Charting the Path from Diagnosis to Treatment:

A Grounded Theory Study of Women with Ovarian Cancer

by

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Dedication

This dissertation is dedicated to Elodie and Adele, whose wonder reminds me daily of the joy of discovery; and to Wayne, who lovingly commits himself to our shared goals, transforming every obstacle into an opportunity to reiterate his devotion.

Acknowledgment

This work would not have been possible without the steadfast support of my beloved family and friends. I am indebted to the members of my dissertation committee for their mentorship, their friendship, and the opportunities I have been afforded because of their generosity. I am especially grateful to Donna Berry for her dedication to fostering my growth as a nurse, writer, and scientist. I would like to thank the faculty and staff at the Phyllis F. Cantor Center at Dana-Farber Cancer Institute for their commitment to training early career investigators. Finally, I am grateful to the many professors and colleagues who, over the course of my career, instilled in me the belief that nursing scholarship is a means by which to advance social justice.

“It was in my heart to help a little, because I was helped much.”

Khalil Gibran
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I. Introduction
Ovarian cancer is the leading cause of death from gynecologic cancer and the fifth leading cause of cancer death among women living in the United States (American Cancer Society [ACS], 2018). In 2018, an estimated 22,240 American women will be diagnosed with ovarian cancer and more than 14,070 will die from it (ACS, 2018). Early-stage ovarian cancer produces vague symptoms, and no currently available screening test is adequately effective and reliable for use in asymptomatic women (U.S. Preventive Services Task Force, 2016). Consequently, 64% of women with ovarian cancer have stage III or IV disease at the time of diagnosis, for which the respective five-year relative survival rates are 39% and 17% (National Cancer Institute, 2014).

Treatment for ovarian cancer often involves complex pelvic and upper abdominal surgery along with several options for chemotherapy, some of which include significant morbidity and toxicity, with varying rates of success (National Comprehensive Cancer Network [NCCN], 2017; Weaver et al., 2018). In younger women, concerns about fertility preservation may further confound difficult treatment decisions (Peddie et al., 2012). Clinicians and researchers alike have sought to improve survival among women with ovarian cancer. Most notably, clinical practice guidelines for the treatment of ovarian cancer were first published by the National Comprehensive Cancer Network (NCCN) in 1996 and have since been updated annually (NCCN, 2017). Adherence to these guidelines has been validated as an indicator of quality care, with women who receive NCCN guideline-concordant treatment experiencing a 33% decrease in disease-specific mortality (Bristow, Chang, Ziogas, & Anton-Culver, 2013). Unfortunately, recent evidence suggests that only 40% of American women with ovarian cancer receive guideline-concordant treatment (Bristow, Chang, et al., 2013; Warren et al., 2017).
The reasons that so few women with ovarian cancer receive the standard of care are largely unknown. Retrospective analyses of cancer registry data have found that health system and provider factors such as low hospital volume, low physician volume, and treatment by a general surgeon rather than a gynecologic oncologist are negatively associated with the receipt of guideline-concordant care (Bristow, Chang, et al., 2013; Bristow, Chang, Ziogas, Randall, & Anton-Culver, 2014; Bristow, Powell, et al., 2013; Cliby et al., 2015; Hodeib et al., 2015; Long et al., 2015). And yet, a population-based study of 6,427 women with ovarian cancer demonstrated that even among women who are seen by a gynecologic oncologist, only 40% receive guideline-concordant treatment (Warren et al., 2017). In their discussion of these findings, the study authors inquired “are gynecologic oncologists not recommending guideline treatment and if so, why? Are women not accepting the treatment offered? What factors are influencing patient decision making?” (p. 491). Indeed, little research has sought to explore the process by which women with ovarian cancer proceed from pre-diagnosis to treatment or to identify individual or contextual factors that may be associated with the receipt of guideline-concordant care.

The purpose of this dissertation was to describe what is known about women’s experiences with ovarian cancer, with an emphasis on identifying factors that may influence decisions about treatment and describing the process by which women with ovarian cancer proceed along the continuum of care. In preparation for future research, the author examined the properties of a widely-used instrument, the Decisional Conflict Scale (O’Connor, 1995). Decisional conflict has been identified as an indicator of decision quality (Becerra-Perez, Menear, Turcotte, Labrecque, & Legare, 2016; Eastwood, Doering, Roper, & Hays, 2008; Gattellari & Ward, 2004; Katapodi, Munro, Pierce, & Williams, 2011); thus, description of the
properties of the Decisional Conflict Scale contributes to the field of decision science more generally and to the intended program of research that follows this dissertation in particular. The objectives of this dissertation are accomplished through the submission and expected publication of the following three manuscripts, which are presented in subsequent chapters of this dissertation.

**Manuscript One**

Manuscript One is a systematic review of potential determinants of the receipt of guideline-concordant care among women with ovarian cancer. The objective of this review was to (a) determine what is known about the individual and contextual factors that may influence whether a woman with ovarian cancer receives guideline-concordant care, and (b) identify patient-centered research priorities in ovarian cancer. The results of this review revealed that the process by which women proceed from pre-diagnosis to treatment is largely undescribed, thus providing a rationale for the study reported in Manuscript Three. Manuscript One was published in *Gynecologic Oncology* (Pozzar & Berry, 2017).

**Manuscript Two**

Manuscript Two is an analysis of the properties of the Decisional Conflict Scale (O’Connor, 1995), the significance of which is described above. Although initial psychometric evaluation of the scale using techniques associated with Classical Measurement Theory found the scale to be reliable and valid overall (Beery, Smith, Kudel, & Knilans, 2011; Katapodi et al., 2011; Knapp et al., 2009; Song & Sereika, 2006), psychometric testing of the support subscale has yielded inconsistent results (Beery et al., 2011; Katapodi et al., 2011; Linder et al., 2011). In addition, the psychometric properties of the low literacy version of the Decisional Conflict Scale have not been evaluated to the same extent as the original version of the scale. Therefore, the
purpose of this analysis was to examine properties of the original and low literacy Decisional Conflict Scales using Classical Measurement Theory and Item Response Theory. Data from two multi-site trials of men with prostate cancer were used to analyze the scales. Internal consistency was estimated with Cronbach’s alphas, while subscale correlations were evaluated with Pearson’s correlation coefficient. Item difficulty, item discrimination, and test information were evaluated using Graded Response Modeling. The likelihood ratio test guided model selection. This methods paper prepared the author for a program of research in decision science and informed future study of, and interventions with, women with ovarian cancer. This manuscript has been submitted to *BMC Medical Informatics and Decision Making*.

**Manuscript Three**

Manuscript Three describes an original study undertaken by the author. This study used a qualitative approach and grounded theory methods. Its purpose was to describe the process by which women with ovarian cancer proceed from pre-diagnosis to treatment. Given the restrictions of content and word count that are imposed by journal authorship guidelines, a detailed description of the philosophical assumptions underpinning this study and the rationale for its selected method are included below. This manuscript is intended for submission to *Gynecologic Oncology*.

**Philosophical assumptions.** This dissertation was conducted using grounded theory methods; therefore, no theoretical framework was identified *a priori*. Nevertheless, it is necessary to explicate the philosophical assumptions that underpinned the methodological approach to this dissertation. This dissertation employed a social constructivist interpretive framework with a postmodern feminist epistemology. Social constructivism was first proposed by the sociologists Peter Berger and Thomas Luckmann in their 1967 book *The Social*
Construction of Reality (Alvesson & Skoldberg, 2009), while postmodern feminism was influenced by Foucault’s writings during the 1970s on the relationship between shifts in power and individual reality (Hesse-Biber, 2013). The following is a brief explanation of the philosophical assumptions embedded within each of these interpretive frameworks.

**Ontological positions.** Ontological statements pertain to the nature of reality (Creswell, 2013). Berger and Luckmann (1967) proposed that reality is not something naturally given; rather, they proposed that reality is constructed through social processes and through the use of language. In its most extreme interpretation, this is to say that all of that which exists has been constructed by people through language and their interactions with the social world (Andrews, 2012). More moderate interpretations propose that what has previously been regarded as natural is instead socially constructed (Alvesson & Skoldberg, 2009). For the purposes of this dissertation, the social constructivist ontology proposed by Charmaz (2014) will be adopted, in which “social reality is multiple, processual, and constructed” (p. 13).

**Epistemological positions.** Epistemological statements pertain to the nature of knowledge (Creswell, 2013). Social constructivism is concerned with the way in which subjective experience becomes collective knowledge (Andrews, 2012). Berger and Luckmann (1967) were influenced by the phenomenologists, who called into question the empiricist view that knowledge is always the product of objective observation (Alvesson & Skoldberg, 2009). According to social constructivism, knowledge is constructed when individuals in a society create mental representations of each other’s actions (Andrews, 2012). Through repetition, these actions come to be perceived as routines, which have a shared meaning among members of a social group (Alvesson & Skoldberg, 2009; Andrews, 2012). The actors who engage in these routines fulfill socially constructed roles; in doing so, both society’s knowledge of the individual
and the individual’s knowledge of self are established (Alvesson & Skoldberg, 2009; Andrews, 2012). In a similar fashion, the repeated interactions of multiple actors in a set group of roles become habituated through the process of institutionalization (Alvesson & Skoldberg, 2009; Andrews, 2012). Over time, institutions come to be taken for granted and are understood in an objective way by future generations (Alvesson & Skoldberg, 2009; Andrews, 2012). If social constructivism is taken to its extreme, then all knowledge is viewed as a product of these processes, even knowledge about the natural world (Alvesson & Skoldberg, 2009).

The epistemological position of postmodern feminism is compatible with that of social constructivism. Feminist inquiry is characterized by theoretical traditions that privilege women’s issues, voices, and experiences (Hesse-Biber, 2013). Among these traditions is the epistemological assumption that “women can be knowers… [and that a woman’s] experience is a legitimate source of knowledge” (Wuest, 1995, p. 128). Postmodern feminist inquiry emphasizes the importance of context and seeks to highlight the variations of women’s lives (Frost & Elichaoff, 2013). It supports the social constructivist view that knowledge is constructed from subjective experience while acknowledging that women’s experiences may vary according to socially constructed characteristics such as race, class, location, and sexual orientation (Frost & Elichaoff, 2013).

**Relevance to the current study.** Until recently, decision making was viewed as a rational, analytic process (Broadstock & Michie, 2000). This perspective is closely aligned with a positivist interpretive framework, which emphasizes universality, cause and effect, and the existence of a solitary social reality (Creswell, 2013). This is perhaps not surprising given that positivism is the dominant interpretive framework of the health sciences (Risjord, 2010). The positivist view of the decision-making process lends itself to the development of interventions
that aim to impart knowledge without accounting for the individual and contextual factors that may affect decision making. Although intervention research has demonstrated that such interventions are ineffective at changing behavior (Gitlin & Czaja, 2015), a recent systematic review of interventions targeting lifestyle risk behaviors found that health education, advice, and lifestyle counseling were the most common components of these programs (King et al., 2015).

Many of these programs focus on the provision of information, which may affect cognitive outcomes such as knowledge. However, didactic or prescriptive interventions may neglect the importance of social, cultural, and affective determinants of health behavior (Gitlin & Czaja, 2015).

In the field of decision science, an emerging view is that the decision-making process is susceptible to the influence of unconscious emotions and past experiences (Jonassen, 2012). This view accounts for the important fact that individuals often make choices regarding their health that are not rational (Jonassen, 2012). A social constructivist interpretive framework has the potential to explore this phenomenon and to call attention to the nuanced ways in which individuals make decisions. It allows health scientists to explore the way in which individuals’ subjective experiences affect their perceived realities, which may in turn affect their decision making. Because a social constructivist interpretive framework asserts that subjective experience is a legitimate source of knowledge, research that employs this philosophical standpoint has the potential to generate knowledge based on individuals’ experiences making decisions, their views of the process, and the factors that they feel play an influential role in that process. This knowledge may serve to complement findings from studies that employ a more positivist approach to decision making research, thus enhancing understanding of decision making as a complex and multidimensional process.
For this dissertation, the value of a postmodern feminist epistemological position lay primarily in this framework’s emphasis on (a) the contribution that women’s subjective experiences can make to knowledge, and (b) the need to acknowledge the diversity of experiences that may exist among women with different backgrounds. Through this lens, the current lack of studies that prioritize women’s perspectives on ovarian cancer treatment is an impediment to the understanding not only of the phenomenon itself, but also of its outcomes. Moreover, this view acknowledges that women may have divergent experiences of making treatment decisions for ovarian cancer and advocates for the examination of these differences. When used in conjunction with a social constructivist interpretive framework, this approach to inquiry allows for the generation of knowledge that may inform development of tailored and individualized interventions to improve the process of making ovarian cancer treatment decisions.

Methods. The objective of this study was to better understand the process by which women with ovarian cancer proceed from diagnosis to treatment and to identify the decision points they may face along the way. Given the limited research on this topic, a qualitative approach was employed to better understand the experiences of women who have participated in this process. Specifically, this study used a cross-sectional descriptive study design and grounded theory method. Grounded theory is a systematic research method that focuses on a process that occurs over time (Creswell, 2013). It was developed by the sociologists Glaser and Strauss (1967), whose aim was to aid social scientists in the discovery of theory from data. In their view, theory that is grounded in data is both more enduring and readily applied to practice than theory that is logically deduced. In a grounded theory study, the researcher uses inductive reasoning to develop categories comprised of concepts that are uncovered during data analysis (Charmaz,
Concepts, categories, and their relationships with one another are refined in an iterative process until the researcher has developed a comprehensive explanation of the process under study. The product of a fully realized grounded theory study is a theory of a process or action that is “grounded” in the data and explains the process or action of interest (Corbin & Strauss, 2015; Creswell, 2013).

Grounded theory was a natural fit for studying the process by which women with ovarian cancer proceed from diagnosis to treatment. Consistent with the philosophical assumptions of social constructivism and postmodern feminism, grounded theory implicitly acknowledges the legitimacy of research participants’ subjective experiences and the potential for diversity therein. Moreover, extant models of patient decision making are of limited utility in the study of ovarian cancer treatment decision making because they assume the patient perceives (a) that there is a decision to be made, and (b) that the decision is hers to make. For instance, the Ottawa Decision Support Framework (O'Connor, 2006) is a well-known conceptual model that has been widely used in the development of patient decision aids (Stacey et al., 2017). According to this model, an individual’s knowledge, expectations, values, and support will predict the extent to which that individual makes a high-quality decision—one that is informed and based on his or her values. Normative models of decision making, on which a great deal of health-promoting interventions are based, depict decision making as a rational, analytic process driven by the evaluation of utility and risk (Jonassen, 2012). These portrayals are incongruent with the evidence described in the review of the literature described in Manuscript 1 (Pozzar & Berry, 2017), which suggests that the degree to which women with ovarian cancer play an active role in treatment decision making varies (Andersen et al., 2012; Jolicoeur, O’Connor, Hopkins, & Graham, 2009) and that some women with ovarian cancer perceive a lack of options in their treatment (Abhyankar,
Velikova, Summers, & Bekker, 2016; Elit et al., 2010; Jolicoeur et al., 2009; Ziebland, Evans, & McPherson, 2006). Likewise, no known theories have adequately described the process by which women with ovarian cancer proceed from diagnosis to treatment. Therefore, a theory that is grounded in the voices of women who have experienced these processes may shed light on the broader issues of ovarian cancer treatment selection, access to ovarian cancer treatment, barriers to standard treatment for ovarian cancer, and directions for future research.

The following three chapters of this dissertation will describe, in manuscript format, three contributions that the author has made to the field of decision science over the course of her doctoral program. Although these contributions are varied in approach and method, they are consistent with the assertion that decision making is complex and influenced by individual and contextual factors. In the final chapter of this dissertation, the author will synthesize the findings of these three manuscripts, summarize their implications for decision-making and patient-centered research in ovarian cancer, and propose the next steps in her intended program of research.
References


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II. Manuscript 1
Review Article

Patient-centered research priorities in ovarian cancer: A systematic review of potential determinants of guideline care

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HIGHLIGHTS
• Race and socioeconomic status are chief among factors associated with receipt of guideline care.
• Women with ovarian cancer prioritize survival and side effects when making treatment decisions.
• Perceived lack of knowledge and the response to diagnosis impede patient engagement in decisions.
• Solicitation of diverse perspectives on treatment decision making is a research priority.

ABSTRACT
Objective. To (a) determine what is known about the individual and contextual factors that may influence whether a woman with ovarian cancer receives guideline care, and (b) identify patient-centered research priorities in ovarian cancer.

Methods. A systematic review of the PubMed, MEDLINE, CINAHL Complete, and PsycInfo online databases. Eligible articles were published in English, described original research, and either (a) identified factors associated with the receipt of guideline care for ovarian cancer, or (b) described treatment decision making by women with ovarian cancer. Studies were excluded in which women with ovarian cancer did not comprise the entire sample of patient participants. Data were collected in accordance with Garrard’s Matrix Method. Study quality was evaluated using the QualSyst tool for evaluating primary research papers. Relevant study findings were imported into NVivo Pro 11 for qualitative synthesis.

Results. The search strategy yielded 502 unique citations, of which 78 full-text articles were reviewed. Thirty-three articles met the criteria for inclusion. Study quality was high overall. Factors associated with the receipt of guideline care included race and ethnicity, socioeconomic status, insurance type, age, comorbidity, disease stage, tumor characteristics, hospital volume, hospital type, physician volume, and geographic location. Influences on treatment decision making among women with ovarian cancer included the desire to prolong survival, the patient-provider relationship, perceived ability to participate in the treatment decision, values and preferences, information needs, side effects, cost of care, and past experiences with chemotherapy.

Conclusions. There is a need for further research that examines ovarian cancer treatment decision making from the perspective of the patient. Priority topics for future research may include the experiences of diverse women receiving treatment for ovarian cancer and the role of shared decision making with providers, referral networks, and practice patterns in the delivery of guideline care.

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1. Introduction

Ovarian cancer is the fifth leading cause of cancer death among women living in the United States, with an estimated 22,440 new cases and 14,080 deaths expected in 2017 [1]. Sixty-four percent of women with ovarian cancer have advanced disease at the time of diagnosis, which is associated with a five-year relative survival rate that ranges from 17% for stage IV disease to 39% for stage III disease [2]. Receipt of treatment consistent with National Comprehensive Cancer Network (NCCN) guidelines [3] is associated with a 33% reduction in disease-specific mortality, yet fewer than half of women with ovarian cancer receive guideline care [4].

The reasons that so few women with ovarian cancer receive guideline care are poorly understood. Over the last decade, analyses of cancer registry data have identified demographic, institutional, and provider characteristics associated with the receipt of guideline care, yet these findings have not been explored in the context of the process by which a woman with ovarian cancer comes to receive a given treatment. Likewise, studies of treatment decision making among women with ovarian cancer are limited [5] and have not specifically addressed the issue of receipt of guideline care.

The purpose of this systematic review was to integrate findings from studies of factors associated with the receipt of guideline care for ovarian cancer with findings from studies of treatment decision making among women with ovarian cancer. In doing so, we sought to provide a nuanced overview of the individual and contextual factors that may influence whether a woman with ovarian cancer receives guideline care. Knowledge of these factors is required to identify priorities for patient-centered research that aims to improve ovarian cancer treatment delivery and outcomes. In turn, the results of this research may help to ensure that the potential of established and novel treatments to improve ovarian cancer outcomes is fully realized.

2. Methods

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [6].

2.1. Data sources

In November 2016, the PubMed, MEDLINE (EBSCOhost), CINAHL Complete, and PsycInfo online databases were searched using the search terms provided in Table 1. Search results were limited to articles published in English in a peer-reviewed journal. The search was not limited to any date range and was updated in June 2017. Additional records were identified by reviewing the reference lists of two relevant literature reviews identified during the initial search [5,7].

2.2. Eligibility criteria

Eligible articles described original research and either (a) identified factors associated with the receipt of guideline care for ovarian cancer, or (b) described treatment decision making by women with ovarian cancer. Articles were excluded if they described studies in which women with ovarian cancer did not comprise the entire sample of patient participants.

2.3. Data collection and quality assessment

Characteristics of all studies selected for inclusion in this review were documented in a spreadsheet according to Garrard’s Matrix Method [8]. Study quality was evaluated using the QualSyst tool for evaluating primary research papers [9]. Studies that employed multiple methods were evaluated using the QualSyst tool for the method that led to the primary study outcome.

<table>
<thead>
<tr>
<th>Table 1: Database search terms and resultant number of records.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Database</td>
</tr>
<tr>
<td>MEDLINE (EBSCOhost)</td>
</tr>
<tr>
<td>CINAHL complete</td>
</tr>
<tr>
<td>PubMed</td>
</tr>
<tr>
<td>PsycInfo</td>
</tr>
<tr>
<td>MEDLINE (EBSCOhost)</td>
</tr>
<tr>
<td>CINAHL complete</td>
</tr>
<tr>
<td>PubMed</td>
</tr>
<tr>
<td>PsycInfo</td>
</tr>
</tbody>
</table>

* MeSH: Medical Subject Heading.
2.4. Synthesis of study findings

Study findings relevant to the purpose of this review were excerpted from each article and imported into NVivo 11 Pro [10] for qualitative synthesis. Excerpts were coded for themes, and findings related to each theme were compared within and between studies.

3. Results

3.1. Study selection

Thirty-three articles met the criteria for inclusion in this review. A flow diagram depicting the results of the above search strategy is provided in Fig. 1. An overview of each study, including details about its purpose, methods, and quality, is provided in Table 2.

3.2. Study characteristics

3.2.1. Quantitative studies

Twenty-one studies employed a quantitative research approach. Fifteen of these were retrospective analyses of preexisting datasets. One such study was conducted in Denmark [11] and the remainder were conducted in the United States. Two studies [12,13] used medical records as their data source, while the remaining 13 used cancer registry data. Six of these used a national cancer registry [11,14–18], six used the California Cancer Registry [4,19–23], and one used the Illinois State Cancer Registry [24]. Sample sizes in the 15 retrospective studies ranged from 48 to 96,802, with all but three studies [12,13,21] including more than 900 participants.

Six quantitative studies used a cross-sectional design. Of these, three were conducted in the United States [25–27], two were conducted in Canada [28,29], and one was conducted in the Republic of Korea [30]. In the quantitative studies that provided a breakdown of participants by racial and ethnic background, between 65 and 89.7% of participants were White, non-Hispanic women.

3.2.2. Qualitative studies

Nine studies employed a qualitative research approach. Eight of these collected data via semi-structured interviews [31–38], while one [39] conducted a single focus group interview. Four of the qualitative studies were conducted in Canada [32–34,36], two were conducted in Australia [35,37], one was conducted in the United Kingdom [38], and one was conducted in the United States [39]. Study authors used content analysis and thematic analysis, and sample sizes ranged from 12...
Table 2
Studies meeting criteria for inclusion.

<table>
<thead>
<tr>
<th>First author(s)</th>
<th>Year</th>
<th>Purpose</th>
<th>Approach</th>
<th>Study design</th>
<th>Data collection &amp; analysis</th>
<th>Participants</th>
<th>QualSyst rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andersen</td>
<td>2011</td>
<td>To better understand the long-term effects of involvement in ovarian cancer treatment decision making on women's health-related quality of life.</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Survey; multiple regression</td>
<td>219</td>
<td>1</td>
</tr>
<tr>
<td>Andersen</td>
<td>2012</td>
<td>To pilot a decision aid designed to assist asymptomatic women with a history of ovarian cancer and rising CA-125 levels in deciding when to start treatment.</td>
<td>Multimethod</td>
<td>Cross-sectional</td>
<td>Survey and semi-structured interviews; thematic and content analysis</td>
<td>20</td>
<td>0.94</td>
</tr>
<tr>
<td>Bristow</td>
<td>2015a</td>
<td>To determine the impact of care at comprehensive cancer centers in southern California on adherence to NCCN treatment guidelines and disease-specific survival.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry; multivariate logistic regression</td>
<td>9933</td>
<td>1</td>
</tr>
<tr>
<td>Bristow</td>
<td>2015b</td>
<td>To estimate whether race or ethnic and socioeconomic strata are independently associated with advanced-stage ovarian cancer-specific survival after adjusting for adherence to NCCN treatment guidelines.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>Linked SEER-Medicare database; multivariate logistic modeling of predictors of nonadherent care</td>
<td>10,296</td>
<td>1</td>
</tr>
<tr>
<td>Bristow</td>
<td>2014</td>
<td>To determine the impact of geographic location on advanced-stage ovarian cancer adherence to the NCCN guidelines in relation to race and socioeconomic status.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry; generalized additive models to assess the effect of spatial distributions of predictor variables on adherence to NCCN guidelines</td>
<td>11,770</td>
<td>1</td>
</tr>
<tr>
<td>Bristow, Chang</td>
<td>2013</td>
<td>To validate NCCN ovarian cancer guideline adherence as a quality process measure associated with improved survival, and to identify structural health care characteristics predictive of adherence to NCCN guidelines.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry; multivariate logistic regression for adherence</td>
<td>13,321</td>
<td>1</td>
</tr>
<tr>
<td>Bristow, Powell</td>
<td>2013</td>
<td>To examine disparities according to race and socioeconomic status indicators in the quality of epithelial ovarian cancer care and survival outcome.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>National Cancer Database; binomial logistic regression</td>
<td>47,160</td>
<td>1</td>
</tr>
<tr>
<td>Chan</td>
<td>2008</td>
<td>To identify the demographic, socioeconomic, and other clinico-pathologic factors that may be associated with the suboptimal treatment of early-stage ovarian cancer in women less than 55 years old.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry and physician questionnaires; chi-square, Kaplan-Meier, Cox proportional hazard methods</td>
<td>135</td>
<td>0.86</td>
</tr>
<tr>
<td>Cliby</td>
<td>2015</td>
<td>To determine the impact of institutional and process of care factors on overall survival and delivery of guideline-adherent care nationally.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>National Cancer Database; multivariable logistic regression</td>
<td>96,802</td>
<td>1</td>
</tr>
<tr>
<td>Donovan</td>
<td>2002</td>
<td>To assess women's preferences for treatment in the case of recurrent ovarian cancer and to identify factors associated with treatment preference.</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Questionnaires and a decision board; analysis of variance, logistic regression, multiple regression</td>
<td>156</td>
<td>1</td>
</tr>
<tr>
<td>Ekwall</td>
<td>2011</td>
<td>To explore what women with recurrent ovarian cancer perceived as important in their communication with the health care team.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; content analysis</td>
<td>12</td>
<td>0.95</td>
</tr>
<tr>
<td>Elit</td>
<td>2003</td>
<td>To identify in women with advanced epithelial ovarian cancer who had just undergone surgery the extent to which they (1) perceived that they had treatment options, (2) understood the treatment related risks and benefits, and (3) preferred to participate in the decision-making process.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; content analysis</td>
<td>21</td>
<td>0.9</td>
</tr>
<tr>
<td>Elit</td>
<td>2010</td>
<td>To explore the treatment decision-making experiences of women with recurrent ovarian cancer.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; thematic analysis</td>
<td>26</td>
<td>0.9</td>
</tr>
<tr>
<td>Erickson</td>
<td>2014</td>
<td>To report the rate of NCCN guideline-adherent treatment of ovarian cancer and determine the reasons why there were deviations from the guidelines.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>Single facility medical record review; chi-square, Fisher's exact test, and t-test to compare groups who did and did not receive guideline care</td>
<td>367</td>
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<tr>
<td>Feldman-Stewart</td>
<td>1996</td>
<td>To define and compare the professional and the reasonable-person standards for provision of information to ovarian cancer patients, and to determine if patient information priorities could be anticipated by surrogate patients.</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Questionnaire; Hartley's F test, Kendall's W</td>
<td>291</td>
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<td>Fitch</td>
<td>2003</td>
<td>To describe the experiences of women who have been diagnosed with ovarian cancer.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; unspecified thematic analysis</td>
<td>18</td>
<td>0.9</td>
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<tr>
<td>Frey</td>
<td>2014</td>
<td>To identify ovarian cancer treatment endpoints that are meaningful to patients and their physicians.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Focus group interview; thematic analysis and intra-case analysis</td>
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<th>First author(s)</th>
<th>Year</th>
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<th>Approach</th>
<th>Study design</th>
<th>Data collection &amp; analysis</th>
<th>Participants</th>
<th>QualSyst rating$^a$</th>
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<td>Gleeson</td>
<td>2013</td>
<td>To identify women’s information and communication preferences about treatment-focused genetic testing in the ovarian cancer context.</td>
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<td>Semi-structured interviews; thematic analysis</td>
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<td>Harrington</td>
<td>2009</td>
<td>To ascertain women’s preferences for treatment of rising CA-125 levels and to determine the impact of regular CA-125 surveillance on psychosocial well-being.</td>
<td>Multimethod</td>
<td>Cross-sectional</td>
<td>Survey and structured interviews; descriptive statistics, chi-square, Wilcoxon signed rank test, thematic analysis</td>
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<td>Havrilésky</td>
<td>2014</td>
<td>To elucidate relative preferences of women with ovarian cancer for symptoms, treatment-related side effects, and progression-free survival relative to choosing a treatment regimen.</td>
<td>Quantitative</td>
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<td>Survey and discrete choice experiment; descriptive statistics, paired t-tests, conjoint analysis</td>
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<td>Hodeib</td>
<td>2015</td>
<td>To investigate the impact of socioeconomic status and other demographic variables on adherence to the NCCN ovarian cancer treatment guidelines among patients with stage I/II disease.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry; chi-square, Fisher’s exact test, multinomial logistic regression</td>
<td>5445</td>
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<td>Howell</td>
<td>2003</td>
<td>To describe the perspectives of women living with ovarian cancer concerning their experiences with recurrence.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; nonspecific thematic analysis</td>
<td>18</td>
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<td>Jolicoeur</td>
<td>2009</td>
<td>To describe the decision-making needs of women with ovarian cancer deciding about treatment of recurrent disease.</td>
<td>Multimethod</td>
<td>Cross-sectional, pilot study</td>
<td>Survey and semi-structured interviews; descriptive statistics, content analysis</td>
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<td>Jørgensen</td>
<td>2012</td>
<td>To evaluate the significance of comorbidity and age on receiving cytoreductive surgery, standard combination chemotherapy, and adherence to chemotherapy treatment.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>The Danish Gynecological Cancer Database, The Danish Cancer Register, The Danish Causes of Death Register, The National Register of Persons, medical record review; logistic regression</td>
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<td>Joslin</td>
<td>2014</td>
<td>To assess the effect of neighborhood-level socioeconomic status and other demographic variables on adherence to the NCCN ovarian cancer treatment administration.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>Illinois State Cancer Registry; binomial and multinomial logistic regression</td>
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<td>Lee</td>
<td>2016</td>
<td>To explore and quantify patients’ preferences for adding bevacizumab based on the best available evidence.</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Discrete choice experiment; descriptive statistics, probit regression model, Mann-Whitney U tests</td>
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<tr>
<td>Long</td>
<td>2015</td>
<td>To investigate the impact of race, socioeconomic status, and health care system characteristics on receipt of specific components of NCCN guidelines for stage III/IV ovarian cancer.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>California Cancer Registry; chi-square, Fisher’s exact test, binomial logistic regression, multinomial logistic regression</td>
<td>11,865</td>
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<td>Meier</td>
<td>2012</td>
<td>To assess women’s attitudes and experiences toward treatment-focused genetic testing.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; thematic analysis</td>
<td>22</td>
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<td>Phippen</td>
<td>2013</td>
<td>To evaluate the optimal cytoreduction rate, NCCN treatment guideline compliance rate and outcomes for advanced stage epithelial ovarian cancer patients at a low-volume institution.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>Medical record review; t-test, Chi-square, Fisher’s exact test, Kaplan-Meier Survival curves</td>
<td>48</td>
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<tr>
<td>Stewart</td>
<td>2000</td>
<td>To investigate what information is most vital for women with ovarian cancer; their preferred role in decision making, and the influence of sociodemographic, disease-related, and psychological factors.</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Questionnaire; descriptive statistics, chi-square, Fisher’s exact test, Spearman rank correlation coefficients</td>
<td>105</td>
<td>0.9</td>
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<tr>
<td>Thrall</td>
<td>2011</td>
<td>To describe the receipt and sequencing of surgery and chemotherapy in the primary treatment of advanced ovarian cancer in the US Medicare population.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>Linked SEER-Medicare database; chi-square, multivariate logistic regression</td>
<td>8211</td>
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<td>Ulanday</td>
<td>2014</td>
<td>To investigate geographical and socioeconomic variations in performance of lymph node dissection for the evaluation of patients with early-stage epithelial ovarian cancer.</td>
<td>Quantitative</td>
<td>Retrospective</td>
<td>SEER 17 registry (excluding Alaska and rural Georgia regions); multiple logistic regression</td>
<td>5243</td>
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<td>Ziebland</td>
<td>2006</td>
<td>To explore descriptions of treatment decisions in the narratives of women with ovarian cancer.</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured interviews; thematic analysis</td>
<td>43</td>
<td>0.85</td>
</tr>
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</table>


To 43. Only one qualitative study reported the racial or ethnic composition of its sample; in the study conducted by Frey and colleagues [39], 86% of participants self-identified as Caucasian. Of the nine qualitative studies included as part of this review, only three studies [32,33,38] explicitly sought to examine the treatment decision-making process among women with ovarian cancer. However,
all nine studies reported findings that addressed aspects of this phenomenon.

3.2.3. Multimethod studies

Three studies employed multiple methods [25,40,41]. Two of these studies were conducted in Australia [40,42] and the third was conducted in Canada [41]. Each collected data using interviews and a cross-sectional survey. Qualitative data were analyzed using thematic and content analysis. Sample sizes in these three studies ranged from 13 to 21.

3.3. Synthesis of results

Factors associated with the receipt of guideline care included race and ethnicity, socioeconomic status, insurance type, age, comorbidity, disease stage, tumor characteristics, hospital volume, hospital type, physician volume, and geographic location. Influences on treatment decision making among women with ovarian cancer included the desire to prolong survival, the patient-provider relationship, perceived ability to participate in the treatment decision, values and preferences, information needs, side effects, cost of care, and past experiences with chemotherapy. Each of these themes are discussed in detail below.

3.3.1. Factors associated with receipt of guideline care

3.3.1.1. Race and ethnicity. Race and ethnicity were significantly associated with the receipt of guideline care in nine studies [14–19,22–24]. Each of these studies found racial and ethnic minority women to be less likely than white women to receive guideline care. Joslin and colleagues [24] found that compared to non-Hispanic white women, non-Hispanic black women were significantly less likely to receive debulking surgery, any surgery, multi-agent chemotherapy, or any chemotherapy. In the analysis conducted by Long and colleagues [23], a treatment regimen consisting only of chemotherapy was significantly more likely for black and Hispanic women than for white women. The relationship between race and receipt of guideline care was found to be non-significant in only one study included in this review [12].

3.3.1.2. Socioeconomic status. Seven study authors found higher socioeconomic status (SES) to be positively associated with receipt of guideline care [15,16,18–20,22,23]. In their study of 9933 women with epithelial ovarian cancer, Bristow and colleagues [20] found that compared to women in the lowest SES category, women in the highest and second highest SES categories were 46% and 23% more likely to receive guideline care, respectively. Similarly, Hodeib and colleagues [22] found that compared to women in the lowest SES category, women in the highest SES category were almost twice as likely to receive guideline care. Conversely, Joslin and colleagues [24] found that while affluence was significantly associated with the receipt of multi-agent chemotherapy or any chemotherapy, it was not associated with the receipt of debulking surgery or any surgery.

3.3.1.3. Insurance type. In three studies, patients who were privately insured were more likely to receive guideline care than those who were uninsured or insured by Medicare or Medicaid [12,15,22]. In one study [23], there was no significant relationship between insurance type and receipt of guideline care.

3.3.1.4. Age. Eleven studies found advancing age to be negatively associated with the receipt of guideline care [4,11,12,14–20,24]. Jørgensen and colleagues [11] found that compared to younger women, women over 70 years old experienced more chemotherapy dose reductions. The older women in this study were less likely to receive a standard chemotherapy regimen, more likely to receive chemotherapy only, less likely to be optimally debulked, and more likely to receive no treatment at all. Similarly, Thrall and colleagues [17] found that as age increased, the likelihood of completing therapy decreased. One deviation from this trend was reported by Phippen and colleagues [13], who observed that compared to participants who underwent suboptimal cytoreduction, participants who underwent optimal cytoreduction were significantly older.

3.3.1.5. Comorbidity. Three studies found a significant negative relationship between number of comorbidities and receipt of guideline care [11,14,16]. In another study, worsening comorbidity was significantly associated with a decreased likelihood of completing therapy and increased utilization of neoadjuvant chemotherapy [17]. The authors of these studies measured comorbidity using an index and did not specify comorbid conditions related to receipt of guideline care. In their exploration of reasons for non-delivery of guideline care in an NCCN Cancer Center, Erickson and colleagues [12] found that among 75 participants who did not receive guideline chemotherapy, the presence of comorbid conditions resulted in 12 participants being given single agent chemotherapy and 4 participants being given no chemotherapy. In this study, comorbid conditions also served as a barrier to the receipt of surgery among women who received neoadjuvant chemotherapy. Phippen and colleagues [13] similarly found that an unspecified number of participants who received neoadjuvant chemotherapy were not well enough to undergo surgery. Neither Erickson and colleagues [12] nor Phippen and colleagues [13] identified the comorbid conditions that precluded participants' receipt of guideline care.

3.3.1.6. Disease stage. Although the authors of seven studies identified significant relationships between disease stage and receipt of guideline care, the direction of these relationships varied by stage and study. Bristow, Chang, and colleagues [4] found that women with stage III or IV disease were more likely to receive guideline care than women with stage I or II disease. Conversely, Erickson and colleagues [12] reported that the stage distribution differed significantly between cohorts of guideline care recipients and non-recipients, with more guideline care recipients having stage I or II disease. The relationship between stage and receipt of guideline care was unclear in the single study that differentiated between substages; Bristow, Powell, and colleagues [15] found that compared to women with stage IA disease, women with stage IC, IB, IIC, IIIC, and IV were more likely to receive guideline care. Importantly, the authors of these studies accounted for stage- and grade-specific variations in NCCN guidelines when assessing for guideline care. In their study, Joslin and colleagues [24] sought to measure extent of treatment rather than strict guideline adherence. They found that compared to women diagnosed at stage III or IV, women diagnosed at stage I or II were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. Nevertheless, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. However, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. Nevertheless, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. Nevertheless, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. Nevertheless, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required. Nevertheless, the finding that women with early stage disease were more likely to receive any surgery but less likely to receive debulking surgery, any chemotherapy, or multi-agent chemotherapy. These outcome variables are of somewhat limited utility when examining the relationship between disease stage and guideline care; current NCCN guidelines do not mandate chemotherapy for stage IA or IB, grade 1 or 2 disease [3], and debulking surgery is not always required.

3.3.1.7. Tumor characteristics. Tumor histology was significantly associated with the receipt of guideline care in three studies. Bristow and colleagues [19] found that compared to women with serous tumors, women with endometrioid, mucinous, or not otherwise specified adenocarcinomas were less likely to receive guideline care. In another study, atypical histology was negatively associated with the receipt of guideline care [20]. Conversely, Erickson and colleagues [12] found that tumor histology was not different between participants who did and did not
receive guideline care. Tumor grade was significantly associated with the receipt of guideline care in six studies [4,15,18,19,21,24]. With few exceptions, participants with low and intermediate grade tumors were less likely to receive guideline care than those with high grade tumors.

3.3.1.8. Hospital volume. In six studies, treatment at a high volume hospital was significantly associated with the receipt of guideline care [4, 14–16,19,22]. However, this was not the case in every included study. In one study, women who were treated at a low volume hospital were less likely to undergo debulking surgery but more likely to receive multi-agent chemotherapy [23]. Likewise, Phippen and colleagues [13] reported that at their low volume military treatment center, 85.4% of patients treated for epithelial ovarian cancer, fallopian tube cancer, or primary peritoneal cancer between 2002 and 2010 received guideline care.

3.3.1.9. Hospital type. Hospital type was associated with the receipt of guideline care in a number of studies. Treatment at an NCI-designated Comprehensive Cancer Center [20] or a hospital with an American College of Surgeons-approved cancer program [4] was positively associated with the receipt of guideline care. When compared with treatment received at an academic or comprehensive community cancer center, treatment at a community cancer center was less likely to follow NCCN guidelines [14].

3.3.1.10. Physician volume. Treatment by a low volume physician was negatively associated with the receipt of guideline care in three studies. Specifically, treatment by a low volume physician was negatively associated with receipt of guideline care [4,22,23], any chemotherapy [22], guideline care overall [4], and any treatment [23].

3.3.1.11. Geographic location. Bristow and colleagues [19] found that proximity to a high volume hospital was significantly associated with the receipt of guideline care. Specifically, travel distance between 20 and 50 miles was positively associated with the receipt of guideline care, while travel distance over 50 miles was associated with deviation from NCCN guidelines. In contrast, Erickson and colleagues [12] did not find distance from an NCCN-designated Cancer Center to be a significant predictor of receipt of guideline care. Relatedly, in a comparison of surgical lymph node assessment across SEER regions, Ulanday and colleagues [18] determined that the likelihood of lymph node dissection varied significantly across several regions of the United States.

3.3.2. Influences on treatment decision making among women with ovarian cancer

3.3.2.1. Desire to prolong survival. Twelve studies [26–30,32,33,37–41] described the importance attributed to duration of survival by women making ovarian cancer treatment decisions. In Donovan and colleagues’ study [26] of treatment preferences among 156 women with recurrent ovarian cancer, 25% of participants indicated that they would never switch to palliative care, even when the duration of expected survival was less than one week. Similarly, Meiser and colleagues [37] found that survival and cancer treatment were reported as participants’ greatest priorities. Likewise, in a discrete choice experiment to determine treatment preferences among women with ovarian cancer, Havrilesky and colleagues [27] found that 76% of respondents assigned a “most important” ranking to the treatment attribute of progression-free survival. In Jolicoeur and colleagues’ study of women with recurrent ovarian cancer [41], participants valued survival over side effects, visit frequency, and route of chemotherapy administration.

3.3.2.2. The patient-provider relationship. Participants in multiple studies emphasized the importance of a trusting, supportive relationship with the health care provider. Participants reported that a good patient-provider relationship promoted understanding of treatment information [31,35], diagnosis of recurrence [32], coping with recurrence [42], and participation in treatment decision making [32]. Continuity of care was identified as being particularly important to achieving these goals. Participants viewed being treated by multiple health care providers as a barrier to developing a trusting relationship [31], a barrier to participating in treatment decision making [32], a reason for miscommunication about treatment preferences [39], and a reason for receipt of conflicting advice [38]. Fitch and colleagues [34] concluded that when women did not receive emotional support or education from their health care provider, they “felt carried along by a tide of events where their input was not integral to the treatment decision” (p. 10). The provider’s treatment recommendation played a key role in participants’ treatment decision making in several studies [32,34,37,38,40].

3.3.2.3. Perceived ability to participate in the treatment decision. Participants in five studies described wanting to be involved in the treatment decision-making process [25,29,31,33,42]. However, participants perceived that their ability to make treatment decisions was limited by their lack of knowledge [31,34,38] and being emotionally overwhelmed [32–34,37,38]. Participants in two studies [33,34] perceived that their need to urgently begin treatment precluded their ability to participate in the treatment decision-making process. Similarly, participants in two studies [32,38] perceived that they had no “real” treatment options if they wanted to survive.

3.3.2.4. Values and preferences. Although the participants in two studies [32,39] reported it was important to discuss goals, values, and preferences with providers, few had engaged in such a conversation. Anderson and colleagues [42] found that only one out of 20 study participants wanted her provider to make the treatment decision on her behalf without considering her needs and preferences.

3.3.2.5. Information needs. As indicated by the studies in which participants viewed lack of knowledge as a barrier to participation in treatment decision making, participants in three studies [29,31,42] wanted to be given more information about their disease and its treatment. Participants in the study reported by Anderson and colleagues [42] wanted to be given all information, good and bad. This is congruent with Feldman-Stewart and colleagues’ [28] finding that information related to life expectancy was ranked ‘most important’ by study participants. Conversely, participants in two studies [33,36] were reluctant to seek information relating to survival statistics, which they viewed as anxiety-provoking.

3.3.2.6. Side effects. Side effects of treatment played an important role in shaping women’s views of treatment options. For example, Havrilesky and colleagues [27] found that 79% of study participants would accept a reduction in progression-free survival to move from severe treatment side effects to mild treatment side effects. In a study of 22 ovarian cancer survivors, Frey and colleagues [39] found that participants were averse to experiencing side effects that would negatively impact their quality of life. Harrison and colleagues [40] found that among their sample of 21 women who had completed primary treatment for ovarian cancer, details about the adverse effects of treatment were ranked as most important for making a decision about second-line treatment. On a positive note, Ekwall and colleagues [31] found that treatment to minimize side effects made treatment bearable.

3.3.2.7. Cost of care. Feldman-Stewart and colleagues [28] found that cost of care was ranked as one of the least important concerns by the 83 women with ovarian cancer who participated in their study. However, cost of medical care was significantly associated with the decision to switch from salvage therapy to palliative care in Donovan and
colleagues’ [26] study. In a study of women’s preferences for adding bevacizumab, cost of the medication was more influential than length of progression-free survival or treatment duration [30].

3.3.2.8. Past experiences with chemotherapy. Past experiences with chemotherapy were found to be influential on participants’ treatment decisions, particularly in studies of women making treatment decisions for recurrent ovarian cancer. In the study conducted by Harrison and colleagues [40], participants described negative past experiences with chemotherapy and cited these experiences as a reason for wanting to avoid further chemotherapeutic or hormonal treatment. In fact, the women in this study were willing to trade years of life in exchange for remaining symptom-free. Likewise, Ziebland and colleagues [38] found that one participant’s negative past experience with Taxol influenced her decision to have single agent chemotherapy, while Donovan and colleagues [26] found that women who had difficulty with chemotherapy were significantly more likely to prefer palliative care upon disease recurrence. Most of the participants in Jolicoeur and colleagues’ study [41] described positive experiences with chemotherapy, which in turn reduced apprehension regarding chemotherapeutic and hormonal treatment of a recurrence.

4. Discussion

The results of this literature review indicate that there is a need for further research that examines ovarian cancer treatment delivery from the perspective of the patient. The majority of studies that explored women’s experiences making ovarian cancer treatment decisions were conducted prior to 2013, when Bristow, Chang and colleagues published the study [4] that validated adherence to NCCN treatment guidelines for ovarian cancer as an indicator of quality care. Since then, the emphasis in the literature has been on the identification of patient and provider demographic variables and logistic factors associated with the receipt of guideline care. As a result, factors such as age, race, ethnicity, socioeconomic status, and hospital volume have emerged as some of the most consistent predictors of receipt of guideline care. As the results of this review indicate, analyses of cancer registry data have provided valuable insight into who is most likely to receive guideline care and its accompanying survival benefit. What remains unknown is why: what happens before or during treatment that precludes some women from receiving the treatment that is supported by the best available evidence?

What little is known about women’s experiences making ovarian cancer treatment decisions comes primarily from studies that were not only conducted prior to the current emphasis on guideline care, but also conducted outside of the United States. Differences in health system payment structures between the United States and Canada, Australia, the United Kingdom, and the Republic of Korea may limit the transferability of the findings of these studies. Indeed, the results of this review suggest that American women who do not have private insurance are less likely to receive guideline care than their privately insured counterparts [12,15,22]. Similarly, findings regarding the influence of cost on women’s treatment decisions were different among samples of American, Canadian, and Korean women [26,28,30]. Moreover, although the quality of the studies that met the inclusion criteria for this review was high overall, the quantitative studies tended to receive higher QualSyst [9] scores than the qualitative studies. The principal reason for this discrepancy was that most of the qualitative studies lacked a statement of reflexivity, which is intended to enhance rigor by disclosing aspects of a researcher’s background that may bias his or her interpretation of qualitative data [43].

The findings of the studies included as part of this review reveal several priorities for patient-centered ovarian cancer research. Within the quantitative literature, the factor that was most consistently associated with the receipt of guideline care was race, which was often analyzed in combination with ethnicity. There is strong evidence that women with ovarian cancer who are black or Hispanic are less likely than women who are white and non-Hispanic to receive guideline care [14–19, 22–24]. Although several of the quantitative studies specifically sought to examine racial and ethnic disparities in patterns of ovarian cancer treatment [15,16,19,21–24], none of the qualitative or multimethod studies described the use of purposive sampling to solicit diverse perspectives on the experience of living with or making treatment decisions for ovarian cancer. A similar observation could be made regarding socioeconomic status, which was significantly associated with the receipt of guideline care in seven quantitative studies [15,16, 18–20,22,23] but the impact of which has yet to be explored in the context of treatment decision making. Given what is known regarding racial, ethnic, and socioeconomic disparities in ovarian cancer treatment and survival [15,16,23], there is a need for future research to emphasize the experiences of women of color and women of low socioeconomic status with ovarian cancer.

The results of this literature review suggest that women with ovarian cancer may prioritize survival when making treatment decisions [26–30,32,33,37–41]. However, the desire to avoid severe side effects of treatment was also a recurrent theme in the studies under review [26,27,31,39–41], one that superseded the desire to prolong survival in some cases [27]. In a recent study, Frey and colleagues [44] found that women with ovarian cancer are more accepting of treatment side effects when the goal of treatment is cure rather than stable disease. Similarly, several studies in this review [26,38,40,41] found that women’s past experiences receiving chemotherapy influenced their decisions later in treatment. Although further research on this topic is needed, these findings highlight the importance of managing side effects early in the course of treatment, when inadequately managed side effects could influence whether a woman completes a recommended chemotherapeutic regimen and the treatment decisions that she makes in the future.

This review suggests that while women with ovarian cancer desire involvement in the treatment decision-making process [25,29,31,33,42], they face several barriers to achieving it. Specifically, women in the included studies reported that lacking knowledge [31,34,38] and being emotionally overwhelmed [32–34,37,38] precluded them from engaging in the treatment decision. This is significant given Andersen and colleagues’ [25] finding that participation in treatment decision making is associated with improved quality of life among ovarian cancer survivors. According to the studies in this review, participation in decision making can be facilitated through a supportive patent-provider relationship and provider continuity [32,39]. However, the extent to which shared decision making influences the receipt of guideline care is unknown and represents a priority area for future inquiry.

Underlying explanations can be inferred for some of the determinants of receipt of guideline care that were identified as part of this review. For example, women with ovarian cancer who are older, have more comorbidities, or have more advanced disease may be less able to tolerate the treatment regimen recommended by NCCN guidelines. Furthermore, it should be noted that there is evidence that optimal cytoreductive surgery is associated with postoperative morbidity and mortality [45,46]. Although this issue is distinct from the association between comorbid conditions and receipt of guideline care, the extent to which comorbid conditions influence treatment decisions and predict outcomes across the cancer spectrum warrants further investigation. Likewise, trends in quality of care by hospital type, hospital volume, and provider volume indicate a need for health systems-level research, which may encompass the analysis of referral networks, practice patterns, and the perspectives of health care providers.

5. Conclusion

There is a gap in the literature regarding how women with ovarian cancer make treatment decisions, particularly as those decisions pertain to receipt of guideline care. Improved knowledge of the individual and
contextual factors that influence ovarian cancer treatment decision making may provide context for the low proportion of women with ovarian cancer who receive guideline care, in turn laying the groundwork for future studies and the development of interventions that facilitate informed decision making among women with ovarian cancer.

Conflict of interest statement
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References
III. Manuscript 2
Item Response Theory Analysis and Properties of Decisional Conflict Scales:

Findings from two Multi-Site Trials of Men with Localized Prostate Cancer

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ITEM RESPONSE ANALYSIS OF DECISIONAL CONFLICT SCALES

Abstract

**Background:** Decisional conflict is associated with decision quality and may affect decision outcomes. In the health sciences literature, the Decisional Conflict Scale is widely used to measure decisional conflict, yet limited research has described the psychometric properties of the Decisional Conflict Scale subscales and of the low literacy version of the scale. The purpose of this secondary data analysis was therefore to examine properties of the original (DCS-12) and low literacy (LL DCS-10) Decisional Conflict Scales using Classical Measurement Theory and Item Response Theory.

**Methods:** Data from two multi-site trials of men with prostate cancer were used to analyze the DCS-12, LL DCS-10, and an aggregated DCS-12 dataset in which five response options were aggregated into three. Internal consistency was estimated with Cronbach’s alphas. Subscale correlations were evaluated with Pearson’s correlation coefficient. Item difficulty, item discrimination, and test information were evaluated using Graded Response Modeling (GRM). The likelihood ratio test guided model selection.

**Results:** Cronbach’s alphas for the total scales and three of four subscales were ≥0.85. Alphas ranged from 0.34-0.57 for the support subscales. Subscale correlations ranged from 0.42-0.71 (P<0.001). Items on the DCS-12 exhibited the widest range of difficulty. Two items on the support subscale had low to moderate discrimination and contributed little information. Only the DCS-12 was informative across the full range of decisional conflict values.

**Conclusions:** Lack of precision in the support subscale raises concerns about subscale validity. The DCS-12 is most capable of discriminating between respondents with high and low decisional conflict. Evaluation of interventions to reduce decisional conflict must consider the above findings.
Keywords: cancer, conflict, decision making, oncology, prostate, psychometrics
Decisional conflict is defined as uncertainty about what action to take when a choice is associated with risk or uncertainty [1]. Since the 1990s, research has suggested decisional conflict plays a key role in determining decision quality and may affect decision outcomes. In the clinical context, high decisional conflict is associated with delayed decision making [2], increased regret [3], and decreased quality of life [4]. Individuals who experience high decisional conflict have been found to be more likely to blame their health care provider for negative outcomes associated with a decision [5]. Interventions that aim to improve decision quality often are evaluated based on their ability to reduce decisional conflict. For example, a 2017 Cochrane review of decision aids for people facing health treatment or screening decisions revealed that decisional conflict was an outcome measure in 63 of 105 included studies [6].

In oncology settings there are exemplar situations, notably localized prostate cancer and early stage breast cancer, that embody a high-stakes decision in the reality that no one medical therapeutic approach can be identified as the most efficacious. These preference-sensitive decisions are challenging and difficult for not only the diagnosed individual and family but also the clinician [7]. Given the influence of decisional conflict on decision quality and its role in the evaluation of interventions, there is a need to critically examine the ways in which decisional conflict is measured in the health sciences literature.

The purpose of this paper is to describe current conceptual and operational definitions of decisional conflict and provide an overview of what is known about the psychometric properties of instruments that measure decisional conflict. We provide new evidence regarding the psychometric properties of the original and low literacy versions of the Decisional Conflict Scale [8].

**Background**
Conceptual Definitions of Decisional Conflict

Decisional conflict was first described by psychologists Janis and Mann, who proposed the Conflict Theory Model of Decision Making [9]. The authors asserted that a cause of error in decision making is the individual’s desire to quickly alleviate the stress associated with making a difficult decision. In this context, decisional conflict refers to an individual’s desire to both accept and decline an option. Decisional conflict was established in the nursing lexicon in 1988, when the North American Nursing Diagnosis Association-International (NANDA-I) added decisional conflict to its taxonomy of nursing diagnoses. NANDA-I refined the construct and defined it as “uncertainty about [the] course of action to be taken when [a] choice among competing actions involves risk, loss, or challenge to values and beliefs” (p. 365) [10]. The defining characteristics of and factors related to decisional conflict according to NANDA-I are provided in Additional File 1.

In the mid-1990s, O’Connor expanded the conceptual definition of decisional conflict to include “a state of uncertainty about the course of action to take” (p. 25) [1]. O’Connor and colleagues later proposed a mid-range theory of health decision making known as the Ottawa Decision Support Framework (ODSF) [11]. The ODSF asserts that decisional conflict represents an unresolved need that adversely affects decision quality. The ODSF states that the modifiable factors that contribute to decisional conflict include lack of knowledge, unrealistic expectations of the likelihood of outcomes, unclear values, unclear perceptions of others’ opinions, social pressure to choose one option, lack of support from others, lack of decision-making skills, and lack of other resources [12]. Together, these modifiable factors comprise an operational definition of decisional conflict [1].

Operational Definitions of Decisional Conflict
The Decisional Conflict Scale (DCS) was first developed by O’Connor in 1995 [1] and is the only known instrument which measures decisional conflict in health and social sciences research. Three versions of the DCS have been developed for use in research, including the original statement format DCS [1], the question format DCS [8], and the low literacy question format DCS [8]. Of these, the original DCS and the low literacy DCS are the versions most widely cited in the literature; as such, the following discussion is limited to these two versions of the scale. Items and subscales of these versions as developed by O’Connor [8] are provided in Additional File 2.

**Original DCS.** The most widely used version of the DCS is a 16-item instrument comprised of five subscales: (1) informed, (2) values clarity, (3) support, (4) uncertainty, and (5) effective decision [1]. The four-item effective decision subscale is only administered to individuals who have made the decision in question. Each item on the scale is phrased as a statement, and respondents can choose from one of five response options: (1) strongly agree, (2) agree, (3) neither agree or disagree, (4) disagree, or (5) strongly disagree. Total scores range from 0 (no conflict) to 100 points (extreme conflict). Scores of 25 or lower are associated with follow-through on decisions, while scores that exceed 38 are associated with delay in decision making [13]. This scale is written at a grade eight reading level and may be difficult for individuals with low literacy levels to interpret and respond to [1, 8]. It has been validated in several languages [14-19] and used in a broad range of medical specialties [20].

**Low literacy DCS.** The low literacy version of the DCS is a 10-item instrument comprised of four subscales: (1) informed, (2) values clarity, (3) support, and (4) uncertainty. Each item is phrased as a question, and respondents can choose from one of three response options: (1) yes, (2) no, or (3) unsure. Total scores range from 0 (no decisional conflict) to 100.
points (extreme decisional conflict). This scale was developed for use with individuals with limited reading and response skills [8].

**Psychometric Properties of the Decisional Conflict Scales**

The original DCS has been established as a reliable and valid instrument appropriate for use in a variety of clinical specialties. Studies of internal consistency have reported Cronbach’s alphas ranging from good to excellent [2, 21-23]. Only one study, to our knowledge, investigated the psychometric properties of the low literacy version of the DCS; in this study, Cronbach’s alpha for the total scale was ≥0.83 [24]. Most efforts to establish construct validity have been successful [2, 22, 23]. These findings suggest that the decisional conflict scales, as a whole, reliably measure the construct of decisional conflict in a way that is congruent with its conceptual definitions [25].

Despite the strengths of the DCS, evidence in support of the reliability and validity of each of its subscales is less clear. Specifically, psychometric testing of the support subscale has yielded inconsistent results. Although the support subscale is theoretically comprised of factors that contribute to uncertainty, the support subscale was poorly correlated with the uncertainty subscale in two instances [21, 24]. Two investigative teams conducted factor analyses and found that items on the support subscale either loaded onto different factors or did not load at all [2, 24]. In the single study that examined the psychometric properties of the low literacy DCS, Cronbach’s alphas for the support subscale were low and ranged from 0.468 to 0.596 [24]. These findings raise the question of whether these items adequately measure support as it is defined conceptually.

The psychometric properties of the low literacy version of the DCS have not been evaluated to the same extent as those of the original version. Further psychometric evaluation of
the low literacy version of the DCS is necessary given its reduced number of items and response options. The remainder of this paper is therefore focused on our efforts to assess the properties of the original and low literacy DCS scales and subscales using a novel approach.

**Item Response Theory**

Prior evaluations of the decisional conflict scales have relied solely on classical measurement theory (CMT) to assess the scales’ psychometric properties. CMT focuses on the performance of a scale as a whole rather than on the performance of individual items [25]. It assumes that items within a test are sampled at random from a domain of relevant items. Reliability is seen as a characteristic of the test and of the variance of the latent trait (e.g. decisional conflict) it purports to measure. Items are treated as random replicates of each other and their characteristics, if examined at all, are expressed as correlations with the total test score or as factor loadings on the putative latent variable(s) of interest. Individual items are assumed to provide the same amount of information about the latent trait [26]. As the number of items on the scale increases, usually so does the scale’s measure of internal consistency [25].

Item response theory (IRT) is an alternative to CMT in that it examines the unique relationship of each individual item as well as the whole scale to the latent trait of interest. It permits the researcher to examine the ways in which the precision of an item or scale may differ for individuals possessing different amounts of the latent trait [26, 27]. Unlike CMT analyses, which are sample-dependent, the item parameter estimates derived from IRT are relatively more independent of the sample from which data are collected [28].

IRT encompasses an assortment of mathematical models for binary or categorical outcomes [26]. It mathematically models the relationship between the amount of latent trait possessed by the respondent and the way in which the respondent responds to items on a scale.
this way, IRT analyses determine the characteristics of items and estimate the level of ‘ability’ or ‘trait’ of respondents. This relationship is depicted by an item characteristic curve (ICC), which is a monotonic probability curve that describes the probability (y-axis) of endorsing the item (with dichotomous response categories) for a continuous level of latent trait (x-axis). In the case of items with polytomous response categories (such as a Likert scale), multiple category characteristic curves (CCCs) are used; each CCC depicts the probability of endorsing a single response category.

The three most popular unidimensional IRT models are the one-, two-, and three-parameter logistic models, so named because of the number of item parameters each incorporates. The three possible parameters are difficulty, discrimination, and guessing. For items with dichotomous response categories, difficulty is defined as the value of the latent trait needed for a respondent to have a 50% chance of endorsing the item. For items with polytomous response categories, difficulty is a range of values that is bounded by the first and last points at which the CCCs intersect [29]. In designing an instrument intended to differentiate between all levels of a latent trait, a researcher should try to have items with difficulties spread across the full range of the trait.

Discrimination is represented graphically by the slope of the ICC or the CCC. It describes how fast the probability of selecting a given response will change as the amount of latent trait approaches the item difficulty. In other words, an item with a high discrimination parameter can distinguish better between low and high levels of the latent trait. Very low discrimination values are between 0.01-0.34, low values are between 0.35-0.64, moderate values are between 0.65-1.34, high values are between 1.35-1.69, and very high values are equal to or greater than 1.70 [30].
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Susceptibility to guessing is the probability that an individual will select a “correct” response or endorsing an item by guessing [30]. Guessing is represented as a vertical shift of the ICC or CCC curves. The value of this parameter can range from 0-1, with values >0.35 deemed unacceptable. For many patient-reported outcome measures, including decisional conflict, susceptibility to guessing is not considered to be an applicable parameter and is typically not modeled [27].

IRT also provides a measure of the precision of an item in estimating the latent trait [30]. This measure is called information and is represented graphically by the item information function (IIF) and the test information function (TIF), which respectively convey the amount of information provided by each item and the measure as a whole. The Graded Response Model (GRM) [31] is one type of two-parameter categorical IRT models for scales with ordered response options (e.g. a Likert scale). It models all items in a scale allowing different difficulties for each item and different or equal discrimination parameters across items. A log-likelihood test is usually used to determine whether models with different discrimination parameters are necessary.

Methods

We conducted a secondary analysis of data from two multi-site trials that tested the Personal Patient Profile-Prostate (P3P), a tailored decision aid for men with localized prostate cancer (LPC). The details of these trials, herein referred to as P3P-I and P3P-II, have been reported elsewhere [32, 33]. Briefly, in P3P-I, baseline decisional conflict was measured using the original DCS among men with LPC who were candidates for at least two treatment options and who had not yet begun therapy. The study was approved by the Fred Hutchinson Cancer Research Center/University of Washington Cancer Consortium Review Board and the review
board at each site. In P3P-II, baseline decisional conflict was measured using the low literacy DCS among men with LPC who had had no more than one consultation visit, had not made a final care decision, and had not begun active surveillance or received any prostate cancer treatment. The study was approved by the Dana-Farber/Harvard Cancer Center institutional review board and the review board at each site.

In these analyses, data from P3P-I were used to analyze the properties of the original DCS. To most effectively compare the original DCS to the low literacy DCS, we excluded data pertaining to the “effective decision” subscale. This subscale is not administered to individuals who have not yet made a decision; herein, we refer to the original DCS that excludes this subscale as the DCS-12. Data from P3P-II were used to analyze the properties of the low literacy DCS, herein referred to as the LL DCS-10. In addition, we analyzed the properties of a hypothetical aggregate version of the DCS-12 in which the original five item response options were aggregated into three response options (strongly agree/agree, neither agree nor disagree, and disagree/strongly disagree). The aggregated version of the DCS-12 was conceptualized for the sole purpose of exploring the effect of reducing the number of response options from five to three, as has been done in LL DCS-10. The aggregate DCS-12 was derived from P3P-I data and scored as the LL DCS-10 is scored, with possible scores ranging 0-100. Cases with complete data on DCS were included in the analysis; no imputation was done for missing data. For all three scales, internal consistency was estimated for the total scale and four subscales by Cronbach’s alphas. Correlations among subscales were evaluated using Pearson’s correlation coefficient. Each of the three scales were modelled using the Graded Response Model (GRM) [31]. Two models were fitted: the constrained GRM, which assumes equal discrimination parameters across items; and the unconstrained GRM, which permits different discrimination
parameters across items. The likelihood ratio test was used for model selection. Category characteristic curves (CCC), item information functions (IIF), and test information functions (TIF) were plotted using the model selected for each scale.

**Results**

**P3P-I Trial**

Baseline and clinical characteristics of the 494 men who participated in P3P-I [32] are provided in Table 1. A total of 21 cases with missing data on any item were removed from the analysis, leaving 473 cases in the analysis.

**DCS-12.** Means and standard deviations for the DCS-12 total and subscale scores are provided in Table 2. Cronbach’s alphas for the DCS-12 total scale and three of four subscales were ≥ 0.85; for the support subscale, Cronbach’s alpha was 0.57 (Table 2). Correlations across 4 subscales ranged from 0.44-0.71 and were significant at the p<0.001 level.

The unconstrained GRM was selected (p<0.001) as a better fit. Item difficulty ranged from approximately -2 to 2 for most items. Two notable exceptions are the items support-1 and support-2, the difficulty of which ranged from approximately -1 to >4. The CCCs for the items on the support subscale are depicted in Figure 1. Item discrimination was high to very high for most items, with discrimination values ranging from 1.6 to 3.8. Exceptions included the items uncertainty-1, support-1, and support-2, which had moderate discrimination values of 1.19, 0.89, and 0.68, respectively. The IIFs (Figure 2) demonstrate that the least amount of information is provided by items support-2, support-1, and uncertainty-1, in ascending order. Items informed-2 and informed-3 provided the most information. As depicted by the TIF (Figure 2), the DCS-12 provides the most test information (range 13-20) across a wide range of latent trait values from -2 to 3 and provides at least some information for nearly the entire range of latent trait values.
The DCS-12 also demonstrates good estimation precision with high test information across a wide range of latent traits from -2 to 3.

**Aggregated DCS-12.** Means and standard deviations for the aggregated DCS-12 total and subscale scores are provided in Table 2. Cronbach’s alphas for the aggregated DCS-12 total scale and three of four subscales were ≥0.86; for the support subscale, Cronbach’s alpha was 0.40 (Table 2). Correlations across 4 subscales ranged from 0.42-0.62 and were significant at the p<0.001 level.

The unconstrained GRM was selected (p<0.001) as a better fit. Most item difficulties fell in the range of approximately -0.5 to 1.5. Again, the items support-1 and support-2 were exceptions, with difficulties ranging from approximately 2.8 to >4. The CCCs for the items on the support subscale are depicted in Figure 1. Item discrimination was high to very high for most items, with discrimination values ranging from 1.5 to 4.3. Discrimination was moderate for the items uncertainty-1 (1.3) and support-1 (0.68), while discrimination was low for the item support-2 (0.47). As is the case for the non-aggregated DCS-12, the IIFs (Figure 2) demonstrate that the least amount of information is provided by the items support-2 and support-1, while informed-2 and informed-3 provided the most information. The TIF (Figure 2) indicates that the aggregated DCS-12 provides the most test information (range 8-18) when latent trait values range from approximately -0.5 to 2 and provides little information for latent trait values below -1.

**P3P-II Trial**

Baseline and clinical characteristics of the 392 men who participated in P3P-II [33] are provided in Table 1. A total of 365 cases had complete DCS data and were used in the following analysis.
LL DCS-10. Means and standard deviations for the LL DCS-10 total and subscale scores are provided in Table 2. Cronbach’s alphas for the LL DCS-10 total scale and three of four subscales were ≥0.88; for the support subscale, Cronbach’s alpha was 0.34 (see Table 2). Correlations across 4 subscales ranged from 0.44-0.68 and were significant at the p<0.001 level.

The unconstrained GRM was selected (p<0.001) as a better fit. The difficulty of most items fell in the range of approximately -1 to 1. Again, the items support-1 and support-2 had anomalous difficulty parameters that ranged from -4.0 to -1.9 for support-1 and -7.4 to -5.5 for support-2. The CCCs for the items on the support subscale are depicted in Figure 1. Item discrimination was generally high to very high, with discrimination values ranging from 1.9 to 4.3 for most items. However, discrimination was low for the items support-1 (0.6) and support-2 (0.4). The IIFs (Figure 2) demonstrate that items support-2 and support-1 provided the least amount of information, while items informed-2 and informed-3 provided the most information. As depicted by the TIF (Figure 2), the LL DCS-10 provides the most test information (range 5-15) when latent trait values range from -1.5 to 1.5 but provides nearly little or no information for latent trait values outside of that range.

Category characteristic curves for items on all three scales are provided in Additional File 3.

Discussion

The results of our CMT-based analyses are consistent with prior research suggesting that while the decisional conflict scales as a whole are reliable, the support subscale may be less so. For each of the three scales that were assessed, the support subscale had markedly lower internal consistency than the other three subscales. This finding raises the question of whether the support subscale measures the same underlying construct as the other subscales. Alternatively,
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these low alphas may be related to a skewed distribution of support scores towards high decisional support [25].

The results of our IRT-based analyses provide a closer look at the properties of the support subscale. For all three scales, the items support-1 (which asks whether the respondent has “enough support from others to make a choice”) and support-2 (which asks whether the respondent is “choosing without pressure from others”) have difficulty parameters that are extreme relative to those of other items. In our analyses of the aggregated DCS-12 and the LL DCS-10, the response options “strongly agree/agree” (on the aggregated DCS-12) and “yes” (on the LL DCS-10) are the most likely response options across nearly the entire range of latent trait values, suggesting that even very conflicted respondents are likely to report that they have enough support to make a choice and are choosing without pressure from others (Figure 1). This finding is consistent with a skewed distribution towards high decisional support. For all three scales, these two items discriminate less between respondents with different amounts of decisional conflict than other items. The discrimination parameters for these items were lower on the aggregated DCS-12 and the LL DCS-10 than on the original DCS-12, yet even on the DCS-12, discrimination parameters for these items were substantially lower than for any other items on the scale. Considering these findings, it is perhaps not surprising that the IIFs for all three scales revealed that the items support-1 and support-2 contribute the least amount of information to the test (Figure 2). The IIF curves for each of these items are relatively flat, indicating that these two items provide relatively little information across the range of potential values of decisional conflict, raising questions about their utility for measuring the scales’ target construct.

The reason that support-1 and support-2 do not perform as well as the other items on the DCS is unclear. The inclusion of items on the DCS that address support and pressure is
theoretically sound. According to the ODSF, factors such as knowledge, expectations, values, and decisional conflict represent an individual’s perception of a decision, while factors such as norms, pressure, support, and decision role preference represent the perceptions of important others [34]. Conducting cognitive interviews that focus on the wording of these particular items may provide insight into respondents’ interpretations and responses.

Our IRT analyses suggest that, compared with the aggregated DCS-12 and the LL DCS-10, the original DCS-12 is most capable of discriminating between respondents with high and low amounts of decisional conflict. The items on the DCS-12 comprise a wider range of item difficulties than those on the aggregated DCS-12 or the LL DCS-10, indicating that the original DCS-12 is capable of discriminating between respondents across a wider range of potential decisional conflict values. Similarly, the TIFs (Figure 2) reveal that the DCS-12 provides more information (higher estimation precision) than the other scales across a wider range of latent trait values. These findings suggest that the tradeoff for a reduced number of response options may be a decline in scale precision, particularly for respondents with high and low decisional conflict. The extent to which the reduction in response options has affected the LL DCS-10’s readability is unclear and is worthy of further study.

The current study was limited by its use of data from two trials with similar, but not identical, samples. Comparison of the DCS-12 and LL DCS-10 in the same sample may provide additional insight.

Conclusions

The original DCS-12 can discriminate between respondents across a wide range of decisional conflict values. The results of this analysis may be used to guide instrument selection for the evaluation of interventions aimed at reducing decisional conflict. Further research is
needed to determine how best to improve the performance of the support subscale and how to meet the needs of low literacy populations without sacrificing precision.

**List of Abbreviations**

DCS: Decisional Conflict Scale  
DCS-12: The 12-item original Decisional Conflict Scale  
LL DCS-10: The 10-item low literacy Decisional Conflict Scale  
CMT: Classical measurement theory  
IRT: Item response theory  
GRM: Graded response modeling  
NANDA-I: North American Nursing Diagnosis Association - International  
ODSF: Ottawa Decision Support Framework  
ICC: Item characteristic curve  
CCC: Category characteristic curve  
IIF: Item information function  
TIF: Test information function  
P3P: Personal Patient Profile-Prostate  
LPC: Localized prostate cancer

**Declarations**

**Ethics Approval and Consent to Participate**

This study involved a secondary analysis of data collected during two multi-site trials, which were approved by the Fred Hutchinson Cancer Research Center/University of Washington Cancer Consortium Review Board and the Dana-Farber/Harvard Cancer Center Institutional Review Board, respectively.
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Consent for Publication

Not applicable.

Availability of Data and Material

The datasets generated and analysed during the current study are not publicly available due to institutional review board regulations, but are available from the corresponding author on reasonable request.

Competing Interests

The authors have no competing interests to declare.

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Authors’ Contributions

Ms. Pozzar drafted the manuscript; Drs. Berry and Hong revised it critically for intellectual content. All authors contributed to the conception and design of the study, aided in analysis or interpretation of data, and approved the final version of the manuscript.

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References


### Table 1. Baseline and clinical characteristics by study

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† An income threshold of 35,000 was used in P3P-I.
Table 2. Means, standard deviations (SD), and Cronbach’s alphas for total scales and subscales

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<td>52.3 (26.9)</td>
<td>52.7 (39.1)</td>
</tr>
<tr>
<td>Informed</td>
<td>38.2 (23.8)</td>
<td>31.4 (35.6)</td>
</tr>
<tr>
<td>Value Clarity</td>
<td>34.9 (21.2)</td>
<td>25.2 (31.4)</td>
</tr>
<tr>
<td>Support</td>
<td>29.8 (16.4)</td>
<td>21.6 (20.6)</td>
</tr>
</tbody>
</table>
Figure 1. Category characteristic curves for support subscale items on the DCS-12, aggregated DCS-12, and LL DCS-10.

Legend

- Probability (y-axis) represents the probability that a respondent will select a response option, given the respondent’s latent trait value (x-axis). In this analysis, decisional conflict is the latent trait being measured.
- For the DCS-12, response options are as follows: 0 (strongly agree), 1 (agree), 2 (neither agree nor disagree), 3 (disagree), 4 (strongly disagree)
For the aggregated DCS-12, response options are as follows: 0-1 (strongly agree/agree), 2 (neither agree nor disagree), 3-4 (disagree/strongly disagree)

For the LL DCS-10, response options are yes, no, and unsure.
Figure 2. Item information functions and test information functions for the DCS-12, aggregated DCS-12, and LL DCS-10.

Legend

- Information (y-axis) represents the precision with which a respondent’s latent trait value (x-axis) can be estimated. Higher information indicates greater precision. In this analysis, decisional conflict is the latent trait being measured.
**Additional File 1.** Decisional conflict defining characteristics and related factors

<table>
<thead>
<tr>
<th>Defining Characteristics</th>
<th>Related Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay in decision-making</td>
<td>Conflict with moral obligation</td>
</tr>
<tr>
<td>Distress while attempting a decision</td>
<td>Conflicting information sources</td>
</tr>
<tr>
<td>Physical signs of distress (e.g. increase in heart rate, restlessness)</td>
<td>Inexperience with decision-making</td>
</tr>
<tr>
<td>Physical sign of tension</td>
<td>Insufficient information</td>
</tr>
<tr>
<td>Questioning of moral principle while attempting a decision</td>
<td>Insufficient support system</td>
</tr>
<tr>
<td>Questioning of moral rule while attempting a decision</td>
<td>Interference in decision-making</td>
</tr>
<tr>
<td>Questioning of moral values while attempting a decision</td>
<td>Moral principle supports mutually inconsistent actions</td>
</tr>
<tr>
<td>Questioning of personal beliefs while attempting a decision</td>
<td>Moral rule supports mutually inconsistent actions</td>
</tr>
<tr>
<td>Questioning of personal values while attempting a decision</td>
<td>Moral value supports mutually inconsistent actions</td>
</tr>
<tr>
<td>Recognizes undesired consequences of actions being considered</td>
<td>Perceived threat to value system</td>
</tr>
<tr>
<td>Self-focused</td>
<td>Unclear personal beliefs</td>
</tr>
<tr>
<td>Uncertainty about choices</td>
<td>Unclear personal values</td>
</tr>
<tr>
<td>Vacillating among choices</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Adapted from NANDA International, 2014, p. 364 [1].

Additional File 2. Subscales and associated items on the DCS-12 and LL DCS-10

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item</th>
<th>DCS-12</th>
<th>LL DCS-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed</td>
<td>1</td>
<td>I know which options are available to me.</td>
<td>Do you know which options are available to you?</td>
</tr>
<tr>
<td>Informed</td>
<td>2</td>
<td>I know the benefits of each option.</td>
<td>Do you know the benefits of each option?</td>
</tr>
<tr>
<td>Informed</td>
<td>3</td>
<td>I know the risks and side effects of each option.</td>
<td>Do you know the risks and side effects of each option?</td>
</tr>
<tr>
<td>Values Clarity</td>
<td>1</td>
<td>I am clear about which benefits matter most to me.</td>
<td>Are you clear about which benefits matter most to you?</td>
</tr>
<tr>
<td>Values Clarity</td>
<td>2</td>
<td>I am clear about which risks and side effects matter most.</td>
<td>Are you clear about which risks and side effects matter most to you?</td>
</tr>
<tr>
<td>Values Clarity</td>
<td>3</td>
<td>I am clear about which is more important to me (the benefits or the risks and side effects).</td>
<td>N/A</td>
</tr>
<tr>
<td>Support</td>
<td>1</td>
<td>I have enough support from others to make a choice.</td>
<td>Do you have enough support from others to make a choice?</td>
</tr>
<tr>
<td>Support</td>
<td>2</td>
<td>I am choosing without pressure from others.</td>
<td>Are you choosing without pressure from others?</td>
</tr>
<tr>
<td>Support</td>
<td>3</td>
<td>I have enough advice to make a choice.</td>
<td>Do you have enough advice to make a choice?</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>1</td>
<td>I am clear about the best choice for me.</td>
<td>Are you clear about the best choice for you?</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>2</td>
<td>I feel sure about what to choose.</td>
<td>Do you feel sure about what to choose?</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>3</td>
<td>This decision is easy for me to make.</td>
<td>N/A</td>
</tr>
</tbody>
</table>

*Note.* Adapted from O’Connor, 2010 [1].

Additional File 3. Category characteristic curves for all subscales on the original DCS-12, aggregated DCS-12, and low literacy DCS-10.

Original DCS-12
ITEM RESPONSE ANALYSIS OF DECISIONAL CONFLICT SCALES

Aggregated DCS-12
Low Literacy DCS-10
IV. Manuscript 3
Preserving Oneself in the Face of Uncertainty:
A Grounded Theory Study of Women with Ovarian Cancer

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Abstract

**Objective:** To describe the process by which women with ovarian cancer proceed from pre-diagnosis to treatment.

**Methods:** Cross-sectional design using a qualitative approach. Participants were eligible if they
(a) were at least 18 years old; (b) had received a diagnosis of ovarian cancer; and (c) were able to
speak and understand English. Data were collected via individual unstructured interviews
conducted either in person or over the telephone. Purposive sampling and data analysis were
consistent with grounded theory methods as described by Strauss and Corbin.

**Results:** Eighteen participants completed the study. Interviews ranged in length from 40 to 90
minutes. Participants described a process of *preserving oneself in the face of uncertainty*.

Participants’ trajectories from diagnosis to treatment were influenced by the quality of patient-
provider communication, the extent of support received from significant others, and aspects of
self-concept. Across the continuum of cancer care, participants sought to preserve physical and
psychological health while also maintaining self-concept.

**Conclusions:** The findings of this study suggest that while women with ovarian cancer are
motivated to preserve physical health, support needs and threats to self-concept may also affect
decision making. Patient-centered care should be a priority in the ovarian cancer care setting, and
efforts to promote guideline-concordant treatment and adoption of novel therapies may benefit
from consideration of these findings.
1. Introduction

Ovarian cancer is the deadliest gynecologic malignancy and the fifth leading cause of cancer death among women living in the United States, with more than 22,240 cases and 14,070 deaths expected in 2018 [1]. Ovarian cancer has an overall five-year relative survival rate of 47%, and for the 60% of women who are diagnosed with distant-stage disease, the five-year relative survival rate drops to 29% [1]. While recent progress in the development of novel cancer therapies such as poly(ADP-ribose) polymerase (PARP) inhibitors and immunotherapy is promising [2, 3], recent research indicates that the majority of women with ovarian cancer still do not receive National Comprehensive Cancer Network (NCCN) guideline-concordant surgery and chemotherapy [4, 5]. Given that the receipt of NCCN guideline-concordant therapy is associated with improved survival [6], improved understanding of factors that may influence the quality of ovarian cancer treatment is essential both to improve treatment and outcomes in the present and to ensure maximal benefit from novel therapies in the future.

Prior research on the determinants of guideline-concordant treatment of ovarian cancer has focused largely on identifying relationships between sociodemographic or clinical factors and quality of care [7]. Several authors have highlighted the need to explore patient, provider, and caregiver perspectives on ovarian cancer treatment decision making [8, 9]. While several studies of women’s experiences living with ovarian cancer have been reported [7], the process by which women with ovarian cancer proceed from pre-diagnosis to treatment is largely undescribed. A recent pilot study by two of the current study’s authors (RP and DB) and their colleagues [9] suggested an understanding of this process may provide insight into the individual and contextual factors that may influence ovarian cancer treatment and outcomes. Therefore, the
The purpose of this study was to describe the basic social process by which women with ovarian cancer proceed from pre-diagnosis to treatment.

2. Methods

This study was approved by the institutional review boards at Northeastern University and Lahey Hospital and Medical Center. Participants were recruited from the Massachusetts chapter of a national ovarian cancer advocacy organization and from one gynecologic oncology practice at a community-based teaching hospital in northeastern Massachusetts. Potential participants were approached by the advocacy organization’s chapter manager or by the clinic’s gynecologic oncologist or nurse practitioner and were invited to speak with the principal investigator (RP) to learn more about the study. Participants were eligible if they (a) were at least 18 years old; (b) had received a diagnosis of ovarian cancer; and (c) were able to speak and understand English. Interested participants were screened for eligibility by the principal investigator and provided informed consent prior to data collection. Participants received a $25 gift card in remuneration for their time.

Data were collected via individual unstructured interviews conducted either in person or over the telephone. The interview guide was based on a protocol developed by authors RP and DB and their colleagues for a pilot study described in detail elsewhere [9]. Interviews began with the opening prompt “please tell me about your experience with ovarian cancer.” When necessary, participants were prompted to discuss the process of establishing cancer care and to describe how their treatment plan was decided. Participants were further prompted to discuss communication with providers, practical aspects of receiving treatment, symptoms and/or side effects of treatment, consideration of treatment efficacy, use complementary or alternative therapies, and family/spousal issues if they did not address these topics spontaneously.
Demographic information was collected using a questionnaire administered verbally by the principal investigator at the end of each interview. Interviews were audio recorded, manually processed to remove any potential identifiers, and professionally transcribed. Transcripts were loaded into NVivo Pro 11 [10] and verified against de-identified audio recordings by the principal investigator prior to analysis.

Consistent with grounded theory methods [11], data analysis began following the first interview and continued concurrently with recruitment throughout the duration of the study. This approach permitted the team to purposively recruit participants who were likely to provide novel insights into the phenomena of interest. During data analysis, selections of raw data representing the same underlying concept were assigned labels in a process known as open coding. Codes were then developed and refined in terms of their properties and dimensions using constant comparison, during which raw data within and between transcripts were compared to determine if data labeled with the same code were conceptually the same or different [11]. Codes were then grouped into categories and preliminary relationships between codes were identified. Each major category was diagrammed to identify its associated contextual factors and consequences. Finally, a core category to which all other categories were related was identified. Throughout data analysis, the principal investigator maintained a record of her thinking in analytic memos and diagrams. The co-investigator (DB) reviewed each step of analysis and was debriefed by the principal investigator a weekly basis. Credibility was enhanced through member checking, in which a brief lay summary of study findings was sent to participants with an invitation to provide feedback about the study’s conclusions to the research team.

3. Results

3.1 Participants and Approach to Purposive Sampling
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Nineteen participants agreed to participate in the study and provided informed consent; however, one participant voluntarily withdrew after a family member suggested she would be unable to accurately recall the details of her experience. Eighteen participants were interviewed in total. During the first phase of recruitment, six (33%) participants were recruited from the patient advocacy organization. Half of these participants were 49 years old or younger, and all had a college degree with an annual household income of $60,000 or more. Thus, during the second phase of recruitment, we sought to enroll participants whose characteristics differed in terms of age, education, and annual household income. During the second phase of recruitment, 12 (66%) participants were recruited from the gynecologic oncology practice. Participants recruited during this phase were older with a wider range of annual household incomes and educational backgrounds than participants recruited during the first phase. After analyzing two interviews with participants who were diagnosed with low risk granulosa cell tumors, we elected to exclude potential participants with this diagnosis from further recruitment to ensure adequate representation of participants diagnosed with high risk tumors. Collectively, participants ranged from 32 to 93 years old and received cancer care from five different treatment facilities across eastern Massachusetts and southern New Hampshire. Detailed participant characteristics are provided in Table 1.

3.2 Interviews

Interviews ranged in length from 40 to 90 minutes, with the average interview lasting approximately 60 minutes. Participants required little prompting to discuss the topics included in the interview guide.

3.3 Thematic Results
The core category identified during data analysis was preserving oneself in the face of uncertainty. Participants in this study encountered a great deal of uncertainty during their experiences with cancer, beginning with symptom onset or recognition of an abnormality and persisting into survivorship. For some participants, survival statistics and recurrence rates were a specter that led them to feel alternately grateful for their survival and fearful of the next round of testing. For other participants, uncertainty plagued treatment decisions and characterized interpretations of physical symptoms even in the absence of disease. Still other participants experienced uncertainty in relation to their social roles, wondering if they would be able to conceive a child, care for children or grandchildren, resume a career, nurture strained relationships, or celebrate a much-anticipated wedding anniversary. During member checking, participants indicated that this theme resonated with them.

“God, is this all there is? Do I just fade away now?” When my diagnosis wasn't clear and when I was going through chemo and I had to face that, it was like, “what do I do with my life?” (Participant 210)

For participants in this study, the uncertainty associated with a diagnosis of ovarian cancer represented a threat not only to one’s physical health, but also to one’s interpersonal relationships and self-concept. In the face of this threat, participants acted to preserve the self. These actions often had implications for participants’ decisions about treatment, selection of cancer care providers, and well-being during survivorship. Herein, we provide an overview of the contexts in which participants were prompted to act to preserve the self and the consequences of those actions. Exemplary quotes representing the process of preserving the self in each of the three major contexts are provided in Table 2. In addition, we provide examples of negative cases.
in which perceived threats to the self were mitigated by the favorable characteristics of the contexts in which they occurred.

3.3.1. Patient-Provider Communication

Communication with health care providers shaped participants’ experiences and decisions along the path from diagnosis to survivorship. Prior to diagnosis, participants engaged with providers primarily for evaluation of symptoms or incidental findings. Following diagnosis, participants relied on providers to convey information while also discussing treatment options and providing anticipatory guidance.

Participants frequently described their cancer care providers in terms of the extent to which they were compassionate and accessible. In addition, participants voiced appreciation for providers who validated their feelings and took their concerns seriously. In turn, communication that was perceived as indifferent, inaccessible, or dismissive often prompted participants to act to preserve their physical or emotional health.

Compassion. On the whole, participants perceived that their providers were compassionate. Communication with a compassionate provider inspired participants’ trust and confidence in the provider, which in turn alleviated some of the emotional burden associated with an uncertain outcome. The trust that grew out of a compassionate relationship often served as the basis for participants’ decisions about where to receive cancer care and from whom. Several participants who had an established relationship with a trusted provider described their reluctance to seek care elsewhere.

*I know my daughter did suggest, she says, “We could, you know, follow up and go to [cancer center] here in [town].” I said “no, I like [the physician] and I feel confident with her and I want to stay with her.”* (Participant 558)
Likewise, participants who characterized their providers as compassionate also perceived that providers were invested in their treatment outcomes. Subsequently, these participants felt confident following their providers’ treatment recommendations.

*I just listened to Dr. [medical oncologist]. Whatever she wanted to do to help me, I said, “Go for it.”* (Participant 614)

*I was fortunate in that all the people I mentioned I had full confidence in. I knew that they were going to try. Whatever it was, it was going to be their very best.*

( Participant 669)

Conversely, participants who experienced a pattern of unsatisfactory communication encounters with a health care provider typically described this experience in terms of the provider’s indifference or lack of compassion. This indifference was often interpreted as a threat to one’s physical or emotional well-being, prompting the participant to act to preserve the self. The specific actions taken by participants to remediate perceived threats to the self were varied. When providers were not perceived to be invested in participants or their care, participants described transferring care to a provider they perceived as more compassionate. Participants’ descriptions of this decision suggest that finding a more compassionate provider served the dual purpose of ensuring the provider would act in the participants’ best interest while also acknowledging the participant as a unique person rather than as “a number.” One participant whose emotional needs were not being met asked her provider directly to change her demeanor. In one case, when a participant’s desire for a compassionate provider was at odds with her need for a provider with a unique clinical skill set, she made a concession in the interest of her physical health.
“If you do nothing,” he says, “You’re not just going to go to sleep, you know.

This is an ugly death.” ...Which, after he said that, I could hardly hear anything he said. So we went home and thought about it, and I was really kind of appalled by how blunt he was. ...But I did get a chance to talk to one person he operated on. Four years later, [she] is still alive with no evidence of disease. ...I don’t really think he could be somebody I would warm up to, but I respect that his strengths are elsewhere. (Participant 175)

Accessibility. When providers were perceived as accessible, participants felt comfortable asking questions during and outside of clinic visits. The importance of provider accessibility is reflected in the finding that providers were instrumental in providing participants with information about disease characteristics, prognosis, treatment options, and test results. Participants viewed this information as an important component of their pursuit of physical health. Provider accessibility also affected participants’ emotional well-being. When information was timely and complete, participants felt confident in their providers and treatment plan, but when information was delayed or incomplete, participants felt anxious and wondered whether there was more that they or their providers could be doing to maintain or restore their physical health. In this context, participants acted to preserve the self by turning to a more accessible source of information: the Internet. Unfortunately, participants who used the Internet as an information source reported that much of the information they found there was frightening, confusing, or not applicable to their individual circumstance. Consequently, some participants avoided seeking information outside of patient-provider communication encounters. Although this approach protected participants from overwhelming or frightening information, it also
involved a concession in that it limited the extent to which participants perceived that they were informed and could engage in treatment decisions.

    *After I had the second surgery, Dr. [gynecologic oncologist] said, “We can do this, we can do that, or we can do this. I recommend this.” Well, you know, there’s really no choice, is there? I have no idea what I’m talking about.* (Participant 563)

**Validation.** Participants voiced appreciation for providers who took their concerns seriously across the continuum of cancer care. Prior to diagnosis, providers who validated participants’ concerns were perceived to be proactive in facilitating the diagnostic workup and subsequent referrals. Conversely, some participants described feeling dismissed by a provider prior to diagnosis and subsequently experiencing delays in care.

    *I discovered a lump in my groin. I went to my primary care physician...and my sister had died two years before, of ovarian cancer. My primary physician told me that I was overreacting, and that it was emotional. He thought that there was nothing serious there.* (Participant 349)

Several participants described a lengthy process of having to seek care from multiple providers to have their concerns addressed and, ultimately, to be diagnosed with ovarian cancer. Given that these participants necessarily sought care prior to diagnosis, the threat they perceived to their physical health was often quite vague at the time they sought care. Participants persisted in advocating for themselves when symptoms endured despite normal examination findings or when they perceived that their concerns were being dismissed.

    *During treatment, participants whose concerns were validated by their providers perceived not only that they were free to express their values and preferences during discussions*
about treatment and follow-up care, but that their providers would listen to them and act according to their wishes. In this context, participants were able to pursue improved physical health while also preserving their autonomy.

*I think intellectually, I knew that there were a lot of downsides to [chemotherapy].*  
*I was like “Oh God, I don’t want to make myself disabled to cure something that might not spread.” ...The oncologist was, she was very upfront, very optimistic, was like “You know, there are things we would stop it for.” I felt confident that she would listen to me and that if things happened, that we would stop.*  

*(Participant 210)*

**3.3.2. Support**

Participants described the importance of receiving both practical and emotional support throughout their experience with ovarian cancer. Participants received support from family, friends, neighbors, colleagues, health care providers, other cancer survivors, and clergy. Elements of practical support included assistance with transportation to and from medical appointments, assistance with dependent care, housekeeping, meal preparation, information gathering, and care coordination. Elements of emotional support included reassurance about one’s prognosis, managing anxiety, and speaking candidly about end-of-life concerns. Participants who received support that met their expectations alluded to the strength of their support network. In this way, the availability of adequate practical and emotional support served to affirm participants’ status as a member of a social group.

*And we had a whole group of friends through it all. I want to say if I invite them over tomorrow, we’d get 60 people here.*  

*(Participant 508)*
In contrast, participants who had unmet support needs found themselves reevaluating their interpersonal relationships and seeking out novel sources of support. For participants who were dependent on others for transportation to medical appointments, inadequate support posed a threat to physical health. Unmet emotional support needs were often described in the context of desiring contact with a fellow survivor.

*I think if I could recommend anything it would be to have...maybe a mentor or somebody who can help you with some of the situations you come up with, who has been through it recently. ...I think if there’s some connection with people with similar difficulties, that's really helpful.* (Participant 661)

Nevertheless, participants who attended support groups often perceived that other survivors were too dissimilar from themselves to meet their emotional support needs.

Participants found it difficult to identify with survivors of a different age or life stage, with a different diagnosis or prognosis, or with different goals of care. This finding is consistent with the proposition that adequate support is essential to preserve not only physical and emotional well-being, but also one’s notion of self. Participants acted to preserve the self by pursuing novel sources of support or, failing that, adjusting their expectations (Participant 674, see Table 2).

*You know, I was on my own. I'm still on my own, and took a while [to recover]. It was hard being all by yourself. I was all alone at home. But I just pushed myself and got used to being in my own surroundings.* (Participant 558)

### 3.3.3. Self-Concept

A diagnosis of ovarian cancer often posed significant challenges to participants’ self-concepts. Participants perceived threats to their social role and self-image. Several participants expressed reluctance to incorporate the diagnosis into their self-image.
It just feels like it was all dream, because you never think of yourself as being one of those patients dealing with-- you know? (Participant 674)

I sort of shy away from the idea of a disease presence as an identity. That I'm a survivor. It's just not who I kind of am. (Participant 210)

When participants perceived that their self-concept was threatened, they took steps to preserve it. In one example, a participant who described herself as a runner described her treatment decision in the context of her desire to maintain that aspect of her self-image (Participant 374, see Table 2). In another instance, a participant described her yoga practice in terms of its role in negating the assumption that an individual with cancer identifies as a warrior.

I feel like there's this metaphor with cancer in your body where everybody's supposed to be a warrior and fighting. And you're fighting it and you're killing it and I hate that metaphor. I don't want to be at war with my own body. I want to calm everything down. (Participant 175)

Being diagnosed with ovarian cancer often represented a challenge to participants’ social roles. Participants described the negative impact the diagnosis had on their career and the resultant financial ramifications. Participants also perceived that the diagnosis changed the way in which they were perceived by colleagues.

They were all wonderful [at work], but it's an awkward situation. It's like a situation you'd never think you'd find yourself in. Maternity leave is so different compared to now you're the sick person in the building. It's odd. You never expect to be that person taking the time off for all that. (Participant 587)

For participants who were mothers, a diagnosis of ovarian cancer challenged their role as a family caregiver. Several participants described taking steps to care for their families and to
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shelter them from the worst of their experiences with cancer, thus preserving their role as
caregiver despite the challenges associated with cancer and its treatment.

_I wanted to keep it cool for my kids, and I think by going back to work as soon as
I could, that kept my kids in a good frame [of mind]. “Mom's going back to work,
shes not sick anymore.” So that was good for them._ (Participant 640)

Participants who were not mothers, but who hoped to preserve fertility, faced a unique
challenge in that a diagnosis of ovarian cancer—even at an early stage—threatened their
aspirations for the future. Participants who faced this challenge made different choices: one
participant described undergoing a unilateral rather than bilateral oophorectomy, one described
undergoing a radical hysterectomy but initiating the adoption process, and one described electing
not to undergo chemotherapy when providers’ recommendations were ambiguous.

In some cases, participants experienced a challenge to their social role but could not take
steps to mitigate it. One participant, who had several comorbidities, described the impact of
treatment on her ability to function independently. This participant was newly dependent on a
family member for several activities of daily living and described adjusting to a new normal,
adopting a new self-concept to allow for preservation of the self (Participant 433; Table 2).

Finally, participants devoted considerable attention to the experience of losing one’s hair
during chemotherapy. Although many participants dismissed the experience as “not [being] a big
deal” or their concern with it as “vain,” participants described the importance of finding a wig
that fit well and appreciated programs dedicated to helping women with cancer manage
appearance-related treatment side effects. Although the fear of losing one’s hair did not affect
participants’ treatment decisions, these efforts reflect participants’ actions to preserve their self-
image, which is threatened by a diagnosis of ovarian cancer.
4. Discussion

The findings of this study suggest that women who are diagnosed with ovarian cancer engage in a process by which they seek to preserve the self in the face of uncertainty. Prior research [12-23] indicates most women with ovarian cancer strive to preserve or restore physical health through timely diagnosis and appropriate treatment; indeed, much of the ovarian cancer literature deals with these essential topics. Likewise, uncertainty in the context of an ovarian cancer diagnosis has been characterized previously [24, 25]. The current study adds to existing knowledge by illuminating several contexts in which women with ovarian cancer may act in ways that are incongruent with the objective of achieving survival, remission, or cure at any cost. Crucially, participants in this study made decisions that allowed them to preserve or restore not only physical health, but also psychological well-being and self-concept, including self-image and social role.

The way in which participants in this study experienced patient-provider communication influenced practical decisions about cancer care, physical health, and psychological well-being. These findings are consistent with the results of prior studies of women with ovarian cancer, which found that communication with a trusted health care provider played a role in provider selection [9], information sharing [13, 26, 27], coping with one’s diagnosis [28, 29], and engaging in one’s care [13, 30]. The finding that unsatisfactory communication encounters may have implications for treatment decision making adds to this literature and highlights the need for more in-depth explorations of patient-provider communication in the ovarian cancer care setting. Likewise, there is a need to develop and evaluate methods by which to support the information needs of women with ovarian cancer. Inadequate information has previously been identified as a barrier to participation in ovarian cancer treatment decisions [22, 26, 30], and the current study
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illustrates the challenges faced by women with ovarian cancer in the pursuit of information outside of the patient-provider relationship.

Participants in the current study emphasized the role of adequate support in preserving the self. Indeed, social ties serve to provide individuals with a sense of belonging, and the influence of support on physical and psychological well-being has been the subject of study for decades [31]. In the ovarian cancer literature, Keim-Malpass and colleagues [32] found that higher social support was significantly associated with fewer patient-reported physical and psychosocial problems over time, while Lutgendorf and colleagues [33] found an association between social attachment and survival. Recent literature has described dissatisfaction with formal support resources among women with ovarian cancer [34], and the current study provides a lens through which to understand the potential ramifications of unmet support needs in this population.

The findings of this study suggest that women with ovarian cancer act to manage several threats to self-concept, including threats to social role and self-image. These threats have been described previously in the broader cancer literature and in the ovarian cancer literature specifically, and may result from changes in physical appearance [29, 35], loss of fertility [29], changes in physical functioning [36], and changes in employment [37]. In a qualitative study of ovarian cancer survivors’ experiences with self-advocacy, Hagan and Donovan [38] touched upon the importance of identity and preserving the self in their major theme of “knowing who I am and keeping my psyche intact” (p. 144). Meanwhile, Norton and colleagues [36] found that greater physical impairment and greater change in body image were associated with lower perceived control over ovarian cancer, while lower perceived control was associated with greater psychological distress. Given the potential ramifications of threats to self-concept, it is
understandable that women in the current study who were unable to mitigate threats to social role or self-image worked to adjust to a new normal. Further research is needed to better understand how clinicians can assist women with ovarian cancer in managing these threats and in adjusting to a new normal, and whether such interventions have the potential to affect distress and other outcomes.

Overall, the process of preserving oneself in the face of uncertainty that is described by the participants in this study is notable for its parallels with the values described in models of patient-centered care. According to the Institute of Medicine (IOM) [39], patient-centered care is “respectful of and responsive to individual patient preferences, needs and values” (p. 3). Likewise, patient-centered communication is informative, empathetic, and considers the patient within his or her unique psychological and social context [40]. In its 2013 report entitled Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, the IOM [41] observed that patient-centered care “is at the core of a high-quality cancer care delivery system” (p. xv). In the cancer care setting, patient-centered communication in particular has been associated with improved adherence to recommended treatment and surveillance [42-44] and has been identified as a potential determinant of quality care [45]. The findings of the current study are congruent with this proposition and highlight the need for further research into the influence of patient-centered care on ovarian cancer treatment and outcomes.

The current study has several limitations. First, although participants were representative of several income and age groups, all but one of the participants were white and non-Hispanic. Second, this study was conducted with participants receiving cancer care in a region of the United States with a high concentration of gynecologic oncologists and academic medical centers. The perspectives of women from different racial and ethnic backgrounds may not be
represented by the conclusions of this study, and the experiences of women in rural settings or without access to specialty care may differ from those represented in this study. Given known racial, ethnic, socioeconomic, and geographic disparities in ovarian cancer treatment and outcomes [46-53], exploration of these themes in a larger, more diverse sample represents a priority for future research. Finally, the qualitative nature of this study dictates that its findings cannot be generalized to the broader population without additional research.

5. Conclusion

The findings of this study suggest that while women with ovarian cancer are motivated to preserve physical health, support needs and threats to self-concept may also affect decision making. Patient-centered care should be a priority in the ovarian cancer care setting, and efforts to promote guideline-concordant treatment and adoption of novel therapies may benefit from consideration of these findings.

Conflict of Interest Statement

Dr. Pozzar was supported by an American Cancer Society Doctoral Degree Scholarship in Cancer Nursing (grant number 130725-DSCN-17-080-01-SCN) and by the Jonas Philanthropies Nurse Scholars initiative during the conduct of the study. Dr. Berry has no financial interests to report.
References


Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>n (N=18)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to 49 years old</td>
<td>4</td>
<td>22%</td>
</tr>
<tr>
<td>50-59 years old</td>
<td>4</td>
<td>22%</td>
</tr>
<tr>
<td>60-69 years old</td>
<td>6</td>
<td>33%</td>
</tr>
<tr>
<td>70 or more years old</td>
<td>4</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduated high school</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>Graduated college</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>7</td>
<td>39%</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>Married or partnered</td>
<td>13</td>
<td>72%</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>17%</td>
</tr>
<tr>
<td><strong>Race and Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>17</td>
<td>94%</td>
</tr>
<tr>
<td>Asian, non-Hispanic</td>
<td>1</td>
<td>6%</td>
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<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full time for pay</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>Working part time for pay</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>On leave from full time work</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>Retired</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>Not working for pay</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Annual Household Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$20,000-39,999</td>
<td>3</td>
<td>17%</td>
</tr>
<tr>
<td>$40,000-59,999</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>$60,000-79,999</td>
<td>3</td>
<td>17%</td>
</tr>
<tr>
<td>$80,000-99,999</td>
<td>3</td>
<td>17%</td>
</tr>
<tr>
<td>$100,000/year or more</td>
<td>7</td>
<td>39%</td>
</tr>
<tr>
<td>Declined to answer</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Insurance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VA or Military</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>Medicare</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>State</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>Private</td>
<td>6</td>
<td>33%</td>
</tr>
<tr>
<td>Medicare and Private</td>
<td>7</td>
<td>39%</td>
</tr>
<tr>
<td>Medicare and State</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Disease Stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early (Stage I or II, no recurrence)</td>
<td>11</td>
<td>61%</td>
</tr>
<tr>
<td>Advanced (Stage III or IV, or recurrent disease)</td>
<td>7</td>
<td>39%</td>
</tr>
</tbody>
</table>
Table 2. Exemplary Quotes

<table>
<thead>
<tr>
<th>Context: Patient-Provider Communication</th>
<th>Exemplary Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Property</strong></td>
<td></td>
</tr>
<tr>
<td>Dismissive</td>
<td>That gynecologist, and it was so insulting, had all my records in front of him and said, &quot;oh, that spotting is nothing. You're not clotting or anything?&quot; I said, &quot;no.&quot; He said, &quot;well, you already had an ultrasound of the pelvic area. I really won't worry about this, but if it makes you feel better, I'll schedule the internal ultrasound.&quot;</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td></td>
</tr>
<tr>
<td>Acting to preserve physical health</td>
<td>I said, &quot;yes, please.&quot; I'm not going to spite myself.</td>
</tr>
<tr>
<td><strong>Consequence</strong></td>
<td></td>
</tr>
<tr>
<td>Preservation of the self</td>
<td>...To have been dismissed, really, because that's how I feel it was when I saw that first gynecologist, is very disconcerting. To think I lost four months because of that is very upsetting. (Participant 748)</td>
</tr>
<tr>
<td><strong>Property</strong></td>
<td></td>
</tr>
<tr>
<td>Indifferent</td>
<td>It began to feel there-- like, like an assembly line. Like, come in, number 1024, mark her off. This is what we’re doing-- and reminding me that I’m gonna die, just in case I didn’t catch it.</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td></td>
</tr>
<tr>
<td>Acting to preserve emotional health</td>
<td>So I thought, &quot;you know what, I can’t go back there.&quot; And I talked to my internist, and she said, &quot;well, they have all your records, and they're renowned.&quot; And I said, &quot;here’s the thing. It’s getting to the point where psychologically, they're damaging me. I just feel damaged.&quot;</td>
</tr>
<tr>
<td><strong>Consequence</strong></td>
<td></td>
</tr>
<tr>
<td>Preservation of the self</td>
<td>I said, &quot;and if I go to another hospital they may not be as well renowned, but maybe they will listen to me and maybe they’ll fight for me. Because they keep burying me every time I go. So I feel like no one is fighting for me. They’re just waiting for me to die.&quot; (Participant 563)</td>
</tr>
<tr>
<td><strong>Property</strong></td>
<td></td>
</tr>
<tr>
<td>Accessible</td>
<td>I got a call, and it was from [my PCP]. ...she said, “okay, there's definitely something wrong. It could definitely be ovarian cancer, and you're going to go see [gynecologist].” …And my husband saw the blood run out of my face. ...And she's very easy to talk to, so I didn't feel uncomfortable asking her about it.</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td></td>
</tr>
<tr>
<td>Acting to preserve emotional health</td>
<td>...I called her that Saturday because I was so sick over it that I couldn't get out of my own way.</td>
</tr>
<tr>
<td><strong>Consequence</strong></td>
<td></td>
</tr>
<tr>
<td>Preservation of the self</td>
<td>She managed to calm me down enough to say, “Okay, next steps are Dr. [gynecologist],” et cetera. (Participant 669)</td>
</tr>
</tbody>
</table>
### Preserving Oneself

<table>
<thead>
<tr>
<th>Context: Support</th>
<th>Exemplary Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Property</strong></td>
<td>I came back and my biggest challenge was dealing with feeling left alone after everything went just perfectly fine [during treatment]. And, because most of my friends, those group of friends that I reached out to, never really reached out to me in a way that ... &quot;So, how are you doing?&quot; You know? But I felt like that was the time that I needed the most help.</td>
</tr>
<tr>
<td><strong>Insufficient to meet expectations</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td>So I reached out to [the hospital]. But they didn't really have a support group for post-chemo patients. But they had started some sort of support group. So I was invited to participate. And I went there twice.</td>
</tr>
<tr>
<td><strong>Seeking additional support</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Consequence</strong></td>
<td>But I never heard back from them. I think it just fizzled away. ...I just decided to, I'm like &quot;You know what, I'm gonna just deal with this myself.&quot; ...I weeded out a lot of people. It wasn't easy, but I kind of needed to do that. (Participant 674)</td>
</tr>
<tr>
<td><strong>Preservation of the self</strong></td>
<td></td>
</tr>
</tbody>
</table>
## Preserving Oneself

<table>
<thead>
<tr>
<th>Context: Self-Concept</th>
<th>Exemplary Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Property</strong>&lt;br&gt;Threatened by challenge to identity</td>
<td>I feel like it was kind of different for me because I ran my first half marathon with the tumor inside me. I didn't really have any other symptoms. I didn't feel sick. ...I was 32, 33.</td>
</tr>
<tr>
<td><strong>Action</strong>&lt;br&gt;Striving to maintain normalcy</td>
<td>...I was just like, you know what... Because this type of cancer doesn't really even always react to chemo, I'm not going to do it [go through chemo]. I made that decision. ...I was like, “I’ve just been training for six months; I'm running this half marathon.”</td>
</tr>
<tr>
<td><strong>Consequence</strong>&lt;br&gt;Preservation of the self</td>
<td>...I didn't know how it [the chemo] would affect my body. I was excited to get back into running afterwards, so I didn't want to put that strain on it [my body]. (Participant 374)</td>
</tr>
<tr>
<td><strong>Property</strong>&lt;br&gt;Threatened by challenge to social role</td>
<td>She [my niece] does things for me, she takes me grocery shopping, and I hate it that I have to be dependent on people. I'm used to getting in the car and going. And I can't do that anymore. I can't drive because of the neuropathy, I don't dare. I'm not used to this, to have to depend on people, that's another hardship for me, you know?</td>
</tr>
<tr>
<td><strong>Action</strong>&lt;br&gt;Adjusting to a new normal</td>
<td>I try to do things for her. And I cook sometimes for her and give it to her so she doesn't have to cook when she gets home from work, and she can cook.</td>
</tr>
<tr>
<td><strong>Consequence</strong>&lt;br&gt;Preservation of the self</td>
<td>You know, my life has changed because of this. (Participant 433)</td>
</tr>
<tr>
<td><strong>Property</strong>&lt;br&gt;Threatened by challenge to self-image</td>
<td>They [providers at the hospital] told me, obviously, that with the chemotherapy I was getting I was going to lose my hair. And I said, “Okay.” And the only thing that they didn't have, and maybe they have it now, but at that time is they just said, “Here you go, here's a list, good luck finding a wig.” For me, for a woman, I think it's just like, [pained noise] “ughh!”</td>
</tr>
<tr>
<td><strong>Action</strong>&lt;br&gt;Striving to maintain normalcy</td>
<td>...[I went to a wig shop run by] an independent person someone had told me about. And it was a horrible experience, because...it was like I was going back to the 1950s. I just felt like, I was like, “Oh my God.” Anyway. I was in such panic that I did buy a wig from that woman.</td>
</tr>
<tr>
<td><strong>Consequence</strong>&lt;br&gt;Preservation of the self</td>
<td>And I walked out with it, and I was like, okay. And then I waited about a week, and I said, &quot;I'm just not comfortable with this.&quot; (Participant 669)</td>
</tr>
</tbody>
</table>
V. Summary and Conclusions
The preceding manuscripts described three scholarly investigations undertaken by the author during her doctoral program. Taken together, the results of these investigations make a unique contribution to the fields of decision science and patient-centered ovarian cancer research. Manuscript One systematically reviewed what is known about factors associated with the receipt of guideline-concordant treatment for ovarian cancer. Its conclusion highlighted the need for additional research exploring the individual and contextual factors associated with the receipt of guideline-concordant treatment for ovarian cancer. In turn, this conclusion served as the justification for the study described in Manuscript Three. Congruent with the social constructivist philosophical lens employed throughout the conduct of this research, Manuscript One illustrated the need for knowledge derived from subjective experience to explain and provide context for associations identified in the quantitative literature.

Manuscript Two critiqued a widely-used instrument using a novel approach to analysis, revealing that although the Decisional Conflict Scale (O'Connor, 1995) is reliable as a whole, its capacity to reliably measure perceived support is limited. In addition, the findings described in Manuscript Two suggest that the low literacy version of the scale provides less information than the original version and is of limited utility for individuals with high or low decisional conflict. Although the investigation described in Manuscript Two employed a quantitative approach to research, the scale that was evaluated using this approach is based on the Ottawa Decision Support Framework, which emphasizes the influence of personal factors on decision quality (O'Connor, 2006). The Decisional Conflict Scale measures several of these personal factors, including knowledge, values, and perceived support (O'Connor, 1995). Although these personal factors vary in conjunction with individuals’ subjective experiences and socially constructed identities, interventions that aim to affect these factors should be evaluated systematically with a
reliable and valid instrument. The results of Manuscript Two suggest a need for further refinement of the support subscale and of the low literacy version of the scale as a whole, an endeavor which is particularly important to the future evaluation of decision aids and other decision support interventions.

Based on the finding that study participants sought to preserve the self in the face of uncertainty, Manuscript Three proposed a process by which women with ovarian cancer proceed from diagnosis to treatment. The findings reported in Manuscript Three suggest women with ovarian cancer may perceive a process by which they negotiate with the health care system to meet a variety of needs. This process represents one possible mechanism by which individual and contextual factors may influence the type and location of treatment received by women with ovarian cancer, signifying the importance of patient-centered research and treatment in the ovarian cancer care setting. Interventions that aim to improve ovarian cancer outcomes—including those that aim to increase the proportion of women with ovarian cancer who receive guideline-concordant treatment—must consider the needs of women that may deter or prevent them from receiving the standard of care. Likewise, clinical practice guidelines and institutional policies ought to incorporate provisions to address impediments to quality care, including but not limited to those associated with suboptimal patient-provider communication, inadequate social support, and changes in social role and identity.

The findings described in Manuscript Three suggest several priorities for future research. First, there is still a need for research that describes the experiences of women with ovarian cancer from underrepresented racial, ethnic, and socioeconomic groups. Although the author sought to recruit women from both rural and predominantly Hispanic communities in Massachusetts and southern New Hampshire for the study described in Manuscript Three,
several barriers proved insurmountable. These barriers included limited financial resources for recruitment and translation as well as the low proportion of ovarian cancer cases diagnosed in racial and ethnic minority women living in Massachusetts (Massachusetts Cancer Registry, 2017). Replication of the current study in a region of the United States with a more racially and ethnically diverse population is warranted; likewise, exploration of the experiences of women with ovarian cancer who live in rural counties with limited access to specialty care is called for. The need for this work is especially pressing given that women with ovarian cancer who are Black, Hispanic, or socioeconomically disadvantaged are less likely to receive the standard of care than the population of women with ovarian cancer as a whole (Bristow, Chang, Ziogas, Anton-Culver, & Vieira, 2014; Bristow et al., 2013; Cliby et al., 2015; Hodeib et al., 2015; Joslin et al., 2014; Liu, Randall, Tewari, & Bristow, 2014; Long et al., 2015) and that there are persistent racial, ethnic, and socioeconomic disparities in ovarian cancer survival (Bristow et al., 2015; Bristow et al., 2013; Cliby et al., 2015; Long et al., 2015).

A second priority for future research is the examination of the relationship between patient-centered communication and ovarian cancer treatment quality and outcomes. Participants in the study described in Manuscript Three emphasized the importance of patient-provider communication that was validating, compassionate, and accessible. This finding is consistent with the Framework for Patient-Centered Communication in Cancer Care developed by Epstein and Street (2007), which asserts that patient-centered communication recognizes and validates the patient’s perspective, promotes understanding of the patient within his or her psychosocial context, fosters the patient’s understanding of the health problem and its treatment, and involves the patient in decision making to his or her desired extent. Indeed, patient-centeredness has been regarded as an essential component of high quality care for nearly two decades. In 2001, the
Institute of Medicine (IOM) report *Crossing the Quality Chasm* identified the need for health care to be patient-centered and take into consideration patients’ preferences, needs, and values (IOM, 2001). In the cancer care setting, patient-centered communication has been associated with improved outcomes, including improved adherence to recommended treatment and surveillance (Kahn, Schneider, Malin, Adams, & Epstein, 2007; Liu, Malin, Diamant, Thind, & Maly, 2013; Tan et al., 2012) and increased discussion of prognosis, treatment alternatives, and patient concerns (Eide, Quera, Graugaard, & Finset, 2004; Ishikawa et al., 2002; Shields et al., 2009; Sohl et al., 2015). Exploration of these relationships in the ovarian cancer care setting will shed light on potential interventions to improve patient-provider communication, which may in turn improve the quality of ovarian cancer care.

A final priority for research entails the development and evaluation of interventions to improve the experiences of women with ovarian cancer and approaches to ovarian cancer care delivery. These interventions may include decision support tools such as decision aids, which are known to improve patients’ knowledge of treatment options, increase patients’ involvement in decision making, and improve patient-provider communication (Stacey et al., 2017). Shared decision making is an element of patient-centered communication, and the IOM has argued that a high-quality cancer care delivery system should support all patients and families in making informed health care decisions (IOM, 2013). Although the relationship between shared decision making and receipt of guideline concordant treatment for ovarian cancer is unknown, receipt of guideline concordant treatment may be included as a dichotomous outcome in future intervention studies. A related intervention may include training in patient-centered communication for gynecologic oncologists, which has been found to effectively improve patient-provider communication in the cancer care setting (Epstein et al., 2017). Finally, interventions to increase
and improve access to support resources for women with ovarian cancer are necessary to provide comprehensive, patient-centered care.

In conclusion, the body of work represented by this dissertation denotes the importance of research that acknowledges the legitimacy of subjective experience. A body of research that is solely concerned with the identification of factors associated with the receipt of guideline-concordant treatment for ovarian cancer does little to explain why these associations occur. The study described in Manuscript Three represents an initial effort to describe the process that is perceived by women with ovarian cancer as they proceed from diagnosis to treatment. The theory that is grounded in the data collected over the course of this study provides context for the relationships identified in the quantitative literature. Additional research using both a quantitative and a qualitative approach is necessary to more fully understand how clinicians and researchers can improve outcomes among women with ovarian cancer. Nurses are particularly well-poised to conduct this work, given that the nursing metaparadigm is comprised of nursing, person, environment, and health (McEwen & Willis, 2006). The body of work represented in this dissertation illustrates the importance of each of these concepts to ovarian cancer care delivery, treatment quality, and outcomes. The author of this dissertation is therefore committed to a lifelong program of research that aims to improve the health of women with cancer by viewing these phenomena through nursing’s unique lens.
References


VOICE Randomized Clinical Trial. *JAMA Oncology*, 3(1), 92-100.


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