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Lived experiences of women with recurring ovarian cancer

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A B S T R A C T

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Outpatient chemotherapy

Background: Women with recurring ovarian cancer are living longer, due to advances in treatment options. They are now often outpatients, experiencing rapid encounters on treatment days. Whether this shift in care meets women's needs has been scarcely explored scientifically.

Purpose of the study: This study aimed to illuminate the phenomenon of living with recurring ovarian cancer as experienced by women in that condition.

Methods and sample: A descriptive phenomenological method was used. Eight open-ended interviews with four women were performed approximately three and five years after the first recurrence of ovarian cancer. During these years the women had repeated clinically and radiologically verified recurrence requiring chemotherapy.

Key results: The phenomenon of living with recurring ovarian cancer meant that the women felt forced to pay attention to the failing body in order to avoid a potential breakdown. The growing limitation of their intermittent strength meant that strength had to be captured and protected. Sharing their lives with others was difficult, due to the different living conditions. The women found no space to mediate their experiences, either in close relationships or with health care professionals. But, the circumstances they lived under also generated a gratitude for the unexpected *extra* time.

Conclusions: The findings revealed that the four women were grateful to live a while longer, but needed to share their state of being. The findings are indeed directed to health care professionals, who need to provide a more patient-centred care to meet the women's needs.

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Introduction

Ovarian cancer and its consequences for the women are described as not getting enough attention from the general population and the medical settings, as well as being inadequately studied by the research community (Power et al., 2008), although the diagnosis has a significant impact on women's lives throughout the disease trajectory (Howell et al., 2003). Women who suffer a recurrence of ovarian cancer are today able to continue treatment, due to the many advances in chemotherapy options and antiemetics (Jelovac and Armstrong, 2011). This implies that women live with the disease for longer than ever before (Herzog and Pothuri, 2006). Lockwood-Rayermann (2006) stated that the

former palliative care of patients with advanced ovarian cancer, who was expected to live a short time, has now been replaced by outpatient chemotherapy spanning years. This change is in accordance with experiences from clinical practice. The increased outpatient care and improved time of survival is a challenge for health care providers (Martin, 2002), and it is unclear whether this shift responds to the patients' needs. Prior studies regarding this issue found that the length of the treatment, and number of chemotherapy cycles, are significant factors when it comes to daily living (Tabano et al., 2002), because repeated cycles have a cumulative toxic effect (Almadrones, 2003) that burdens patients both temporarily and permanently (Sun et al., 2007). Women receiving aggressive cancer treatments are described as being at risk for developing psychiatric morbidity (McCorkle et al., 2003). However, there is still a gap in knowledge regarding how women describe their world when living with recurring ovarian cancer from a life-world perspective. There is a need to highlight this area. The aim

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of this study was to illuminate the phenomenon of living with recurring ovarian cancer as lived and experienced by women in that condition.

Method

A phenomenological approach was adopted throughout the whole study. Data were collected through interviews and analysed using a descriptive phenomenological method developed by Giorgi (Giorgi, 2009), which focuses on lived experience. With this method we aimed to illuminate the structure/essence of the phenomenon of living with recurring ovarian cancer over two years, starting approximately three years after the first recurrence.

Setting and selection of participants

The study was implemented via a gynaecologic oncology department at a university hospital in central Sweden. Twelve women with the first recurrence of ovarian cancer participated in two studies (Ekwall et al., 2007, 2011). Through the clinical registry of patients receiving care at the clinic, we found that six of these women were still alive three years after the first recurrence. We asked them if they wanted to continue to describe their experiences. Four women were willing to participate in the present study. These women were interviewed twice, three and five years after the first recurrence. They were given fictive names: Alice, Bea, Clara, and Doris. Alice was 61 years of age at the time of the first interview, Bea 66 years, Clara 46 years, and Doris 69 years. For Alice, eight years had passed since her first diagnosis of ovarian cancer stage 1C. Bea had her cancer diagnosis (stage IIIC) 10 years prior to the first interview; Clara was diagnosed (stage IIC), 9 years before the first interview; and Doris was diagnosed (stage IIIC), 6 years prior to the first interview. Alice, Clara, and Doris were married; Bea was a widow at the first interview, but remarried between the two interviews. All had grown-up children.

During the years of data collection the women had repeated clinically and radiologically verified recurrences and were treated with various chemotherapy regimens as outpatients and spent a few days as inpatients for evaluation of treatment and for symptoms and side effects that required medical resources. Fig. 1

Ethical considerations

Information about the study was sent to the women before each interview. In about one week's time the women were contacted by

telephone and asked if they wanted to participate. A research nurse unknown to the women handled the request for participation.

They were informed that they were free to decline without having to explain why. Confidentiality was guaranteed before each interview, and all documents regarding the women's identities were kept in a locked cabinet.

Respect for the women's integrity, autonomy, and privacy constituted the foundation of the interviews. This meant that the interviewer (EE) strived to be sensitive to what the woman did and did not want to tell. The interviewer did not intrude, if the woman showed signs that could be interpreted as resistance.

The health care region's research ethics committee approved the present study.

Data collection procedure

Through the two open-ended interviews with each woman, the interviewer wanted to gain insight into the women's descriptions of the phenomenon of living with recurring ovarian cancer. The interviews were audio-recorded, occurred in the women's homes, and lasted for one to two hours. Initially, the interviewer asked the women to narrate their experiences of living with recurring ovarian cancer, and encouraged the women to speak freely. Sometimes, probing for further information was required for depth and clarity and to elicit richness of details. Where necessary, the interviewer asked the women to reiterate parts of their stories to clarify ambiguities. When there was a period of silence, the interviewer waited for the interviewee to go on, being attentive, present, and flexible as to what the woman expressed.

Data analysis

Eight interviews with the four women, transcribed verbatim, formed the structure of the phenomenon under study. The analysis aimed to highlight the meaning of living with recurring ovarian cancer, taking care to render the women's narratives without adding anything (based on previous knowledge), or omitting anything they said (Giorgi, 2009, p. 128).

The analysis was carried out by the authors, separately and together. In the following steps we

1. listened to and read the eight interviews. Results from this step yielded an overall sense of the "whole";
2. divided the text, being sensitive to the phenomenon under study, into cohesive meaning units to make the description manageable—taking care to maintain a caring perspective;

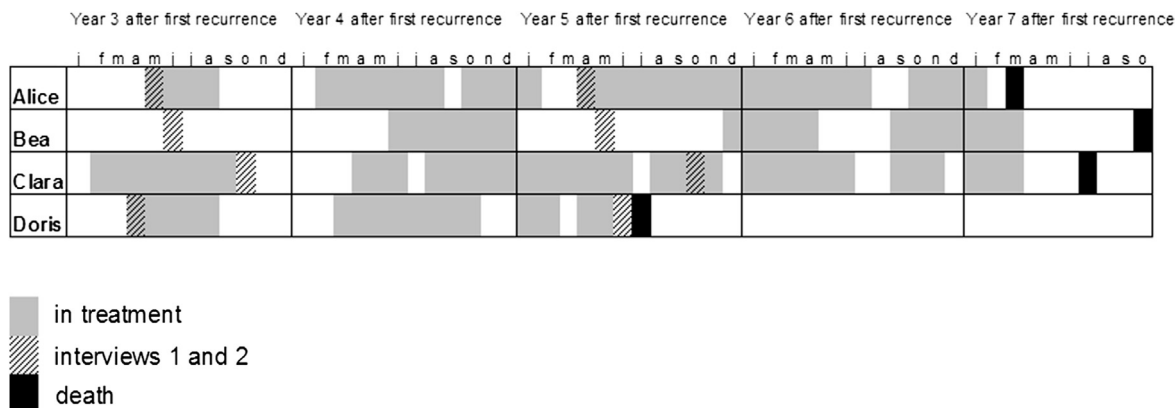


Fig. 1. Demographics, treatment duration and time of data collection.

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