsky, 2017). Federal Drug Administration (FDA) approved primary treatment for newly diagnosed ovarian cancer is surgery and chemotherapy with two to three agents. The response to the primary regimen is varied and depends on the stage of disease and other factors (Kim, Ueda, Naka & Enomoto, 2012), making it difficult to predict whether remission will be achieved. Approximately 80% of women diagnosed with stage III and IV ovarian cancer will experience recurrence after first line chemotherapy (Hanker, 2012).

The responses to primary treatment; platinum sensitive, platinum resistant, and platinum refractory, are used to frame decisions about treatment and disease trajectory and to determine eligibility criteria for clinical trials (Jelovac & Armstrong, 2011). The terms are defined by the progression free interval (PFI), which is from the time that the patient completes her last cycle of a platinum agent to the time that the cancer returns (progresses). Platinum sensitive disease is that in which a patient has a complete response (no evidence of disease) or a partial response (30% reduction in overall tumor burden) to chemotherapy that lasts for 6 months from the time she received her last platinum treatment. Patients with platinum resistant disease recur within six months of their last platinum treatment, and platinum refractory disease progresses during treatment. Typically patients with advanced disease at diagnosis will have resistant or refractory disease and the prognosis for patients with platinum refractory disease is poor. Response rates for refractory disease are approximately 10% with duration of less than 8 months (Spriggs, 2003; Oronsky, 2017). Therefore, for the purposes of this study, patients with platinum-sensitive or platinum-resistant disease will be targeted as the treatment options for patients with platinum-refractory disease are very limited.

When a first OC recurrence is diagnosed, several treatment options are available depending on the treating institution. FDA approved agents, such as gemcitabine and pegylated liposomal doxorubicin (PLD) have shown modest response rates of approximately 11% to 26% (Jelovac & Armstrong, 2011). If the patient's tumor is considered platinum sensitive, she will most likely be given a platinum agent again, as recommended by the National Comprehensive Cancer Network (NCCN) 2017 guidelines. Platinum sensitive

patients receiving second line treatment with a platinum agent, either alone or in combination, can have up to a 60% response rate and duration of response of approximately 10 months (Jelovac & Armstrong, 2011).

With continued therapy, all patients become resistant to therapy and the duration of response diminishes with each treatment (Hanker et al., 2012). Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or one of the FDA approved therapies. Each of the choices may have a different trajectory, side effect profile, and treatment schedule (**Table 1**). Regardless of the option chosen, response rates are low, about 20-50% (Oronsky, 2017). The goal of treatment after recurrence is to slow progression, manage the growth of the cancer, and manage symptoms. With subsequent recurrences, the goal is to manage symptoms, prolong life, and maintain an acceptable quality of life. Because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values, knowledge about treatment options, and her expectations for both treatment and quality of life play a major role in the decision (Jolicoeur, 2005).

# Table 1. FDA Approved Regimens and Toxicities (Dunton (2002); Spriggs 2003;

Armstrong, 2011)

Agent	Hematologic Toxicities	Non-Hematologic Toxicities	Cumulative Toxicities	Response Rate (Platinum Resistant)
Liposomal doxorubicin (given once every 4 weeks)	Neutropenia Anemia Thrombocytopenia	Palmar-plantar erythrodysesthesia (PPE) Stomatitis alopecia	PPE Mucositis Cardiotoxicity	12-17%
Gemcitabine (days 1 and 8	Thrombocytopenia	Nausea/vomiting Peripheral edema	Cardiac and pulmonary	13-22%

every 21 days)		Lethargy Non-cardiac pulmonary edema	toxicity Thrombotic angiopathy	
Topotecan (daily for 5 days every 21 days; or days 1, 8 & 15 every 28 days)	Neutropenia Anemia thrombocytopenia	Alopecia Stomatitis		12-19%

*Shared decision making: Patient perspectives.* There are four essential components of shared decision making in the medical encounter; 1) it typically involves the patient, a provider, and at times a family member or supporter, 2) all parties involved are invested in participating in the decision 3) information is shared by involved parties 4) and the decision is agreed upon by the patient and provider (Charles, Gafni & Whelan, 1997). Studies exploring the patient perspective of shared decision making reveal that most patients prefer sharing in the decision making process, and that the patients define shared decision making as not only interactive communication, but having a trusting and respectful relationship with the provider (Chewning et al., 2012; Shay & Lafata, 2014). In several studies, provider opinion was an essential part of decision making and goals of treatment and patient values were less frequently discussed (Markovic, Manderson & Quinn, 2006; Abhyankar, Bekker, Summers & Velikova, 2010; Shay & Lafata, 2014). In addition, multiple studies support giving patients honest information and providing opportunities for self-management in the face of anxiety-laden situations (Shulman-Green, 2012; Gleeson et al, 2013; Shay & Lafata, 2014).

Women faced with a treatment decision for recurrent ovarian cancer expressed implicit trust in the healthcare providers ability to guide them in their decision, and in some cases allowed the provider to make the decision for them as a result of having either too few or too many options. Elit, Charles, and Dimitry (2010) identified past experience with treatment and provider recommendation as key factors in patient treatment decision making. An examination of patient-provider communication from the patient's perspective revealed that often the patient is often overwhelmed and unable to recognize and communicate needs, and therefore will defer making a choice (Elit, Charles & Gold, 2003). Elit, Charles and Gafni (2010) found that patients were not satisfied with the amount of information provided at the time of recurrence and also felt that their options were limited. In addition, patients felt that open discussion about values and preferences was lacking, while providers tailored information exchange depending on perceived ability of the patient to handle information as well as other provider judgments about patient education and socioeconomic status. Elit, Charles & Amiram (2010) described contextual factors that impacted treatment decision-making, such as the exchange of information, the values of the patient, and the role of the patient in making the decisions about treatment. Results showed that patient care needs changed through the trajectory, and that there is need for more patient reported outcomes measures overall. Shared decision making: Provider perspectives. Similar to studies of patient perspectives, studies from providers' perspective suggest that barriers to communication are problematic. Two articles discussed an exploratory descriptive approach, and both were discussing different aspects of the same research project regarding treating oncologists' perceptions of communicating information to patients with recurrent ovarian cancer (Elit et al., 2012, 2015). The analysis of focus group data from this study revealed that oncologists modify the type and depth of information given to patients depending on patient cues, and that the same information is not given to all patients. Additionally, providers reported withholding information if they sensed that the patient was too emotional or becoming overwhelmed. Interestingly, a study of

patients' perspectives by the same authors found that patients reported feeling as though they had many unanswered questions and wanted more information about treatment options. These studies examining communication from the oncologists' perspective did not include other members of the health care team (Elit et al., 2012, 2015).

Few studies specific to recurrent OC decision-making and the shared decision making process have been reported in the literature. In the analysis of the articles included in the review, the authors concluded that the decision making process can be divided into three distinct stages; information exchange, deliberation, and making a decision about treatment. Authors found that the stage of deliberation was least investigated while the majority of studies involved information exchange (Elit, Charles & Amiram, 2010).

Given that choosing a treatment regimen for OCR depends not only on clinical aspects such as rate of cancer growth but also on quality of life aspects such as side effect burden and physical activity, shared decision making in this context is essential. Currently, however, a knowledge gap exists regarding women's experiences with decision making for OCR and the perspectives of healthcare providers as key members of the decision making team. The proposed study will examine the nature of the decision making process between women with a diagnosis of ovarian cancer recurrence, and their providers.

# **Theoretical Framework: Decision Support**

The Ottawa Decision Support Framework (O'Connor et al., 1998) is the theoretical model used for this program of research (see Figure 1). This framework emphasizes that participant decisional needs influence the quality of the decision and the decision making process, and provides the basis for tailoring supportive mechanisms to improve patient outcomes. Participants in the decision making process are defined as the patient, family and healthcare team, and the determinants of decisions include baseline patient knowledge, values, expectations, and decisional conflict. Participant decisional needs, for example, are the amount and nature of information desired about treatment choices, the need for help in reducing decisional conflict, and honoring a patient's values. These needs, when met or unmet, directly impact the quality of the decision and lead to satisfaction or regret with the decision.

# **Figure 1. Decision Support Framework (O'Connor et al., 1998)** Gray boxes will be the primary focus of this research project.



# **Methods**

Design: A descriptive qualitative study with thematic analysis will be used to evaluate the process of decision making as experienced by women with OC recurrence and healthcare providers.

Setting: The setting for this study will be the outpatient gynecologic oncology cancer care clinic at the University of Virginia Health System (UVAHS), Emily Couric Cancer Center (ECCC). The UVAHS is a research-intensive academic medical center and regional referral center serving much of central and southwestern Virginia. The ECCC is a National Cancer Institute designated institution with more than 130 researchers from multiple fields dedicated

to cancer research. The gynecologic oncology program serves thousands of patients yearly, with approximately 30% being patients with OC recurrence. The clinic provides comprehensive services including laboratory, radiology, chemotherapy infusion, and consultation rooms within a single space.

## Sample and Sampling Plan.

Women with a diagnosis of recurrent OC, including epithelial ovarian, fallopian tube or primary peritoneal cancer, and ECCC gynecologic oncology physicians and nurses will comprise the study sample.

Approximately 15 patients with a diagnosis of OC are seen each week in the clinic, with 2 to 5 of these patients diagnosed with OC recurrence. Patient inclusion criteria are: 1) diagnosis of OC recurrence within the past 4-6 weeks, 2) 18 years old or older, 3) English speaking, 4) Plans to receive treatment for recurrent ovarian cancer, 5) Either platinum sensitive or platinum resistant.

The gynecologic oncology team consists of 5 physicians (5 attending physicians), 1 advanced practice nurse, and 3 nurses. Inclusion criteria for healthcare providers are: 1) provide care for patients with OC recurrence in an outpatient setting, 2) physician, nurse, or advanced practice nurse.

A target for patient enrollment is 15 women, although data collection will continue until saturation of findings is reached. Additionally, 8-10 healthcare providers will be recruited. **Instruments**. All instruments are provided in Appendix 1.

**1. Interview Guide.** Guidelines for interview questions for healthcare providers, nurses, and patients. The purpose of the questions is to elicit an open discussion of the factors contributing to the decision making about treatment options following OCR diagnosis. The interview questions for the patients are designed to gather information about the type of information provided to them, as well as the nature of the discussion, and what factors the patients considered important in making the decision. The interview guide for the providers is to elicit information about the provider's perspective on the information provided and the nature of the discussion with the patient, and to identify unmet needs in the decision making process.

Examples of interview questions for patients: "What treatment options were discussed with you?" and, "What types of things did you consider when making your decision?", "Was there anything that could have been better in terms of information or resources?"

Examples of interview questions for providers/nurses: "Please tell me about how a diagnosis of ovarian cancer recurrence is delivered to patients", "What kind of information is provided to patients and partners?" "What kinds of things are considered when making a treatment decision with a patient?" and "What resources would be helpful in guiding the decision making process?".

**2. Patient Information Form.** Basic demographics (age, race, education, marital status) will be collected. A review of the demographics will allow an assessment of the participant profile and scope of representation.

**3. Medical Record Review Form.** The participant's electronic medical record will be used to gather functional information about each participant's health status. Tumor type (ovarian,

fallopian tube or primary peritoneal) histology, stage, platinum status and treatment history will be collected on a one-page form.

# Procedures

This protocol will be submitted to the Peer Review Committee (PRC) and the Institutional Review Board (IRB) for Human Subject Research (HSR) for approval. OnCore, the University of Virginia Cancer Center database, which serves this function for numerous oncology trials, will serve as the electronic data capture (EDC) database for this study.

Enrollment and data collection will begin following IRB approval. Potential participants will be identified by a staff member during the clinic visit. If interested in learning about the study, the staff member will inform the PI who will then provide further details and obtain informed consent. Their interest in participating will be determined in person (if at the clinic visit) or by telephone.

At the time of enrollment, the patient will complete the demographic forms and the medical record review form will be completed by the PI. A time for the interview/s will be scheduled at the participants' convenience. Interviews with patients will take place within 4-6 weeks of the diagnosis of recurrence. Interviews with physicians and nurses will not be specific to a particular patient, but will target the broader decision making process for OC recurrence.

Interviews will be conducted by the PI who will be trained and mentored in qualitative interviewing and analysis. Specific digital recording mp3 players will be used to record semistructured interviews. Field notes will be documented immediately after the interviews and will include observations, personal notes, and analytical notes (Polit & Beck, 2012). Interviews will be transcribed verbatim using a professional transcription service. The transcripts will then be read while listening to the original interview by a third person (research coordinator) to ensure the quality of the transcription. Identifiers (names, dates) will be removed from the transcribed documents. To protect confidentiality, names and other identifying information will not be written on any instrument. Participants will be identified only by a numbering scheme that identifies role (patient or provider).

Consent forms and tapes will be kept in a locked (PI's) office in the University of Virginia OB/GYN department. Tapes will be transcribed verbatim as soon as possible after the interview and erased after transcription is completed and reviewed. The transcripts will be kept on a secure firewall protected computer in a locked office space in the OB/GYN dept. Data collection sheets and all study-related documentation will be kept on a HIPAA-compliant secured computer drive maintained by the University of Virginia, School of Medicine. Qualitative interviews will be transcribed verbatim into Microsoft Word data files and then uploaded to Dedoose qualitative software management for analysis (password protected and HIPAA compliant qualitative analysis software).

The study schema includes estimated time to complete the instruments; the overall patient burden of time is less than one hour (**Table 2**).

Events and Instruments by Participant	Administration Time	Baseline Visit	Study Visit
Study Nurse			
Eligibility Screen	5 min	Х	
Consent Form	10 min	Х	
Medical Review Form	20 min	Х	
Interview	30-45 min		х
Provider			
Consent Form	10 min	X	
Provider Demographic	2 min	X	

Table 2. Study Schema of Participants and Measures by Timepoints

Form			
Interview	30 min		Х
Patient			
Patient Information Form	2 min	Х	
Interview	30 min		Х

# Analysis

A qualitative descriptive approach using thematic analysis of semi-structured interviews and field notes, using the methods outlined by Braun & Clarke (2006), will inform the exploration of recurrent ovarian cancer treatment decision-making. Trustworthiness (credibility, transferability, dependability and confirmability) will be ensured through the use of triangulation of data and persistent observation, detailed literature review and inquiry audits of process notes (Lincoln & Guba, 1985). Interviews will initially be read and re-read and notes written down of initial ideas. The interviews and field notes will be transcribed verbatim and imported into the qualitative software DeDoose (www.dedoose.com) to assist with data organization and analysis. Transcripts will be cross-checked for accuracy. Initial coding will be theory driven based on the decision support framework, and will include both semantic and latent codes. Collating and organizing relevant codes will lead to emergent themes. A thematic map will be developed to help visualize the analysis and to organize both candidate and sub-themes, which will then be compared to the overall data set to check for accuracy. Members of the team will cross check codes and emerging themes. Themes will be refined through naming and description, and rich, compelling examples that tell a descriptive story will be selected for publication.

Tabl	le 3.	Analy	tic N	lethod	ls by	Study	Aims	
labl	le 3.	Analy	tic N	lethod	ls by	Study	Aims	

Specific Aims	Analytic Methods
1. To explore the experiences of women	Descriptive statistics of demographic
making decisions about treatment for	information; Thematic analysis of semi-
recurrent ovarian cancer	structured interviews and field notes, theory

	driven coding for elements of determinants of decision needs.
2. To explore healthcare providers' (doctors and nurses) experiences of clinical decision making for recurrent ovarian cancer	Thematic analysis of semi-structured interviews and field notes, semantic coding for salient issues in provider-patient communication.
3. Triangulate the findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of OC recurrence	Collating analysis of data from aims 1 and 2 to validate themes and capture different dimensions to create a fuller description.

# Timeline

The study duration is for 18 months, with overlap of some tasks to account for delays or the

ability to work simultaneously on different elements (Table 4). The estimated accrual for this

study is approximately 2-3 participants a month for 10-12 months.

	Months																	
Tasks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
PRC/IRB Submission	X	X	X	X														
Quality/procedure review with chair and/or member(s) of dissertation commimttee		x		X	Х	х	x	X	X	х	Х	Х	Х	X	X	Х	Х	Х
Subject identification				X	Х	X	X	X	X	Х	Х							
Qualitative Interviews					X	X	X	X	X	Х	Х	X	Х	Х				
Data analysis							X	X	X	Х	Х	X	X	X	X			
Disseminate results															Х	Х	х	Х

Table 4. Time Table for Major Tasks of the Study by Months

# Limitations

This study is limited by the small number of participants, and that all patient participants will be

recruited from the same institution. The institution in which this study will be occurring is a

small rural academic hospital in which clinical trials is a primary goal for treatment for most of the patients. As a result, the participants in this study have limited options for care in this geographic location, and have long-term relationships with their provider, which may affect an honest discourse on the decision making process. The researcher has been working with this group of providers and nurses and patient population for over 10 years, potentially distorting both observations and responses from participants.

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# CHAPTER THREE

# Manuscript 1

# Submitted to Nursing Forum, 9/12/19

# Shared decision making in recurrent ovarian cancer: a concept analysis

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## Abstract

*Aim*: To explore the concept of shared decision making in the unique setting of recurrent ovarian cancer.

*Background*: The majority of patients with ovarian cancer will have a recurrence, which is treated as a chronic condition. Treatment options vary in toxicity, schedule and route of administration, yet have similar efficacy. A deeper knowledge of shared decision making may lead to insights about how women can be best supported through the treatment decision making process.

Design: Concept analysis.

Data sources: Databases searched were: CINAHL, Web of Science,

OVIDMedline and PubMed.

*Review methods*: Walker and Avant's 8 step method of concept analysis was used in this study. Eleven articles were analyzed, and the attributes, antecedents, and outcomes of the concept were identified. The Communication Model of Shared Decision Making was used to identify antecedents.

*Results*: The attributes of engaged communication, clarifying values, and coming to a consensus were identified as being salient in shared decision-making.

*Conclusion*: Understanding the concept SDM in the context of OCR can help nurses establish effective communication with patients regarding patient values, goals of care and information exchange leading to an agreed upon course of action, with which the patient is content.

KEYWORDS: concept analysis, nursing, shared decision making, ovarian cancer

# **1 INTRODUCTION**

The majority of patients (65%) diagnosed with ovarian cancer recur, and recurrent ovarian cancer (OCR) is treated as a chronic condition as few patients will ever be disease free again.<sup>1</sup> When the disease recurs, patients are faced with a different set of decisions as compared to the initial occurrence. First, an array of treatment options is available as opposed to a standard treatment plan. Second, regardless of the option chosen, treatment may be effective for a period of time but the cancer cells ultimately become resistant to this therapy and a new regimen must be selected. Third, the choice to cease treatment or to pursue palliative care is presented throughout the treatment trajectory. Regardless of scenario, the patient and her family are faced with choices about type and method of treatment, length of treatment, and finally, cessation of treatment. Thus, in the landscape of OCR treatment decision making, patients, their families and providers are involved and the values and emotions driving these decision-making conversations are multifaceted and complex. The purpose of this concept analysis is to explore the concept of shared decision making (SDM) in the unique setting of OCR using Walker and Avant's 8-step method of analysis,<sup>2</sup> These include 1) selecting a concept, 2) determining the purpose of the analysis, 3) identifying the various uses of the concept, 4) identifying defining attributes, 5) constructing a model case, 6) identifying antecedents, 7) identifying consequences, and 8) defining empirical referents. Ultimately, a deeper knowledge of antecedents to the decision making styles of women may lead to insights about how women can be supported and how the dynamic of women as advocates for themselves can affect health care decisions.

#### **2 ORIGIN AND USES OF SHARED DECISION MAKING**

SDM has its roots in informed consent which is based on the fundamental notion that capable adults have the authority to accept or decline offered treatments and procedures based on their own goals and values.<sup>3</sup> A study of physician attitudes published in JAMA in 1961<sup>4</sup> reported that close to 90% of physicians withheld diagnosis of cancer from their patients, while earlier surveys revealed that the majority of patients (over 80%) prefer to be told of a cancer diagnosis. In 1984, a study in which 210 patients were surveyed regarding their preferred level of participation in decision making reported that only 37% of respondents reported that they participated in treatment decisions<sup>5</sup>. Over the last 30 years the landscape of medical care has changed dramatically, however. In 2001, the Institute of Medicine's report, Crossing the Quality *Chasm*, highlighted the importance of patient-centered care which takes into account patients' preferences and values.<sup>6</sup> SDM involving patient-provider partnership and collaboration. information sharing about goals of care, patient values, treatment options, and risks and benefits, and consensus are the cornerstones of shared decision making.<sup>7</sup> Many state and federal policies now describe SDM as the pinnacle of patient-centered care and an indicator of high-quality of patient care<sup>8</sup>.

In OCR, with continued therapy all tumors eventually become resistant to therapy and the duration of response diminishes with each new treatment regimen.<sup>9</sup> Regardless of the option chosen, response rates are low, about 20-50%.<sup>10</sup> Therefore, the decisions about treatment after recurrence should include engaged discourse with the patient about of goals of care. Whether it is to slow progression or to manage symptoms, because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values and expectations for both treatment and quality of life play a major role in the decision.<sup>11</sup>

# **3 METHODS**

A literature review was conducted to identify attributes, antecedents, consequences, and empirical referents related to SDM in the situation of OCR. From these, model, borderline, and contrary cases were constructed.

# 3.1 Data Collection

Multiple databases were searched, including CINAHL, OVIDMedline, Web of Science, and PubMed. Search terms included *shared decision making*, *recurrent ovarian cancer*, and *adult*. Peer reviewed research articles published in English, full text available were included. Of the 107 articles found, 11 met all criteria for this literature review (Figure 1).

Figure 1: Prisma Flow Diagram<sup>12</sup>



# **4 CHARACTERISTICS AND DEFINING ATTRIBUTES**

A major defining attribute of SDM is the interaction between patient and provider, such that there is information exchange and engagement on both sides in working towards an agreed course of action<sup>7</sup>. All 11 articles included in the review of literature cited information exchange as one of the primary foundations of SDM (Table 1). Other attributes most commonly observed in the articles were identifying patient values<sup>13,14</sup>, discussing the different treatment options<sup>15,16</sup>, reviewing risks and benefits, and having shared responsibility for the decision as well as consensus.<sup>14,17,18</sup>

### **5 ANTECEDENTS AND CONSEQUENCES**

SDM while acknowledged as a measure of excellence of care, remains a challenge to achieve in the context of OCR. Women faced with a treatment decision for OCR expressed implicit trust in the healthcare providers ability to guide them in their decision, and in some cases allowed the provider to make the decision for them as a result of having either too few or too many options.<sup>15</sup> An examination of patient-provider communication from the patient's perspective revealed that often the patient is often overwhelmed and unable to recognize and communicate needs, and therefore will defer making a choice.<sup>17</sup> Studies also revealed that patients were not satisfied with the amount of information provided at the time of recurrence and felt that treatment options were limited.<sup>11,16</sup> In studies examining patient treatment preferences, open discussion about values and goals of care resulted in active participation in the treatment decision making process.<sup>19,20</sup> One study described contextual factors that impacted treatment decision-making, such as the amount of information provided about disease status, the risks and benefits of treatment, and the role of the patient in making the decisions about treatment, and found that patients diagnosed with recurrence are more interested in taking an active role in treatment decision making, and rely on past experience and provider recommendation to make decisions.<sup>17</sup>

Similar to studies of patient perspectives, studies from providers' perspective suggest that barriers to communication are problematic. These studies revealed that oncologists modify the

type and depth of information given to patients depending on patient cues, and that the same information is not given to all patients.<sup>21,22</sup> Additionally, providers reported withholding information if they sensed that the patient was too emotional or becoming overwhelmed.<sup>21</sup> Interestingly, a study of patients' perspectives by the same authors found that patients reported feeling as though they had many unanswered questions and wanted more information about treatment options.<sup>22</sup>

According to the Communication Model of Shared Decision Making (Figure 2)<sup>23</sup>, antecedents of SDM are communication competency, personality, and sociodemographic characteristics, while contextual factors impacting communication are disease severity, emotional state, role expectations and information preferences. This model was used to define antecedents as it takes into consideration social and contextual factors often overlooked in the patient physician encounter. Consequences of SDM are decreased anxiety, increased knowledge, satisfaction with choice, and adherence to treatment regimens.<sup>13,14,19,20</sup>



Figure 2 Communication Model of Shared Decision Making<sup>23</sup>

# 6. CASES

Using the attributes, antecedents, and consequences of SDM in the setting or ovarian cancer recurrence, three cases have been constructed; a model case of SDM in OCR, a borderline case highlighting still-gray areas, and a contrary case that demonstrates an absence of SDM in the physician patient encounter.

# 6.1 Model Case

This model case has the defining attributes of foundation of knowledge about a disease process, determining the need for a decision, risks and benefits of each option, clarification of values and goals of care, agreement on a plan of care.

A 52 year old is diagnosed with recurrent ovarian cancer that has manifested in her colon. She is symptomatic from the tumor, including pain, decreased appetite, and emesis. She is
aware of the recurrence, and has seen the scans showing the location of the tumor. She has verbalized understanding that she is at a decision point and is articulate in expressing her emotions as well as her goals of care. The provider is receptive to her feelings and is able to provide comfort and healthy dialogue surrounding realistic expectations. Treatment options presented are to manage symptoms only, participate in a clinical trial to try to control the cancer, or try carboplatin and paclitaxol again, which she has taken previously and will not be as effective this time. She is aware that if she chooses symptom management alone, she will have approximately 6 months to live, and with aggressive treatment she may have about 2 years to live. She discusses with the provider maintaining her current quality of life for the benefit of spending valued time with her family, without the burden of multiple visits for chemotherapy, and possibly suffering from side effects of treatment. She and the provider discuss and agree on the goals of treatment that include palliative comfort care, maintaining her expected quality of life, and time with her family. She expresses satisfaction with the decision.

#### **6.2 Borderline Case**

This borderline case has the defining attributes of knowledge about a disease process, determining the need for a decision, risks and benefits of each option, but does not include clarification of values and goals of care, or mutual agreement on a plan of care.

A 78 year-old widow is diagnosed with recurrent ovarian cancer. She is currently asymptomatic, and her provider tells her she can either have a treatment that has few side effects, be more aggressive with a clinical trial, or she can wait a few months to decide. She understands that without treatment her cancer will continue to grow and her life expectancy is about a year. She is told that treatment may stabilize the cancer growth and will have side effects such as hypertension and arthralgia. She verbalizes concern about joint pain interfering with her love of gardening, and is fearful that she would need another medication to treat the possible side effect of hypertension. The provider also explains that the option of a clinical trial is a phase I trial with no known benefit but may have severe side effects. She is also visibly anxious about increasing the treatment burden on her family. The patient clarifies that watching and waiting may allow the cancer to grow but she will be able to continue her activities until she becomes symptomatic. The patient verbalizes interest in watching and waiting, mentioning that she has a number of events and trips planned as well as great satisfaction with her current quality of life. The physician invites the clinical trial coordinator into the room to discuss the phase I clinical trial. The patient graciously takes the consent document and leaves the clinic without a follow up appointment, concerned that she is making the wrong choice.

## **6.3 Contrary Case**

This contrary case has none of the attributes of the concept.

An 85 year-old widow is diagnosed with her 4<sup>th</sup> recurrence of ovarian cancer. She is symptomatic but is not comfortable discussing her pain, as she has always seen herself as being stoic. The provider informs her that her cancer is inoperable and that she has no options for treatment. She tearfully accepts this information and feels hopeless. The provider asks if she has any questions, but she does not see the point in discussing anything further. The physician lets her know that he will make a referral to palliative care and that they will call her soon with an appointment.

#### 7. EMPIRICAL REFERENTS

Shared decision making as a component of patient centered care has had a tremendous impact on healthcare, as patient centered care is included in the Patient Protection and Affordable Care Act and is considered a measure of high-quality patient care.<sup>24</sup> Multiple tools

have been developed to attempt to measure SDM. The 9-item Shared Decision Making Ouestionnaire (SDM-Q-9)<sup>25</sup> and the Shared Decision-Making Scale<sup>26</sup> are two examples of tools that have been developed to specifically measure SDM, while several others measure potential elements of SDM, such as anxiety and decisional conflict. The SDM-Q-9 was developed in Germany as a result of a research consortium created by the Ministry of Health with an emphasis on ways to measure constructs of SDM in order to improve patient care.<sup>20</sup> The Shared Decision Making Scale is a 20 item scale that evaluates SDM in the oncology setting and can help determine the efficacy of interventions to encourage SDM.<sup>26</sup> In the literature review of shared decision-making in recurrent ovarian cancer, none of the tools developed to specifically measure SDM were used, providing an opportunity for future research. Anderson et al used a knowledge assessment to determine effective information exchange, and measured consequences of effective SDM through the Decisional Conflict Scale (DCS) and the State-Trait Anxiety Inventory (STAI).<sup>13</sup> Likewise, Harrison et al used the Prospective Measure of Preference (PMP) to evaluate participants' first choice of treatment, and the Hospital Anxiety and Depression Scale (HADS) to measure emotional state after the participant had made a choice of treatment.<sup>19</sup> Demographic data were collected in the majority of the studies, which included level of education, age and severity of disease. Empirical referents are included in Table 1.

## 8. DISCUSSION AND RECOMMENDATIONS

This concept analysis, using the Walker and Avant<sup>2</sup> method, explored the concept of SDM in women faced with ovarian cancer recurrence. The defining attributes of engaged communication, clarifying values, and coming to a consensus were explored. Antecedents and consequences of SDM were illustrated through model, borderline and contrary cases. Understanding the concept SDM in the context of OCR can help nurses establish effective

communication with patients regarding patient values, goals of care and information exchange leading to an agreed upon course of action, with which the patient is content.

Shared decision making is a concept that can be more thoroughly examined in the context of OCR as none of the articles found used current methods for objectively evaluating SDM. Because of its complexity, multiples avenues exist in the decision making encounter to develop mechanisms to ensure and support SDM, which can then be tested and measured. Determining patient social and contextual factors, such as emotional state and role preference in decision making, as well as evaluating knowledge gaps and access to resources can be ways to identify and address patient needs and expectations. In conclusion, supportive measures can be developed through future studies identifying specific provider and patient needs to accomplish satisfactory outcomes in decision making in ovarian cancer recurrence.

Reference	Concept Attributes, Antecedents and	Empirical Referent
	Consequences	
Anderson et al.	Attributes:	Cassileth Information Styles
$(2011)^{13}$	Information exchange; values	Questionnaire
	identified	Knowledge Assessment
	Antecedents: Sociodemographics	Decisional Conflict Scale (DCS)
	Consequences: anxiety, satisfaction	State-Trait Anxiety Inventory (STAI)
	with choice	Demographics
Chekerov et al	Attributes: Information exchange,	Demographics
$(2017)^{20}$	patient preference	CA 125 levels
	Antecedents: Sociodemographics	Progression Free Survival
	Consequences: compliance with	Overall Survival
	treatment	

 Table 1
 Literature review: Attributes, Antecedents, Consequences and Empirical Referents

Ekwall, E., Ternestedt, B., Sorbe, B. & Graneheim, U. (2011) <sup>18</sup>	Attributes: Information exchange, shared responsibility, consensus Antecedents: Disease Severity, Communication, Role Expectation Consequences: Satisfaction with treatment decision	Qualitative
Elit et al, (2010) <sup>17</sup>	Attributes: Information Exchange, Risks and benefits of options, consensus Antecedents: Role Expectation, sociodemographics, disease severity, emotional state Consequences: Satisfaction with decision	Demographics
Elit et al (2012) <sup>21</sup>	Attributes: Providing information Antecedents: Sociodemographics, communication competence, disease severity Consequences: not evaluated	Demographics
Elit et al (2015) <sup>22</sup>	Attributes: Providing information Antecedents: Communication competence, emotional state, role expectation Consequences: not evaluated	Qualitative
Finlayson et al (2019) <sup>15</sup>	Attributes: Information exchange, discussing options Antecedents: Disease severity, sociodemographics Consequences: lack of knowledge, increased emotional stress	Qualitative
Harrison et al (2009) <sup>19</sup>	Attributes: Information exchange, patient preference Antecedents: sociodemographics Consequences: satisfaction with choice, increased knowledge	CA 125 Prospective measure of preference (PMP) Impact of Event Scale (IES) Brief Illness Perception Scale (BIPS) Hospital Anxiety and Depression Scale (HADS)

Havrilesky et	Attributes: Information exchange,	Progression free survival
al $(2014)^{14}$	patient values, risks and benefits,	Trial Outcome index of the Functional
	consensus	Assessment of Cancer Therapy-
	Antecedents: Disease severity,	Ovarian (TOI-FACT-O)
	sociodemographics,	MD Anderson Symptom Index
	Consequences: not evaluated	(MDASI)
Howell, D.,	Attributes: Information exchange,	Qualitative
Fitch, M. &	discussing options	
Deane, K.	Antecedents: severity of disease,	
$(2003)^{16}$	communication competence,	
	personality, emotional state	
	Consequences: satisfaction with	
	choice	
Jolicoeur,L,	Attributes: Information exchange	Qualitative
O'Connor, A.,	Antecedents: Role expectation,	
Hopkins., L.&	sociodemographics, disease severity	
Graham, I.	Consequences: decisional conflict,	
$(2009)^{11}$	patient knowledge	

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## CHAPTER FOUR

# Manuscript 2

Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence

# For submission to Oncology Nursing Forum

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## <u>Abstract</u>

*Purpose:* To improve the shared decision making process for women diagnosed with an ovarian cancer (OC) recurrence through exploring the experiences of women and providers making treatment decisions, and to triangulate the findings to provide a fuller picture of shared decision making in the context of OC recurrence.

*Methods:* A descriptive qualitative study with thematic analysis of semi structured interviews and field notes related to the interview was used to evaluate the process of decision making as experienced by women with OC recurrence and healthcare providers.

*Results:* 25 patient participants and 10 provider participants were interviewed. Results revealed major themes of living with cancer and maintaining hope from the patient perspective, and the art of treatment management and maintaining hope from the provider perspective.

*Conclusion:* Exploration of the treatment decision making process for key stakeholders in an outpatient cancer clinic will provide important foundational knowledge for intervention development to build and support shared decision making for complex treatment decisions such as OC recurrence.

## **Introduction**

Ovarian cancer (OC) has the highest mortality rate of all of the gynecologic malignancies, with the five-year relative survival rate of under 45% (Webb & Jordan, 2017). In the United States, stage IV ovarian cancer five-year survival rate is 17%, with most patients (70%) diagnosed at Stage III or IV (American Cancer Society, 2017). Patients often achieve remission, but the risk of recurrence is 60-70% depending on stage of disease and volume of disease after primary surgery (Teo, 2014). Recurrent OC is treated as a chronic condition and few patients diagnosed with recurrence will ever be disease free again (Thigpen, 2012).

When a recurrence is diagnosed, women must make decisions about which of the available treatments they would like to initiate. For these women, decision making requires not only an understanding of various treatment options, but also an assessment of goals, a high level of trust in the treatment team, consultation with loved ones, and useful communication over an extended period of time. With the advent of targeted chemotherapy and new biologics, many women will have numerous options ranging from standard treatments to experimental therapies to maintenance of comfort.

#### **Background and Significance**

OC is colloquially a term used for a heterogeneous variety of tumors that involve the ovary, fallopian tube, and peritoneum (Kroeger & Drapkin, 2017). It is now believed that the majority (60%) of these cancers arise in the fallopian tube (Kroeger & Drapkin, 2017), and while the lifetime risk of developing OC is less than 2%, it ranks fifth in cancer deaths for

women and is the most lethal of the gynecologic malignancies (Oronsky, 2017). The US Food and Drug Administration (FDA) approved primary treatment for newly diagnosed ovarian cancer is surgery and chemotherapy with two to three agents. The response to the primary regimen is varied and depends on the stage of disease and other factors (Kim, Ueda, Naka & Enomoto, 2012), making it difficult to predict whether remission will be achieved. Approximately 80% of women diagnosed with stage III and IV ovarian cancer will experience recurrence after first line chemotherapy (Hanker et al, 2012).

All patients eventually become resistant to therapy and the duration of response diminishes with each treatment (Hanker et al., 2012). Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or one of the FDA approved therapies. Each of the choices may have a different trajectory, side effect profile, and treatment schedule. Response rates are low, about 20-50%, for any chosen therapy (Oronsky, 2017). The goal of treatment after recurrence is to slow progression, manage the growth of the cancer, and manage symptoms. With subsequent recurrences, the goal is to manage symptoms, prolong life, while maintaining an acceptable quality of life. Treatment response rates are similar but the regimens vary in side effect profile and frequency and duration of treatment, therefore patient preference in terms of her expectations for both treatment and quality of life play a major role in the decision (Jolicoeur, 2005).

A review of the literature by Elit, Charles & Gafni, (2010) concluded that the treatment decision-making process in ovarian cancer can be divided into three distinct stages; information exchange, deliberation, and making a decision about treatment. The stage of information exchange included patients' satisfaction with information, what they retained, and

what information both parties deem important. The deliberation stage is described as discussion of values, and the preferred decision making (DM) role of the patient, while making the decision includes the options discussed and how the decision is made (Elit, Charles & Gafni, 2010). In studies examining exchange of information, women faced with a treatment decision for recurrent OC expressed a need for information about their disease status and available treatment options, however options were perceived as limited and information was difficult to obtain (Howell, Fitch & Deane, 2003; Ekwall, Ternestedt, Sorbe & Graneheim, 2010; Elit, et al., 2010). In addition, patients felt that open discussion about values and preferences was lacking, while providers tailored information exchange based on their education and socioeconomic status (Elit et al., 2010;Elit et al., 2013). Jolicoeur, O'Connor, Hopkins & Graham (2009) identified that the majority of patients were satisfied with the role they had taken in the DM process, and that past experience with treatment and current health status were most important in treatment decision-making.

Given that choosing a treatment regimen for OCR depends not only on clinical aspects such as rate of cancer growth but also on quality of life aspects such as side effect burden and physical activity, shared decision making in this context is essential. Currently, however, a knowledge gap exists regarding women's experiences with decision making for OCR and the perspectives of healthcare providers as key members of the decision making team. The purpose of this study was to examine the nature of the decision making process between women with a diagnosis of ovarian cancer recurrence and their providers.

#### Methods

A descriptive qualitative study with thematic analysis was used to explore the process of decision making as experienced by women with OC recurrence and healthcare providers. This approach allows for *a priori* knowledge of the subject matter while enabling organic development of themes. This study was approved by the [Institution] Protocol Review Committee (PRC) and the Institutional Review Board (IRB) for Health Sciences Research (HSR).

## **Participants and Setting**

The setting for this study was the outpatient gynecologic oncology cancer care clinic at the [Institution] Cancer Center at a research-intensive academic medical center and regional referral center serving much of central and southwestern Virginia. The [Institution] is a National Cancer Institute designated institution with more than 130 researchers from multiple fields dedicated to cancer research. The gynecologic oncology program serves thousands of patients yearly, with approximately 30% being patients with OC recurrence. Approximately15 patients with a diagnosis of OC are seen each week in the clinic and 2 to 5 of these patients have OC recurrence.

A purposive sample of women with a diagnosis of recurrent OC, including epithelial ovarian, fallopian tube or primary peritoneal cancer was recruited from the [Institution] Cancer Center. Patient inclusion criteria are: 1) diagnosis of OC recurrence within the past 4-6 weeks, 2) 18 years old or older, 3) English speaking, 4) plans to receive treatment for recurrent ovarian cancer, and 5) cancer is either platinum sensitive or platinum resistant. Gynecologic oncology physicians and nurses were recruited from the [Institution] Cancer Center and through referral. Inclusion criteria for healthcare providers are: 1) provide care for patients with OC recurrence in an outpatient setting, 2) physician, nurse, or advanced practice nurse.

#### **Data Collection**

Semi-structured interviews were conducted for patients and healthcare providers. Demographic data; age, stage of disease, number of lines of therapy, race and time from diagnosis to first recurrence were acquired at the beginning of each interview. For both types of participants, interview questions were designed to elicit open discussion of the factors contributing to decision making about OCR treatment options. Patient interviews also addressed the information provided to them, the nature of the discussion, and factors they considered important in making their decision. Provider interviews elicited information about their perspectives on what information they provide, how they provide it, and what resources would be helpful in guiding the decision making process.

## Procedures

Patients were recruited via chart review and referral from the healthcare team. Healthcare providers were recruited via email or phone call. Face-to-face or telephone interviews were conducted according to participant preference. Data were collected until saturation was achieved (Sandelowski, 1995). Field notes were documented immediately after the interviews and included observations, personal notes, and analytical notes (Polit & Beck, 2012).

## **Data Analysis**

Thematic analysis of semi-structured interviews and field notes, using the methods outlined by Braun & Clarke (2006), informed the exploration of recurrent ovarian cancer treatment decisionmaking. Trustworthiness (credibility, transferability, dependability and confirmability) was ensured through the use of triangulation of data and persistent observation, detailed literature review and inquiry audits of process notes (Lincoln & Guba, 1985). Interviews were read and reread and notes written down of initial ideas. The interviews and field notes were transcribed verbatim and imported into the qualitative software DeDoose (<u>www.dedoose.com</u>) to assist with data organization and analysis. Transcripts were cross-checked for accuracy. Initial coding was theory driven based on the decision support framework, and included both semantic and latent codes. Collating and organizing relevant codes lead to emergent themes. A thematic map was developed to help visualize the analysis and to organize both candidate and sub-themes, which were then compared to the overall data set to check for accuracy. Members of the team cross checked codes and emerging themes. Themes were refined through naming and description, and rich, compelling examples that tell a descriptive story have been selected to illustrate major concepts.

#### Findings

Twenty-five women diagnosed with ovarian cancer recurrence were interviewed, and were primarily Caucasian (84%), greater than age 50 at diagnosis (72%), advanced stage at diagnosis (80%) and had greater than 4 lines of therapy (60%). Eight physicians and 2 nurses were interviewed, with an average of 7 years experience working in gynecologic oncology. Patients and nurses were all recruited from the same institution, while physicians were recruited from 5 different medical centers.

Three core themes emerged from data analysis. From the patient perspective, living with cancer and maintaining hope, and from the provider, the art of treatment management and also maintaining hope, were identified. Both patient and provider perspectives on maintaining hope are described together to give a rich description of the delicate tension between understanding the meaning of a diagnosis of ovarian cancer recurrence while remaining optimistic.

## Living with Cancer

Overall, this theme centered on women's experiences of managing their new normal and adjusting their expectations for their future. Recognition of prognosis made time more precious, while seeking treatment helped patients feel as though they were actively doing something. Three subthemes emerged; living life to the fullest, being in treatment, and acceptance. **Living life to the fullest**: Patient participants identified spending time in gratifying activities and with people who enriched their lives. Some created bucket lists that involved travel with close friends and family members. Most expressed having to pace activities due to fatigue, but activities that brought joy and fulfillment were prioritized, such as gardening and spending time with friends.

P110: I'm not as active as I normally would be because of the shingles, because I can't read, but I, we sleep late. I have a wonderful breakfast and I walk my adorable dog and that's great, and I tend to take more naps than I use to but we do go to the theatre or the ballet and I see friends and it's nice.

P106: You know, to just get up in the morning and just function like everybody else that doesn't have cancer. I want to be able to do live my life...'cause I'm active. I want to be able to play with my grandkids and see my kids and go do what I want to do. Go up and down stairs if I have to or run if I have to. I kind of, I kind of live my life as I think in my mind I don't have cancer.

**Being in treatment**: Patients expressed the view that ovarian cancer recurrence would be treated as a chronic condition, and that they would continuously be in treatment until there was a decision to stop or until no more treatment options were available. Treatment was worth the burden to gain time and being in treatment was seen as an active role in fighting the cancer. Comfort was taken in having multiple options for treatment after the current regimen ultimately failed.

P118:...just have to take breaks, and cancer's over here and I have to, you know, do my chemo and the stuff that I need to do, and that's chemo project and that's how I think about it. So when I say I want to carry on, it's just I want to live life.

P116: I'm happy to be in treatment. I spent most of the summer waiting to figure out what treatment I was gonna be on when I knew the cancer was spreading. So I'm just happy to be moving forward.

P124: I think I'm brave enough and I have enough courage that I'll try just about anything, and that doesn't mean I'll drink out of the poison chalice but, you know, yeah, I mean the hair loss or vomiting or diarrhea or - I've had them all. I've had the Doxil where the skin has shredded off my feet, you know. The Avastin pumped up my blood pressure. You know, the Taxol, yes, you know, the diarrhea and the different - I mean I've had them all. None of them seemed - there's a risk and a reward, and the reward, you know, having the CA 125 go down which I know is not the be end all, but to at least have that going in the right direction was worth all the other stuff.

Acceptance: As part of the cancer journey the acknowledgement of mortality was evident in most interviews. Patients brought up coming to peace with dying and many had made plans preparing for a future without them.

P120: We usually have Christmas and Thanksgiving together. The last few years we have cause every year I keep thinking that maybe this will be the last one, you know, let's all get together and it's been fun.

P105: I'm getting my funeral arrangements done and paid for them so my son don't have to make them. I even wrote my own obituary. Short and sweet. Uh, you know, I don't want him to have to take care of anything.

P125: But I've accepted it, you know. I know I'm gonna die from it. I know this is gonna kill me. I don't have any other health problems.

## The Art of Treatment Management

Through mentorship and over time in practice, providers develop their own style of patient care. This core theme encompasses how providers contribute to shaping patient treatment trajectories. Subthemes included assessing goals of care, determining needs, and having difficult conversations.

Assessing goals of care: Determining and clarifying patient values was key in enlisting the patient in shared decision making. As the care trajectory evolves, so does the conversation, as patient care goals change over time and providers recognize the importance of aligning treatment options with a patient's perception of quality of life.

LIP2: I point blank ask patients what is most important for them, if it's to have as much time with their family where their feeling the best or is it to have the most aggressive therapy possible, and I think you'd be, and I'm surprised by what people answer. LIP5: How do you feel about going back on chemo right now? Like what are your main concerns? If it's really getting down to time, you know, like this is, a time to talk about just coming off treatment entirely, do you have any big goals - and this person has a couple kids through high school - like going to graduation, is there a wedding, is there some big event that you really wanted to have as a goal, you know, living as long as possible, or being strong when that event happens so you can enjoy it.

**Determining patient needs:** Evaluating patient needs, both in terms of information and access to resources was necessary in helping the patient fully understand their diagnosis, treatment options and having a realistic expectation of treatment efficacy.

LIP3: The toxicity to start, what toxicity and if they're going to have frequency of appointments in travel because certainly if someone's on a weekly regimen you want to make sure they understand that it's going to mean coming in every week, if that's going to be a huge disruption ... I think it starts with toxicity and then it kind of trickles down to duration of treatment and frequency of treatment and then there's probably cost in there too, although we don't run into that as much.

LIP2:...she's still working, how young they are, if she's very young, you know, if she has young kids, she's probably otherwise healthy if she's 47 with this, you know, how robust she is, how far away she lives from our clinic sort of to travel to come for therapy, how well she has tolerated other therapies as far as not only her sort of physical well-being but objective things like her counts and side-effects from the other therapies.

LIP1: We'll go through the drugs individually and...I'll go - and I'll use paper usually if there's a lot of different options and, you know, then each option I'll write down key sideeffects and timing because sometimes with people with busy lives how often they have to come is an important thing so I'll go through each drug and make sure they understand and make sure they understand the timing as far as coming and also what hospice has to offer and what's available.

**Having difficult conversations:** Salient in the provider-patient encounter were both the timing and the pacing of end-of-life discussion. Providers expressed the challenges of having open dialogues with patients about prognosis and death, which was made even more difficult the deeper the patient-provider relationship.

LIP2: I usually have a little silence and let them sort of guide where we're going next. I obviously offer support, you know. I feel like most of the time these people when they're coming back, if we've already told them the results they've processed some of those results and so usually once we have a moment of support they're ready to sort of move on and talk about it, but sort of have a silence and let them guide where we're going next.

LIP09: It's a difficult balance and we're human and the intonation is to not hurt somebody even when you have to tell them bad news and I do worry that I hold back more than I should

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and I'm not doing a patient justice because I'm trying to protect myself, so it's how could we do that better, how could we be better prepared for that conversation, how can we set the stage, you know, at the very beginning, that eventually we're gonna have to have this discussion. And I think we're starting to do that better, you know, at the time of diagnosis, but it is - it's the thing that kills you emotionally when things get - the most soul saps I feel from work are on clinic days when I have to have three or four end of life discussions.

LIP10:...this is gonna be sad. That she's gonna die and I'm gonna have to decide how blunt to be about that. And so there'll be the difficulty of me just being sad because I can't probably help her very much and also the difficulty of deciding how much of that to tell her.

#### **Maintaining Hope**

Both patients and providers expressed the need to maintain hope. Patients verbalized mechanisms to remain optimistic, while providers verbalized balancing prognostic information with the possibility of positive response to treatment.

Patients:

P106: Say I had a limit on it. Somebody would say like oh, so you only have three months to live. I don't want nobody telling me that. I don't want nobody to say, oh well, you know, you got two months to live. Don't tell me that. I don't want to know because I think that people dwell on that and then you just give up.

P119: The best thing I can think of is just keep your attitude as upbeat as you can. You know, to me so much is about - of course it's about faith and belief, but to me that just comes

natural, not so much religious as spiritual. That's just the way it feels to me and you know, it's I go around and think, "Don't worry about this, you're healing, you're almost there, you're okay. Go with this." You know, I push myself too far some days and people will fuss at me and say, "Don't do that. You're overdoing, you need to...." But that's what keeps me going, that's what keeps me well. I have to do this. I have to do it for me.

## Providers:

LIP09: They're just the sweetest people in the world and you don't want to completely walk out and, you know - the whole goal of palliation and palliative care and hospice is to preserve quality of life, and if you walk in there and squash any hope then I feel like the emotional impact of that is as significant as toxicity of chemotherapy sometimes, so we try to balance that as best we can without hiding anything or, you know, not telling the whole story.

LIP01: So when a patient comes and it's clear that it' 's ovarian cancer and they need additional treatment, I think we need to - you know, we don't want to take away hope, so I think we need to say, "These are the statistics. We don't know how it relates specifically to you, but for the majority of people who have this disease process it's very treatable.

#### Discussion

This study revealed that while the overt discussion of how to help a patient with ovarian cancer recurrence live a fulfilling life does not occur between provider and patient, it is inherent in the journey of these patients that they will strive for balance and joy in their every day lives. In turn, providers solicit feedback on values and goals of care to support patients in achieving their best

quality of life while in treatment. In an earlier study, Elit et al., (2010) found that the discussion of values was lacking in treatment planning for OCR, and that patients did not perceive the need to know treatment details such as side effects and names of drugs. Alternatively, Havrilesky et al, (2014) found that the discussion of specific treatment side effects, and how they may impact quality of life, helped determine patient preference. In another study, patients who felt that they were acknowledged as a unique person by the clinical team facilitated a treatment discussion that was both sensitive to values and inspired sharing in the DM responsibility (Ekwall, et al., 2011). While the current study did not focus on exchange of information regarding details of side effects, it did elicit positive perceptions about open communication regarding values and goals of care, which contributes to a discussion of treatment options and ultimately SDM.

For many of the patients in this study, acceptance that their time was limited motivated them to treat each day as a bonus. Patients verbalized mechanisms to live life to the fullest while managing treatment and symptoms of OCR. They emphasized doing what makes them feel good, pacing activities, and not allowing fatigue or other side effects interfere with precious moments with friends and family. For example, treatment, which acted as a reminder of illness, was compartmentalized to allow patients to lead satisfying lives despite their diagnosis. Results of an earlier study revealed that for patients, diagnosis of recurrence is not only evidence of advancing disease, but that death is imminent, and mechanisms to allay anxieties included gaining control over their futures by seeking treatment and understanding treatment options (Howell, Fitch & Deane, 2003).

Both patients and providers spoke of maintaining hope. The patient perspective is a subjective experience of living with cancer and understanding it is a terminal illness, while sustaining optimism to manage daily life. Simultaneously, the provider is mindful not to eliminate patient feelings of hope, or create a false sense of hope, while guiding the patient ultimately to end of life. Interestingly, a study reviewing provider perspectives found similar sentiments of attempting to maintain hope while providing realistic expectations (Elit et al, 2012; Elit et al, 2013). However, studies exploring the patient experience revealed the perception that not only was information about recurrence too embedded in statistics and stark, but also that the care team had given up on the patient as indicated by a lack of options for treatment (Howell, Fitch & Deane, 2003; Elt et al, 2010; Ekwall, Ternestedt, Sorbe & Graneheim, 2011; Havrilesky et al., 2015).

The current study revealed that not only are providers maintaining hope for their patients, but they are themselves maintaining hope. All of the providers spoke of that one patient that responded unexpectedly to a last attempt at treatment, or the patient who had a bowel obstruction due to progression, but was operated on and lived 2 more years. To instill hope in others, one must be hopeful. This is evidenced by not only the sincere motivation to keep patients hopeful, but also in the pursuit of options and clinical research. This mechanism to instill hope in the patients as a reflection of their own hope, may also be a way to remain resilient in the face of treating such a patient population that has such poor outcomes. The providers interviewed for this study are aware of the statistics and the mortality of this disease, but continue to identify hope for both patients and themselves.

The patients who were interviewed often described a feeling of optimism and hope, in spite of awareness of mortality. This was not only supported, but perpetuated by the providers, however also seemed an internal coping mechanism. Patients spoke of avoiding support groups as they tended to be depressing, or avoided speaking with friends with a cancer diagnosis for the same reason. The patient preference was overwhelmingly to focus only on the positive as a way of coping. The patients' perception of having continued options for treatment also instilled a sense of optimism. Patients appreciated the idea of more options, even if they were not aware of the details of those options. The mere fact that there was something next seemed to provide hope, in that it may have indicated hope from the medical perspective. To the patient, the experts providing options may imply that there is a chance of efficacy.

Patients in the current study expressed the need to maintain hope and remain positive as a way of moving forward with both treatment and life. Hope, for both patients and providers, is a tenuous balance between knowledge of overall mortality and the belief that each patients experience is unique and unpredictable.

SDM involves enlisting patients in the decision making process to determine how best to balance treatment and personal goals (Charles, Gafni & Whelan, 1999). The providers in the current study described these aspects of SDM in terms of preparing for the appointment, reminding themselves of the patient's story, tailoring discussion of treatment options, and maintaining hope. Patients engaged in SDM by sharing their values and goals, and thereby contributing to the treatment decision.

### Limitations

This study is limited by the small number of participants, and that all patient participants were recruited from the same institution. Because of the limited number of providers available, providers from other academic institutions were recruited. The institution in which this study primarily occurred is a rural academic hospital in which clinical trials are a primary goal for treatment for most patients with OCR. As a result, the patient participants in this study have limited options for both second opinions and care in this geographic location. The researcher has been working with this group of providers and nurses and patient population for over 10 years,

potentially distorting both observations and responses from participants. For the duration of this study, the researcher was not providing care for this patient population. However, the familiarity with this disease process and patient treatment trajectory may have impeded the researcher's ability to objectively analyze the data.

#### **Implications for nursing**

Evaluating patient needs for both information and resources is important in determining viable options for care. Patient goals of care may not be overtly expressed by patients, so spending time communicating with patients about their values and what they enjoy doing on a daily basis will help guide treatment decisions. Maintaining quality of life is a subjective experience that can change over time, and should be an ongoing dialogue to solicit that information.

### Knowledge translation (3 points indicating new knowledge that may influence practice)

- Understanding patient goals of care and access to resources is key in determining treatment options.
- Providers should try to recognize feelings of self-protection that can be barriers to honest discourse with patients.
- Understanding that maintaining hope is a necessary mechanism for patients to live life to the fullest.

#### Conclusion

This study aimed to explore decision making in the context of ovarian cancer recurrence, from both the provider and the patients' perspectives. Two sides of the same coin, the patient and providers experiences, as discussed in this paper, are connected and dependent. The patients' ability to live with her cancer while being in treatment and remain hopeful is tied to the provider's artful management of her trajectory, and unspoken agreement to not remove hope. The balance of treatment and maintaining quality of life is difficult to sustain, but the constant engagement of both patient and provider make it possible. The difficult discussions led by providers ensure that patients can honor their values while accepting their mortality.

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# CHAPTER FIVE

# Manuscript 3

The Woman's Perspective- Treatment Decision Making in the Context of Ovarian Cancer

Recurrence

For submission to Supportive Care in Cancer

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### Abstract

*Purpose:* To explore the treatment decision making process for women diagnosed with ovarian cancer recurrence using a relationship-based decision making perspective.

*Methods:* A descriptive qualitative study with thematic analysis of semi structured interviews was used to evaluate the process of decision making as experienced by women with OC recurrence.

*Results:* 25 women were interviewed. Results revealed major themes of contributing, caretaking and delegating the responsibility of the treatment decision. Several subthemes emerged for each primary theme, which included staying strong and supporting others, and having an active role in the decision about treatment versus deferring the decision to the provider.

*Conclusion:* Exploration of the treatment decision making process through a relationship-based decision making perspective will provide insights that may lead to intervention development to better support and encourage shared decision making for complex treatment decisions such as OC recurrence.

## Introduction

Approximately 22,530 women will be diagnosed with ovarian cancer in the United States, and over 13,000 will die of ovarian cancer this year (SEER data, 2019). Symptoms are vague and often not recognized as being ovarian cancer, and it often takes up to four visits to a primary physician for masses to be identified (Boac et al, 2018). Delays in diagnosis contribute to the disproportionately large percentage of women diagnosed with late stage ovarian cancer, and ultimately to the high mortality rate (Goff, Mandel, Muntz & Melancon, 2000). In the United States, stage IV ovarian cancer five-year survival rate is 17%, with most patients (70%) diagnosed at Stage III or IV (American Cancer Society, 2017). After primary treatment, the risk of recurrence is 60-70%, depending on stage of disease (Teo, 2014). Ovarian cancer (OC) has the highest mortality rate of all of the gynecologic malignancies, with the five-year relative survival rate of less than 45% (Webb & Jordan, 2017).

#### **Background and Significance**

When recurrence is diagnosed, women must make decisions about which one of the available treatments they would like to initiate, sometimes as soon as possible, depending on symptoms and disease burden. Recurrent ovarian cancer is treated as a chronic condition and few patients will ever be disease free again (Thigpen, 2012). While there are a number of approved chemotherapies for recurrence, none have shown great efficacy, with a response rate of 20-50% (Oronsky, 2017). Approvals for bevacizumab and poly (ADP-ribose) polymerase (PARP) inhibitors have shown some promise in progression free survival (PFS) but have not had great impact on overall survival (OS) (Pan, Gong, Huynh, & Cristea, 2019). Contributing to this bleak landscape of treatment options is the knowledge that regardless of treatment chosen, all patients

with continued therapy eventually become resistant to the therapy they are on, and the duration of response diminishes with each treatment (Hanker et al., 2012). Thus, there is motivation for developing new therapies and making sure clinical trials are available, for both the individual woman with limited options, and society as a whole to improve outcomes.

Women are often primary caretakers and significant breadwinners for their families and take these and other roles into account when making treatment decisions. A majority (up to 68%) of caregivers are women, and up to 66% of caregivers are also employed either full or part time (APA, 2019). Therefore women not only have to navigate the multifaceted landscape of options, from immunotherapy to multiple agents with complex treatment schedules, but they also are most typically responsible for taking care of their own children or grandchildren, and/or caring for elderly parents.

Decision making from a relationship-based perspective acknowledges the social context in which the decision is being considered, and puts the relationships of the decision maker at center stage. This perspective takes into account the caring relationships that most women have, with the multiple roles that they typically hold, in both family and community. The caring relationship is the foundation of relationship-based decision making, and while there are many ways to define caregiving, at its root it includes caring, nurturing and engaging another's will, or needs (Lindemann, 2006).

This paper will examine the landscape of treatment decision making for ovarian cancer recurrence using a relationship-based decision making perspective. It will focus on women's feelings, values, and experiences in the context of the complex negotiation involved in making health care decisions, while being woman, mother and caretaker, and taking into account self and others (Parker & McFarlane, 1991). This perspective acknowledges social context and power

dynamic, and the value of relationships above self (Gilligan, 1987). Taking this into consideration allows for a rich interpretation of the data that honors the values of women. This research is about women and for women, with the aim to improve the overall experience of women making treatment decisions for ovarian cancer recurrence.

#### Methods

## **Participants and Setting**

This paper focuses on analysis of data using a relationship-based decision-making perspective. The details of the methods are described elsewhere (Lothamer et al, 2019, under review). Briefly, the setting for this study was the outpatient gynecologic oncology cancer care clinic at the [Institution], a National Cancer Institute designated, research-intensive, academic medical center and regional referral center serving much of central and southwestern Virginia. The gynecologic oncology program serves thousands of patients yearly, with approximately 30% being women with OC recurrence. A purposive sample of women with a diagnosis of recurrent OC, including epithelial ovarian, fallopian tube or primary peritoneal cancer was recruited from the [Institute].

## **Data Collection and Procedures**

Semi-structured interviews were conducted for women at their convenience. Interview questions were designed to elicit open discussion of women's experience with treatment decision making for recurrence. Women were approached at a time of lower emotional stress, determined by time lapsed between knowledge of recurrence and a decision confirmed regarding future treatment. It was explained that the interviewer was a student nurse, with a past working relationship with the care team however no current influence on care. Face-to-face interviews were conducted according
to the woman's preference, and in a manner that reduced a power hierarchy, such as, no lab coat was worn, the interview was informal, and the interviewer was addressed by her first name. Data were collected until saturation was achieved (Sandelowski, 1995). Field notes were documented immediately after the interviews and included observations, personal notes, and analytical notes (Polit & Beck, 2012).

#### **Data Analysis**

A relationship-based decision-making perspective, looking specifically at.... shaped data interpretation, incorporating women's relationships and social context in exploring the woman's experience of recurrent ovarian cancer treatment decision-making (Hall & Stevens, 1991). Thematic analysis of semi-structured interviews and field notes was executed using the methods outlined by Braun & Clarke (2006). Interviews were read and re-read and notes written down of initial ideas. The interviews and field notes were transcribed verbatim and imported into the qualitative software DeDoose (www.dedoose.com) to assist with data organization and analysis. Initial coding included both semantic and latent codes. Collating and organizing relevant codes lead to emergent themes. A thematic map was developed to help visualize the analysis and to organize both candidate and sub-themes, which were then compared to the overall data set to check for accuracy. Themes were refined through naming and description, and rich, compelling examples that tell a descriptive story have been selected to illustrate major concepts.

#### Findings

Twenty-five women diagnosed with ovarian cancer recurrence were interviewed. They were primarily Caucasian (84%), age over 50 at diagnosis (72%), diagnosed with advanced stage disease (80%) and had been treated with more than 4 lines of therapy (60%). Several themes emerged which were indicative of the primary role of women in both society and in their

families. Contributing and caretaking were two primary themes prevalent in the interview results. Decisions about type of treatment hinged primarily on the woman's ability to continue to both contribute and take care of family members, resulting in a discussion focused on side effects and logistics, and less on efficacy. The third major theme is delegating the responsibility of the treatment decision. Women recognize their limited medical knowledge and because they have trust in the clinical team, or may have profound faith in God, they defer the responsibility of the treatment decision to those with a greater knowledge or perceived power. There was a spectrum of involvement in the decision, however, with some women taking more of an active role, and some less.

#### Contributing

The theme of contributing emerged from the multifaceted ways women define themselves and their contributions to society. Being able to work, participating in a clinical trial as a form of contributing to science and to the treatment of other women, and staying physically strong during treatment are subthemes of powerful and meaningful contributions that women subtlety expressed.

**Continuing to work:** Patient participants not only had the desire to work, but some were the primary breadwinners, or responsible for providing health insurance for family members. The sense of contribution, when not fulfilled, led to feelings of guilt. Women who were able to continue to work negotiated with their work environment to allow space to honor themselves.

P102 I was taking care of my brother. He's handicap and um, I was doing that for a long time until I seen the doctor and I asked the doctor, I said, ah, I can, I can, I go back to work. And he said no, not full time. Maybe a little bit part time so I just didn't go back to work at all. Right now I'm drawing a little bit of social security part disability. A little bit. That's it.

But I don't feel right. I don't feel like drawin money from Social Security. I feel a lot better if I just get out and do something. Work and make my own money, I feel much better, you know, it just makes me feel by drawing that kind of money from Social Security, I just felt like I told my husband, I said, I feel like I'm giving up and I feel like, I mean, you know, it's just, I feel better if I was making my own money.

P121. I work in - a big kind of winding building and I work in one of the far corners down a long hallway where I can close my door and pretty much people will leave you alone if your door is closed. So when I'm not feeling well a lot of times I just shut my door and then I just keep working and I just kind of work through it. And people are pretty understanding about that at work. Most of them know what's going on with me and my boss certainly knows and, you know, she tries to be mindful that sometimes I'm just not feeling good.

**Participating in research:** Patients' willingness to participate in investigational therapies offered in clinical trials was for the potential benefit as well as altruism. The women wanted to see participation as a contribution to science that may one day help another woman in the same situation.

P120 She said she thought I would qualify for one and you know, it was up to me whether to do it or not and I thought well, hopefully it will help me and if it doesn't it might help somebody down the road... I'm 70 years old, what can I do at my age to help anybody so maybe this is it.

P112 I mean, I'll try anything for the cancer that they try so they can test to see if they can make a cure, give a cure for it, so that's fine with me, yeah. Any way I can help.

**Staying strong:** The subtheme of staying strong included both physical and emotional strength. Maintaining health and keeping physically active were mentioned in multiple interviews. This was not only for the physical activity, but also as a way of coping with the stress of their situation. Women bemoaned waiting hours for treatment, or sitting in a chair receiving treatment for hours, and suggested having treadmills or a track in the treatment center so they could walk while being treated. Emotional strength manifested in staying positive for those around them. Intentionally adopting an optimistic veneer both alleviated family members' concern, and maintained the status quo.

P107 They gave me a plan that helps me not, helps me cope with what I'm dealing with and being able to exercise so I could feel a little better, um, and get a little stronger because my muscles are weak.

P103 You want, you know, what is best for the, for me, and you know, for the family and it's hard to stay positive but if you can be positive it really makes a difference.

P105 I think I, I think I see the positive in people and in things and situations. What is it? I see the glass half full, so I think I'm pretty strong. I wish everybody was like that, but they're not. And I can be weak too, but I'm very, very happy I wake up happy and talking, smiling.

#### Caretakers

The theme of women as caretakers included subthemes of patients putting others before themselves. Those subthemes were caring for family members who have a perceived greater need, such as a disability, and providing support for family members in terms of coping with the diagnosis and treatment of OCR.

**Caring for others:** Patients verbalized being the primary, and sometimes sole, caretaker of other family members. Treatment decisions incorporated evaluation of impact of side effects and number of visits to the Cancer Center and were centered on continued ability to care for others.

P123 I have one sister who is disabled. She had measles when she was two - I'm the youngest sibling, the youngest one, and it kind of affected her nervous system so we've always, you know, she always lived with my mother and father and of course they're dead now, but we all pitch in and just kind of keep an eye on her.

P111 I did have the neuropathy in my feet that I don't want it to get any worse because I'm the only one that drives. My husband, he has dementia now and he's not able to drive so I'm the one that's doing the driving so just kind of try to avoid getting any worse if any way is possible.

P107 My mother is someone I do have to care for. I am an only child. I do not have any children and I am no longer married as well. Yeah, it's difficult. It's difficult to take care of someone else and just figure out how to take care of yourself. Um, but I knew since I'm basically the only one I need to do something.

P 106 And working, I mean, even if I need to work, you know what I'm saying? I gotta be able to take care of my mom. There's nobody else. So I gotta be strong enough and be able to do all that.

**Supporting others:** Women spoke of undergoing treatment more for family members than for themselves, and for ensuring that family members were taken care of in the midst of managing their own terminal disease.

P104 I have a senior graduating and I didn't know if I would make it five years to see that. And so I've checked off a lot of things in my life and made them happen. I'm traveling a lot and continue to travel and continue, continue to set goals for my kids that I have gotten to check off I didn't think I'd ever get to see. But one was traveling in Europe for six weeks, the other was eagle scout for my youngest son.

P120 I mean there were days that I thought I'm not gonna get through this but I did... I wasn't real thrilled you know, but I know I've got to do something...For my family. Not for me. I'm ready, I'm ready to go, but I just worry about them.

## **Delegating responsibility**

The theme of delegating responsibility of the decision for which type of treatment comes from a sense of being less knowledgeable about the medical information, as well as a sense of trust in the provider. One subtheme was deferring the treatment decision to another, whether faith-based or based on perceived expertise, and another was making more of an informed decision, and taking an active role in the process of determining next treatment.

**Deferring the decision:** Women expressed trust in the medical knowledge of their provider and allowed the provider to take over the responsibility of the decision. Women deferred the responsibility and went with what provider opinion, as much as through a faith in God as trust in the provider.

P118: I just go with what is suggested by my oncologist. I have complete faith in that and it was never a question of if or if not. No, I'm gonna carry on and if chemo is what I need that' s what I'm gonna do, so I didn't question it.

P107: As I said before, it's up to God what my journey's going to be, it's only up to her (the doctor) how my journey goes.

P123: I think before the olaparib I remember we talked about various treatments and so he was the one that suggested these treatments. You know, I'm not, I don't know a lot about medicine. I've learned more by own experience.

P114: ah, we talked about a couple and I asked her, I said honestly, you know, what would be my best option? And we came to this one being my best option for right now to see how this road takes us and hopefully it does what it needs to do.

Active role: Women interviewed also expressed naturally taking a more active role in the decision, seeking out information about their options and determining what they deemed the best course of action.

P119: I she, I think as a general rule, she (the doctor) felt like that as quickly as it recurred that there is probably some platinum resistance there so that made that not a good option. The fact that this is around and near some very major organs, liver, pancreas, that radiation or proton therapy would not work well and there were some other factors from my last that made immunotherapy not a good choice for me as well, so this seemed to be the best course for me to follow.

P110: Whatever the doctor said that's what I will do. And I'm still doing it. I mean, I ask her questions and sometimes I challenge her but I always take her opinion because I know she's the best and she wants to do the best, yeah, so, whatever she says is what I do. I have had second opinions at Dana Farber and NIH and recently at Sloan Kettering but it's not actually made any difference. They always confirm that I'm doing the right thing.

P103: Well we looked at the options for chemo, and we looked at the options, and the clinical trial felt right to me because it's not as um, I didn't have to have infusions and the side effects were a lot less. So I chose the, the clinical trial.

#### Discussion

This study revealed the innate sense of responsibility arising from a caring perspective, which is a deeply rooted moral obligation that places relationships above self (Gilligan, 1987). Women interviewed for this study expressed a need to be able to continue to contribute and to be able to care for others. Treatment decisions were made based on side effect aversion and logistics as opposed to the potential response to disease. Those with greater medical knowledge or perceived power were allowed and took responsibility for the treatment decision, although there was a range of involvement in the final decision.

Present in the interviews was an overwhelming theme of placing relationships of others above self. Contributing and caretaking were two primary and interconnected examples of this. A sense of contributing included the ability to continue to work, as well as to participate in clinical research that may improve conditions for other women. For example, the women involved in this study were grateful for the opportunity to contribute as participants and to share their stories as a way of benefiting others. In addition, maintaining both physical and emotional strength was verbalized. Examples included staying strong to continue to function as primary caretakers and remaining positive as a way of alleviating concern and anxiety of others. In this way, women revealed their prioritization of relationships over themselves as individuals. This reflects a deep moral obligation of caring. However, it also revealed the potential for the women to lose their sense of self, and to be vulnerable to exploitation of a naturalized tendency (Lindemann, 2006). Futhermore, the decisions made regarding treatment did not come from the perspective of impact on self, but rather, impact on relationships (Gilligan, 1987). In order to support women in their decision-making needs, it would be important to identify the relationships that have an impact on treatment decisions, and how those relationships impact treatment decisions.

The responsibility of the treatment decision was delegated to a higher power, whether the physician of God. Verbalized by women diagnosed with a recurrence are thoughts about dying and never being cancer free again (Elit et al., 2010). Therefore, news that the cancer is back, or resistant to treatment, may prime the woman to feel powerless. She subsequently abdicates responsibility of her decision to her physician but controls the decision to do so. So while she allows herself to be directed by the medical expertise of the physician, she establishes her value in contributing and caretaking, and trusts the physician to take that into consideration. This again reveals the value of relationship, now with the provider. Women trust provider opinion as the medical experts, acknowledging the power differential of information, station and training, but are cognizant of giving over responsibility of treatment choice. This is in some ways reminiscent of paternalistic medical practice. But taking into consideration the context of interdependence and attitude of trust, one could argue that in her powerlessness in the face of cancer recurrence, the woman controls the choice to abdicate responsibility (Sherwin, 1989).

#### Limitations

The small number of participants limits this study and that all of the women were recruited from the same institution. The institution in which this study primarily occurred is a small rural academic hospital in which clinical trials is a primary goal for treatment of recurrent ovarian cancer. All providers are dedicated to the pursuit of continued options of treatment for women, such that perception of value of continued treatment may be obscured by the very fact that there are options for continued treatment. The majority of women interviewed were both Caucasian and of a Christian faith, which narrows the scope of intersectionality. Additionally, women in this study have restricted options for care in this geographic location, as there are few hospitals available.

#### Conclusion

In contemplation of treatment decisions, women expressed contributing and caretaking as primary goals, and focused on the impact treatment would have on relationships, from both side effects and logistics, and focused less on the efficacy of treatment. Additionally, women recognized their lack of medical expertise and as a result gave responsibility of the treatment choice to either the provider of to God. A spectrum existed as to level of involvement, with some women completely allowing the provider to direct care, whilst some took a more active role in the decision. Regardless of level of participation, women made a conscious decision of level of involvement.

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#### CHAPTER SIX

#### Conclusion

In 2001, the Institute of Medicine's report, *Crossing the Quality Chasm*, highlighted the importance of patient-centered care, which incorporates patients' preferences and values into decisions about treatment. Patient-provider partnership and collaboration, information sharing about goals of care, patient values, treatment options, and risks and benefits, and consensus are the cornerstones of shared decision making. A major defining attribute of SDM is the interaction between patient and provider, such that there is information exchange and engagement on both sides in working towards an agreed course of action (Charles, Gafni & Whelan, 1999). Prior studies exploring the patient perspective of shared decision making show that most patients prefer sharing in the decision making process and that patients define shared decision making as not only interactive communication, but having a trusting and respectful relationship with the provider (Chewning et al., 2012; Shay & Lafata, 2014).

In the context of recurrent ovarian cancer the treatment decision is complicated on multiple levels by the ever present option to cease curative interventions and pursue palliation, or that the wrong treatment choice may have unanticipated and severe side effects. Emotionally, the fact that an option to stop treatment exists is a stark reminder of mortality and although intellectually the patient may recognize limited time, she may also have goals to see the birth of a grandchild, or to travel with friends. The future is uncertain and the treatment decision may not be the right one. Therefore, the decision is considered value-laden, in that it incorporates the patient's goals in terms of quantity versus quality of life (Johnson et al., 2010). Patients faced with value sensitive decisions of this magnitude feel more comfortable in having the physician

give recommendations or even direct the decision, provided there is a trusting relationship (Kon, 2010).

In the current study, providers described SDM in terms of preparing for the appointment, reminding themselves of the patient's story, and tailoring discussion of treatment options. Prior studies revealed that women faced with a treatment decision for recurrent ovarian cancer verbalized implicit trust in the healthcare providers ability to guide them in their decision and allowed the provider to make the decision for them as a result of having either too few or too many options (Elit, Charles, and Dimitry 2010). While there was a range of involvement by women in the treatment decisions, those with greater medical knowledge or perceived power were both allowed and took responsibility for decisions. Women in this study verbalized a deep trust in their providers and engaged in SDM by sharing their values and goals, thereby contributing to the treatment decision, but often deferred or delegated the responsibility of the decision to the provider. Because of the value laden nature of this decision, and the trustin the provider, the choice to allow the provider to direct the decision is still considered on the continuum of SDM (Kon, 2010). While the existence of options instilled hope in the patients, the knowledge of these options was lacking. There was a passive element to DM by the patients, in that few could name the therapies they were receiving, or the mechanism of action, and primarily focused on side effects and scheduling.

Prior studies from the provider perspective also suggest that barriers to communication are problematic. Studies revealed that oncologists modify the type and depth of information given to patients depending on patient cues, and that the same information is not given to all patients. Additionally, providers reported withholding information if they sensed that the patient was too emotional or becoming overwhelmed (Elit et al., 2012, 2015). Similarly, providers interviewed in the current study verbalized that they did not want to crush patients' hope, as the effects of that could be as "toxic as chemotherapy," and that they were challenged by having difficult conversations about mortality with the patients. Providers discussed the pacing and timing of discussions, as well as the insight that their discussions may be hindered by self protection, or by a deep relationship with the patient. However, the information necessary to make informed decisions is embedded in the reality of mortality. It is paramount that patients understand, to the extent that they can, that they will not be cured, and that they will eventually die from ovarian cancer.

This study revealed that women with OCR valued *living* with cancer, in terms of enjoying life and continuing to engage in all of the activities she associates with her identity and with a positive quality of life. Women chose to remain optimistic, while providers guided them through their disease trajectory being careful to walk a fine line between maintaining hope and providing realistic expectations. This study also revealed the patient's innate sense of responsibility arising from a caring perspective, which places relationships above self (Gilligan, 1987). Women interviewed for this study expressed a need to be able to continue to contribute and to be able to care for others. Thus, decisions were made based on side effect profiles and treatment burden as opposed to the potential response. Women wanted to continue to fulfill their roles within relationships in spite of treatment, and made decisions based on the needs of others as opposed to self. Recognizing this value, getting to a place in the encounter where this is transparent and discussed can lead to a deeper conversation of needs and goals, and ultimately contribute to SDM.

Because of its complexity, multiples avenues exist in the decision making process to ensure and support SDM, which can then be tested and measured. According to the Communication Model of Shared Decision Making in making cancer treatment decisions, antecedents of SDM are communication competency, personality, and sociodemographic characteristics, while contextual factors impacting communication are disease severity, emotional state, role expectations and information preferences (Siminoff & Step, 2005). This model may be useful in developing a tool to help providers with challenging communication with patients. A questionnaire may be able to elicit the preferred role preferences of patients, or their communication style and emotional state. Establishing the patient's emotional state prior to an encounter may be a way to gauge receptivity to making a decision, or having an end of life conversation. Determining patient social and contextual factors, emotional state, and role preference in decision-making, as well as evaluating knowledge gaps and access to resources can be ways to identify and address patient needs and expectations.

In a recent Institutes of Medicine (IOM) Report (2014), the use of a reliable decision aid (DA) was encouraged to promote shared decision making and increase knowledge of treatment options. DAs have been shown to help patients make value-based decisions and increase participation in the decision, which affect treatment choices and ultimately impact quality of life (O'Connor et al, 2003). The development and testing of a decision aid in an outpatient cancer clinic may have a positive impact on both the way that providers and nurses approach each complex treatment decision, and the way that patients reach a decision with the care team. In conclusion, supportive measures can be developed through future studies identifying specific provider and patient needs to accomplish satisfactory outcomes in decision making in ovarian cancer recurrence.

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# **Summary of Appendices**

# Appendix 1 Study Instruments Interview Guide

Interview Guide Patient Information Form Participant Information Form Medical Record Review Form Appendix 1

Date

Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence PI: Heather Lothamer, MSN, RN Interview Questions

# **Patient Interview Questions**

- 1. How long have you been in remission?
- 2. Can you tell me about when you learned that your cancer had come back?
- 3. What treatment options were discussed with you?
- 4. Were other people part of your decision?
- 5. Can you share with me how you made your decision?
- 6. What types of things did you consider when making your decision?

7. What did you use to help with the decision, family members, internet, information from the healthcare team?

- 8. Was there anything that could have been better in terms of information or resources?
- 9. What advice would you give another woman going through this situation?

# **Provider/Nurse Questions**

- 1. Please tell me about how recurrence is delivered to patients.
- 2. When and how does the next treatment discussion begin?
- 3. What kind of information is provided to patients and partners?
- 4. How are clinical trials brought into the discussion?
- 5. What questions do you ask to try to help them decide which option to choose?
- 6. Do you have a preferred option or do choices for next steps depend on the patient?
- 7. (If depends on patient), what kinds of things do you take into account when offering options?
- 8. What kinds of things are considered when making a treatment decision with a patient?
- 9. What resources would be helpful in guiding the decision making process?

Patient ID\_\_\_\_\_ Date\_\_\_\_

# Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence PI: Heather Lothamer, MSN, RN

#### Patient Information Form

**Instructions**: Please provide some background information <u>about yourself</u> by **checking** ( $\sqrt{}$ ) your response. If you do not care to answer a question, leave it blank.

- 1. What is your marital status?
  - a. Single (never married) \_\_\_\_\_
  - b. Separated or divorced (not living with a husband / wife) \_\_\_\_\_
  - c. Married (living with a husband / wife) \_\_\_\_\_
- 2. How old were you at your last birthday?
- 3. How many years of schooling have you completed (starting from 1st grade)? \_\_\_\_\_
- 4. Do you have support from family and/or friends\_\_\_\_Y
- 5. What is your ethnic background? Hispanic/Latino\_\_\_\_\_ Non Hispanic/Latino\_\_\_\_\_
- 6. What is your race?
  - a. Caucasian \_\_\_\_\_
  - b. African American
  - c. Asian \_\_\_\_
  - d. Native American

Thank you!

Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence PI: Heather Lothamer

# Medical Review Form

	m d y	Person amending form, last name
Patient Initials ( <i>First, Middle, Last</i> ) Patient Study		Person Completing Form, Last Name
OVARIAN: DISEASE DESCRIPTION		
(1) Date of definitive histologic diagnosis of primar	y tumor	
(2) Primary site O Ovary O Fallopian tube O Peritoneum		
(3) Stage at diagnosis (FIGO) OIA OIB O		
(4) Histologic grade O1 O2 O3 OUnki	nown	
(5) Histologic type <i>(check all that apply)</i> □ Serous adenocarcinoma □ Mucinous ad	lenocarcinoma	
Clear cell carcinoma Mixed epithe	elial carcinoma 🛛 Other, specify	, 77 0
Endometrioid adenocarcinoma      Adenocarcinoma, unspecified		
OVARIAN: FINDINGS FROM PRIMARY SURG	ERY	
(6) Primary surgery type (check all that apply)		
Total hysterectomy	Pelvic node sampling/dissection	
Bilateral salpingo-oophorectomy	Para-aortic node sampling/dissection	
Unilateral salpingo-oophorectomy Other, specify		
(7) Size of residual disease (Maximum size after resection is complete. If none or microscopic only, enter 0.)		
(8) Is ascites present? (prior to initial staging surgery) ONo (less than 50cc) OYes OUnknown		
(9) Cytology result (pelvic) O Positive O Negative O Suspicious O Not done		
(10) Is pleural effusion present? ONo OYes O	Unknown (11) Is it maligna	nt? ONo OYes OUnknown (not tapped)

DISEASE DESCRIPTION - PRIOR HISTORY
(1) Date of definitive histologic diagnosis of primary $\begin{bmatrix} m \\ - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / \begin{bmatrix} - & - & - & - \\ - & - & - & - \end{bmatrix} / (1 ) /$
Image: Selection of the se
Radical Trachelectomy  Cervical conization  None
FIRST CHEMOTHERAPY INFORMATION
(5) Date started (5) Date ended (6) Date ended (7) No. of courses (1)
(8) Specify agents
(9) Best response O C O P O S O I O X O U (10) Date of best response // / / / / / / / / / / / / / / / / /
(11) Did patient have clinical recurrence/progression U Yes U No (12) Date of recurrence/progression [ ] / [ ] / [ ]
SECOND CHEMOTHERAPY INFORMATION
(13) Date started $M / M / M / M / M / M / M / M / M / M $
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