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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.

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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

^a MeSH: Medical Subject Heading.

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.

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

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