

Living With Ovarian Cancer: Transitions Lost in Translation

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Background: Living with ovarian cancer involves uncertainty, fear of recurrence, and premature death while preparing for a life after treatment. The women depend on health care professionals while moving from being healthy to experiencing ovarian cancer.

Objective: To explore experiences of women living with ovarian cancer and their interactions with health care professionals.

Methods: Five focus group interviews were conducted with the same 4 women, between 2018 and 2020. The interviews were analyzed using systematic text condensation.

Results: Living with ovarian cancer involved a set of transitions from health to illness and disease. These transitions were difficult for the women to articulate to health care professionals, friends and family, and to themselves. All participants expressed the experiencing of existential and emotional chaos and paradoxes. As their illness developed, it impacted their ability to articulate changes to their body and sense of self and to their own identity negatively. Consequently, the women felt that their ability to communicate their needs to others, including to health care professionals, deteriorated as the disease progressed.

Conclusions: Women living with ovarian cancer experience transitions lost in translation within themselves and in communication with persons in their personal, familial, and medical realms.

Implications for Practice: A better understanding of their existential suffering and how it is easily lost in translation may refine care and support for these women throughout their illness and disease trajectory.

Foundational: Communicating and understanding illness and disease in ovarian cancer is essential to provide personalized care and support to ovarian cancer patients.

Keywords: Communication, Disease, Focus group, Health personnel, Ovarian neoplasms, Qualitative research

Introduction

Ovarian cancer is the leading cause of death from gynecological malignancies and the eighth-leading cause of cancer deaths among women worldwide.¹ The disease is heterogenous, with several different histological subtypes, and the cancer is often diagnosed at advanced stages after it has metastasized outside the ovaries. The understanding of ovarian cancer pathogenesis is growing, and molecular and phenotypic profiling are being integrated into clinical trials and wider practice, but the survival rate

remains poor for women diagnosed at an advanced disease stage. Ovarian cancer is incurable in 75% of this group of patients.²

Most patients with newly diagnosed ovarian cancer receive the same standard treatment, comprising cytoreductive surgery combined with platinum-based chemotherapy. At recurrence, patients still receive multiple therapies (primarily chemotherapy and/or targeted drugs), but the focus shifts from curative to palliative care. The median overall survival rate for women with advanced ovarian cancer (stages III and IV) is 4.5 years.³ During this period, surgery and chemotherapy, in addition to the disease's trajectory, will cause major physical, psychological, and social complications and obstacles for those living with the disease.⁴

Background

The concept of “living with cancer” entails the adversities encountered upon realizing the cancer diagnosis, readjusting one's life and eventually reconciling with cancer.⁵ Women living with advanced ovarian cancer describe a trajectory that involves navigation between uncertainty, loss of social relationships, fear of recurrence and premature death at the same time as preparing for a life beyond the cancer treatment.⁶ The women are at the mercy of themselves, their own consciousness,⁷ and their inner resources to sustain hope, strength, and a desire to face life,⁸ as well as their ability to articulate their experience.⁹ Interestingly, women diagnosed with advanced ovarian cancer encounter multiple transitions simultaneously as they move from being healthy to experiencing illness and disease.¹⁰ The sufferings lead to loss of capacity and distress, anxiety, depression and sustained trauma. Consequently, patients will isolate themselves and their fear and feeling of losing the future and the perception of life as one envisioned it to be will be reinforced.^{9,11,12}

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Extant research directed toward improving health care predominantly has focused on ovarian cancer as a disease, that is, its biological determinants and attributes.^{13,14} However, the experience of living with ovarian cancer and being subjected to its specific forms of illness poses several specific challenges to be managed.¹³ Over the years, extant studies have examined the interaction between ovarian cancer patients and health care personnel, focusing on treatment decisions, patient-centered care, and patient-centered communication.^{15,16} Although health care today is viewed as both participatory and patient-centered, discussions between patients and health care professionals on prognoses and treatment goals appear to be scarce within the ovarian cancer care setting.^{17,18}

Given the likelihood of dying from this disease, these women need empathetic and respectful communication with health care professionals. However, health care professionals apparently rarely focus neither on how patients cope with their new reality nor their expectations concerning treatment, emotions, relationships, social functioning, or daily life.¹⁹ Some studies have examined the types of skills required by health care professionals to enable effective communication, as well as existing barriers for the consistent provision of such quality communication.^{19,20} Women diagnosed with ovarian cancer highlight the importance of health care professionals' knowledge about the psychosocial impact from the disease.⁶ Thus, this lack of recognition potentially hinders the provision of optimal care.

The present therapeutic practice is not yet sufficiently informed by qualitative research on the cancer trajectory's psychological dimensions.²¹ In this study, we explore the lived experience of a group of ovarian cancer patients over a period, focusing on their experience of illness and their interactions with physicians and other health care professionals. In this way, we seek to contribute to the knowledge on ovarian cancer in terms of holistic health care.

Aim

This paper aimed to explore how women living with ovarian cancer experience their illness and their interactions with physicians and other health care professionals in Norway. Such insights may improve the understanding between women living with ovarian cancer and health care professionals, and lead to refinements in care and support for these women throughout their illness and disease trajectories.

Methods

This study used the validated consolidated criteria checklist for reporting qualitative research (COREQ).²²

Design

A qualitative explorative design was used through multistage online focus groups, where the same group was interviewed at 5 sequential time points.

Sample

Five women, all diagnosed with ovarian cancer, were recruited using a purposive sampling strategy to elucidate the particular of this study.²³ All participants had to meet the following inclusion criteria: (a) having undergone surgical treatment for advanced ovarian cancer; (b) being over 18 years old; (c) having Norwegian as their mother tongue; and (d) having access to a computer with an Internet connection. Furthermore, patients treated at our own institution were excluded due to personal relationships with the researchers. Possible participants were identified through the national patient organization Gynkreftforeningen,

which sent out prerequisites. Only women who expressed interest were contacted and invited to participate.

Data Collection

Five online focus group interviews were conducted between September 2018 and May 2020. The first authors—K.R.G., an oncological nurse, and S.D., an experienced researcher and nurse, as moderator and co-moderator, respectively—conducted the focus groups using a synchronously computer-mediated communication (CMC) platform with sound and video. The CMC platform allowed participants to remain in their own homes while taking part in the group interviews together with all other participants. This facilitated recruitment of participants across geographical distances within Norway.

The interviews lasted from 90 to 120 minutes each, and a semistructured interview guide with open-ended nondirectional questions was developed. The guide included introductory questions, a main part, and a concluding part. The main part contained questions that addressed the women's life situations and their experience regarding information and communication, family relationships and social networking, as well as their relationships with nurses, physicians, and health services in general. During the interviews, themes that the women mentioned were probed. Data collection was discontinued after the fifth interview, when the saturation point had been reached. All participants were informed about the content of the interview guide upfront. The moderators took care to ensure during interviews that the participants could take their time and also abstain from pursuing sensitive and emotionally demanding topics. It was furthermore agreed that individual follow-up telephone calls would be made when interview sessions had appeared distressful in order to attend to the emotional well-being of the participants and try to alleviate distress. K.R.G. made such follow-up calls the following day after 2 group sessions.

Ethical Considerations

The Regional Committee for Medical and Health Research Ethics (Reference ID: 2017/941) approved this study. Participation was voluntary, that is, the participants were informed in writing and orally about their right to withdraw from the study at any time with no consequences, and that their confidentiality would be protected, before they signed the informed consent form.

Data Analysis

The interviews were transcribed verbatim into text data and inductively analyzed using Malterud's systematic 4-step text condensation (STC) strategy, an elaboration of Giorgi's psychological phenomenological analysis.²⁴ Authors K.R.G., S.D., and R.S. started by individually reading the transcripts several times to establish an overview of the data. These 3 authors individually identified themes, which were consolidated by a consensus meeting into a set of eight preliminary themes (step 1). During step 2, the preliminary themes were discussed and sorted into meaningful units and coding groups. During step 3, we divided each coding group into subgroups to highlight different facets in each of the coding groups. Step 3 also included creating artificial quotations, or condensates, from the subgroups representing the meaningful units' content described during step 2. Finally, during step 4, concepts were developed from the coding groups from step 2 and condensates from the subgroups in step 3. The concepts are presented as subsections in this article's Result section and in the Discussion section.

Rigor

Trustworthiness was established using Kvale's²⁵ guidelines, and credibility and dependability criteria were applied. Three of the authors (K.R.G., S.D., and R.S.) performed the analysis

independently, then held discussions throughout the analysis process to reach a consensual interpretation. All interviews were conducted and transcribed verbatim in Norwegian. Data analysis was also based in Norwegian. In the process of writing the article, the authors translated our findings, conceptualizations, and empirical quotes into English. To ensure the accuracy of the translation of empirical quotes, co-authors individually and independently checked Norwegian originals and their English translations.

Results

Participant Characteristics

All participants had a histologically confirmed advanced ovarian cancer diagnosis and had undergone surgical treatment at different university hospitals in Norway during the 2011–2015 period. All had received chemotherapy after surgery, and some participants had received several lines of cancer therapy and were seriously ill with remaining disease. One participant was receiving treatment during the study period. The study participants comprised a homogenous group demographically and socioeconomically, that is, they all were born in Norway, held higher education degrees and were between ages 50 and 70. All participants had full-time jobs before they received their diagnoses, and they all returned to full-time or part-time work after the treatment period.

General Findings

The unison general finding from the group interviews was that the women described and discussed the complex nature and implications from the transitions in which they moved from being healthy to being ill, regardless of the disease stage at the time of diagnosis. They described how these transitions contained emotions, existential thoughts, and experiences of illness that were difficult or impossible to articulate to others and even to themselves. This set of transitions amounted to illness trajectories that were similar for all participants, from the prediagnosis phase, with diffuse and unexplained symptoms, to the dramatic diagnosis of ovarian cancer, leading to a treatment and follow-up phase characterized by disease symptoms, adverse effects from the treatment and the existential uncertainty about their prognosis. From the analysis of the interview transcripts, 3 themes emerged that overlap and interact, each shedding light on one of three specific aspects of these transitions. The 3 aspects were one's sense of self, one's close relationships and one's communication with health care professionals.

Theme I: Lost Within Oneself

The most prominent theme within this study was “lost within oneself” and describes the women's troubled sense of self concerning who they are, the loss of their prior identity, and the interpretation of their illness. All the women described how living with ovarian cancer challenged or even destroyed their old sense of self as they entered their new situation of unhealth. The women expressed this loss of their prior identity as an experience of existential and emotional chaos and paradoxes, of being thrown out into a life situation that cannot be conceptualized and articulated properly. The participants described the traumatic experience of entering the life of living with ovarian cancer as a hopeless and unreal situation:

It's such a traumatic situation, such an unreal situation to be in, where your thoughts just rage through your head, and I was scared and frightened (...). There were so many emotions going on that one fails to receive any information when everything is so hopeless.

The participants frequently described their experiences as a sense of being in an inner transition. They expressed a transition of moving from who they were before the diagnosis—with the self, body and mind they knew—to this new and uninvited “I” with which they still were unfamiliar. Their bodies' size and shape changed, as did sexual and bowel functions. The women suffered from fatigue, insomnia, and neuropathic pain, which they attributed to the cancer treatment. Simultaneously, they could experience themselves as treated and temporarily cured from cancer and, as such, if not healthy, not ill either: As one of the participants put it:

I wouldn't say that I'm healthy, but I don't feel sick either...

Simultaneously, this state of being in limbo between health and illness also was described as a state of profound uncertainty about future cancer relapse and death, that is, having received a death sentence with an unknown date of execution:

Cancer left me unleashed in space all alone, trembling, and floating, losing your footing. The whole foundation is shaken by it, losing yourself, losing your life. I have never had my everyday life back.

This uncertainty included how they viewed their own bodies—that one can feel fine and be in decent shape, and still the cancer returns and progresses without the body telling them so. One of the participants described this as such:

I went for walks in the mountains with the dog, and I really thought that I was in great shape.

The participants managed this uncertainty by introducing mental distance from both the disease and their lives before cancer. Memories of their former life were painful. As for their future, they expressed the alternation and paradox of both accepting and resisting their fate, of experiencing both grief and acceptance. They described both an inner fight against the cancer to ‘take over’ their lives and identities, while also accepting it as part of them and as something that eventually would consume the whole of them:

We try not to focus on cancer, but to focus on life, on the experience of life. Beautiful things and pleasant experiences, and if you allow yourself to give them access and shut the other [i.e., the cancer] out. (...) I do not want to give death a place yet; there is no question about that. It will have to come when it comes.

A similar paradox was described regarding how they related to peers, that is, other women with ovarian cancer. On the one hand, they described the value of meeting other women who shared and understood their situation. On the other hand, they described their experience of having to distance themselves from the other women, particularly those who were more advanced in the disease trajectory and were approaching death:

When you are sick, you have more than enough with yourself. You probably don't think about such things (...) at all, but in retrospect, it is incredible to meet peers who have had the same disease and who knew what I was talking about. Someone who understood me, and I them. (...) It made me feel less alone knowing others were experiencing the same as, that it wasn't just me (...).

What amazes me is how abruptly death has come upon some of them. It's kind of not gradually fading away, it's just... (pause) but that's the way it is too. You can't escape reality.

Perhaps, the most striking finding is how the women were explicitly aware of their conscious efforts to manage the distance between their own uncertainty and fear in the presence of other women's approaching death. One of the participants summarized this:

I taught myself a technique: It is them; it is not me...

Theme II: Loss of Identity in Close Relationships

The second theme, “loss of identity in close relationships,” describes the experience of not being able to communicate to friends and family how they live with cancer, and how this inability changes and threatens social relationships. The instant feeling of being alone after diagnosis was prominent in all five focus group interviews, even though all the participants were surrounded by family and friends, and the relationships were close:

... It feels like being in a vacuum, being released into space all alone ... drifting, losing your footing, the whole ground beneath you is shaking. (...) You are losing, you are losing your life.

They expressed their illness experience as “brutal” and expressed a desire to protect those close to them from this beastly and harsh life experience:

It has been easier for me talking to people who are not so close to me than those I have around me every day because I have in a way felt that it was bad enough that I should get sick and that it would be a strain for my family. I had no desire to inflict on them more worries and anguish. I wanted their lives to go on.

An element of communication with family and friends was the difficulty translating their experience, feelings and thoughts into words:

... The things I said (were) understood as something else than what I meant. And you know, the truth lies within the one hearing it. (...) It's just that the understanding was not right...

To expose oneself in this situation involved exposing others to the cruelty of suffering and death. In this process of articulation, an element of ambiguity and paradox exists, an element that one participant expressed as “plain torture.”

Some of the participants chose being open about their disease. As another expressed it:

I have chosen to be open ... and I feel that this openness has helped me, but it also came with a cost. No matter what social contexts I am in, everyone knows that I have cancer (...). I can see that they become a little like ... you don't know what reaction people will have. Therefore, sometimes, I feel that I must constrain myself to protect them because I don't know how much they are able to receive.

Openness also could be tiring and exhausting, as care from others could be experienced as a burden that left the women with the feeling of being weak and vulnerable, and simultaneously having to take responsibility for those at the receiving end of the openness. As one participant expressed it:

... It was bad enough that I got ill in the first place. I didn't want to be a burden to my family, having gone through treatment. I was cured (and) healthy. I did not want to (inflict) more worries (on them). I just wanted their (lives), as well as my life, to move on. Even though I had my ailments, I chose not to bring them upon my close ones.

Theme III: Lost in Translation Between the Life World and Medical World

The third theme describes how the experience of living with cancer is lost in communication with health care professionals and accordingly may be neglected in the health care received. The participants had been going through an illness trajectory with two rather separate phases: prediagnosis and postdiagnosis. Correspondingly, their contact with the medical world also passed through a trajectory with three phases: prediagnosis; the moment of diagnosis, then surgery; then further treatment and follow-up. We demonstrate below how the translation challenges change as the trajectories develop.

The problem of translation in prediagnosis was obvious: The illness symptoms were not interpreted correctly, neither by the

women nor their general practitioners, as ovarian cancer. The participants expressed the difficulty of living through that phase and the later grief of having received their diagnoses at a late stage:

I went to the gynecologist, who did an ultrasound, and everything was normal. Then I started (to) get a little stomach-ache, so I went to my general practitioner, and he did not understand anything.

Another woman described this phase of the trajectory:

You see, the most important thing is to be believed. I have met physicians who don't believe me because of what I am experiencing and the feeling of something being wrong in my body can't be verified by some medical test, and then there is no evidence.

At the time of diagnosis and surgery, the women described the experience of being lost when first introduced to the possibility of the diagnosis of ovarian cancer, as one participant put it:

I was afraid of collapsing on the floor. I didn't, but it felt that way. They left me, they sent me out alone. They should not have done that.

During the period of further treatment and follow-up, the challenge of communication between the life world and medical world changed. The participants described in many ways how health care professionals did not address aspects of their suffering and how they failed to communicate. One participant said the following:

It's heartbreaking. (...) The choices you make have led you into this situation ... realizing and living the consequences, and then being in this situation with someone who is not capable (of helping) you ...

The participants described how they were unable to communicate their experience of illness and suffering in a way that health care professionals could understand. This left them in a state of feeling misunderstood. Similarly, the women expressed how communication also was difficult in the other direction—from health care professionals to themselves:

We don't understand each other; you are not where I am. You can't get to where I am; you can't understand where I am.

Regardless of this, health care professionals held an important place in the women's lives. The women spoke of how they had been seeking their health care professionals' attention and searching for someone to talk to them and ask how they were coping, but to little avail:

No one has ever asked me how I feel, if I need any support or help on any set psychosomatic, psychological or practical art.

Another participant added:

In the end ... one is just so devastated (...) This body being so insecure, so unpredictable, the need for something to be secure arises. A physician one can trust, who tells the truth and provides the information one needs. Because... security, to which degree this situation can ever be provided with security, is the one thing that makes it all bearable.

The women called for health care professionals to address their suffering from living with cancer, and not only the disease's progression. Many of their statements pointed in this direction:

When the relapse comes, and it will come, you get support to carry out the treatment, but no one asks how you really feel, how the relapse affects them as a human being.

Discussion

Our findings demonstrate how communication is lost in the transitions between various stages when moving from being

healthy to experiencing illness after being diagnosed with ovarian cancer, both within oneself and in interactions with family and friends, and with health care professionals. Our results highlight how the absence of words and the ability to articulate the illness experience results in these women not receiving the help they need when living with ovarian cancer.

The experience of losing one's identity when being diagnosed with cancer is well-documented in extant qualitative cancer research.^{26,27} In our study, the participants described a trajectory of paradoxes in both accepting cancer as being a part of them, and simultaneously they depicted a fear of being *lost within themselves*. The paradoxes experienced when living with cancer—being healthy but ill, living but dying, resisting but accepting—have been reported previously in Leal and colleagues.²⁸ However, our results strongly indicate that the experience of being lost within oneself was related to a disruption of the women's sense of self. The participants described living with ovarian cancer as being in a constant inner transition that included physical, emotional, and social changes. However, descriptions of this disorientation—the experience of being in between—are not new. Our findings are similar to those of Thompson,⁹ who demonstrated how cancer patients experienced alienation from life and a sense of being in between, of being in liminality. In this article, we explicate the participants' description of these transitions containing an existential element, and how the illness experiences were difficult or even impossible to articulate to others—or even to themselves.

The second theme identified was *loss of identity in close relationships*. The transitions were illustrated by the participants' experience of being between uncertainty and in need for knowledge and skills regarding their body, identity, and relationships to family and friends. However, the participants described these transitions as private. A recent study indicates ovarian cancer to have impact both on individuals and caregivers,¹² suggesting the disease to cause loneliness and a lack of understanding and isolation from caregivers. In our study, the paradoxes were illustrated by the descriptions by the participants, a feeling of exposing others to the experiences of cruelty and torture that the women endure, and simultaneously the need to be open. In particular, our findings describe patients' difficulty communicating their illness experiences so that family and friends can understand.

In the theme *lost in translation between the life world and medical world*, the participants described a feeling of health care professionals misunderstanding them. The two previous studies supporting our findings^{16,19} emphasize the discrepancy between the women's illness-driven needs for care and the disease-focused care that hospitals and health care professionals offer. One paradox is that the medical technologies that identify the disease are the same that function as the substrate for the disruption of the sense of self, strongly conditioning the illness experience.²⁸ According to Hofmann and Svenaeus,²⁹ illness is a basic human experience. The "torture" that our participants described seemed to be less about the cancer and more about the existential chaos the women found themselves thrown into. Although the experience of illness can be revealed in the interaction between cancer patients and health care professionals, our findings show that the experience of illness seems to be neglected in the health care received.

Limitations

This study's main limitations are that the number of participants was relatively low, and that the participants comprised a rather homogenous group. This allowed us to identify clear signals in the material, but at the possible expense of diversity. Although the consistency throughout the diachronic set of interviews reassured us regarding the credibility of the findings, we intend to address these weaknesses in future research projects.

Conclusion and Implications

This study's findings indicate that the experience of illness in the context of ovarian cancer is lost in translation, both within patients, but also in communications with friends and family, physicians and other health care professionals. Indeed, health care professionals need a greater awareness of both the nature of the illness experience and how it is communicated. Whereas most previous research on ovarian cancer have focused on medical aspects, such as biomarkers and treatment, this study focuses on understanding the illness experience. The experience of illness and suffering described and revealed has been created by the cancer diagnosis itself, the treatment, and the follow-up period. However, the experience has not been adequately captured and given the needed amount of attention compared to the diagnostics and disease management.

Although the findings in our study are based on interviews with a small sample size, we believe these findings may help nurses, and other health care professionals to better understand the existential suffering experienced by women living with ovarian cancer, and how it is easily lost in translation. This understanding may refine care and support these women throughout their illness and disease trajectory. Future research with larger samples may yield a deeper understanding of the specific challenges of this patient group. We believe, however, that the findings in this study highlight the importance of understanding the illness experience of living with ovarian cancer and through the disease's trajectory for providing personalized quality care to this patient group.

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