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

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BACKGROUND

The lifetime risk of developing ovarian cancer (OC) is less than 2%, but ovarian cancer ranks fifth in cancer deaths for women and is the most lethal of the gynecologic malignancies. Approximately 80% of women diagnosed with advanced OC will experience recurrence after first-line chemotherapy. Recurrent OC is treated as a chronic condition and few patients diagnosed with recurrence will ever be disease free again. With continued therapy, all patients become resistant to therapy and the duration of response diminishes with each treatment. Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or an FDA approved therapy. Because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values, knowledge about treatment options, and expectations for both treatment and quality of life play a major role in the decision.

PURPOSE AND AIMS

The purpose of this study was to describe the decision making process for both women diagnosed with recurrent OC and gynecologic oncology healthcare providers.

Specific Aims:

- Explore the experiences of women making decisions about treatment for recurrent OC
- Explore healthcare providers' experiences of clinical decision making for recurrent OC
- Triangulate the findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of OC recurrence

METHODS

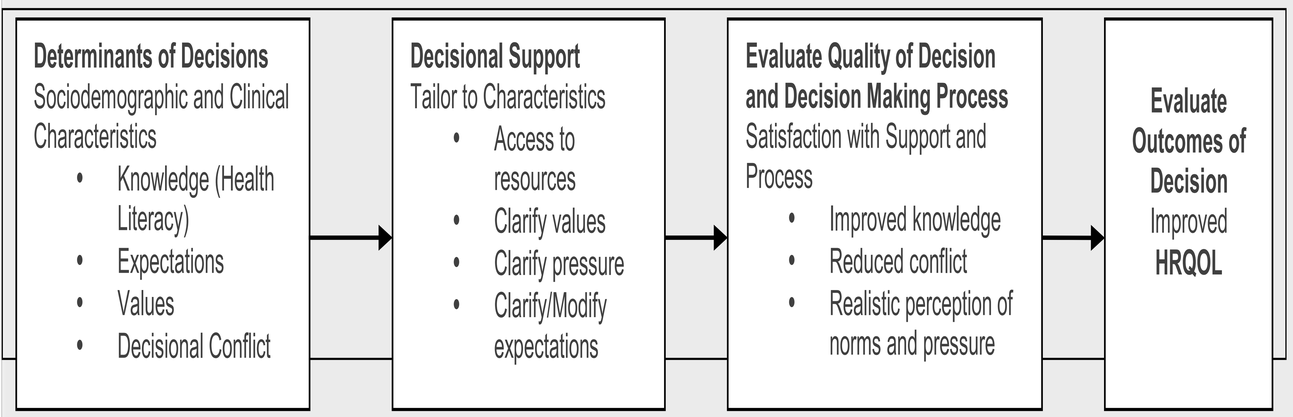
Descriptive qualitative study with thematic analysis of semi-structured interviews and field notes.

Participants: Women with a diagnosis of recurrent OC, and gynecologic oncology physicians and nurses.

Setting: Outpatient Cancer Center Clinic in an Academic Hospital

Analysis: Interviews and field notes were transcribed verbatim and imported into qualitative software to assist with data organization and analysis. The Decision Support Framework guided analysis of transcripts. Initial coding was descriptive, collating and organizing relevant codes will lead to emergent themes. Analysis is ongoing.

Figure 1. Decision Support Framework (O'Connor et al., 1998)



RESULTS

25 women diagnosed with ovarian cancer recurrence were interviewed, and were primarily Caucasian (84%), greater than age 50 at diagnosis (72%), advanced stage at diagnosis (80%) and had greater than 4 lines of therapy (60%). 8 physicians and 2 nurses were interviewed, with an average of 7 years experience working in gynecologic oncology.

MAJOR THEMES: PATIENTS

Patients verbalized a deep faith in God as a source of contentment and solace. God as the healer and guiding decisions was noted throughout, as well as God working through the physicians.

"And I just really feel like I have to have faith that God is holding me where I need to be and hopefully it' s here because I've got a lot to live for."

'Just keep fighting and looking up to God. First of all, look up to God and then he can do the work through the doctors and let your faith work.'

Experiencing life without the worry of cancer was a mechanism patients used to maintain a positive attitude, either through intentional avoidance or compartmentalization.

"You have to live your life as if you don't have it."

"I like my life so I had compartmentalized it. Here' s life, I'm living life. Here' s cancer over here, a little project that I have to work on and that' s the way I look at it. I just keep moving on."

MAJOR THEMES: PROVIDERS

Providers established goals of care with patients to determine options for treatment that balanced quality of life and quantity of life. Providers also temper information in order to preserve hope.

"I point blank ask patients what is most important for them, if it' s to have as much time with their family where their feeling the best or is it to have the most aggressive therapy possible, and I think you'd be, and I'm surprised by what people answer. I think we have preconceived notions about what people might want."

"And as long as they're not making decisions that are medically unsafe or bad for them then, you know, then sometimes it' s okay for them to stay hopeful even when there' s no hope."

CONCLUSIONS

Patients and providers experience a delicate tension between remaining positive and acknowledging the diagnosis of ovarian cancer recurrence. Patients verbalize living life as much as possible, while providers aim to maintain hope. Patients faith enabled acceptance of their diagnosis.

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