



Research Article

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Navigating the Complexities of Ovarian Cancer Care: Perspectives from Nurses

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Abstract

Objective: Ovarian cancer remains the most lethal gynecological cancer, and the cancer disease and treatment can cause severe physical and psychological side effects that reduce quality of life. Patients often feel that their illness experience is inadequately addressed by the healthcare system. Nurses are poised to play a vital role in addressing and providing follow-up care for these experiences. The objective of this study was to gain access to the understanding of the patient-provider relationship, as seen from the nurses' perspectives.

Method: We conducted five focus group discussions with nurses (n = 26) in oncological hospital units in Norway. Data were analyzed using a descriptive phenomenological approach.

Results: This study found that the complexity of treatment options and the abundance of information sources contribute significantly to patients' uncertainty and present a major challenge for nurses. Nurses are highly attuned to patients' emotional turmoil and often struggle with addressing patients' uncertainty while navigating the disease and illness in ovarian cancer. The results demonstrate that despite their clinical expertise in ovarian cancer, nurses may find it difficult to fully understand patients' emotional states as they undergo treatment. Additionally, while nurses strive to deliver holistic care to ovarian cancer patients, they encounter barriers such as time constraints, leading to prioritizing practical tasks over existential discussions. Furthermore, concerns about potentially harming the nurse-patient relationship while providing holistic care create dilemmas for nurses.

Conclusion: This study sheds light on the patient-provider relationship in ovarian cancer care from nurses' perspectives. It highlights the challenges nurses face in addressing patients' emotional needs during complex treatments. Despite clinical expertise, nurses struggle to grasp and address patients' emotions, compounded by abundant treatment options and time constraints. Balancing holistic care with practical demands poses additional complexities, showcasing the multifaceted role they play.

Keywords: Ovarian cancer; Nursing; Illness experience; Patient-provider relationship; Focus group discussion

Introduction

Ovarian cancer is the most lethal among gynecological malignancies, with an overall survival rate in Norway of 51.3% (2018–2022) [1,2]. The clinical manifestation and therapeutic management of ovarian cancer are multifaceted and protracted, giving rise to a spectrum of physiological and psychological sequelae that significantly impact patients' needs and quality of life [3]. These factors intertwine intricately with the overall illness experience in ovarian cancer [4]. Although ovarian cancer most often results in lasting interactions with the healthcare system and healthcare professionals, research indicates that patients often feel that their illness experience is inadequately addressed in discussions with medical professionals [5]. Consequently, ovarian cancer patients may struggle to fully understand the consequences of their illness and treatment, as well as its potential impact on their lives.

Recent advances in ovarian cancer have led to new and more complex treatments with the aim of better and more specific and personalized care [6]. The consequence is longer timespans of the ovarian cancer trajectory, which paradoxically also give rise to new challenges for healthcare systems and healthcare providers and raises new concerns regarding the quality of cancer care [7]. Furthermore, the duration of cancer trajectories presents cancer patients with opportunities but also challenges regarding physical, psychological, emotional, and practical aspects [8,9].

Numerous factors have implications for cancer care and the caregiving process [10], including advances in biomedicine. In oncological settings, medical professionals face the challenge of managing a growing array of molecular-based cancer subtypes, comorbidities and combination therapies and associated side effects. Modern cancer treatment tends to prioritize treating cancer as a disease. This study applies the conventional definition of disease as an 'organic and psychological disorder' as compared to the subjective psychological awareness of dysfunction known as 'illness', referring to the lived experience of cancer and cancer care [11].

When cancer is considered a disease, rather than considering the complex interactions between illness and disease trajectories and thereby individual care, concerns about the 'dehumanization' of modern medicine arise [12]. Moreover, the complexity of clinical issues often necessitates a focus on the disease aspect of health, sometimes leading to a perception of patients as mechanical systems rather than holistic individuals [13,14]. Nurses' roles are also evolving due to advancements in healthcare and in response to the changing therapeutic landscape. There are increasing expectations for nurses to incorporate knowledge of omics sciences into their practice [15] while continuing to proficiently assess patients' physical and emotional conditions, medical histories, health behaviors and their families' understanding of the disease and treatment [16].

Many studies focus on the needs of cancer patients, and the most prominent unmet needs among cancer patients are related to psychological complaints [17]. Additionally, research suggests a need for healthcare providers to increase their knowledge of cancer

patients' physical and psychological requirements [18]. There are few, if any, studies investigating how healthcare professionals understand and respond to these needs. Ovarian cancer patients struggle to communicate their illness experiences to healthcare providers greater provider involvement in understanding their illness experiences [5]. A recent study suggested that physicians fail to address patients' experiences of illness for various reasons, such as time constraints, and some doctors feel it is the responsibility of nurses to care for and follow up on the illness experiences of ovarian cancer patients [19]. A few published studies have investigated nurses' experiences in meeting the various needs of cancer patients, such as supportive care [20], and emotional support [21], but papers on how nurses understand and act upon the lived experience of ovarian cancer are scarce. This study aimed to gain an understanding of the patient-provider relationship in ovarian cancer from the perspective of nurses.

Materials and Methods

Design

This study was inspired by Giorgi's descriptive phenomenological approach [22], with a qualitative design involving the use of focus group discussions (FGDs).

Sample and recruitment

The disease trajectory for ovarian cancer patients involves both hospitalizations and outpatient consultations and treatments. We used a purposive sampling strategy, contacting departments at university and local hospitals (inpatient wards and outpatient clinics) in Norway who treated and followed up women diagnosed with ovarian cancer and inviting registered nurses and oncological nurses to participate in the study. The setting was selected because of how women with ovarian cancer are managed and monitored in Norway. The healthcare involves a collaborative effort between university hospitals and local hospitals, each with distinct treatment responsibilities.

Data collection

FGDs were conducted using a semi-structured interview guide with open-ended questions designed to elicit verbal descriptions of nurses' understanding of what it is like living with ovarian cancer. The questions focused on three main topics: understanding individuals diagnosed with ovarian cancer; identifying what participants found important during their conversations with the patient group and pinpointing what was meaningful for participants in their interactions with patients with ovarian cancer.

Five FGDs were conducted between September 2023 and December 2023. The FGDs were conducted face-to-face by an oncological nurse (KRG), PhD candidate and an experienced qualitative interviewer. The discussions lasted from 55 to 63 minutes and were conducted in Norwegian. To familiarize the participants with the subject of the discussion, a concise overview of the project was presented. Efforts were made to create a positive and safe environment that would encourage participants to freely share their experiences and narratives. Furthermore, the participants were encouraged to explore diverse perspectives

on the questions posed, fostering verbal exchange and the enhancement of each other's viewpoints and reflections, even in cases of disagreement [23]. The interviewer also followed up on topics that the participants themselves raised in the discussions, attempting to let the participants elaborate on those relevant to the objective of the study. Some questions were posed to each participant individually, while others were open for all participants to respond to.

After conducting five FGDs, a scarcity of novel data was registered, as were observed instances of data redundancy. Hence, we concluded that saturation had been achieved and made the decision to discontinue further FGDs. All discussions were audiotaped and transcribed verbatim. The transcriptions were anonymized and securely stored together with the audio recordings and informed consent forms.

Data analysis

We analyzed the data material inspired by the descriptive phenomenological method described by Giorgi [22]. The analysis was conducted by the authors KRG, SD and RS individually and collaboratively. Initially, we engaged in a simultaneous process of listening to the audio files while reading the transcripts. Subsequently, the transcripts were carefully read several times to gain an overview of the interviews separately and constantly striving to maintain openness to the material. We then identified meaningful units from each interview and progressed to examine these units and transform them into second-order descriptions. During this phase of the analysis, we convened to discuss the interviews, the meaningful units, and the second-order descriptions to establish a structure that could encapsulate the material. In the concluding phase of the analysis, we scrutinized the organization of experiences within individual interviews before consolidating our insights across the entire dataset. We compared and contrasted our insights to reach the following understanding: The relationship and communication between ovarian cancer patients and nurses and the understanding of the professional role of nurses can be divided into 1) how to be a competent nurse in ovarian cancer care 2) nurses' understanding of ovarian cancer and 3) nurses' perspectives on ambivalence, hope and false hope in ovarian cancer.

Ethics

This study was conducted in accordance with the General Data Protection Regulation and is registered with the University of Bergen's System for Risk and Compliance (ID: F2741). The study did not collect health information or sensitive personal data and therefore did not require approval from the Regional Committees for Medical and Health Research Ethics or registration at the Norwegian Agency for Shared Services in Education and Research (Submission assessment: ID no: 727498).

All participants were informed verbally and in writing about the research project before signing the consent form.

Results

Participants characteristics

Five focus groups were formed with 4–6 participants in each

group. In total, 26 nurses participated, of whom 17 were oncological nurses. Two of the participants were men. The mean age was 41 years (range 23–64 years). The majority worked at university hospitals, and the mean clinical experience by year was 15 (range 1–40 years).

Constituents emerging from qualitative analysis

How to be a competent nurse in ovarian cancer care

The informants described their interactions with patients with ovarian cancer as an arena in which patients sought reassurance. Competence was perceived as a crucial factor in building trust and providing reassurance to patients. This competence was not associated with extensive expertise in biochemistry or treatment alternatives. Rather, nurses must be skilled in understanding the holistic aspect of the individual, providing reassurance and support to patients and their families, and instilling a sense of security in an otherwise uncertain life situation. The informants encountered a dilemma: Nurses felt the need to discuss palliative care when physicians talked to patients about treatment options, as they grasped the potential consequences and the chance that treatment might not lead to a cure. Furthermore, the informants noted that physicians often did not provide thorough information, leaving patients insufficiently updated about their condition and treatment choices. They were concerned about what they perceived as a lack of honesty in physicians' communication, which led to false hope among patients and posed challenges for nurses. *"It's often difficult for us [to inform and communicate with patients] when we know how bad it actually looks and that the physician has said something that actually paints a rosier picture of the disease to the patient. And then we can't talk to them [the patients] about it [the truth of the disease] until they've received information from the physician".* The competence of the nurses lies in their knowledge about the disease trajectory. The 'truth' they knew about the illness placed nurses in situations where they experienced the need to balance this truth with patients. They understood that revealing the truth about the disease could diminish patients' hope, and they feared that conveying the truth could harm the patient–nurse relationship. Therefore, they often refrained from disclosing the truth about the disease. *"I guess I feel like sometimes we're being a bit dishonest, even to the family ... you have to find a way around without lying, but"...* The informants expressed the challenge of emotionally distancing themselves from patients' suffering while maintaining their duties. They formed bonds with patients and experienced grief upon their passing. Additionally, they struggled to provide effective nursing care due to a limited understanding of patients' mental states and uncertainty about sharing information without causing distress or damaging the patient–nurse relationship. *"It makes it difficult to provide the nursing care you'd like to because you tread cautiously and don't address what we want to talk about. Like when patients are very optimistic, and you might know something really bad. Then, you feel rotten. You feel absolutely rotten when you then go in and say, 'Yes, this will be fine'".*

The informants understood their role to include comforting and advising patients, supporting them and listening attentively. Building strong relationships and having ample time are essential

for nurses to fully engage with patients' experiences of illness. *"For me, good nursing is about building a relationship with patients to better understand their problems and what I can do to help them. At the same time, when you have a good relationship, it's difficult to bring up things that are hard to talk about because I'm afraid of crossing a boundary".* The practical tasks, such as collecting biological and vital data inherent in the nurse-patient relationship, often result in limited time for discussing existential questions. *"I want to spend time with the patients, try to show that I have time, even if I might not actually have it ... so then I'm in a bit of a dilemma ... and they [the patients] show that they want to talk, they want to discuss other things, not just treatment"...* Nevertheless, the informants found their role towards patients meaningful; the reassurance they conveyed to patients fostered a good patient-nurse relationship, enabling patients to mobilize their own strengths. *"Working with patients with ovarian cancer is meaningful, but at the same time, I feel this heaviness and emptiness ... you feel so helpless because you want to do so much to help them, but at the same time, there's not much you can actually do".*

Nurses' understanding of ovarian cancer

The informants provided deep insights into how ovarian cancer affects patients both physically and psychologically. They related how ovarian cancer had a complex impact on patients' lives, causing not only physical symptoms but also significant psychological challenges and that these combined effects could greatly disrupt patients' lives and their sense of identity. The informants described the impact that ovarian cancer has on basic bodily functions. This disruption extends beyond the physical realm, affecting patients' ability to participate in social activities and maintain a sense of normalcy in their lives. *"Well, ovarian cancer, it displaces so many of your natural functions that are common to being human, it's maybe the stomach ... it starts to slow down, you feel nauseous, you can't eat in social situations"...* it affects a lot of what is living a normal life. As the disease progressed, the nurses perceived it to become more brutal, affecting various aspects of patients' bodies with treatment and disease-related complications, resulting in hospitalizations and a deprivation of patients' independence. *"When they come back with a relapse, when there's a need for a pyeloscopy ... that's when the disease starts taking away your independence ... they begin to rely on home care, and they have to think about whether they can shower, be social ... then there are infections ... it's a really brutal disease".*

The informants also described how they perceived that the traumatic disease and resulting physical changes caused patients to lose their sense of identity and self-perception, essentially feeling as though they had lost themselves. *"It's a very mental strain, the whole situation, but especially the fact that you lose yourself".* Several of the informants described a patient group that lacked a comprehensive understanding of the seriousness of their disease. *"May be the toughest part to deal with is knowing that what's been communicated hasn't quite sunk in [with the patient] ... that the truth [about the disease] hasn't been fully grasped".* The trajectory of ovarian cancer was characterized by uncertainty for the patients, and the informants described how patients lost their confidence in their own bodies, originating from the absence of cancer-specific

symptoms prior to diagnosis. *"There are so many vague symptoms, so having a concrete number to which they can relate. Seeing it black and white, whether it's gone up or down. I think knowing that number is a desire to be reassured. And you can be as long as it goes down or stays stable".* The informants described how this uncertainty and lack of trust persisted as patients harbored fears of disease recurrence, worrying that their bodies would not exhibit signs of illness and consequently relying more on medical tests rather than their own bodily cues. *"It's the only concrete and measurable thing they [the patients] can see. They can't control what's happening inside their bodies; the only tangible thing they can see is whether it [cancer biomarkers CA125] is moving or not".* At the beginning of the treatment process, the informants found that the patients' health status improved, and that the treatment was meaningful. After several lines of treatment, in which the informants observed the patients becoming increasingly debilitated due to side effects and complications, the patients remained equally motivated for treatment. *"Patients often undergo numerous lines of treatment. And perhaps they feel some sort of hope if they're offered one last round of weekly Taxol [paclitaxel] or Avastin [bevacizumab]".* Even if patients were described as ever more active on the internet, searching for information about their condition, the informants also described how patients found it difficult to grasp the complexity of cancer treatments. Patients struggled to understand that the possibilities offered by new treatment regimens may not necessarily apply to them, which in turn led to anxiety and distress.

Nurses' perspectives on ambivalence, hope and false hope in ovarian cancer

Hope was a recurring theme in the discussions. The informants described that hope among patients with ovarian cancer was often linked to biomarkers, new medications, and participation in clinical trials. The truth of the brutality of the disease was linked to objective measures, such as biomarkers to provide reassurance, control and hope. *"Even though deep down they know it might not lead to the end result they have hoped for, they still cling to the hope that something [in medical technology] will happen to cure them.* Introducing new treatment options redirects attention back to hope rather than enduring hopelessness. This hope prevented the informants from introducing palliation and palliative measures because they perceived that, for the patients, discussing palliative care was equal to facing death. *When patients undergo multiple lines of treatment, they may understand that it's meant to prolong their lives, but I believe some also hope it will cure them. They've been informed about it, but then they may think, 'Yes, but there are many chemotherapy sessions, we can try this ...' They're told, 'You should be able to live normally for a long time with this', but then they might start to doubt that. There's also the question of when to incorporate palliative care services or symptom relief. When they come for check-ups, they're told, "Everything looks fine here, and all is well".* The informants did not want to deprive patients of their hope, while the informants remained realistic in their understanding that many patients would not survive this disease. It's a delicate balance. *"One should be careful not to say it's false hope, because there's always a possibility that even if it's small, nothing is impossible".* However, the informants were concerned that patients lost valuable time in

these treatment regimens, time that could have been spent with their loved ones. In this way, they found patients to be waiting for the inevitable recurrence instead of spending their time living their lives. *"Patients don't prioritize their time correctly if they keep hoping for a completely unrealistic treatment. So, you see it when they come out [of treatment or the study] ... it wasn't what they had imagined ..., they could have had more time [with their family]"*. The relationship between patients and their relatives was described as challenging, characterized by the patients' desire to shield their loved ones from their own suffering. *"They [patients with ovarian cancer] want their family's life to continue as normally as possible; they want to spare the family [from their own suffering]"*. Throughout the course of ovarian cancer, the informants observed the relationships that patients have with each other. They described patients sharing experiences and fostering hope and optimism as they saw individuals living with the illness even after many treatment regimens. *"Talking to other patients can give a lot of hope that there are many treatments available because the others have been there for so long—so there's hope"*.

Discussion

This study provides a detailed understanding of how nurses navigate the complexity inherent in ovarian cancer as both a disease entity and an illness experience. They described how they navigated the risks of patients knowing too little to manage their condition well and of patients losing hope during the uncertain journey of cancer. Changes in the healthcare system in recent years have led to a transformation in the care and treatment of cancer patients. Nurses' evolving roles in healthcare necessitate proficient assessment of patients' physical and emotional well-being, medical histories, health behaviors and understanding of the disease and treatment [15]. This study confirms the importance of healthcare professionals' competence in interactions with cancer patients that foster reassurance. The nurses did not explicitly describe their own competence, but the scope of the discussions required a wide range of knowledge about the trajectory of the disease, balancing information and how they distanced themselves from patients. The nurses' understanding of the patient–nurse relationship was anchored in their understanding of ovarian cancer as a severe condition. The richness of their descriptions of the suffering faced by ovarian cancer patients adds to the body of evidence indicating that nurses have a thorough understanding of what it is like to live with cancer [24]. However, factors such as time constraints, assigned practical tasks and the need for emotional and relational distance hinder their ability to fully engage with patients' illness experiences. This challenge to delivering holistic care has been noted previously and linked to educational systems, work environments and motivational factors [21,25], suggesting that contemporary cancer treatment poses demands that the healthcare system is unable to fully address [26].

The nurses understood the suffering that ovarian cancer imposes on patients, while also fearing to fully acknowledge their suffering, apprehensive that doing so might impede their ability to continue working as nurses. The emotional burden of caring for seriously ill cancer patients and how this responsibility can result in distress has been well documented in previous research [27].

The nurses described a need to protect themselves in emotionally stressful situations and meetings while simultaneously caring for their patients. Unfortunately, maintaining this emotional distance may result in isolated patients and a healthcare system considered to lack empathy [28].

Hope was a recurring theme during the interviews. The primary challenge encountered by nurses in caring for ovarian cancer patients revolved around the quandary they faced when physicians introduced new treatment modalities to patients in the palliative phase of their cancer trajectory without also initiating the palliative care track. The informants described the patients', the physicians', and their own hope for better treatment options and prognosis for ovarian cancer. They found themselves navigating patients' hopes for cures and prolonged lives and what they perceived as false hopes associated with medical advancements that offered little chance of a cure but instead consumed valuable time that patients could spend with their families. The nurses' hope was more like a desire than a concrete vision, given their realistic view that many ovarian cancer patients would succumb to their illness. Still hopes that a treatment may exist that can have an effect [29], in addition to providing an escape from facing the illness [30]. Women living with ovarian cancer relate hope to the presence of bodily comfort, and hope is what makes life with the threat of death bearable [31].

The nurses found themselves navigating a delicate balance between recognizing the importance of providing information for reassurance and discussing palliative care, while being uncertain about the information already conveyed to patients by their gynecologists. One common association of discussion regarding palliative care is its perceived association with patients losing hope. The results from this study and others [19], indicate that there is a significant fear among healthcare professionals of taking hope away from patients. In this study, the depiction of nurses working with ovarian cancer patients is that they are highly aware of a suboptimal constellation in which patients and physicians cultivate partially false hopes. However, they cannot address this directly but must skillfully navigate needs for care, needs for hope and the need to maintain trusting relationships with their colleagues and patients.

Study limitations

All participants were grouped by department, meaning that the group members were acquainted with each other before the discussion commenced. This could have influenced the group dynamics, both in terms of being willing to share their experiences and the possibility that some participants might be more hesitant to openly discuss their reflections. Another implication is that group dynamics could potentially affect the interviewer's ability to intervene in discussions [23]. In addition, the sample consisted of 2 men and 24 women, and there is a possibility that a more balanced gender distribution could have influenced the dynamics within the groups and the results in this paper.

Clinical implications

The findings from this study highlight the importance of interventions aimed both at enhancing nurses' opportunities at

work to discuss concerns regarding potential overtreatment versus palliative care, and to include provision of adequate resources so that healthcare workers have enough time allocated to each patient to address their individual needs, thereby promoting more effective patient-centered care within the realm of ovarian cancer treatment.

Conclusion

This study provides valuable insights from the perspective of nurses into the patient-provider relationship and communication dynamics within the context of ovarian cancer. The findings illuminate the challenges nurses face in addressing patients' emotional needs and uncertainty amid the complexities of ovarian cancer treatment. Despite their clinical expertise, nurses often grapple with fully understanding and effectively addressing patients' emotional states, particularly given the overwhelming abundance of treatment options and information sources. Moreover, the study highlights the delicate balance nurses must strike between delivering holistic care and managing practical constraints, such as time limitations, which may lead to prioritization of necessary tasks over meaningful discussions. The dilemma of maintaining the nurse-patient relationship while providing comprehensive care further emphasizes the complexity that nurses face when caring for ovarian cancer patients.

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Conflict of Interest

Bjørge reports personal fees from AstraZeneca GSK, and MSD, and Thomsen reports personal fees from Bayer, Eisai Co. and AstraZeneca. Bjørge and Thomsen report on financial support from AstraZeneca for a researcher-initiated trial. The other authors declare no conflicts of interest.

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