Unveiling the Complexities: Patients' and Healthcare Providers' Perspectives on Understanding and Managing Ovarian Cancer

Karen Rosnes Gissum

Thesis for the degree of Philosophiae Doctor (PhD)
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Scientific environment

The research team for this PhD project comprised members of the INOvA (Innovative Novel Ovarian cancer treatment Approaches) research team set up by Line Bjørge and Emmet McCormack at the Department of Clinical Science, University of Bergen. The PhD project has also been a part of Roger Strand's "integrating ELSA" (ethical, legal, and social aspects of cancer biomarkers) research group, aimed at fostering awareness about ELSA, at the Centre for the Study of the Sciences and the Humanities, University of Bergen. Both research groups are affiliated with the Centre for Cancer Biomarkers CCBIO, a Centre of Excellence at the Faculty of Medicine, University of Bergen. In 2013, CCBIO received funding from the Research Council of Norway (project no. 223250).

The following Norwegian institutions have been partners and collaborators in this project: Department of Obstetrics and Gynaecology, Haukeland University Hospital Bergen; Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen; and Department of Gynecology and Obstetrics, Sørlandet Hospital, Kristiansand.

This research was conducted during the period March 1, 2020 to March 31, 2024, under the supervision of Line Bjørge (MD, Dr. Med., MBA, Prof.), as the main supervisor, along with Roger Strand (Dr. Scient., Prof.), Ingvild Vistad (MD, PhD, Prof.), Sigrunn Drageset (RN, PhD, Associate Professor), and Liv Cecilie Vestrheim Thomsen (MD, PhD, Researcher), as co-supervisors.

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Abbreviations

BRCA1	BReast CAncer gene 1
BRCA2	BReast CAncer gene 2
CA125	Cancer antigen 125
CRS	Cytoreduction surgery
HGSOC	High-grade serous ovarian cancer
HRD	Homologous recombination deficiency
HRQoL	Health-related quality of life
IDS	Interval debulking surgery
NACT	Neoadjuvant chemotherapy
OC	Ovarian cancer
OS	Overall survival
PARPi	Poly-ADP-ribose polymerase inhibitor
PDS	Primary debulking surgery
PFS	Progression-free survival
QoL	Quality of Life
WHO	World Health Organization

Abstract in English

Background: Ovarian cancer presents a profound challenge to the medical field on account of its seriousness and complexity. Despite advances in the field, particularly in precision oncology, the prognosis of ovarian cancer remains poor. Patients living with ovarian cancer endure a multifaceted journey, including debilitating side effects, which pose a challenge to our healthcare system. Given the gravity of the disease, patients require more than just clinical expertise from their healthcare providers; they need compassionate communication and holistic care. To deliver effective care, healthcare professionals must be well-versed not only in the medical complexities but also in the broader aspects of the disease and its impact on patients' lives. Despite extensive documentation on ovarian cancer as a disease, information on the illness and patient and healthcare worker perspectives of living with ovarian cancer are still lacking.

Aims: This project aimed to investigate how patients and healthcare professionals understand and act upon the illness and disease trajectory of ovarian cancer.

Materials and Methods: By employing phenomenology as methodology and adopting a qualitative design, a total of five focus group discussions with one group of patients with ovarian cancer (n=4), nine individual interviews with gynecologists in oncological settings (n=9), and five focus group discussions, each with a different group of nurses working with gynecological oncological patients (n=26) were conducted.

Results: Patients with ovarian cancer undergo a profound upheaval as they transition from health to unhealth and grapple with loss of identity and estrangement from their bodies. Expressing the complexities of their experiences proves challenging, prompting patients to withdraw even as they seek supportive relationships with healthcare providers. Both gynecologists and nurses perceive ovarian cancer as a brutal and devastating condition. While nurses strive for holistic care, gynecologists primarily focus on disease treatment and the potential offered by medical technology. Despite advancements in technology that have the potential to understand the disease and improve the prognoses of patients, healthcare professionals' understanding of patients' illness experience is still limited. Furthermore, healthcare professionals often maintain a certain distance from the profound tragedy of the disease as they grapple with the emotional weight, and time constraints imposed by the system, inadvertently obstructing their comprehension of patients' illness experiences.

Conclusion and implications: This project delves into the complex dynamics of understanding and managing ovarian cancer from the perspectives of patients and healthcare providers. Through phenomenological inquiry, we have unveiled the journey of these patients as they grapple with profound physical and emotional challenges. The findings emphasize the significance of holistic support in delivering care that better addresses the individual needs of ovarian cancer patients. Overall, this project underscores the need for healthcare professionals to embrace a more patient-centered approach, and that healthcare professionals need to be aware of and acknowledge the experiences and needs of ovarian cancer patients related to patient care and disease progression beyond the medical-technological treatment of the disease.

Abstract in Norwegian

Bakgrunn: Eggstokkreft er en alvorlig og kompleks sykdom, som fremdeles har en dårlig prognose til tross for betydelige medisinske fremskritt, inkludert innen presisjonsonkologi. Pasienter med eggstokkreft gjennomgår et omfattende og komplekst sykdomsforløp med store bivirkninger av sykdom og behandling, og å gi riktig behandling av denne pasientgruppen skaper dermed betydelige utfordringer for helsevesenet. Sykdommens natur gjør at pasientene trenger at kommunikasjonen med helsepersonell går utover rent medisinske detaljer. Det er avgjørende at helsepersonell har kunnskap om de ulike sykdomsaspektene ved helse for å kunne gi god og tilpasset omsorg til pasientene. Tross betydelig kunnskap om sykdomsforløp og sykdomsmekanismene i eggstokkreft, finnes lite informasjon om sykdomsopplevelse og pasienters og helsepersonells perspektiv på å leve med eggstokkreft.

Målsetting: Dette prosjektet hadde som målsetting å undersøke hvordan både pasienter og helsepersonell forstår og håndterer eggstokkreft gjennom hele pasientforløpet.

Materiale og Metode: Fem fokusgruppediskusjoner med pasienter med eggstokkreft, (n=4), ni individuelle intervjuer med gynekologer i gynekologiske onkologisk avdelinger, og fem separate fokusgruppediskusjoner der hver gruppe besto av sykepleiere som arbeider på sykehusavdelinger der gynekologiske kreftpasienter behandles (n=26), ble gjennomført med fenomenologi som metode, og med et kvalitativt design.

Resultat: Eggstokkreft markerer en enorm endring i livene til pasientene, da de går fra å være friske til å være syke, og må lære å leve med tap av identitet og en frakopling fra sine egne kropper. Kompleksiteten av deres erfaringer er ofte utfordrende å formidle til andre, noe som fører til at pasienter trekker seg tilbake selv om de ønsker støtte og hjelp fra helsepersonell gjennom endringsprosessene. Både gynekologer og sykepleiere oppfatter eggstokkreft som en brutal og tragisk sykdom. I sine møter med pasientene, streber sykepleiere etter å gi helhetlig omsorg, mens gynekologene hovedsakelig fokuserer på behandling av sykdommen og mulighetene og håpet som ligger i medisinsk teknologi og de store fremskrittene innen dette feltet de siste årene.

Til tross for hvordan den teknologiske utviklingen bygger et større potensiale for å forstå sykdom og forbedre pasienters prognose, er andre aspekter av pasienters opplevelse i sykdomsforløpet begrenset. Videre identifiseres en tendens for helsepersonell til å holde en viss avstand fra pasientens opplevde tragedie, både som resultat av tidspress i sykehushverdagen og de følelsesmessige utfordringene behandlerne opplever i møte med pasientene. Dermed skaper helsepersonell utilsiktet en barriere mot å forstå pasientenes sykdomsopplevelser.

Konklusjon og konsekvenser: Dette prosjektet belyser den komplekse dynamikken som eksisterer rundt forståelse og håndtering av eggstokkreft, både hos pasienter og helsepersonell. Fenomenologiske undersøkelser avdekket den flerdimensjonale reisen pasienter gjennomfører mens de navigerer gjennom kreftforløpet, og må lære å leve med fysiske og følelsesmessige utfordringer i stadig endring. Funnene understreker betydningen av helhetlig støtte for å kunne gi omsorg som bedre dekker de individuelle behovene til pasienter rammet av eggstokkreft. Overordnet indikerer funnene i denne avhandlingen at behandling av eggstokkreft krever en mer pasient-sentrert tilnærming, og at helsepersonell trenger å kjenne til, og å anerkjenne, de unike erfaringene og behovene til eggstokkreftpasienter relatert til pasientbehandling og sykdomsforløp utover den medisinsk-teknologiske behandling av sykdommen.

List of Publications

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Contents

Introduction

In Norway, around 500 women have been diagnosed with ovarian cancer (OC) yearly over the last five years (1-5). Despite the implementation of new treatment algorithms that have contributed to extending survival, OC is still the most lethal form of gynecological cancer. In Norway, overall 5,248 women live with this disease entity, and 2,625 of them have lived with the diagnosis for more than 10 years (5).

The trajectory of OC includes different key points: diagnosis, treatment selection, relapse, new treatment, follow-up, and palliative care. This is a complex journey in which patients encounter various symptoms of the disease and side effects of treatment, as well as several other life challenges. Altogether, these challenges point to a diverse set of needs in patients diagnosed with and receiving treatment for OC (6-9).

Most patients diagnosed with OC receive standardized treatment regimens throughout their disease trajectory that are complex and protracted. In more than half of the patients, the treatment and care strategy will, at some point, shift from curative to palliative. Unfortunately, the optimal strategy for the care of patients living with OC and the individualization of follow-up regimens for cancer survivors have still not been defined. Based on the diverse set of needs of this group of patients, an integrated approach that focuses on disease and treatment opportunities is necessary, one that prioritizes disease and treatment opportunities alongside the women’s lived experience of their illness. Such an approach would help address their desire to recover or live for as long as possible, while also promoting personalized health and well-being.

1. The World of Ovarian Cancer

1.1 Incidence, mortality, and survival

OC is the 8th most common neoplasm among women worldwide, with more than 300,000 new cases being diagnosed in 2020, and is the leading cause of death from gynecological malignancies in industrialized countries (10). In Norway, there is a 1.5% risk of developing OC by the age of 80 years (2018-2022), and approximately 500 women are diagnosed every year. The majority (65% in 2018–2022) are diagnosed at an advanced stage and about 275 are likely to die from the disease in Norway annually (5).

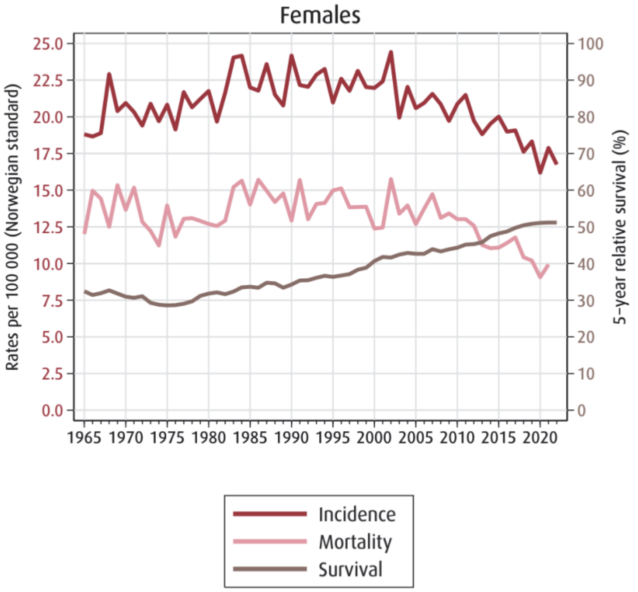


Figure 1.1. *Trends in the incidence and mortality rates and 5-year relative survival rates for OC in Norway from 1965 to 2022.*

Reproduced with permission from "Cancer in Norway 2022 - Cancer incidence, mortality, survival and prevalence in Norway" published by the Cancer Registry in Norway (2023) (5).

Globally, the occurrence of OC has been on a declining trend for several decades. From 1975 to 2011, the incidence of OC fell by 26%, and the decrease in incidence has been particularly significant from 2002 (11) (Figure 1.1). The decrease is more evident among women aged ≥50 years than in those aged <50 years, among non-Hispanic white women, and for the high-grade serous ovarian carcinoma (HGSOC) subtype of OC (11-14). The increased use of oral contraceptives has been highlighted as the most significant contributor to this decrease (11, 14, 15). In addition, tubal ligation and both prophylactic (for individuals with a genetic predisposition) and opportunistic salpingectomy are also drivers (11, 13, 14, 16). However, as the reclassification of some OC tumors (clear-cell cancers and high-grade endometroid carcinomas) has led to changes in the distribution of subtypes, it is possible that the decline has been overestimated (17, 18).

The intensified cytoreductive surgical efforts, the use of multiple lines of chemotherapy and the implementation of targeted therapeutics as maintenance therapy have resulted in an increase in the 5-year survival rate from 34.8% (1976–1980) to 51.3% (2018–2022) in Norway (Figure 1.1). However, for those with advanced stage OC at diagnosis, the relative survival rate is still low in Norway (37.9% in 2018-2022) (5).

1.2 The ovarian cancer trajectory

“Cancer is a disease of uncontrolled proliferation by transformed cells subject to evolution by natural selection” (19, pp. 1142). The processes associated with cancer processes not only transform the cells in the body, but also affect the individual’s entire experience of life: “The structures of everyday life and the forms of knowledge which underpin them are disrupted” (20, pp. 169). Cancer is an all-encompassing experience: It is characterized by a transition from a normal life, where thoughts and emotions flow effortlessly in the background, to a state where the body demands interruption and undivided attention. This transformation leads to an unhomelike existence in a world characterized by disorientedness, resistance, helplessness, and despair (21). In his book

The wounded storyteller, Arthur W. Frank describes life before illness strikes as guided by "destination and map," and that the experience of illness leads to a loss of both (22).

The cancer trajectory has been described as a dynamic change in both health and illness (23), and as an indefinite journey with specific key points of vulnerability (24) that one must pass through: diagnosis, treatment, follow-up, relapse, new treatment, palliation, and (for some) an early death. It is also important to acknowledge that individual experiences of these passage points can be highly different (25). From the clinical perspective, the cancer trajectory has been suggested to consist of two phases: curative and palliative. However, due to the increasing proliferation and complexity of treatment, advances in medical technology, and the availability of numerous therapeutic options, it is no longer possible to draw a clear distinction between these phases (26). The unclear demarcation is challenging both for healthcare professionals and patients, as they may hold varying perspectives on the current position of the individual patient within the cancer trajectory (Figure 1.2) (27). The passage entails a discussion about end-of-life care that, often, neither the physician nor the patient wishes to initiate, even though it is a vital aspect of the transition (26). Therefore, the "passage" has been described as a silent transition from curative to palliative care (27).

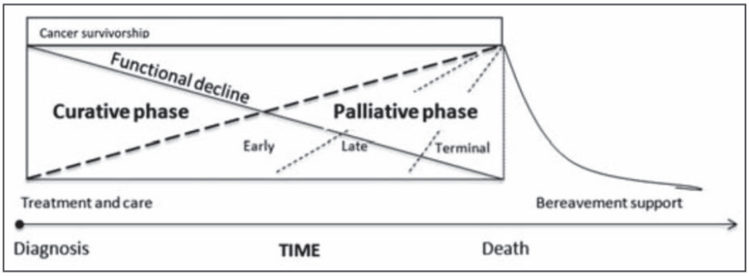


Figure 1.2 *Phases of treatment and care for cancer patients.*

Reprinted with permission from "The Cancer Trajectory — A Model of Phases" by Grov (2014) (27).

OC is frequently referred to as the "silent killer," a metaphor that denotes its insidious nature wherein symptoms manifest gradually and inconspicuously and eventually lead to the emergence of this detrimental disease. The course of OC differs considerably from numerous other cancer types, and it presents with distinctive features across various dimensions. Most patients with OC are e.g. diagnosed in the late stage, and the treatment is further complicated by our limited knowledge of the phenotypic and biological heterogeneity, chemoresistance, and few predictors of survival and mortality, as well as its high probability of recurrence (28-30). The symptoms of OC are often obscure, and women experiencing them may, at least initially, misinterpret them as normal bodily changes, e.g., as a component of the menopause process. For physicians, too, OC represents a diagnostic challenge. Patients with early-stage disease typically have no warning signs, while the symptoms, when present, are vague and non-specific, for example, indigestion, weight loss, unusual fatigue, and constipation (Table 1.1).

Table 1.1 *Symptoms of OC and their frequency.*

Symptoms	Frequency (%)	Symptoms	Frequency (%)
None	5	Back pain	23
Increased abdominal size	61	Pain during intercourse	17
Bloating	57	Inability to eat normal	16
Fatigue	47	Palpable mass	14
Abdominal pain	36	Vaginal bleeding	13
Indigestion	31	Weight loss	11
Urinary frequency	27	Nausea	9
Pelvic pain	26	Bleeding	3
Constipation	25	Diarrhea	1

This table has been reproduced from Goff et al. (2000) (31) and Goff (2012) (32).

The gastrointestinal symptoms (nausea, early satiety, abdominal distention, tenesmus, and constipation) and gynecological symptoms (pelvic pain, vaginal bleeding, and pain with intercourse) can, in part, be explained by the intra-abdominal localization of tumor tissues in the form of solid tumors, peritoneal carcinomatosis, or ascitic fluid (Table 1.1) (33-36). However, none of these symptoms are disease specific, and they typically appear only a few months (3–6 months) before the diagnosis is made. Therefore, efforts are being made to increase awareness of the OC symptoms to diagnose OC earlier. Nevertheless, despite multiple attempts to combine symptom-related indexes, serum biomarkers (such as CA125), and screening tools (such as ultrasonography), the efficiency of these methods is still not sufficient to justify the introduction of combined screening/diagnosis models for the identification of early-stage disease (37, 38).

Survivors of OC often describe their journey as being akin to facing a formidable opponent—one that seems to cast a threatening prognosis upon them. Navigating this trajectory involves encountering conflicting information and can lead to misunderstandings and feelings of helplessness (39). As OC is often detected when it is at a severe, late stage, patients are required to quickly make treatment decisions and are not given enough time to ask questions or to understand the consequences of the treatment modalities offered (40, 41). The stressful situation generates emotional insecurity and a fear of relapse; on the other hand, the diagnosis also leads to a shift in perception that encourages individuals to adopt a novel cognitive perspective on their life and surroundings (39).

1.3 The concept of health

The OC trajectory described in Sections 1.1 and 1.2 encompasses various aspects of OC, including its biomedical manifestations; patients' experiences; and the complex relationship between OC, life, and death. Diverse stakeholders within the healthcare system may approach these features in distinct ways that are influenced by their individual perspectives on health.

The concept of health is complex, and its definition necessitates input from biomedical, behavioral, and social sciences (42). The World Health Organization (WHO) defines health as "A state of complete physical, psychological and social well-being, not merely the absence of disease or infirmity" (43). This definition has been called multidimensional and holistic, as it consists of three interconnected elements: physiological, mental, and social (44, 45) (Figure 1.3). The physiological aspect involves exploring biological components through various medical examinations to identify the biological cause of malfunction. The mental aspect encompasses psychological and emotional states as well as individual comprehension, coping mechanisms, and the search for meaning in life (45). The social element refers to the individual's social role(s), as well as his/her and others' expectations of its fulfilment (45).

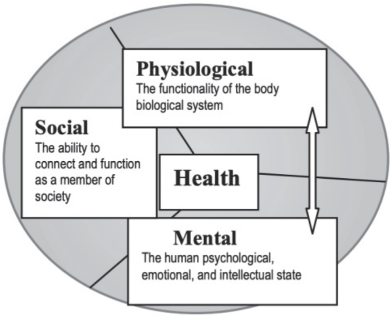


Figure 1.3 *Health, disease, and illness as conceptual tools.*

The diagram was published in the article "Health, Disease, and Illness as Conceptual Tools" by Amzat J. and Razum O. (2014) (45). (Creative Commons Attribution).

While health is often linked to the concept of normalcy, the definition of what is considered normal is not fixed. Instead, health is shaped by factors such as pathology; the normal distribution in a given context; economic, political, and social power; cultural history; and individual life projects, body plans, and social identities (46, 47). Accordingly, the WHO definition of health has received criticism for its overreach and utopian character (46-50). In fact, in the research presented in this thesis, an all-encompassing concept of health as "complete well-being" is not relevant. Indeed, the OC trajectory is laden with disease and suffering. However, we have retained, as an important analytical perspective, the distinctions between the three interrelated aspects of disease, illness, and sickness, even though each element intertwines with the others in an intricate relationship (46, 47, 51-53). These three aspects are commonly referred to as the *triad of disease, illness, and sickness*. As will be clearified below, the focus of this thesis has been on the aspects of disease and illness, while the aspect of sickness has not been specifically pursued in our work. This choice was made, in part, because of our prior research interest in how physiological and psychological information and experience are communicated between patients and healthcare professionals and, in part, because our investigation into the lived experiences of patients with OC revealed rich findings in terms of illness (54). However, the aspect of sickness may, of course, be important in the context of OC, too, and should, therefore be pursued in future research.

1.3.1 Disease and illness

There is no consensus on the definitions of disease and illness, moreover they are frequently used interchangeably in everyday language, including within the field of medicine (55). A likely explanation for the lack of consensus is that definitions build on different theoretical assumptions and represent different models of health and unhealth, such as the biomedical model, the biopsychological model, the holistic model, and the mechanical model among others (56-59). Tables 1.2 and 1.3 illustrate the diversity of definitions and their underlying assumptions.

Table 1.2 *Various definitions of disease proposed over the years.*

Author	Year	Definition
M. Susser	1968	“Disease is an organic and physiologic disorder” (46, pp. 541).
H. Fabrega	1972	“Disease in its generic sense is a linguistic term used to refer to a certain class of phenomena that members of all social groups, at all times in the history of man, have been exposed to” (60, pp. 184).
C. Boorse	1975	Diseases are “various deviations from the functioning of a healthy body” (47, pp. 55-56).
M. Marinker	1975	“Disease is a pathological process” (61, pp. 82).
H.T. Engelhardt	1975	“Disease is used in accounting for physiological and psychological (or behavioral) disorders, offering generalizations concerning patterns of phenomena which we find disturbing and unpleasant” (62, pp.126).
G.L. Engel	1975	Disease is “biomedical, with molecular biology its basic scientific discipline (…) fully accounted for by deviations from the norm of measurable biological (somatic) variables” (63, pp. 130).
L. Eisenberg	1977	“Diseases are abnormalities in the structure and function of body organs and systems” (58, pp. 11).
G. Hesslow	1993	“Disease is a deviation from some kind of ideal design” (64, pp. 3).
A. Twaddle	1994	“Disease is a health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities and/or a reduced life expectancy” (51, pp. 8).

Table 1.2 indicates some of the challenges faced in defining disease. Susser (46), Boorse (47), Marinker (61), Eisenberg (58) and Engel (57) all sought to define disease in terms of pathology or biological (or even molecular) dysfunction or disorder. In

contrast, Engelhardt (62) and Fabrega (60) define disease as a linguistic or social construct. The importance of this difference becomes clear when claims about the presence of disease are disputed based on behavioral abnormalities, gender identities, and sexual behavior, as well as certain somatic conditions, such as body height, that deviate from the population mean. In all these cases, both claims of disease and definitions of disease can become highly contested.

Regardless of the conceptual intricacies involved in defining disease, a common theme that emerges in all the proposed definitions is a state (or process or function) that deviates from what is considered normal (by society, by the medical profession, or by some subset thereof). In particular, the medical profession tends to focus on the disease aspect of the health problem and operationalize it as clinical or biomedical findings, that is, something that physicians may touch or measure (61). However, to designate a condition as a disease does not by itself imply the need for medical intervention (53).

Table 1.3 *Various definitions of illness proposed over the years.*

Author	**Year**	**Definition**
M. Susser	1968	"Illness is a subjective state of psychological awareness of dysfunction" (46, pp. 541).
S.S. Kety	1974	"Illness is a process that moves from the recognition and palliation of symptoms to the characterization of a specific disease in which the etiology and pathogenesis are known and treatment is rational and specific" (65, pp.186).
C. Boorse	1975	"Illnesses are merely a subclass of diseases, namely, those diseases that have certain normative features reflected in the institutions of medical practice" (47, pp. 56).
M. Marinker	1975	"Illness is a feeling, an experience of unhealth which is entirely personal, interior to the person of the patient" (61, pp. 82).
L. Eisenberg	1977	"Illnesses are experiences of disvalued changes in states of being and in social function" (58, pp. 11).
A. Twaddle	1994	"Illness is a subjectively interpreted undesirable state of health. It consists of subjective feeling states (e.g., pain, weakness), perceptions of adequacy of their bodily functioning, and/or feelings of competence" (51, pp. 10).
H. Carel	2016	"Illness is an internal personal emotional experience of health" (66).

Similar to disease, illness is considered to be a mode or aspect of unhealth (61). Illness is usually defined in terms of personal or subjective states, or as lived experiences (46) (See Table 1.3). As with disease, the exact definition of illness depends on underlying assumptions about the nature of health and unhealth. According to Kety and Boorse (47, 65), illness depends on the presence of disease and must be validated as such within a biomedical model. On the other hand, Marinker, Eisenberg, and Carel define illness wholly in terms of the lived experience of the individual (58, 61, 66), implying that illness can also be present in the absence of disease.

From tables 1.2 and 1.3, it appears that the definitions of illness are as controversial as those of disease. On the one hand, when conducting research on the lived experiences of patients, it is necessary to use a non-reductionist concept of illness as something that has its own existence and is equivalent to disease. On the other hand, fully decoupling illness from disease implies that any pain, suffering, or trouble in life can be seen as illness and, hence, as an appropriate substrate for medicalization.

In the case of diagnosed OC, there is no question about the presence of disease (See Section 1.4) as well as illness (Section 1.5). However, caution is warranted in conceptualizing these two interrelated aspects of unhealth in the context of OC. In our research, we have sought to explore aspects of the lived experiences of patients with OC that cannot be deduced from biomedical and clinical information. Indeed, given the significant impact of suffering that women report in their OC trajectories, we consider the risk of excessive medicalization of patients with OC as being small. Accordingly, we have chosen an inclusive definition of illness, along the lines of Marinker and Carel (61, 66). According to their definition, we understand illness as an internal, personal experience, and this has been adopted as an analytical lens for seeing and recognizing how diverse aspects of the patients’ lifeworlds indeed are part of the OC trajectory.

1.4 Ovarian cancer—The disease aspect

The evolution of modern medicine has heightened the significance of the disease aspect, and this is in alignment with the advancements in biomedical sciences rooted in physiology, biochemistry, and cell and molecular biology (42, 67). This part of the thesis explores the medical aspect of OC and provides insights into the understanding and treatment of OC within the context of current medical knowledge.

Table 1.4 *Histological subtypes of epithelial ovarian cancers and their common characteristics.*

	HGSOC	**EC**	**LGSOC**	**CCC**	**MC**
Incidence	70%	11%	3%	12%	3%
Median age at diagnosis (years)	61	56	43	55	53
Common stage at presentation	Advanced	Early	Advanced	Early	Early
Possible sites of origin	Fallopian tube	Endometrium, fallopian tube	Fallopian tube	Endometrium, fallopian tube	Tuboperitoneal junction
Patterns of spread	Very early transcoelomic spread	Usually confined to the pelvis	Transcoelomic spread	Usually confined to the pelvis	Usually confined to the ovary
Response to platinum-based chemotherapy	Chemo-sensitive	Chemo-sensitive	Chemo-resistant	Chemo-resistant radiosensitive	Chemo-resistant
Therapy response	Good	Good	Poor	Poor	Poor
Prognosis	Poor	Favorable	Intermediate	Intermediate	Favorable
Tumor marker(s)	CA125	CA125	CA125	CA125	CA125, CEA
Genetic risk factor	*BRCA 1/2, P53, RAD51C, RAD51C, BRIP*	*Lynch, MLH1, MSH2, MSH6, HNPCC*	Serous borderline tumor	*Lynch, MLH1, MSH2, MSH6, HNPCC*	Not known
Common gene mutations	*BRCA1/2, TP53, HR* defects	*CTNNB1, ARIDA1A, PTEN, MSI*	*BRAF, KRAS, NRAS, ERBB2, PIK3CA*	*PIK3CA, ARD1A, PTEN, MSI*	*KRAS, HER2, CDKN2A*
Precusor lesions	STIC	Endometriosis	Endometriosis, serous BOT	Endometriosis, BOT CCC	Cystadenoma, Brenner BOT

BRCA 1/2=breast cancer susceptibility gene 1/2; CA125=cancer antigen 125; CEA=carcinoembryonic antigen; HNPCC=hereditary non-polyposis colorectal cancer; TP53=tumor protein 53; HR=homologous recombination; STIC=serous tubal intraepithelial carcinoma, MSI= microsatellite instability

The data in the table are based on Kuroki and Guntupalli 2020 (68), Prat et al. 2012 (69), and Cummings et al. (2021) (70).

1.4.1 Ovarian cancer tumors

The ovaries have a complex structure that comprises cells from all three germ layers. As a result, ovarian malignancies can arise from stromal cells, germ cells, sex cord cells, and epithelial cells and present with distinct cancerous traits. With research on the pathogenesis of OC progressing, it has come to light that about 90% of ovarian tumors develop due to the transformation of epithelial cells, leading to the designation epithelial ovarian cancers (EOCs) (71-73). For many years, it was believed the origin of EOCs was the surface epithelium or epithelial inclusion cysts in the ovaries, but recent studies indicate the origin to be mostly either from the ovarian epithelium, fallopian tube epithelium, or the endometrium (74, 75).

EOC can be subdivided into at least five well-defined and different subtypes (Table 1.4), each with different etiologies and genetic, phenotypic, and clinical features (69, 73, 76-79) (See Table 1.4). The most common and most lethal histological subtype is HGSOC, which originates from non-invasive precursor lesions in the fallopian tubes called serous tubal intraepithelial carcinoma (80). HGSOC has distinct molecular characteristic such as mutations in the tumor suppressor protein 53 gene, homologous recombinant deficiency (HRD), and copy number changes (81-84).

1.4.2 Risk factors and predispositions

There are several phenotypic and genotypic factors associated with the risk of developing EOC, and the risk differs according to ethnicity and geographic location. In addition, different EOC histological subtypes are linked to specific risk inducing factors. The most prominent susceptibility factor is a family history of ovarian or breast cancer. For example, germline mutations in the BReast CAncer (BRCA) genes *BRCA1* and *BRCA2* are associated with a higher risk of developing EOC (especially HGSOC) (85, 86). Infact, 9–24% of all individuals diagnosed with EOC are *BRCA1/2* mutation carriers (87). If no risk reduction strategies are instituted, germline *BRCA1* carriers have a lifetime risk of 44% of developing EOC, in contrast to a lifetime risk of 17% for carriers of germline *BRCA2* mutations (88). The most potent risk-reducing strategy in *BRCA1/2* carriers is surgery in the form of bilateral salpingo-oophorectomy, which has the potential to reduce the probability of EOC development by 80% (89, 90). With increasing awareness about the role of the fallopian tubes in the pathogenesis of EOC, as well as the consequences of early menopause, a two-step alternative has been suggested: interval salpingectomy at age 35–40 years followed by delayed oophorectomy at menopause (91-93). Delayed oophorectomy may reduce the incidence of OC by 29–64% and allow women to maintain their natural hormone levels for an extended period by reducing the negative effect of early menopause (91, 94, 95).

Another important predisposing genetic factor for EOC, is the hereditary Lynch syndrome caused by germline mutations in the deoxyribonucleic acid mismatch repair genes, although its incidence is significantly lower than that of germline *BRCA1/2* mutations (96). Women with Lynch syndrome have a 3–17% risk of developing EOC. In addition, they have a predisposition for several other forms of cancer such as colorectal, endometrial, stomach, kidney, pancreatic, brain, and some skin cancers (97). According to the Manchester International Consensus Group (98), it is recommended that women with Lynch syndrome undergo risk-reducing surgery, including hysterectomy and bilateral salpingo-oophorectomy, no earlier than the age of 35–40 years or at any appropriate time point (97), however, there is variability in practice regarding the choice of preventive treatment.

Inflammation constitutes a general risk factor for cancer. For example, endometriosis, a form of chronic inflammation, has been shown to increase the risk of EOC, with the correlation being the strongest for endometroid and clear-cell EOCs (Table 1.4) (99-103). Bilateral salpingo-oophorectomy has been suggested as a protective strategy to reduce the risk of EOC in patients with endometriosis, but clinical trials are needed before a clear conclusion can be drawn (104). Another non-genetic significant risk factor for EOC is ovulation. Reviews of epidemiological studies have found that the lifetime number of ovulations, exemplified through the correlations that are known to exist between early menarche and delayed menopause, can influence the risk of EOC (105, 106). The reason for the observation is not clear, but it has been suggested that inflammation might play a role. The use of oral contraceptive pills decreases the incidence of EOC, and the preventive effect increases with the duration of oral contraceptive pill use (15). Moreover, numerous studies have explored obesity as a potential risk factor for OC. However, the results are inconsistent and do not lead to a definite conclusion, despite significant evidence indicating that obesity can negatively impact the prognosis of EOC (107-109).

1.4.3 Diagnosing, staging and screening

As the symptoms vary across patients, it is difficult to establish a standard diagnostic algorithm. Instead, the predominant symptoms are used as a guide to make decisions about the diagnostic methodologies. Diagnosis is based on a combination of imaging and laboratory examinations. The presence of intraabdominal fluid (ascites) and the characteristics of tumors are assessed by ultrasonography of the genitalia and abdomen. In addition, other imaging methods such as computed tomography (CT), magnetic resonance imaging (MRI), and positron-emission tomography-CT are used either alone or in combination. CT has been the preferred diagnostic modality for years, on account of its high specificity, sensitivity, and accuracy for the detection of tumor volume and tumor localization (110-112). Alongside these imaging techniques, certain serum cancer biomarkers, such as cancer antigen 125 (CA125) and carcinoembryonic antigen (CEA), are analyzed. The latter is included in the diagnostic laboratory test package to differentiate between OC and gastrointestinal cancers. CA125 is classified as an EOC-associated biomarker, and its levels are often elevated at diagnosis in patients with EOC (113, 114). Human epididymis protein 4 (HE4), which is also classified as an EOC-associated biomarker, has not yet been included in the diagnostic algorithms for EOC used in Norway. In some cases, particularly in stage III and stage IV disease, biopsy guided by ultrasonography, CT, or even laparoscopy may be necessary to initially establish a provisional diagnosis and later make a clinical decision regarding treatment strategies.

Staging is the description of the size of the cancer and where it is located. OC is staged according to the International Federation of Gynaecology and Obstetrics staging system from 2014 (updated in 2021) (Table 1.5) (75). Staging is based on perioperative judgements in combination with histopathological evaluation (75) and is used to stratify patients into prognostic groups, to make treatment decisions, and to gather evidence that could be used for the standardization of indicators related to survival and prognosis.

Table 1.5. *International Federation of Gynaecology and Obstetrics staging classification for cancer of the ovary, fallopian tube, and peritoneum.*

Stage I: Tumor confined to the ovaries or fallopian tube(s)		
IA:	Tumor limited to one ovary (capsule intact) or fallopian tube; no tumor or fallopian tube surface; no malignant cells in the ascites or peritoneal washings	
IB:	Tumor limited to both ovaries (capsules intact) or fallopian tubes; no tumor on ovarian or fallopian tube surface; no cells in the ascites or peritoneal washings	
IC:	Tumor limited toone or both ovaries or fallopian tubes, with any of the following:	
	IC:1	Surgical spill
	IC2:	Capsule ruptured before surgery or tumor on ovarian or fallopian tube surface
	IC:3	Malignant cells in the ascites or peritoneal washings
Stage II: Tumor involves one or both ovaries or fallopian tubes with pelvic extension (below the pelvic brim) or peritoneal cancer		
IIA:	Extension and/or implants on uterus and/or fallopian tubes and/or ovaries	
IIB:	Extension to other pelvic intraperitoneal tissues	
Stage III: Tumor involves one or both ovaries or fallopian tubes, or peritoneal cancer, with cytologically confirmed spread to the peritoneum outside the pelvis and/or metastasis to the retroperitoneal lymph nodes		
IIIA1:	Positive retroperitoneal lymph nodes only (cytologically or histologically proven):	
	IIIA1(i)	Metastasis up to 10 mm along the greatest dimension
	IIIA1(ii)	Metastasis more than 10 mm along the greatest dimension
IIIA2:	Microscopic extrapelvic (above the pelvic brim) peritoneal involvement with or without positive retroperitoneal lymph nodes	
IIIB:	Macroscopic peritoneal metastasis beyond the pelvis up to 2 cm along the greatest dimension, with or without metastasis to the retroperitonea lymph nodes	
IIIC:	Macroscopic peritoneal metastasis beyond the pelvis more than 2 cm along the greatest dimension, with or without metastasis to the retroperitoneal lymph nodes (includes extension of the tumor to the capsule of the liver and spleen without parenchymal involvement of either organ)	
Stage IV: Distant metastasis excluding peritoneal metastases		
IVA:	Pleural effusion with positive cytology	
IVB	Parenchymal metastases to extra-abdominal organs (including the inguinal lymph nodes and lymph nodes outside the abdominal cavity)	

The information in the table are based from "Cancer of the ovary, fallopian tube, and peritoneum: 2021 update" by Berek et al. (2021) (115).

1.4.4 Treatment

Based on the results from the diagnostic procedures, the decision about the preferred treatment apporach is made by a specialist multidisciplinary team (116, 117). The treatment decision is influenced by the clinical (age, performance status, comorbidity, nutritional status), biological, and molecular complexity of the disease, which is determined based on factors such as preoperative disease burden, feasibility for optimal surgical resection and a beneficial surgical outcome (118).

Surgical treatment

The surgical outcome of complete cytoreductive surgery (CRS) is today defined by the amount of the residual tumor, with no visible residual (R0) disease being the ideal outcome. Macroscopic R0 disease has been shown to be the single most important, independent, and prognostic factor for overall survival (OS). The practice is supported by results from retrospective trials, as randomized trials have not been performed due to ethical reasons. CRS incorporates hysterectomy and bilateral salpingo-oophorectomy, removal of the omentum, and a comprehensive exploration of the peritoneal cavity. Additional procedures are conducted as needed to achieve complete cytoreduction. Evidence shows that the experience and education of the surgeon have a major impact on the outcome of surgery, and that being treated by a gynecologic oncologist and at a teaching hospital improves survival significantly (119-121).

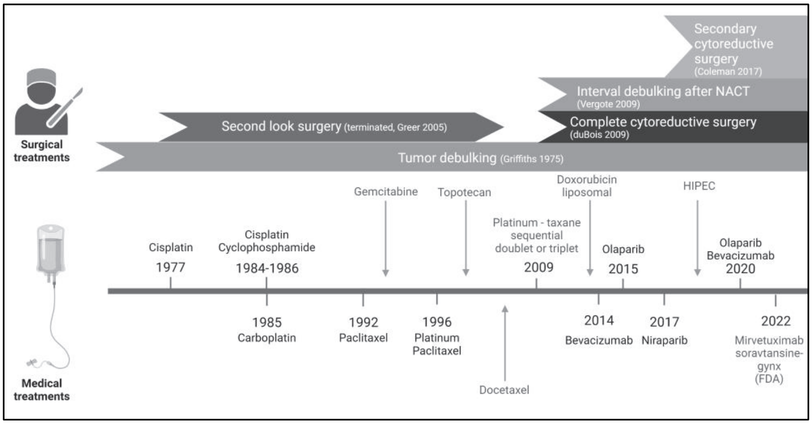


***Figure 1.4** OC treatment timeline*

The information is adapted from several publications (119, 122-125). The diagram was created using biorender.com.

OS remains the primary endpoint, however the assessment of QoL has gained prominence as a central outcome measure in surgical cancer treatment (See also

Section 1.5). To achieve the necessary surgical outcome many patients with OC require extensive surgery with the risk of higher morbidity and mortality. However, it still remains unclear which patients are most likely to benefit from primary debulking surgery and how extensive the surgical effort should be (121). After the initial surgery, most patients are offered chemotherapy, often combined with maintenance therapy with bevacizumab and/or PARPi.

Some patient groups are not suitable candidates for surgery due to age, high degree of comorbidity or complication risk, or complete cytoreduction is evaluated as not achievable due to tumor localization. For many years, the combination of CRS followed by multiple cycles of chemotherapy was the only available treatment regimen for OC at diagnosis (Figure 1.4). Today, patients having advanced, inoperable disease (stage III/IV) or poor performance status, can alternatively be offered an alternative treatment strategy that involves using neoadjuvant chemotherapy (NACT) to reduce the tumor load before considering CRS/interval debulking surgery (IDS). The decision of PDS versus NACT/IDS should be considered on an individual patient level (120, 126). NACT/IDS was introduced to minimize surgical complications and to improve the likelihood for satisfactory tumor reduction. Recently, there has been an increased research focus on comparing survival and QoL outcomes between PDS and NACT/IDS (127, 128) (See also Section 1.5). Hopefully insights gleaned from the ongoing TRUST trial which involves ultra-radical surgery will shed light on the advantages of compared to primary debulking surgery.

Although both PDS and NACT/interval debulking, accompanied with first-line chemotherapy improves survival, approximately 80% of the patients with advanced disease will experience relapse. The role of secondary surgery has been investigated for several decades. Results from three randomized phase III (129-131) favors secondary cytoreduction followed by chemotherapy in terms of clinically meaningful benefits for pre-selected patients, however long-term benefits are still not clear. At present, secondary cytoreduction is not considered a part of the standard clinical care for platinum-non-eligible relapsed OC in Norway, and should only be considered at localized and potential platinum–sensitive relapses (132).

At the end-stage patients with OC may experience multiple symptoms (malignant bowel obstruction, dysfunctional peristalsis, unremitting pelvis pain, fistula formation, tumor necrosis, pelvic sepsis, and chronic hemorrhage) caused by increasing tumor burden in the abdomen (133). Palliative surgery might be considered for symptom relief. The complexity of the interventions differs from advanced surgical procedures with potentially complications threatening QoL to minor interventions like nasogastric tubes, pigtail catheters, and percutaneous gastronomy tubes (133).

Chemotherapeutic regiments

Systemic platinum-based regiments were first introduced in the treatment of OC in the late 1970s, and as a potential rechallenge in the late 1980s (134) (Figure 1.4). During the next decades gemcitabine, topotecan, docetaxel, platinum-taxane sequential, doublet or triplet and doxorubicin liposomal were introduced. The strategies for managing recurrent OC have shifted from a scheduled-based decision-making process to patient-centered, biologically driven algorithms.

Platinum-based regiments are important components in the treatment of OC. Cisplatin was the first platinum-based chemotherapy to be introduced, however results from two randomized trials comparing cisplatin / paclitaxel with carboplatin / paclitaxel in women with stage III and IV EOC after surgery showed that carboplatin (an analog of cisplatin) had the same efficacy as cisplatin. At the same time the tolerability and QoL score were higher in the carboplatin treatment groups (135-137). From 1996 paclitaxel was incorporated in the platinum-based regimen, and today all patients with stage $\geq$ II are offered adjuvant treatment with 6 cycles of platinum-taxane regimens. A minimum of 3 cycles is recommended for patients with high-risk disease like clear-cell carcinomas, and stages Ia grade 3, Ib or Ic grade 2 or 3 (85, 138, 139).

Patients that are selected for NACT receives the same regimen with a total of 6 platinum/taxane chemotherapy cycles, dosed as 2-4 cycles pre-operatively and 2-4 cycles post-operatively (132, 140, 141).

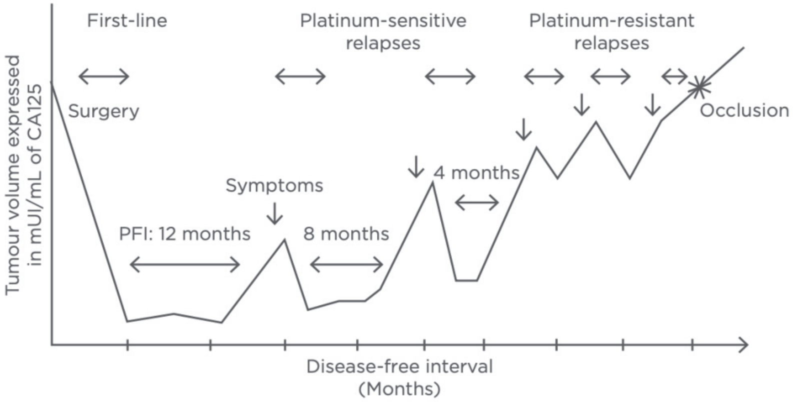


Figure 1.5. *The natural evolution of OC. PFI: platinum-free interval.*

The graph has been reproduced from “A Theoretical View of Ovarian Cancer Relapse” by Giornelli and Mandó (2017) (142) (Creative Commons Attribution 4.0).

Drug resistance emerges in 80-90% of those patients initially diagnosed with widespread disease, making this an important hindrance in managing OC (143). The median PFS after first-line therapy with carboplatin / paclitaxel is 17.5 months, while the subsequent relapses will occur with shorter intervals (Figure. 1.5) (144). At relapse the patients may be assigned to one of multiple treatment regimens, although the aim of the treatment shifts from curative to palliative.

Relapses are divided into two groups: the platinum-eligible and the platinum-non-eligible. Based on present knowledge, platinum-based systemic treatment should be considered for all patients who have a reasonable likelihood of responding to these regimens at recurrence (134). Guidelines from 2019 defines platinum-non-eligible as progression immediately after platinum-based therapy or those having contradictions to platinum (145, 146). Well-established platinum-combination drug regimens used after first line treatment are carboplatin/paclitaxel, carboplatin/gemcitabine and carboplatin/pegylated liposomal doxorubicin. However, the combination of carboplatin/paclitaxel provides cumulative toxicities such as neurotoxicity and myelosupression that may influence treatment selection later on during the treatment trajectory (147). Gemicitabine/carboplatin has shown to prolong progression free survival (PFS) among platinum-eligible patients, also with a risk of myelosuppression, while pegylated liposomal doxorubicin/carboplatin has less toxicity, yet cardiotoxic, and is partly therefore often the preferred choice of treatment in second line (148, 149).

Unfortunately, at some point the OC disease will become platinum-non-eligible. Patients with platinum-non-eligible OC will most often be offered gemcitabine, pegylated liposomal doxorubicin or weekly paclitaxel. In addition, targeted therapeutics have been tested and are increasingly used in recurrent settings. Later recurrences will manifest themselves with progressively shorter intervals (Figure 1.5) and at the end, the treatment, if offered, will only result in short-lasting symptom relief and the use of chemotherapy regimen should therefore be restricted.

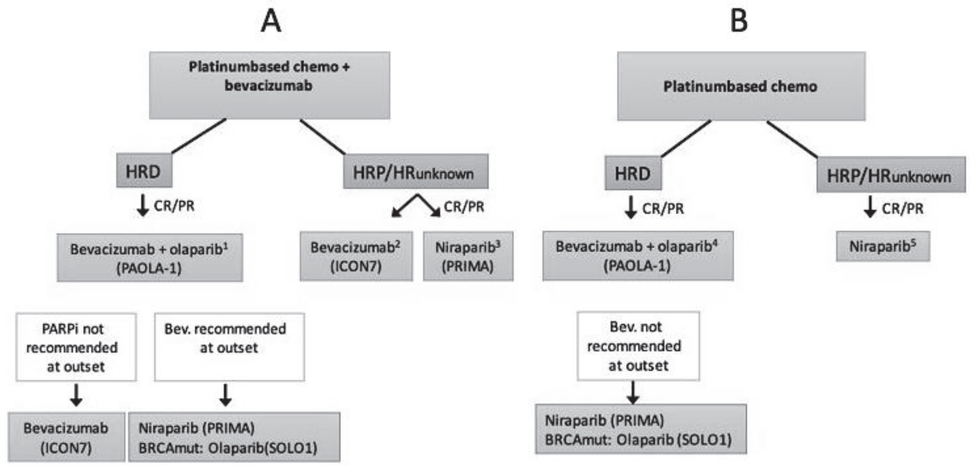
Targeted therapeutics

For many years the combination of CRS and chemotherapy was the only available treatment options for OC. Since the landmark paper by Hanahan & Weinberg in 2000 describing characteristics that enable tumor expansion and metastatic spread as “hallmarks of cancer”, there has been an increased focus to identify more selective therapeutic targets and more individual treatment approaches also for patients with OC.

In Europe only drugs targeting the hallmarks genomic instability (the PARPi–olaparib, niraparib, rucaparib) and angiogenesis (the vascular endothelial growth factor-inhibitor bevacizumab) are approved. The Food and Drug Administration, United States, has in addition, approved two drugs that target folate receptor α (FRα), mirvetuximab soravtansine-gynx for platinum-resistant OC and the fluorescently labeled antibody pafolacianine to be used for image-guided surgery.

Angiogenesis plays an important role in the development of OC, both for tumor growth, establishment of metastases and production of ascites (150, 151). Many clinical studies have evaluated the effects of angiogenesis inhibition (151-153). Bevazicumab was the first targeted therapy approved in Norway for use in patients with advanced OC stage III or IV, as first-line therapy in combination with standard chemotherapy and maintenance monotherapy. The effect of bevacizumab is best for the so-called high-risk subgroup (stage III or IV with >1 cm residual tumor tissue) (154). Results from two larger phase III trials, the GOG-0218 and the ICON7 indicate that bevacizumab is generally well tolerated, although hypertension was reported more frequently as an adverse event in the groups receiving bevacizumab (155, 156). The first results from the PAOLA-study, combining maintenance with bevacizumab and PARPi was published in 2019, showed a significantly increase in PFS (22.2 months vs. 16.6 months) among those also receiving olaparib (157, 158). Ever since there has been a discussion in the professional environment focusing on how one can identified the patients with the largest benefit from the combination (132). Bevacizumab may also be used as part of NACT regimen, however with caution due to its potential interference with postoperative healing and therefore medication should be withheld for 4-6 weeks prior to interval debulking surgery. Moreover, findings from the AURELIA trial demonstrated that chemotherapy combined with bevacizumab improves PFS with 6.7 months for platinum-non-eligible OC relapses (149). In addition, bevacizumab administered every 3-4 weeks may also reduce the ascites production (159).

Cells are using different mechanism to repair damage on their DNA. Normal cells will mainly repair the double strand breaks with the help of homologous recombination, while the PARP enzyme support the single-strand repair. PARP inhibitors are a group of drugs that target a cell's ability to repair single-strand breaks. As many cancer cells already have compromised double-strand break repair capabilities (called HRD), the introduction of PARP inhibitors means that these cells cannot repair damaged single-strand break either. This will result in cumulation of unrepaired DNA damage and the tumor cells will die trough a mechanism called syntetic lethality. Cancer cells with defects in *BRCA1/2* and/or homologous recombination deficiency have been shown to be particularly sensitive to PARP inhibitors (160, 161). Testing for germline *BRCA* 1/2 and HRD status are recommended at OC diagnosis (162, 163). The introduction of HRD testing in Norway has been challenging and at present almost all tests are performed abroad. The results serve the dual purpose of identifying familial predisposition to cancer and guiding therapy selection.



Footnotes:

[1] Can be replaced with niraparib if not recommended.

[2,3] There is no study comparing bevacizumab and niraparib in this group. Treatment decisions are based on patient's preferences, and pros vs. cons.

[2] Bevacizumab is preferred in cases of inoperable disease, RD >1 cm, and/or stage IV. ICON7 (unselected for HR status) showed a 5-month improvement in overall survival for patients with inoberable disease, RD >1 cm, and stage IV who received bevacizumab.

[3] Niraparib is preferred when RD < 1 cm and should also be considered if HRD testing has not been performed. There is uncertainty about the effect in the HRP group since the PFS gain of 2.7 months in PRIMA is based solely on an exploratory

[4] Can be replaced with niraparib in the case of a contraindication.

[5] It's uncertain whether there is a benefit from niraparib since patients in stage III with no residual disease were not included in PRIMA. Treatment should be considered based on patient's preferences and the pros and cons. Alternatively, no maintenance treatment may be an option.

Abbreviations/definitions:

EOC=Epitelial ovarian cancer; **RD**=Residual disease; remaining tumor after surgery; **NACT**=Neoadjuvant chemotherapy; **HRD**=Homologous recombination deficiency: Impaired ability for homologous recombination, either due to BRCA1/2 mutation and/or genomic instability; **HRP**=Homologous recombination proficiency: Preserved ability for homologous recombination; **CR**=Complete response; **PR**=Partial response; **HRunknown**=Homolog recombination status unknown because of 1.HRD test not performed (assume that up to 30% are HRD), and 2. HRD test performed but not assessable (due to insufficient tissue, inadequate sample due to NACT, test error, or inconclusive result).

Figure 1.6 *Flow chart depicting PARPi regimens (alone and in combination) for high-grade advanced (stage III/IV) primary platinum-sensitive EOC.*
(A)The regimen for stage IV, inoperable RD comprising NACT is shown.
(B) The regimen is shown for cases with no RD
The information has been produced from "Gynecological cancer — guideline" by the Directorate of Health 2024 (164) (Reprinted with permission).

The most well-characterized PARPis are olaparib, niraparib and rucaparib (165), and their effects have been shown in multiple clinical trials (7, 157, 166-169), and due to the exceptional effects shown, both in the primary setting and at recurrence in platinum-sensitive disease, in the last decade the United States Food and Drug Administration and the European Medicines Agency have approved the use of these different PARPis as maintenance therapy for OC. In Norway the use olaparib and niraparib maintenance are approved as maintenance therapy in the primary setting for prespecified groups alone or combined with bevacizumab. (Figure 1.6). Maintenance therapy with olaparib or niraparib is also recommended at recurrence for patients with PARPi näive HGSOC that have experienced response on platinum-based chemotherapy until progression.

The recent published study OReO which investigated the impact of PARPi rechallenge in platinum-sensitive relapsed HGSOC demonstrated only a negligible clinical effect and rechallenge with PARPi is currently not recommended (170). Several attempts have been and are ongoing to improve the response rates of PARPis by combining PARPis with other targeted drugs, however drug resistance is a remaining challenge (171).

During the last decade immune checkpoint inhibitors have been increasingly used in the treatment of other solid tumors due to their capability to potentially trigger antitumor responses (172). Clinical efficacy of immunotherapy in OC has however not yet been identified, and immunotherapeutics are not in use in clinical practice (173).

Treatment de-escalation

The introduction and implementation of bevacizumab and PARPis have improved PFS rates and it seems like introduction of PARPi as front-line treatment now translates into an OS benefit, at least for subgroups of patients (174). These observations have facilitated a shift in focus towards the concept treatment de-escalation (175, 176). The idea signifies a paradigm shift in treatment strategy moving away from maximum tolerated doses to adopting the smallest effective dose. This attempt aims to minimize unnecessary toxicity, enhance QoL, and promote a more personalized approach to cancer treatment and care (176). Numerous active clinical trials (NOW, OLAPem, NUVOLA (177), IMPACT , NANT, OPAL-C, N-PLUS, NEO) seek to customize OC treatment by refining first-line chemotherapy by exploring strategies to minimize systemic interventions, both for patients selected for PDS and NACT/IDS. The results from these trials are still not mature.

Follow-up care in OC

Between or after treatment patients with OC will be offered scheduled follow-up appointments with a gynecologist. The purpose of follow-up is to detect relapses, monitor side effects, and address psychosocial challenges such as anxiety, depression and fear of recurrence (178). The term *side effects* is commonly used to describe and report harmful side effects of pharmaceuticals and surgeries: “Jointly unintended effects due to the causal capacities or invariances of an intervention" (179, pp. 1), however the definition may vary across health researchers and health authorities.

In Norway OC follow-up is recommended every 3-6 months during the first 2 years, there after every 6 months for a total of 5 years (132). However, some patients with low self–management struggle to adhere to the recommended follow-up regimen, demonstrating the need for additional information and guidance for this group of patients (180). There is no evidence for recommending routine follow-up to improve PFS and OS (146), and the present regimen is based on tradition.

Palliative treatment and palliative care

Despite advancements in primary OC treatment, the majority, as noted, will ultimately experience relapse and succumb to the disease. Surgery, chemotherapy, and targeted therapy all play a role in the palliative treatment of OC. However, it is important not to confuse palliative treatment with palliative care. Palliative care extends beyond the conventinal scope incorporating elements like family-centered care, the optimization of QoL, and the prevention and treatment of symptoms. It involves caring for the whole person rather than solely focusing on the disease.

Palliative care starts when cure is no longer a possibility - the reality for many patients with OC already at the beginning of their cancer trajectory. However, according to a survey among members of the European Network of Young Gynae–Oncologists there is no formal training or teaching of palliative care for gynecologic oncologists or gynecologists working with gynecologic oncology (181). Findings from a small mixed-method study indicates the presence of two worldviews of palliative care among physicians: the biomedical perspective and the holistic perspective (182). The study differentiates between the biomedical perspective, which emphasizes curative goals and associates palliative care primarily with end-of-life care, and the holistic perspective, considering it an ongoing component integrated into the overall treatment approach. From a patient perspective there are several barriers of accepting and attending palliative care, one being the importance of a palliative care recommendation from their gynecologist (183).

Although Norway has developed a robust palliative care system, the transition from curative treatment to palliative treatment and care is unclear (see Section 1.2). The Norwegian Directorate of Health is presently seeking input on new guidelines regarding limitation of life-prolonging treatment. The new guidelines strive to enhance the QoL for patients in the final stages, uphold patients' rights to self-determination, foster informed decision-making processes, and mitigate overdiagnosis and overtreatment during the terminal phase of life (184).

1.5 Ovarian cancer – The illness aspect

This section is devoted to the scientific knowledge on the illness aspect of OC. As explained previously (Section 1.3.1), we have chosen the view of illness as an inclusive concept comprising the physical, psychological, and social dimensions, both quantitative and qualitatively reported in terms of the side effects of treatment, health-related quality of life (HRQoL), and the lived experience of OC.

1.5.1 Health-related quality of life (HRQoL)

Over the years, there has been growing acknowledgment that to be diagnosed with advanced cancer and to undergo intensive, aggressive, toxic, and radical cancer treatments can profoundly influence patients' perception and experience of health. In their paper *Measuring quality of life: Using quality of life measures in the clinical setting* Higgins & Carr argue that "No illness exists in a vacuum", indicating a need for capturing the personal and social context of a human along with information of the outcome of disease and treatment (185, pp. 1297).

The term HRQoL was introduced as a tool to measure how the disease and medical treatment affect people's health (186, 187). Factors that forcast a decline in HRQoL include financial problems, social support, parenting concerns, feeling desperation about the future, and stress (188-191). In spite of its arguably narrow scope on health and illness (192, 193), the HRQoL measure enable us to monitor "the difference, or the gap, at a particular period of time between the hopes and the expectations of the individual and the individual's present experiences" (194, pp. 125). This encompasses various outcomes, including health status, physical functioning, symptoms, psychosocial adjustment, well-being, life satisfaction, and happiness – thereby including all of life and not just the physical health status (185, 186). This is illustrated by Wilson and Cleary (187) in their conseptual model of HRQoL, which covers five measures for patient outcomes, see Figure 1.7.

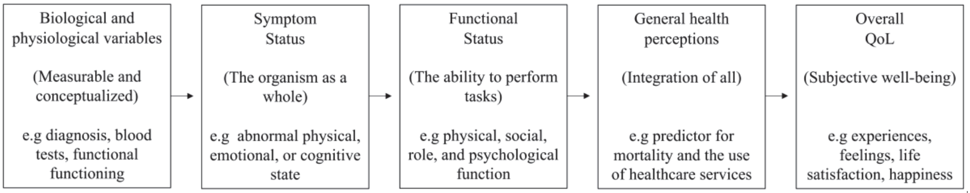


Figure 1.7 *Model of patient outomes and their relationship in HRQoL* (195).

In clinical practice, HRQoL is commonly assessed by standardized patient-reported outcomes measures (PROMs), especially within the field of cancer (195). The objective of PROMs is to "obtain information of the patient experience and health status by the one experiencing it, and to measure the health-care quality" (196, pp. 3, 197). In other words, PROMs can be used to assess and document which aspects of life have had the greatest impact following cancer disease and cancer treatment over time (200). However, while there exists a considerable body of literature on PROMs, challenges persist regarding the reliability and validity of the tools employed to assess them (195). Originally, PROMs were developed for use in clinical research (198, 199). As the number of clinical trials grew, the need for improved quantification of HRQoL by PROMs emerged. Additionally, there has also been increased focus on collecting patient experiences (that is, patients' feelings, their physical and psychological outcomes, and their perspectives on disease and treatment) through PROMs in order to improve patient-centered quality of care and to evaluate the healthcare systems (200, 201).

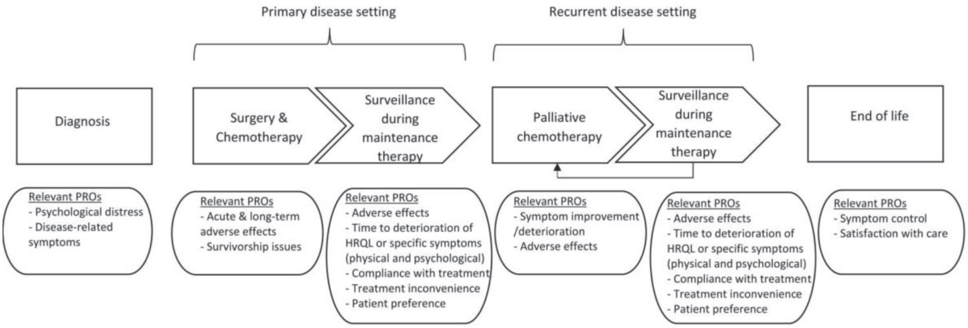


Figure 1.8 *Relevant patient-reported outcomes to assess throughout the disease and treatment trajectory in OC clinical trials and practice.*

The schematic is reproduced from "Patient-Reported Outcomes in Ovarian Cancer: Facilitating and Enhancing the Reporting of Symptoms, Adverse Events, and Subjective Benefit of Treatment in Clinical Trials and Clinical Practice" by Campbell et al. (2023) (202) (Creative Commons - Attribution-NonCommercial 3.0 Unported).

PROMs are divided into two groups, namely generic and disease-specific, and the different PROMs may be used throughout the entire disease and treatment trajectory (199) (See Figure 1.8). There are several well-established PROMs for OC that include both generic and disease-specific forms such as the general European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30) (203) and the disease-spesific version for OC (QLQ-OV28) (204), as well as the Functional Assessment of Cancer Therapy - General (FACT-G) (205), and the OC-spesific version FACT - OC (FACT-O) (206).

Studies have indicated that PROMs promotes discussions on patient outcomes as well as symptom control (207) and may be used in end-of-life patient-physician communication to improve care (208). Unfortunately, PROMs is seldom used in clinical practice due to barriers such as time, workload, cost, and patient burden (209). Three years ago, the Cancer Registry of Norway initiated a comprehensive three-year survey containing questionnaires for capturing patients' personal health experiences, potential delayed effects, and HRQoL for specific cancer diagnoses. This program is anticipated to mark the initiation of a novel paradigm shift for both the reporting and measurement of illness (210).

1.5.2 PROMs in Ovarian Cancer: patients experience

As outlined in Section 1.2, most patients with OC tend to follow a consistent disease-specific trajectory and navigate through distinct key points of vulnerability. Diminished HRQoL among patients with OC is associated with long-term physical side effects, strained family relationships, social isolation, and loneliness—all of which are intricately connected to the experience of illness (211). Furthermore, the inherent progression of OC, as outlined in Section 1.4, exposes most women diagnosed with OC to the likelihood of experiencing numerous side effects that influence their HRQoL (Table 1.6). The pattern of these side effects differs between patients, and the effects can stem from the disease itself and its progression, as well as the subsequent treatments employed. While some of these effects are expected and/or are dose-dependent, it is not possible to predict some of the other effects. Further, while some of the side effects may arise during or shortly after treatment (acute/short-term side effects), others may appear several years after the end of treatment (latent/long-term side effects). While the acute symptoms induced by the cancer itself and its treatment typically diminish within a year after treatment (212), it is crucial to remember that the extensive treatment and associated side effects can still significantly impact the treatment-decision process for subsequent treatments as outlined in (213).

Although approximately 70 % of patients with OC in Norway undergo surgery (214), there are few reported side effects that are linked directly to surgery. However, patients undergoing PDS have a higher risk for complications than those undergoing NACT/IDS (215). In a large cohort of patients with OC, it was observed that potential complications arising from both PDS and NACT/IDS in the short term include pleural fluid accumulation, infections, and bleeding (216). A comprehensive list of additional complications and side effects is provided in Table 1.6. Regarding the impact of surgical complexity on postoperative QoL, the evidence in the literature is inconclusive (217, 218).

Chemotherapy is a systemic treatment that is designed to inhibit tumor growth (219). Although the purpose is to target malignant cells, chemotherapy also has an impact on normal proliferating cells. This may lead to tissue damage and other toxic effects (220-

222). Peripheral neuropathy is a common side effect of chemotherapy with taxanes that not only manifests during the treatment phase but also persists among individuals who have achieved long-term survivorship (223-225). However, although platinum-based treatment has several side effects (Table 1.6), results from a review by Pergialiotis et al. indicate that patients report improved QoL after receiving platinum-based treatment (226). Another frequently reported side effect of chemotherapy is "chemo brain," which is described by many as brain fog and is associated with carboplatin use (227). In the case of chemotherapy, numerous patients with OC have explained that the period following the end of treatment is more challenging than the treatment itself (228).

Table 1.6 *Overview of the most frequently reported side effects of OC treatment.*

PDS or NACT/IDS	Pleural fluid, hydronephrosis, infections, bleeding, stoma necrosis, intra-abdominal abscess, anastomosis leakage, venous thromboembolism, lymphoedema, and urinary tract injury.
Chemotherapy (platinum/taxane)	Allergic reaction, leucopenia, neutropenia, thrombocytopenia, anemia, alopecia, fatigue, nausea, constipation, diarrhea, peripheral sensory neuropathy, vomiting, changes in appetite, cardiovascular disease, reduced kidney function, frequent urination, musculoskeletal pain, dry and sore mucous membranes in mouth and throat, depression, anxiety, feeling sad, frequently being irritated, paronychia, dissatisfaction with one's appearance, and lack of energy.
Bevacizumab	Hypertension, proteinuria, and bleeding.
PARPi	Shortness of breath, fatigue, pale skin, tachycardia, bruising/bleeding, diarrhea, immunodeficiency, constipation, abdominal pain, nausea, headache, cough, and sleep problems.
Immunotherapy	Infusion reaction, and autoimmune reactions in the lungs; intestines; liver; hormone-producing glands; kidneys, or other organs.
Disease burden/recurrence	Fatigue, insomnia, appetite loss, frequenturination, abdominal bloating/discomfort, dyspnea, pain, constipation, and emotional functioning.

The side-effects listed are based on those published in severa sources (216, 225, 229-236).

The presence of effusions such as ascites is common during the disease course, and the accumulation of ascitic fluid is known to cause diminished mobility, increased pain and discomfort, and a notable decline in both physical and mental well-being in many patients with OC (237).

In the case of recurrent OC, the disease burden is often high. A survey among women with recurrent OC who have undergone at least two lines of chemotherapy found that many of them reported experiencing fatigue, insomnia, appetite loss, urinary problems, and abdominal discomfort (including nausea, vomiting, bowel dysfunction, and anorexia) (Table 1.6) (236). Interestingly, the same study also compared outcomes reported by the patients with physician's reports of symptoms and demonstrated that the symptom burden reported by patients was higher than the level of burden assessed by physicians.

Patient-reported outcomes of illness in ovarian cancer survivors

Very few studies that have investigated the long-term sequelae of OC. Nevertheless, it is well-established that patients with OC struggle with persistent psychological concerns, sexual inactivity, and post-treatment fatigue (238). Additionally, anxiety, neuropathy, and the looming fear of recurrence have been identified as supplementary concerns (239, 240) (See Table 1.7 for detailed list of patient-reported-outcomes).

Table 1.*7 Patient-reported late-term effects of OC.*

Late term effects	Fatigue, neuropathy, cognition, anxiety, pain, loss of interest in sex, memory problems, sleep loss, depression, and alopecia
Emotional impact	Fear of recurrence, fear of dying, fear that treatment will not work, getting life back on track after treatment, regaining sexual intimacy with a partner, relating to family and friends

In order to gather more information of the long-term effects of cancer in survivors, the European Organisation for Research and Treatment of Cancer Quality of Life Group has launched a project, SURV100, that aims to create a questionnaire tailored for individuals who have survived cancer (241) and a clinical trial for investigating QoL during follow-up of gynecological patients (242). In addition, there has been greater focus in recent years on "response shift" in the reporting of PROMs through pre-diagnosis/treatment and post-diagnosis/treatment assessment of PROMs. The term refers to the ability of cancer patients to adapt to and cope with the changes, both physical and psychological, imposed by cancer and its treatment (243). The transition is portrayed as a process involving reassessment, readjustment, and conceptualization. The exploration and measurement of this transformation offer valuable insights into the adaptive capacities of cancer patients throughout their cancer trajectory (243). In the context of OC, measuring response shift can provide insights into the symptom burden at specific points in the disease trajectory. An example of this is the longitudinal measurement of symptoms of fatigue, anxiety, and depression, which have been found to be high immediately after surgery but improve during chemotherapy treatment (244).

1.5.3 Patient narratives of the ovarian cancer experience

Patients' narratives provide rich descriptions and details of their illness experience that PROMs cannot grasp (245, 246). Emotions, feelings, and moods may individually or collectively, influence the experience of illness (246), such as intertwining of fear of premature mortality with the pervasive impact of fatigue (247). Fatigue goes beyond just feeling tired. It encompasses the way individuals navigate their daily activities and their interactions with family and friends, as well as shapes their identity and sense of self (6).

A phenomenological approach aimed at understanding the cancer experience would focus on delving into how the presence of cancer and the process of undertaking treatment infiltrate the patients' inhabiting of a body afflicted by a condition rather than merely dealing with a body affected by a disease (21). These experiences vary widely and resist easy generalization, yet they offer a more profound understanding of the phenomenons compared to insight gained from PROMs (248).

Challenges related to existence among cancer patients have been studied for several decades. The cancer experience is described as being colored by uncertainty, unpredictability, isolation, vulnerability, injustice, discomfort, and redefinition, as well as being in a state of liminality, being alienated, and distancing oneself from the rest of society ("threshold people") (245, 249). Furthermore, cancer survivors have expressed how the experiences caused by cancer include existential changes such as fear of recurrence, fear of illness, and fear of death (246, 250).

Surviving cancer can profoundly reshape one's life and offer a second chance. However, living beyond cancer may change one's life and is experienced differently by individuals. While some patients describe life beyond cancer as being given an opportunity to have a second chance at life and to enjoy it, others describe life beyond cancer as experiencing a form of suffering stemming from life's constraints, having inner struggles with becoming more selfish, and the sence of burden on society (that is, they report experiencing illness even when they are viewed as healthy by society) (251).

Time frame

As detailed in Section 1.2, the trajectory of OC is marked by early onset of functional decline, with many patients already in the palliative phase at diagnosis. Being diagnosed with OC is a confrontation with death, opens patients to the idea of life being temporal, and forces the experience of new challenges such as diagnostic delay, vulnerability during treatment, side effects, lack of treatment options, lack of support from and withdrawal of family and friends, and changes in sexuality and intimacy (252, 253). The existence is characterized by physical transformations, and the burden of side effects is underpinned by a pervasive sense of existential threat. At first there is a shock from seeing how much the disease affects everything; this is followed by a period of adjustment as patients come to terms with their new reality and; eventually, efforts to adapt and live within this altered state (254).

The perception of time also undergoes a significant transformation for those diagnosed with a serious disease, and in their resent publication, Moskalewicz et al. (255) highlight how patients with OC describe their relationships as time changes. The past becomes a distant "before" the disease; the present is reduced to a narrow window out of sync with social rhythms; and the future is dominated by an anxious anticipation of medical updates and the specter of mortality (255).

On completion of the initial treatment, women express deep joy and gratitude yet simultaneously grapple with feelings of anxiety, concern, and uncertainty about the possibility of disease recurrence (256-258). In the event of relapse, women with OC feel hopeful that new treatments will impede the disease's progression and also feel profound gratitude for any additional time granted, underscoring the profound shift in perspective that accompanies a life lived in the shadow of OC (259). Furthermore, they also undergo a sense of loss regarding their future, a disconnection from themselves and their surroundings, and the burden of responsibility for the outcomes they may confront (258).

Bodily changes

In her book *Memoir of a Debulked Woman,* Susan Gubar describes her personal journey through OC as “I suffered less from the disease, more from grotesque surgeries and procedures performed by the most enlightened and proficient practitioners of contemporary medicine” (260). The surgical removal of female organs can evoke emotions of sadness and alienation due to the void left behind, discomfort arising from temperature fluctations, and shifts in sexual relationships (261). The physical journey is characterized by the fear of stress on vital organs induced by chemotherapy and the loss of strength (259). Despite rendering patients’ bodies fragile, chemotherapy is synonymous with life (259). The sensation of comfort is strongly tied to both resources and challenges and can be defined as “the balance point between an individual’s resource pool and the challenges faced” (262, pp. 230).

Both the disease and the treatment are regarded as dangerous, significantly influencing women’s body, and shaping their perception of their own body (263). However, rather than comparing their bodies to other women with OC, they assess their present bodily experience in relation to their pre-treatment period during the disease, which leads to a sense of comfort (263).

Apart from the treatment and the illness transforming women’s perception of their bodies, there is also an account of an anticipatory experience regarding changes in the body being an indicator of potential recurrence (256, 264, 265). As the disease progresses, patients with OC may experience physical limitations, and as a result they may feel compelled to monitor and protect their bodies to preserve their physical functioning (259). However, despite the grueling nature of the treatment and the extensive array of side effects, women diagnosed with OC choose to undergo the treatment, motivated by the dual goals of prolonging their lives and providing support to their families (266). As their bodily strength fades, and the need for help and care grows stronger, the experience of vulnerability in interactions with healthcare professionals also increases (263).

Uncertainty and hope

Uncertainty in illness is described as “the inability to determine the meaning of illness-related events” (267, pp. 225). The experience of uncertainty is well described among women diagnosed with OC and is associated with a sense of abnormality, recurrence, late effects, treatment, treatment decisions, the future, relationships, patient–physician relationship and communication, social support, social role, self-image, health, and finances (256, 257, 268, 269). Women living with OC find themselves with restricted access to information about the disease. Simultaneously, they navigate a sense of ambivalence in relation to the information they receive about the disease—both beneficial and distressing—and this leads to increased uncertainty (35, 256, 270). The array of uncertainties faced by the women create an experience in which safeguarding “their sense of self” becomes necessary, and this influences their choice of caregivers, decisions regarding treatment, and overall sense of well-being (257).

When confronted with a serious and life-threatening disease that carries the prospect of death, hope emerges as a pivotal dimension in navigating the challenges of the illness and the accompanying experience (271). However, hope is not a static condition. Rather, the pendulum swings between hope and despair, and the experience of low hope is associated with reduced QoL and low self-esteem (272). An individual’s hope is based on the life situation of the person and their perseption (271). In his book *The Anatomy of Hope*, Jerome Groopman describes the biological effect of placebo, belief, and expectations within the concept of hope (273). By preserving hope in medicine, one is provided with a way out of the harm caused by the tragic disease and the failure of a cure (274). Hope impacts decisions across life’s facets (271). One of the few studies exploring the hope experienced by women living with OC found that hope among patients with OC is linked to the presence of bodily comfort (275). Moreover, hope is what enables women to live with the threat of death caused by OC. Hope can be shaped by interactions. healthcare professionals and support from caregivers (254). In clinical practice, physicians experience difficulties in finding a balance between nurturing the hope of cancer patients while simultaneously providing a realistic perspective of the prognosis (276, 277).

1.6 Interaction with formal careproviders

The vital role of interactions between cancer patients and healthcare professionals for providing optimal care is well-recognized (278, 279), and have been thoroughly described (35, 250, 252, 253, 256, 263, 270, 279-281). Despite this established knowledge, interactions between healthcare professionals and cancer patients is often challenging and fails to meet the patients' needs. This challenge is exacerbated by the evolving informational and physical needs of patients throughout the various stages of the disease and their cancer journey (250, 282, 283).

Navigating life with cancer involves the initial shock of diagnosis and the feeling of loss of control over one's life. At the same time, patients also need to manage the disease independently while seeking guidance from healthcare professionals (251). Interactions between patients with OC and healthcare professionals necessitates a two-way approach. Patients must express their needs clearly and receive acknowledgment, respect and assistance from healthcare professionals (279). In this context, it is crucial to acknowledge that patients encounter unique difficulties in expressing their experiences, especially when grappling with recurrence as opposed to earlier stages of the disease (259).

As described in Section 1.4, extensive research is being conducted to improve the therapeutic options and prognosis of OC. However, the discussions around the extension of survival requires not only information about the disease, but also that the health care provider and patient delve into consequences and potential complications of the treatment and extended survival, and the constraints as well as psychosocial concerns associated with cancer progression (281, 284, 285). The OC patients' perception of being acknowledge as unique individuals during interactions with healthcare professionals is essential for cancer patients experience of being recognized as a unique person (285). Hence it is concerning that individuals with OC may face decreasing levels of compassion and empathy within the healthcare system (286) even as healthcare professionals increasingly recognize the importance of preserving patients' well-being (35, 253, 279). This can further be exacerbated if the information provided is inconsistent, especially about the so called "Little Big Things"; small, yet significant factors like treatment scheduling, pharmacy services, parking, insurance, and discharge procedures (253).

A recent national Norwegian cancer strategy initiative acknowledge the complexities inherent in new treatment options and decisions and aims at improving access to information, engage patients, and involve users in cancer care (287). The significance of interactions between cancer patients and healthcare providers is highlighted, emphasizing the importance of receiving compassionate care and support as well as the necessity for expertise and resources from both cancer patients and their healthcare providers (287).

2. Aims of the Study

2.1 Background

Despite advancements in surgical techniques and the introduction of new therapeutic options, OC remains the leading cause of mortality among gynecological malignancies.

As discussed in the previous section, the understanding of OC spans two distinct aspects of health: disease and illness. While the disease aspect focuses on OC from a strictly clinical perspective (i.e., in terms of clinical diagnosis, treatment, and prognosis), the illness aspect is inclusive of the physical, psychological, and social dimensions and patient-centered aspects such as HRQoL and the lived experience of OC. Unfortunately, balancing the precision-focused approach of modern oncology with the personal stories of illness that are deeply intertwined with life and mortality remains a challenge (250, 282, 283). The disease trajectory of OC represents a myriad of needs that pose significant challenges to the current healthcare system, resulting in patients often finding themselves in a state of persistent uncertainty (39, 256, 257, 268, 269). Therefore, it is important to tailor communication strategies to the experiences of patients with OC (288).

An imbalance in the attention given by the healthcare system and its professionals to the illness and disease dimensions exists both in clinical practice and in science. Few, if any, publications have thoroughly explored how patients with OC and healthcare professionals perceive and respond to the OC trajectory or how they define their multifaceted roles as physicians and nurses and the nuances of OC as an illness (289-291). However, we identified one paper that addresses how the families of patients with OC experience the disease trajectory, with its emotional variations, hope, optimism, and changes in response patterns (292). While there is a considerable body of research addressing the lived experience of patients with cancer (293-296), there are, as far as we know, few (if any) studies exploring how the lived experience of cancer is understood and integrated by specialist physicians and nurses. Furthermore, there is a notable absence of studies exploring how the roles of healthcare professionals have evolved in response to changes in the healthcare system, advancements in medical technology.

2.2 Specific Aims

1. To investigate the experiences of OC and their interactions with healthcare providers from a patient perspective (**Paper I**).

2. To explore how gynecologists and nurses understand the disease and illness aspects of OC (**Paper II-III**).

3. To investigate how healthcare professionals act upon the disease and illness in the trajectory of OC (**Paper II-III**).

***Table 2.1** PhD Study Summary*

Overall aim	To investigate how patients and healthcare professionals understand and act upon the illness and disease trajectory of ovarian cancer		
	Study I	Study II	Study III
	Paper I	Paper II	Paper III
Title	Living with Ovarian Cancer: Transitions Lost in Translation	Hope and Hopelessness in the Face of Ovarian Cancer: Perspectives from Gynecologists	Navigating the Complexities of Ovarian Cancer Care: Perspectives from Nurses
Research aim	To explore how women living with ovarian cancer experience their illness and their interactions with physicians and other health care professionals in Norway	To gain an understanding of the patient-provider relationship in ovarian cancer from a gynecologists' perspective	To gain an understanding of the patient-provider relationship in ovarian cancer from the perspective of nurses
Design	A qualitative design inspired by phenomenology		
Participants	Women living with ovarian cancer (n=4)	Gynecologists involved in the diagnosis and treatment of ovarian cancer (n=9)	Nurses/oncological nurses involved in caring for patients diagnosed and treated for ovarian cancer (n=26)
Data collection	Focus group discussions (1 group, 5 interviews)	Individual interviews (9 interviews)	Focus group discussions (5 groups, 5 discussions)
Analysis	Malterud's systematic text condensation	Giorgi's descriptive phenomenological method	

3. Methods and Data Collection

The aim of this thesis was to gain insight into the lifeworld of ovarian cancer. Three qualitative studies, as outlined in Table 1.7, were carefully designed based on the concept of phenomenology, which was the chosen methodology. Utilizing a phenomenological approach in this thesis involves capturing the diverse perspectives, experiences, and insights into the lifeworld of OC. This entails elucidating the experiences of both OC patients and their healthcare providers.

3.1 Phenomenology as methodology

In the literature, methodology is defined in various ways. A common aspect of these definitions is that the purpose of methodology is to justify the choice of method in a research project (297). This thesis is oriented towards understanding phenomena rather than investigating causality within problems or situations. As a result, a phenomenological methodology has been employed (in terms of data collection and choice of analysis) in the entirety of the thesis, as well as for individual papers (297, 298).

Phenomenology is, in short, the study of phenomena. It is both a philosophy and a methodology that "points to an interest in understanding social phenomena from the actors' own perspectives and describing the world as experienced by the subjects" (299, pp. 26, 300). A phenomenon is "anything that can present itself to consciousness" (301, pp. 10). This PhD project focus on investigating the phenomenon of the *"lived experience"* of individuals affected by OC and the "*professional understanding"* that healthcare experts bring to their comprehension of this condition as both a disease and an illness. Giorgi describes the lifeworld as "the world all humans initially encounter," from which "all other specialized worlds emerge" (e.g., the academic world and the world of science) (301, pp. 10-11). While the research process employed here is inspired by Amedeo Giorgi's scientific descriptive phenomenological method (300, pp. 93-113, 301), it does not follow Giorgi's approach method in all its details.

3.1.1 The research process

Throughout the project, we navigated a careful balance, ensuring alignment with situations closely resembling those in which the phenomenons under investigation manifests (See to Section 3.1), while remaining faithful to the overarching research objectives. In order to investigate the lived experiences and qualified understandings of the illness and disease of OC, our investigations required the identification of environments in which these phenomena are naturally manifested (301). Accordingly, the participant groups selected included patients coping with OC, gynecologists engaged in diagnosis and treatment, and nurses responsible for the treatment and care of patients with OC. Exploring the experiences and understandings within the lifeworld perspective of these actors offers a nuanced insight into the diverse dimensions of the lived experiences and professional understandings of the aspects of disease and illness.

Consciousness holds a privileged status in phenomenology and refers to "the medium of access to whatever is given to awareness" (302, pp. 236). In the initial phase of the project, I identified my assumptions held on ovarian cancer and the patients suffering from this cancer, assumptions derived from my past experiences. By thoughtfully adopting a natural attitude, I sought to suspend preconceived notions—transitioning from reflection to a more analytical, scientific phenomenological attitude (301). This was necessary, as I conducted all the interviews and participated in the analysis of the data. To avoid any unchecked biases, the analysis of the interview data in the various sub-studies of this thesis involved not only the interviewer(s) but also additional contributors (301).

The focus was on capturing participants from their lifeworld perspective, rooted in their attitude and natural outlook. Instead of solely focusing on the interview subjects themselves, a phenomenological reduction was employed to clarify the denotations expressed by the participants (298, 301, 303). As described by Giorgi, "No claim that an analysis is phenomenological can be made without the assumption of the attitude of the phenomenological reduction" (301, pp. 98). Unlike research with a pure focus on eidetic reduction, this thesis has taken a more pragmatic approach to phenomenology in order to gain a more open and rich description of the lifeworld of OC and incorporates detailed descriptions from patients living with OC and gynecologists and nurses providing healthcare to the same patient group.

Phenomenology can be practiced using various methods and designs (304). According to Giorgi (305), interviews and descriptions provided by individuals experiencing a particular phenomenon constitute the fundamental source for comprehending a phenomenon.

3.2 Lifeworld interviews

Investigating how patients with OC, gynecologists, and nurses view life with the disease involves dvelving into their personal experiences and viewpoints. Therefore, we aimed to grasp the core meanings in the themes of living with OC by shedding light on stakeholders' conscious experiences through lifeworld interviews, as achieving a comprehensive understanding of the stakeholders' lifeworld might be too ambitious. The primary goal was to, as closely as possible, unravel their experiences and insights into the phenomenon (306).

3.2.1 Preparing for interview-based research

The interviews and discussions conducted were inspired by Kvale and Brinkmann's recommendations on performing qualitative interviews with a phenomenological approach (306). The basis for research interviews is professional conversations between two or more people regarding a theme of common interest, and where the moderator facilitates good discussions (307).

Knowledge was gained from both focus group discussions (Papers I and III) and individual interviews (Paper II). Focus groups can be more stimulating than individual interviews as they allow participants to hear others' perspectives, facilitating the development of shared insights (308, 309). In addition, focus group discussions are also time-efficient, as they can shed light on diverse viewpoints within a single session and offer the possibility of fostering a deeper understanding of the discussed phenomenon. In both focus group discussions and individual interviews, the interaction and trust between the moderator and the interviewee are crucial. While focus group discussions provide knowledge that results from group dynamics, individual interviews yield knowledge that is unaffected by anyone other than the interviewee (310). However, focus group discussions are better suited for eliciting interviewees' own perspectives on sensitive health topics than individual interviews (311, 312). Moreover, focus group discussions are recommended if the aim of the study is to explore the patient perspective (313). While the advantage of individual interviews lies in their capacity to provide more detailed information than what focus group discussions can offer, participants in individual interviews can also more easy share detail that may be sensitive and intimate to them (314). Based on these advantages and limitations of focus group discussions and individual interviews and our aims, we chose to conduct focus group discussions for Studies I and III and individual interviews in Study II.

Two semi-structured interview guides were developed, one for Study I, and one for Studies II and III, with broad and open-ended questions to allow the participants to illuminate the phenomenon from their own perspective (302, 306, pp. 46). Additionally, I facilitated participants to dwell on the questions, and the questions were formulated to suit the participants (315). According to Giorgi (302, 316), it is crucial for descriptions to focus on context and unveil underlying meaning. Therefore, these aspect as well as previous reseach was taken into accound when formulating the questions. The interviews were meticulously scheduled to *focus* on the participants' described experiences and understandings of living with OC. The aim was to create interview guides that struck a balance, and to facilitate a process through which interviewees could uncover new connections and insights they may not have realized before.

The semi-structured interview guide for Study I was thematized and designed to collect knowledge about different and selected topics during the five interviews that were conducted. In Study I, multiple focus group discussions involving the same four participants were organized. This approach allowed for flexibility in planning the interview timeline and enabled participants to actively influence the direction of the discussion. The setup facilitated discreet revisiting of crucial interactions with interviewees aiming to uncover nuanced perspectives and illuminate complexities and contradictions that might have otherwise gone unnoticed. (317, 318).

The starting point for Study II was the main finding from Study I. In Paper I, the participants described the experience of not being understood by the gynecologists, and they explained that their experience of living with OC became lost in their communication with health care professionals. Therefore, when thematizing the semi-structured interview guide for the interviews with gynecologists, the aim was to design questions that would deepen and provide insight into gynecologists' understanding of "living with ovarian cancer."

The starting point for Study III was another main finding in Study I: the women did not find that their experience of illness was encompassed in their encounters with healthcare providers. Additionally, though not directly discussed in Paper II, some of the participants in Study II expressed that nurses offered superior care compared to physicians. Therefore, Study III delves into how nurses perceive their roles during patient encounters and their awareness regarding patients' illness experiences.

In the planning of qualitative interviews, the term "sample size" is used in connection with achieving "saturation," which is conceptualized as data saturation and indicates a phase in the interview process in which the emergence of substantial new information becomes noticeably scare (319). For this thesis, data saturation has guided the sample size. This means that we did not set a target sample size at the outset of each sub-study but, rather, allowed the content of the interviews to determine when the sample sizes were sufficient.

3.2.2 Conducting interviews

Qualitative research interviews can take various forms. This thesis has used both focus group discussions and individual interviews in the form of both computer-assisted interviews and face-to-face interviews. In all the interviews, the aim was to gain insight into the interviewees' unfiltered descriptions of their primary experience and understanding of OC. As the moderator, I possessed substantial knowledge about the disease, its treatment, and the side effects, apart from my own experience from working with this patient group prior to the interviews. I combined what I knew with a curious mindset, staying open to different viewpoints. Further, I tried to set aside my own assumptions and be open to the interviewees' stories about their experiences on the topics, while also keeping the research questions in mind. I also attempted to balance my prior knowledge with a qualified naivety, in order to bracket my own understanding while being open to other perspectives and adopting a phenomenological stance when encountering the interviewees' descriptions of their own experiences on the topics. At the same time, I attempted to bear in mind the research questions.

A consistent theme throughout all the interviews was the experience of "living with OC." The exploration of the *meaning* behind this concept sparked curiosity among the interviewees, with many repeating the term multiple times in an inquisitive tone. The interview guides encompassed both factual questions such as "Could you tell a bit about your understanding of what it's like living with ovarian cancer based on your experience, education, and knowledge?" and meaning-based inquiries such as "How did you experience the conversations with the nurses and physicians during the course of treatment?" Moreover, certain statements and responses were presented to the interviewees to seek their confirmation or denial of the expressed information. To capture the most accurate and specific account of their experiences, emotions, and actions, participants were encouraged to provide detailed explanations using everyday language.

The focus group discussions with patients and the individual interviews with gynecologists were conducted online. I was aware that the dynamics and interaction during the interviews might be affected by the absence of a shared physical setting. Therefore, I consciously ensured that the interviewees felt respected by demonstrating understanding, attentive listening, and genuine interest, all while staying focused on the interview's main theme. Additionally, I consistently monitored the sensitivity and emotional impact of certain questions and subsequent discussions. The goal was to ensure that participants found the experience enriching and felt rewarded by their participation. Individual assessments were conducted during the interviews, and in one particular instance, follow-up contact was initiated with all participants from the patient focus group. This was done to address specific aspects that emerged during one interview session and to measure the participants' reactions. The follow-up contacts were not recorded, and their content is not included in any papers or in this thesis.

The interviews were all recorded and transcribed verbatim. I transcribed eight of the focus group discussions and five of the individual interviews, while an external transcriber worked on the remaining interviews.

3.3 Study populations

Three different cohorts were analyzed: patients with OC, gynecologists, and oncological/registered nurses. All participants were recruited through purposive sampling procedures to ensure that only participants who would be able to elucidate the phenomenon under study were recruited (320).

Patients with OC were recruited through the national patient organization for gynecological cancer, Gynkreftforeningen. Four women were recruited and participated in a total of five focus group discussions between September 2018 and May 2020. They were all diagnosed with OC, had undergone surgery, and had received at least one line of chemotherapy. Due to the limited number of participants in Study I, I have chosen to provide minimal information about the participants in both Paper I and in this thesis to preserve their anonymity.

For Study II, gynecologists from university hospitals were preferred, but we also opened up participation to gynecologists from local hospitals as long as they met the inclusion criteria. Information about the project was distributed to three university hospitals in Norway, and those interested in participating were asked to contact the project manager by email. Nine gynecologists, representing four different hospitals, participated in the individual interviews. They were sonducted during the period October 2022 and February 2023. All participants were female, and their mean age was 41 years. The majority of the participants were specialists working at university hospitals, and their average clinical experience in gynecology was 12 years.

Oncological/registered nurses who treated and followed up women diagnosed with OC were recruited from departments at university and local hospitals (inpatient wards and outpatient clinics) in Norway. Information about the project was distributed to three university hospitals in Norway, and those interested in participating were asked to contact the project manager by mail. A total of 26 oncological/registered nurses agreed to participate in five different focus group interviews. The participants represented three hospitals in Norway, and the majority of the participants were female. Their mean age was 40.8 years, and their average clinical experience as nurses was 15 years.

3.4 Analysis method

I approached the interviews with an open mind in order to value the experiences shared by participants. I also considered my own awareness and pre-existing knowledge when reviewing the interview material, with the aim of accurately describing the phenomena. In the selection of the analysis methods for the three sub-studies, the goal was to choose approaches that best suited the specific aims of each sub-study. In qualitative research, the interviewer or moderator is a research tool. As an oncological nurse with extensive experience caring for patients with OC and collaborating with gynecologists in oncological settings, I actively assessed my own intersubjectivity throughout the entire research process, placing particular emphasis on self-awareness during the analysis phase.

This thesis applies Kirsti Malterud's method of systematic text condensation and Giorgi's descriptive phenomenological method for analysing the data material.

3.4.1 Systematic text condensation

The data collected for **Paper I** underwent analysis utilizing the systematic text condensation method developed by Malterud (321). Systematic text condensation represents an extension and an elaboration of Giorgi's five-step descriptive phenomenological method (305). Both strategies value the phenomenological attitude and employ descriptive approaches through analytic reduction involving a dynamic shift between decontextualization and recontextualization of the data material. Systematic text condensation allows for theoretical reflections and offers a more specific procedure for condensation of the data material compared to Giorgi's method, even though the source knowledge may be similar in both approaches. Additionally, it is worth noting that systematic text condensation is particularly effective for managing data from a limited number of participants, as illustrated in the context of the first paper (321).

The initial step in Malterud's (321) analysis involves gaining an overall impression by reading all the transcripts continuously. Due to the extensive amount of data generated in the first study, it was important to keep an open mind while maintaining a bird-eye view. As the analysis involved a limited number of participants, it led to a more comprehensive exploration of the transcripts. This diversity was particularly beneficial, as each of the members of the research teams brough a unique background to the table, fostering discussions on what should be considered relevant descriptions and ultimately shaping the emergence of preliminary themes. After the discussions, we identified and systematically organized the descriptions provided by the participants, aligning them with the research questions. These identified descriptions were then classified as meaningful units, paving the way for a structured coding process that was aligned with the identified preliminary themes. This intricate and time-consuming process involved iterative steps. We initially observed the codes horizontally to identify connections and similarities. Following this, we conducted decontextualization to extract pertinent units from within the coded groups. The challenge lay in refining and condensing the content while ensuring the support of relevant quotes in the transcripts. Throughout, the affirming process was used to validate our themes, transforming them from mere descriptions into a coherent narrative that encapsulates the essence of the phenomena.

3.4.2 The descriptive phenomenological method

The data analysis for **Papers II** and **III** adhered to the scientific principles of the descriptive phenomenological method as conceptualized by Amedeo Giorgi (300). Giorgi's desire was to understand the whole human, based on the belief that the entirety of an individual's lived experiences of a phenomenon is thematized through one's consciousness (302, 305). He believed that the knowledge one creates must transcend the specific and momentary, and to achieve that, one must first account for one's own understanding and then test it among colleagues, receive their input, and ultimately arrive at a shared understanding (322).

Giorgi's method is descriptive, which he considers to be a more "faithful" approach to the data (323, pp. 542). The influence of scientific phenomenological reduction is evident at every step of Giorgi's analytical method and has a comprehensive impact on the analysis (301). In our analyses, we employed the steps as described by Giorgi (300, pp. 93-113, 301, pp. 128-137). The first step is *read for sense of the whole.* A prerequisite for the analysis to be phenomenological is that we, the analysts, adopt a scientific phenomenological attitude, by listening to the audio recordings, reading the transcripts multiple times, and altering the reading approach gradually. We focused on the entirety, the basic sense, and the descriptions directed towards the phenomenon of interest. Since the datasets for both Study II and Study III were extensive, grasping the entirety of the material was challenging. Hence, the subsequent step was to deconstruct the descriptions provided by the participants in order to demarcate the raw data from the transcripts into a considerable number of *meaningful units* that might throw light on the phenomena, without interrogating them. This was a meticulous process wherein we were consistently required to be mindful of our own attitude towards what we were reading and to strive for openness. The next step is at the heart of Giorgi's method: *the transformation of the participant's natural attitude expressions into phenomenologically psychologically sensitive expressions*. This step of the analysis was challenging because the descriptions need to precisely depict the phenomenon as experienced and described by the participants, without speculations or other factors influencing them. At this point, it was advantageous that several of us had participated in the analysis, as this allowed us to engage in discussions about the data. We critically evaluated and questioned the relevance of the meaningful units, as well as each other's perspectives and attitudes towards them, examining them collectively and transforming them to new dimensions and then, to second-order descriptions. In seeking to delineate *the inherent structure of the phenomenon*, our approach involved synthesizing a cohesive whole from the interplay between meaningful units and the second-order descriptions. This analytic phase necessitated a careful review of both the evolving structure and our methodological steps, with the aim being to conclusively validate the constituents we ultimately identified. This systematic approach requires the consistent application of reductionist principles throughout the study, in alignment with the rigor and objectivity inherent in the scientific method.

3.5 Ethics

The studies performed have received the necessary ethics approvals. The study described in Paper I was approved by the Committee for Medical and Health Research Ethics (REK), Western Norway (REK Vest) (ID: 2017/941) as it falls under Norwegian legislation for health research and collects health data from the participants. The studies presented in Papers II and III do not constitute health research in the legal sense in Norway as they do not collect health data. REK Vest evaluated the project and found that an approval from them was not required (ID: 727498). In accordance with Norwegian data protection legislations, the study described in Paper II was registered with the Norwegian Agency for Shared Services in Education and Research (Ref. no. 887555) and with the University of Bergen's System for Risk and Compliance (ID: F2090). At the time the study presented in Paper III was undertaken, the University of Bergen had implemented the European General Data Protection Regulation (GDPR) requirements, and the research project was registered with the University of Bergen's Register for Data Protection (RETTE) (ID: F2741).

3.5.1 Ethical considerations in qualitative interviews

While the ethical considerations above are linked to procedural ethics for conducting research, research ethics in practice refers to ongoing ethical considerations during the entire research process (324). The research undertaken here encompassed confidential data pertaining to patients as well as insights from healthcare professionals. While the information concerning healthcare professionals may not fall under the category of sensitive data, as defined by data protection regulations, it encapsulates viewpoints and experiences of profound significance that are occasionally of a delicate and existential nature. Accordingly, throughout the process of recruiting the participants for the interviews, analyzing the data, and writing and publishing the results, I continually worked to protect the dignity and integrity of the participants and their right to confidentiality and anonymity. Especially when writing the results sections for each study, particular attention was paid to mitigating any potential harm to participants while remaining true to the findings derived from the interviews and subsequent analysis (325). I will especially emphasis that as the first study included a limited number of participants and the sample size of the second study as well was small, I selected quotations in a way that would avoid the reidentification of participants.

4. Main Results

4.1 Paper I

We conducted five longitudinal focus group discussions with four women over a 16-month period. Employing systematic text condensation, we identified three themes pertaining to the experiences of women living with OC and their interactions with healthcare professionals in Norway: inner turmoil, loss of identity in relationships, and misalignment between personal and medical realms. Our findings suggest that patients with OC undergo a complex transition from health to unhealth, which impacts various aspects of their lives, including their relationships and their communication with healthcare providers. The diagnosis of OC triggers an inner turmoil, characterized by a loss of identity and body, which leads to inarticulateness and makes it challenging for patients to communicate their experiences. Further, while patients express a need for physicians to acknowledge their suffering throughout their OC journey, they perceive a widening gap between their personal experiences and medical interventions as their journey progresses.

4.2 Paper II

We conducted individual interviews with nine gynecologists working in oncological settings across four different local/university hospitals in Norway. Employing a descriptive phenomenological approach, our analysis unveiled three key components that shed light on the patient–provider relationship and communication from the gynecologists' viewpoint: interactions with patients, understanding of OC, and self-perception. Our findings revealed that interactions between patients with OC and gynecologists are characterized by routine procedures and limited timeframes. Gynecologists primarily focus on gathering disease-related information, providing biomedical details, and making treatment decisions, while also respecting patient autonomy and the right to information. Although they acknowledge the seriousness of OC, gynecologists place little emphasis on the illness perspective or existential dimensions. Another pertinent finding was that hope plays a central role in their interactions with patients, intertwined with medical advancements and clinical studies. Gynecologists strive to provide hope for life while maintaining a delicate balance to avoid instilling undue optimism. They perceive their role primarily as managing the biomedical aspects of the disease—a perception contrary to their preconceived notions of the medical profession. Interestingly gynecologists posit that nurses are better suited to address the experiential aspects of illness as they maintain emotional distance to effectively fulfill their professional duties.

4.3 Paper III

We established five focus groups comprising 26 oncological/registered nurses from gynecological oncological departments across three hospitals in Norway. The three key themes that arose were: how to be a competent nurse in ovarian cancer care, nurses' understanding of ovarian cancer, and nurses' perspectives on ambivalence, hope, and false hope in ovarian cancer. Our investigation uncovered insights into the intricate challenges faced by nurses in managing the OC trajectory. One significant finding was that nurses possess deep insights into the complex nature of OC, encompassing both physical symptoms and significant psychological challenges. Hope emerged prominently in the discussions, often linked to biomarkers, new medications, and participation in clinical trials. Objective measures like biomarkers were seen as sources of reassurance, control, and hope for the patients in facing the severity of the disease. However, the introduction of new treatment options sometimes hindered the acceptance of palliative measures, as informants feared it would imply acknowledging death for patients. Balancing hope with realism, informants aimed to maintain patients' hope while acknowledging the grim reality that many may not survive the disease. They observed that physicians often provided insufficient information, leaving patients uninformed and fostering false hope, posing challenges for nurses. Additionally, nurses struggle to emotionally detach from patients' suffering, although limited insights into patients' mental states made effective care challenging, as nurses grappled with sharing information without causing distress or harming relationships.

5. Discussion

Despite advancements in precision oncology, OC presents notable challenges to the field of gynecological cancer due to its severity and complexity. Patients face a multifaceted journey that is characterized by debilitating side-effects and strain on healthcare systems. Beyond clinical expertise, patients require compassionate communication and holistic care. Thus, it is essential that healthcare professionals understand both the medical intricacies and the broader impact of the disease on patients' lives in order to provide effective care.

This PhD project focuses on investigating the phenomenon of the *"lived experience"* of individuals affected by OC and the "*professional understanding*" that healthcare experts bring to their comprehension of this condition as both a disease and an illness. Accordingly, the focus is on these actors' personal and/or professional knowledge and how they act upon it.

This thesis is based on three manuscripts (Papers I, II, and III) that collectively investigate the lived experience of OC, as well as how healthcare professionals understand and act upon the illness and disease trajectory of OC (Papers II and III). In Paper I, the focus was on investigating the experiences and understandings of OC from the patient perspective. In Paper II and Paper III, we investigated the understanding of the patient–provider relationship and communication from the perspectives of gynecologists and nurses. In the following paragraphs, we will interpret the results in light of recent publications and existing knowledge and discuss their future implications.

5.1 Methodological considerations

This project uses a naturalistic approach that is inspired by the concept of phenomenology. Within naturalistic approaches, there have been several discussions on which criteria are conducive to creating trustworthiness, as discussed below (326, 327).

In the 1980s, Lincoln and Guba (328, pp. 289-331) developed four criteria for achieving trustworthiness in naturalistic inquiries: credibility, transferability, dependability, and confirmability. The criteria are well-recognized and have become a standard within qualitative inquiry, although they have been subsequently modified and criticized by others. For instance, according to Creswell (329), it is not necessary to apply all four criteria introduced by Lincoln and Guba. Moreover, there is no consensus on which criteria are the most important.

5.1.1 Credibility, transferability, dependability, and confirmability

I have endeavored to conduct this study in a way that ensures the credibility of our results. I have done this by maintaining my awareness of my own role as a researcher throughout the research process and recognizing myself as a human research instrument with a potential source of bias that may influence the results, as described by Lincoln and Guba (328).

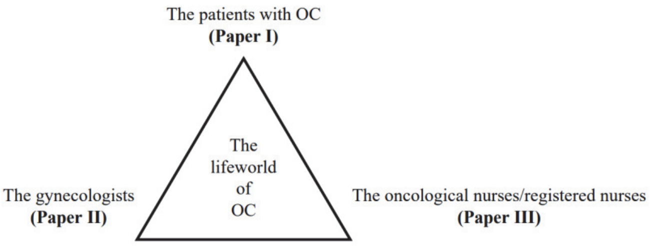


Figure 5.1 *The Triangulation of the lifeworld of OC.*

To enhance the credibility of findings and interpretations this study employs Lincoln and Guba's triangulation method (Figure 5.1) (328). By integrating three distinct sources (patients with OC, gynecologists in oncological settings, and nurses in gynecological oncological departments) that represent varied aspects of empirical reality and understandings, the project delves into a multifaceted exploration of the lived experiences within the OC lifeworld (Figure 1.9). The diverse viewpoints were regarded as originating from multiple and distinct sources, and the intention was not to seek confirmation, but to elaborate and shed light on each source's understanding of the illness experience in the OC trajectory and how healthcare professionals act upon it. However, this project only uses qualitative interviews for collecting empirical data. This could be a limitation, as the use of multiple methods could have revealed other aspects of the phenomenons (330).

I also strived for credibility by employing a method that Lincoln and Guba (328, pp. 308) describes as peer debriefing and what Giorgi (301, pp. 134) refers to as the "critical other." Throughout the PhD process, I have been involved in several research groups where I have had the opportunity to discuss and present the three studies included in this thesis. In the process, I have been presented with critical questions by others who have not been closely involved in the research process about the choices I have made in the course of the research process. Additionally, a total of seven co-authors, including supervisors have participated in the research process for the studies included in this thesis. We have also endeavored to attain dialogical intersubjectivity within our findings (328). We had several meetings to discuss the thesis, and for each study and each dataset, consensus and credibility were achieved through peer debriefing, rational discourse, honesty, discussions, and mutual critique (306, pp. 273). Moreover, the findings in Paper II have been peer-checked by three gynecologists with extensive clinical experience in gynecologic oncological settings.

According to Lincoln and Guba (328), transferability refers to whether a set of findings is applicable to other contexts. An essential condition for ensuring transferability is the provision of rich and detailed descriptions. All three papers included in this thesis provide descriptions from the participants, who were selected based on strict inclusion criteria, which were elaborated in earlier in this thesis document (See sections 3.3.1 to 3.3.3). In addition, in each study, we recruited and included participants continuously until we reached data saturation (See Section 3.2.1). That is, we stopped conducting further interviews and discussions when no new themes emerged. Although the demographic findings of the participants in cohorts presented in Papers II and III is representative for the specialists in gynecology and nurses in Norway (331, 332), we cannot definitively assert the replicability of our findings based solely on the descriptions provided in the papers presented in this thesis.

In addition to ensuring transferability, we have also strived for transparency, both within the papers and in this thesis, by providing comprehensive descriptions of the methodology, research process, materials and analysis methods. However, as the research papers are rather brief communications with strict word limits set by journal guidelines, this precluded us from providing optimally thick descriptions in the published papers. We will consider the possibility of anonymizing selected additional parts of the analyzed datasets and publishing them later as open data, provided that privacy and confidentiality can be fully ensured.

Throughout the research process, I have made numerous choices that may have influenced our findings, in addition to those described in the sections above and in Section 3. One of the choices made was to conduct either focus group discussions or individual interviews in the three studies. The benefits of focus group discussions and individual interviews are described in Section 3.2.1. However, while some researchers emphasize that focus group discussions can lead to a deeper understanding of the phenomenons under investigation, the use of focus group discussions in phenomenological research has been criticized for its potential to lead to contamination of the participants' descriptions (333, 334). In the case of Study I, focus group discussions were chosen because of the sensitive nature of some of the topics and questions in the interview guide, as well as the possibility of sharing experiences with someone in a similar situation. We hoped that this form of discussion would open up expressions and descriptions of emotional views through the group interaction (299, pp. 150). In Study II, individual interviews with the gynecologists were chosen due to the possibility of confidential topics arising, as this format would allow them to freely share their reflections. Additionally, use of individual interviews in study II were also selected for practical reasons, on account of the gynecologists' demanding clinical schedules. There is a possibility that focus group discussions with the gynecologists could have provided descriptions of more sensitive health topics, and importantly, a deeper understanding of the phenomenons than what emerged from our results (308, 309). In study III, unlike the interview approach with gynecologists, focus group discussions were chosen with the nurses because of the desire for discussions that could open up conversations in which the participants, through verbal exchange, could explore different viewpoints, both emotional and expressive, collectively (306).

5.1.2 Openness and meaning

Some of the criticism leveled against naturalistic inquiry is that it is based on perceptions, subjective assessments, opinions, and biases (335, pp. 415-416). Moreover, in the course of naturalistic inquiries, the researchers' behavior may influence data collection, selection, and the interpretation of data (336). According to van Wijngaarden et al. (326), openness, meaning and essence are relevant for determining trustworthiness in phenomenological studies (326). However, I have chosen not to describe or discuss essence further, as establishing essence was not one of our goals. Nonetheless, throughout all stages of the research process, I have strived to maintain an awareness and openness of my own pre-understanding and behavior when encountering the meaning and essence of the participants' descriptions of the phenomenons.

During the course of the research, I have been conscious and reflective about my own contribution. As an experienced nurse with extensive clinical experience in the field of gynecologic cancer, I have a deep understanding of the roles of both gynecologists and nurses in treating patients with OC. In conducting my research, I was mindful of the need to remain sensitive to my biases, acknowledge my subjectivity, strive for objectivity, and maintain openness throughout the process (306, pp. 273).

Throughout the PhD project, as a whole and in the three studies, I have been the main actor involved in planning the PhD project, planning the three studies, designing interview guides for all studies, conducting the interviews, and finally, writing the thesis as well as the three studies. Although I was mindful of my own preconceptions, experiences, viewpoints, and perspectives, I cannot guarantee that the choices made along the way and the results stemming from those choices have not been influenced by me and my pre-understandings. However, I was aware of these challenges from the outset of the project, and as a result, I have had several rounds of introspection to identify my preconceptions, both independently and with my co-authors and supervisors, based on the critical questions they posed to me along the way. I also wrote down my pre-understandings before commencing each study in order to increase my awareness of them and be able to bracket them. Some of these pre-understandings were: nurses spend a lot of time discussing illness with patients with OC, the role of nurses is to advocate for the patient in their interactions with the healthcare system, and nurses are visible and important to patients with OC. It was also my preconception that physicians are clear in their communication with patients with OC about prognosis and when cure is no longer possible.

Throughout the interviews and analysis my attention was directed towards discerning the fundamental essence of the phenomenons by prioritizing its structural aspects over the individual informants or their specific expressions (326). This was challenging as much of the content of the interviews and the informants themselves impacted me as a person and elicited an empathetic cognitive response in me. According to van Wijngaarden et al., meaning inherently relies on context (326). Consequently, I have strived to address contextuality in all three papers and in this thesis document (see Section 3.2.2 and 3.3), as well as in the conclusions.

One of the strengths of this work is that several co-authors and supervisors have participated in choosing the methodology, formulating the research questions and aims, analyzing the data materials, and providing external validation of the results. Moreover, even though the majority of the interviews were conducted by one interviewer, the co-authors involved in the various studies had diverse experiences: that is, some of them had clinical experience as nurses or gynecologists in a gynecologic oncology setting, while others had no professional medical experience but thorough knowledge of qualitative research and its methodologies. The diverse experiences of all the co-authors and supervisors enabled us to test and discuss the methodologies and findings based on the diverse perspectives we collectively held. Additionally, I have spent considerable time on the research process, and this has resulted in the maturation of both the research rocess and the findings. Thus, while our findings may not be universally applicable, they still hold significance for a broader audience beyond our team and the participants involved in the studies.

5.2 Understanding of disease and illness in the ovarian cancer trajectory

5.2.1 The lived experience of ovarian cancer

Living with and beyond cancer implies a multitude of experiences. In this thesis, the lived experience refers to, as introduced in Section 1.3, phenomenons that occurs within the context of an individual's daily life (337). Understanding the experience of living with cancer is pivotal for upholding the principle of respect, fostering an effective healthcare system, and achieving a comprehensive understanding of the needs of those impacted by cancer (338). Indeed, the perception of the cancer experience can diverge significantly depending on whether one adopts a medical viewpoint centered solely on the disease or a broader perspective that encompasses the personal and social dimensions of illness.

Disease and illness are theoretical aspects of health and do not necessarily reflect the care and attention that patients receive from healthcare systems and healthcare professionals (339). Advancements in medical technology have reshaped perspectives and approaches within medicine, altering how healthcare professionals perceive and address disease. Despite its reductionistic nature, this (the disease perspective) approach often overlooks the intricate bodily experiences associated with illness (245).

The French anthropologist Marc Augé observed the paradox embedded in the experience of illness, noting that it is simultaneously the most individualized and the most socially interconnected phenomenon (340). This notion finds resonance in the primary insight gleaned from Study I, which elucidated the transition experience of patients with OC from a state of health to one of illness. It should be noted that the participants in Study I were all at an advanced stage in their OC journey, with several having undergone multiple lines of chemotherapy. Moreover, many of them were in a palliative treatment phase, which potentially shaped their perceptions and depictions.

The participants in Study I articulated an internal journey characterized by the loss of their former identities that led to a state of disorientation and discomfort as they grappled with a newfound sense of unfamiliarity. The term *illness identity* is well described in the literature (341-344). In her paper *The Body, Identity, and Self: Adapting to Impairment*, Kathy Charmaz describes, in a similar way to our informants, how one's identity is altered as a result of illness disrupting what was previously taken for granted about having a functioning body, and how identity changes when incorporating chronic illness or disability into one's sense of self (342).

A person's experience of identity is processed through self-reflection and through interactions with others (341). In Study I, participants expressed difficulty in communicating their illness experiences to healthcare professionals, highlighting a common struggle in effectively expressing personal narratives of illness to the medical community. This observation finds support in a recent study that underscores the need for healthcare providers to have access to the lived experiences and emotional landscape of patients with OC in order to deliver the personalized care they require and desire (345). Moreover, in his book *The Wounded Storyteller*, Arthur W. Frank asserts that the bodily experience of illness is inarticulate: that means, it is expressed through pain and symptoms (22). Thus, encouraging and fostering opportunities for patients to share narratives of their illness experience may facilitate a reconnection with their bodies, and counteracting feelings of alienation (22). Interestingly, despite this awareness, healthcare professionals caring for patients with OC often encounter difficulties in adequately addressing their suffering. Intriguingly, these observations align with accounts provided by participants in Study II concerning their interactions with patients diagnosed with OC.

Illness is an inclusive concept that encompasses the psychological and social dimensions, as well as the physical side-effects of OC and OC treatment (See Section 1.5). Consequently, patients with cancer need to be able to communicate with physicians about insight into their cancer disease, prospects for new treatment options, and guidance on pain management (346). Thus, effective communication between patients with cancer and physicians about these subjects should all be given significant value as focused on in Section 1.6, especially given that previous research has highlighted conflicting desires and needs in patients with cancer with regard to communicating with healthcare professionals (250, 282, 283).

A key finding in Study II was the notable absence of discussions on illness experiences among gynecologists within the context of OC. Their interactions with patients with OC were primarily centered on gathering information about the eligibility of the patient for various treatment alternatives and informing patients about available courses of action. This narrowing of focus restricts the breadth of knowledge available for clinical decision-making and actions, consequently diminishing not only the value of gynecologists themselves as knowledgeable practitioners but also their potential for establishing understanding and connection with the patient. However, it is conceivable that the descriptions provided by the gynecologists in our research were influenced by the medical profession's conventional understanding of disease and illness in healthcare (See also Section 5.2.2). That is, physicians are trained to contextualize descriptions of illness within the framework of the disease process, often using disease-specific examples as a reference point instead of focusing more holistic (347). As Marinker also pointed out in his article *Why make people patients?* the experience of illness often provokes a silence within medicine, and rather than breaking the silence and paying attention to illness, the physician translates the patient's experiences of illness into disease (61). However, patients' experience of illness is a different reality—one in which illness and disease may not necessarily correlate, and illness simply represents their own experience (347). Nonetheless, the physician's comprehension of disease and illness holds significant weight for patients. Therefore, when the physicians solely focus on identifying deviations from the ideal and correcting mechanical issues during patient encounters, there is a risk the patients do not address other aspects of their journey with OC and consequently, that the physicians might overlook what truly matters to the patient (64).

While participants in Study II acknowledge patients' experience of illness in terms of the physical side-effects of both the disease and treatment, it is important to recognize that diseases such as OC affect the entire body, not just the specific area where symptoms manifest. Therefore, failing to treat the body as a cohesive entity increases the risk of worsening the overall impact of the disease for the OC patients (348). Further, while gynecologists acknowledge OC as a tragic disease and possessed knowledge of various aspects of its illness experience, there appears to be an incongruence between physicians and patients regarding the magnitude of patients' symptoms and OC-related side-effects. Notably, physicians tended to underreport psychological side-effects such as anxiety and depression (236), factors known to impact how cancer patients manage their disease and make decisions (349).

5.2.2 The professional understanding ovarian cancer

Both the gynecologists and nurses included in the different cohorts understood OC as a tragic, brutal, and fatal disease that inflicted significant suffering on patients, both physically and psychologically. These perspectives are consistent with the disease and illness paradigm presented in Sections 1.4 and 1.5. In Section 5.1 the trustworthiness of our findings was discussed, and their legitimacy highlighted. Although similar findings highlighting a lack of emphasis on the illness experience have not been reported for the OC trajectory previously, comparable data have been documented for various other forms of cancer (293, 350-352). Despite the shared base of knowledge of the healthcare personnel, a notable divergence emerged through this project. In Paper II, the gynecologists revealed that they predominantly focused on elucidating the physical manifestations of the disease with minimal attention to the subjective experiences associated with OC. In contrast, nurse informants in Study III not only offered more comprehensive insights into the emotional and social challenges faced by patients but also demonstrated a consistent focus on addressing these aspects in their daily practice. Despite the ongoing transformation in the national health care system to also include reporting and measurement of illness (210), the findings in Papers II and III were not unexpected. In his paper *Disease and illness: Distinctions between professional and popular ideas of sickness*, Leon Eisenberg states that "Patients suffer illnesses; doctors diagnose and treat diseases" (58, pp. 9). Hence, the significance assigned to disease by medical professionals stems from their pivotal role within the medical sphere (53). The nurses operate within a separate professional paradigm (353), and our findings substantiate this distinction.

The illness experience can be understood as a plea for care that requires attention (61). The challenge lies in meeting patients' need for emotional support and providing them with quality attention, which is contingent upon the capabilities of physicians within the healthcare system they operate in. In his paper *Why Make People Patients*, Marshall Marinker discusses how physicians create patients by diagnosing them, which results from an analysis of bodily functions that challenges both the social power of the physician and the moral rethoric (61). According to Marinker patients seek medical attention due to illness, which may encompass disease, illness, or sickness: *"if the role of patient is characterized by a weakening of personal autonomy; by translating the experience of suffering into a description of appearances and behaviours; by changing the request for understanding into a surrender to analysis, then it must be that the role of doctor is inherently destructive of patients"* (61, pp. 81). Thus, the focus on the disease aspect may be detrimental to patients' overall cancer journey and well-being. The disconcerting disparity between patient expectations and care needs, and the prevailing clinical practices with professionals' perceptions of disease and illness, warrants attention as it impacts the provision of quality healthcare profoundly as well as shapes patients' experiences and management of their cancer trajectory. Furthermore, the identified discrepancies accentuate the need for and growing emphasis on user participation in healthcare decision-making (354).

Both the gynecologists and the nurses participating in our studies underlined resource constraints, including limitations in time and personnel, as primary impediments for them to be genuinly present in the patient meetings and to fulfill their roles effectively. This observation is significant as inadequate time allotment results in physicians lacking the opportunity to fully understand the lived experience of OC. Time constraints as a hinder to interact in patients´ experiences of illness are also highlighted by Anatole Broyard in *Intoxicated by My Illness,* as a barrier to physicians finding fulfillment in their work (355). Unfortunately, similar obstacles to providing comprehensive care have been found in many developed countries. This is due to increasing costs of advanced medical technology and drugs, higher patient expectations, longer treatment periods, and a growing number of elderly people living with chronic conditions (356). Additionally, the gynecologists in Study II found that guidelines and checklists further restricted the scope of observations and information gathering during their allotted time with patients. As a result, they refrained from asking open-ended questions about the patients´ lived experience and focused on the vital parameters, treatment decisions, and side-effects. Achieving holistic cancer care for conditions like OC will remain difficult until both disease and illness perspectives are equally prioritized and integrated. Change implementation is urgent because new and advanced treatments already have created new needs in cancer patients' journeys, journeys which the healthcare system and professionals already find complex to understand, difficult to control, and economically burdensome (357).

Both gynecologists and nurses revealed disparities between their expectations to, and actual knowledge about the other professional group, highlighting a gap between perceived and observed realities. A notable finding was that some physicians in Study II believed that nurses were more capable of prioritize patients' illness experiences since they were not bound by the same time constraints as gynecologists. Our discussions with nurses in Study III provided descriptions that both confirmed and challenged this perception. On the one hand, the nurses offered detailed insights into the illness experience associated with OC, while on the other hand, they also conveyed challenges related to time constraints, particularly in outpatient settings. The extent to which this phenomenon reflects resource constraints, role constraints or a combination thereof remains uncertain. Nevertheless, these results will advocate for the formal integration of nurses within multidisciplinary teams to enhance the information flow, care planning and implementation, surpassing the current informal arrangements in Norway.

Ideally, the healthcare system should address all aspects of health, not merely disease (46). This sentiment is echoed in the national ethical guidelines for physicians and nurses, which emphasize the imperative to prioritize individual health. However, findings from Studies II and III indicate that this picture is somewhat more nuanced in clinical practice. In Study II, gynecologists, as highlighted previously, were mostly enganged in a therapeutic dialog with patients, whereas nurses in Study III were conducting a more thorough assessment to ascertain the multifaceted requirements of individuals. The differing actions of gynecologists and nurses toward disease management highlight their distinct priorities in interactions with OC patients. These observations also underscore the distinct perceptions of their roles held by gynecologists and nurses. As distinct professionals, physicians and nurses may have different approaches to holistic care and support (358). This contradicts the professional ethical guidelines for physicians, which state that physicians are tasked with healing, alleviating disease, comforting, and assisting the sick in their journey towards recovery and supporting the healthy in preserving their well-being (359). Nursing involves "promoting health, preventing illness, restoring health, alleviating suffering, or contributing to a dignified death" (360). The nurses in Study III acknowledged and adhered to the nursing paradigm of totality, which views patients holistically, by taking into account their physical, emotional, psychological, social, and spiritual dimensions, including hope. The nurses in Study III emphasized understanding of the comprehensive needs of individuals. However, findings from Study III indicate that nurses do not act upon this, not because they do not wish to, but due to time constraints, communication breakdowns, divergent treatment goals, and fear of disrupting the patient-provider relationship. Also, they mentioned having trouble starting and maintaining discussions on challenging topics such as prognosis, treatment choices, palliative care, and potential death, because they were not sure how much information patients had already received from the gynecologists. Additionally, their reluctance to start discussions about patients' lives came from their own uncertainty about the prognosis and what the future held. This created a moral dilemma between their perceived role as holistic caregivers and the limitations imposed by the system's requirements and organization.

This dilemma highlights a paradox: while nurses possess the knowledge to offer comprehensive care to patients, they were reluctance to initiate such discussions due to the challenge of finding the balance between honesty and maintaining hope (349). Hope emerged as a central theme in both Studies II and III, seen as both an essential illusion and a potential driver of medical advancement. Hope plays a significant role in the experience and understanding of OC. Hope is a vital resource for patients with cancer to adapt to life with cancer and to enhance their well-being and quality of life (361-363). It serves to foster connections between gynecologists, nurses, and their patients, providing a relational anchor when concrete solutions are lacking. Exploring hope prompted reflection on disciplinary practices and their role within broader systems. Gynecologists in Study II relied on hope to alleviate patient distress and protect themselves amidst limitations and pressures. In Study III, nurses expressed concern about withholding information from patients to avoid lowering their hopes, sometimes resorting to deception to preserve the patient-nurse relationship. Yet, they were cautious of offering false hope regarding life-prolonging treatments, recognizing the importance of patients' time.

Effective decision-making hinges upon our knowledge and comprehension of the patients' values and preferences, and it is imperative to recognize that these may undergo dynamic shifts over the course of the cancer trajectory (9) (See Section 1.2). Moreover, decisions made early in the cancer trajectory can profoundly impact both the disease progression and the patient's illness experience. The presence of anxiety, fear, and worry significantly impact decision-making processes among cancer patients (364). As Atul Gawande writes in his book *Being Mortal*, individuals with serious diseases often have priorities in their lives beyond those related to prolonging life, such as avoiding suffering, not being a burden to others, and having good relationships with family and friends (349). This is expressed aptly in the following statement from the same book: "*One has to decide whether one's fears or one's hopes are what should matter most.*" Hence, when nurses and physicians withhold realistic information regarding life expectancy from patients, it poses a risk of patients making treatment decisions they may later come to regret (365, 366). Nurses in Study III noted how physicians communicate optimism and hope is crucial for the cancer patients (367). However, some of the nurses perceived this optimism and hope as being false and felt that communication about palliative care and death was delayed. These findings highlight the unspoken nature of the transition from curative to palliative treatment intentions among patients with OC, gynecologists, and nurses, as none of them are willing to initiate this shift (26) (See Section 1.2). The concerns expressed by nurses are congruent with the descriptions provided by participants with OC in Study I, where communicating suffering to healthcare professionals became increasingly difficult over the illness trajectory.

Patients frequently found themselves grappling with feelings of hopelessness as they navigated through various choices along the disease trajectory, often encountering a perceived absence of viable solutions. The implementation of precision oncology has had a major impact on cancer care in terms of information dissemination, complex concepts, uncertainty, and decision-making, based on trust in physicians and their attitude towards precision medicine toos (368). The hope initiated by new cancer treatments is important for both patients and healthcare professionals. This is not surprising, considering the changes observed in terms of PFS and OS in OC in the last few decades (369). However, hope's fragility and ambiguity can sometimes lead to unrealistic expectations~~.~~ where the hope for medical advancements and clinical trials overshadows patients' experience of living with a life-threatening illness with a fatal outcome. By fostering hope regarding the efficacy of new medications the patients might prioritize optimism over factual considerations when making treatment decisions. Despite the counterarguments, hope, whether false or not, is an important resource to cope with living with the illness for patients with advanced and life-threatening diseases. Additionally, hope is not a static condition but a continuous process of change, wherein patients struggle to acknowledge the reality of their illness (370).

The lack of emphasis on the illness trajectory during the interactions between patients with OC and gynecologists, as uncovered in Study II, is in alignment with the results of Study I, where participants described how their illness experience was overshadowed by the focus on the disease itself. Gynecologists, like patients, may focus on knowledge about the possibilities within medicine. As Craig A. Irvine writes in his paper *The Other Side of Silence: Levinas, Medicine, and Literature*, to *"do their job, to answer their call, physicians must arm themselves with knowledge; they must* *shield themselves from the nakedness of the suffering that calls them to action. Without this knowledge, they would be utterly ineffectual. Paralyzed or obsessed in the face of this other~~s~~'s suffering, they could help no one”* (371, pp. 14). This quote underscores a pivotal discovery: the emotional burden borne by physicians and nurses when confronted with the substantial challenges posed by OC. As a result, gynecologists and nurses emotionally distance themselves from the patients as a means of safeguarding their own well-being (Studies II and III). This mirror the challenges identified in Study I among OC patients, specifically the perceived missing compassion from healthcare professionals. Prior research has identified ongoing issues of compassion and empathy deficits in the interactions between OC patients and healthcare professionals within healthcare systems (253). Based on the findings in this thesis the proposition is that the emotional toll of illness as described by patients becomes overwhelming for a considerable number of gynecologists and nurses.

5.3 Research questions revisited

To revisit our original research questions, our project set out to delve into the perceptions and responses of both patients and healthcare professionals regarding the trajectory of OC (Table 2.1).

Aim 1. By delving into the firsthand experiences and perspectives of participants, our investigation sheds light on how patients conceptualize OC as a journey from healthy to unhealthy that is marked by a profound sense of identity loss which may prove challenging to convey to healthcare providers. To summarize, the patients experience overwhelming emotions related to feeling disconnected from their bodies and are reluctant to share their suffering with loved ones. Further, patients with OC seek acknowledgment of their illness experience from healthcare professionals, but as the OC journey unfolds, a disconnect between patients' experiences and medical perspectives emerges and becomes reinforced.

Aim 2. Both gynecologists and nurses view OC as a harsh and emotionally taxing condition. Nurses exhibit a deep comprehension of the diverse challenges patients with

OC face, addressing not only their physical ailments but also their emotional well-being, which encompasses elements such as hope, social interactions, and familial dynamics. Moreover, they try to foster open communication and provide a supportive environment where patients feel comfortable sharing their experiences. Gynecologists primarily focus on providing information about the disease, offering limited insights into patients’ subjective experiences with OC. Further, while nurses prioritize comprehensive care by considering various aspects of patients’ lives, gynecologists prioritize disease management and the potential benefits of medical advancements. Importantly, gynecologists typically rely on biological data and clinical indicators to understand the disease, and this hinders their holistic understanding of the patient's condition and their needs beyond the medical aspect.

Aim 3. Nurses as well as gynecologists often prioritize the disease aspects of OC and aim to instill hope and positivity in patients despite the challenges posed by the diagnosis. Despite their goals being similar, gynecologists tend to rely heavily on medical technology as a source of hope, often sidestepping deeper exploration of patients’ illness experiences, while nurses grapple with the delicate balance of fostering hope while gently guiding patients towards palliative care, thereby allowing space for the full expression of their illness experiences. Both professionals face obstacles such as time constraints and emotional burdens, which hinder their ability to fully comprehend and engage with patients’ illness experiences. This can result an emotional distance from patients due to the weighty nature of their illness experiences.

Overall, the themes that have emerged in response to the research questions and aims illuminate the multifaceted landscape of OC care and highlight the crucial role of holistic support. Our findings emphasize the need for healthcare professionals to embrace a patient-centered approach by acknowledging individuals’ unique experiences and needs, beyond mere disease treatment. Although our findings are not generalizable, I believe they can still be meaningful for others beyond ourselves and the participants who took part in the sub-studies.

6. Conclusions

In this study, inspired by a phenomenological approach, new knowledge has been gathered about the experiences and professional understandings of OC from the perspectives of patients with OC, gynecologists, and nurses. Patients with OC go through a multifaceted journey as they navigate throughout their cancer trajectory, living with profound physical and emotional challenges. In addition, the findings underscore the importance of holistic support in providing effective care for individuals affected by OC.

Despite the limitation posed by the small number of participants in our study, the following conclusions can be drawn:

1. Patients with OC, gynecologists, and nurses perceive OC as a tragic, brutal, and fatal disease (Papers I, II, and III).
2. The illness experience of OC is difficult to articulate and gets lost in translation in patients' communication with healthcare professionals (Paper I).
3. Patients with OC desire closeness to healthcare professionals, but as the disease progresses, healthcare professionals tend to distance themselves from patients' experience of illness in order to protect themselves (Papers I, II and III).
4. The healthcare system is governed by strict timeframes and guidelines, and as a result, addressing the disease aspect of health inadvertently becomes the main task and focus for healthcare professionals (Papers II and III).
5. Healthcare professionals preserve patients' hope by focusing on the possibilities within medical technology, also when guiding patients into a palliative care pathway and address their experience of illness is the main need of the patient (Papers II and III).

7. Future perspectives

This thesis provides insights into the experience of living with OC from three different perspectives: patients with OC, gynecologists, and nurses. By investigating the lived experiences of patients with OC and the professional understandings of gynecologists and nurses, the project sheds light on the challenges in caring for patients with cancer in today’s specialist healthcare services from the aspects of illness and disease.

There is a need for further research to consolidate the findings because the data material in the studies is limited. Moreover, living with cancer today has become increasingly challenging as a result of the technological advancements observed across various cancer diseases. It would be interesting to examine how one can balance the care provided in healthcare to achieve more patient-centered care. In addition, based on our findings, we see a need for incentives to make the illness aspect of health more visible and included in the education of healthcare providers, especially with regard to how illness is communicated. We also perceive a need to conduct more qualitative studies on how to improve healthcare systems and services.

Family, friends, other informal caregivers, and the broader society are also involved in the phenomenon of living with OC. Their understanding of OC as an illness and a disease holds significance for the phenomenon of living with OC. The sickness aspect of health is also becoming increasingly significant as more patients with cancer develop chronic illness, and they need to continue to live their lives in a society that often perceives them as healthy. In addition, family and other informal caregivers are likely to be assigned more tasks in the future healthcare system due to a shortage of formal healthcare givers. This group of individuals and their perspectives and experiences also need to be investigated.

As a consequence of the challenges that the healthcare system will face in the coming years, there is a need for further research focusing on the following topics:

- Validating and expanding the findings of this thesis.

- Exploring additional perspectives and experiences of patients with OC, gynecologists, nurses, and informal caregivers (e.g., family and friends) in order to provide a more comprehensive understanding of the challenges and opportunities in OC care.
- Exploring and delineating how PROMs and patients' own descriptions can enhance the patient–physician relationship and communication in the context of treatment decisions in oncology.
- Examining the consequences of healthcare with a primary focus on the disease aspect of health and exploring ways to strike a balance between disease management and providing comprehensive, patient-centered care that addresses the broader aspects of living with OC.
- Investigating the impact of societal perceptions on individuals living with OC, particularly as more patients transition into chronic illness, and examining how societal perceptions of health and illness influence patient experiences, treatment decisions, and healthcare interactions.
- Exploring the increasing responsibilities and roles of family members, friends, and informal caregivers in supporting individuals with OC within the healthcare system and investigating strategies to better support and integrate informal caregivers into the healthcare team to improve patient outcomes and experiences.

Future research endeavors aimed at addressing these points can deepen our comprehension of the experience of living with OC and lead better standards of care for individuals impacted by this condition. Regardless of the strides made in medical advancements and expertise, genuine progress will remain elusive until we integrate comprehensive and empathetic patient care aligned with their lived experiences into our medical capabilities.

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Original Research

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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 prerequests. 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's[25] 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 unsecure, 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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Kvinneklinikken

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

Hvordan påvirker kirurgisk behandling livskvaliteten til pasienter med eggstokkreft

Dette er en forespørsel til deg om å delta i et forskningsprosjekt for å øke kunnskapen om sammenhengen mellom kirurgisk behandling og livskvalitet hos pasienter med kreft i eggstokkene. Det er gjort få studier på området, og det er følgelig uklart i hvor stor grad det er omfanget av den kirurgiske behandling eller om det er sykdommen selv som påvirker pasientenes livskvalitet.

Fokusgrupper er velegnet til å finne forbedringsområder ut hva kvinnene opplever eller savner, samt gi ideer til hva som bør gjøres annerledes. Hensikten med fokusgruppe diskusjonen er å inkludere brukerperspektivet fra kvinner som har vært behandlet med avansert kirurgi med påfølgende cytostatikabehandling for kreft i eggstokk. Kvinnenes erfaringer vil danne grunnlaget for innholdet i dybdeintervjuer senere i forskningsprosjektet.

HVA INNEBÆRER PROSJEKTET?

Det vil bli beregnet til 1 time og 30 minutter til fokusgruppe diskusjonen. Du vil bli spurt om å dele dine erfaringer, tanker og opplevelser rundt behandlingen du har mottatt for kreft i eggstokk. Du vil delta i fokusgruppeintervju sammen med 3 til 4 andre kvinner som har gjennomgått kirurgi og cytostatikabehandling for kreft i eggstokk. Om det viser seg at tiden til diskusjon ikke strekker til vil flere sesjoner for fokus-gruppe diskusjoner bli satt opp. Kvinnene vil før hver sesjon få tilsendt mail med ulike datoer og tidspunkt for samtale slik at fokus-gruppe diskusjonene best kan passe inn i deres hverdag.

Fokusgruppe diskusjonene vil foregå over SKYPE med bilde og lyd. Du må ha tilgjengelig egen datamaskin. Diskusjonene vil bli tatt opp, transkribert og analysert i ettertid. Informasjon og kunnskap som fremkommer i fokusgruppen er taushetsbelagt og vil bli anonymisert videre i forskningsprosjektet.

MULIGE FORDELER OG ULEMPER

Ved din deltagelse kan du bidra til å gi oss forbedret kunnskap om livskvalitet i forbindelse med behandling av eggstokkreft. Data som genereres vil kunne hjelpe oss å tilby framtidige pasienten bedre behandling og oppfølgning.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Line Bjørge eller studielege Karen Rosnes Gissum på telefon 55974200 eller mail line.bjorge@helse-bergen.no eller karen.gissum@vid.no.

FORSIKRING

Deltagere i studien vil være dekket av Norsk Pasientskadeerstatning.

Kvinneklinikken

OPPFØLGINGSPROSJEKT

Dersom det er aktuelt med et oppfølgningsprosjekt vil du bli kontaktet igjen.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnr. hos REK: 2017/941.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato	Signatur
	Rolle i prosjektet

Intervjuguide fokusgruppe diskusjon

Hensikten er å få høre om erfaringer og tilbakemeldinger fra kvinner som har vært behandlet med avansert kirurgi med påfølgende cytostatikabehandling. Kvinnenes erfaringer vil danne grunnlaget for innholdet/ spørsmål i dybde-intervjuer i fase III i INFLUENCE studien, for å sikre inkludering og implementering av brukerperspektivet.

Fokus-grupper er velegnet til å finne forbedringsområder ut hva brukerne eller andre opplever eller savner, samt gi ideer til hva som bør gjøres annerledes.

Introduksjon:

- Kort presentasjon av prosjektet og intervjuer
- Informasjon om opptak av intervjuet
- Informasjon om taushetsplikt

Innledende:

Det er hensiktsmessig å først be deltakerne om å snakke løst og fast om temaet for å få tak i spontane tanker og meninger. Deretter kan man lede diskusjonen inn på spesielle deler av temaet.

- Hva heter dere (runde med presentasjon av deltagere) og hvor lenge siden er det dere mottok diagnosen kreft i eggstokk?
- Mottar dere aktiv behandling nå?
- Har dere blitt operert, hvor mange ganger og når i behandlingsforløpet?
- Har dere mottatt cytostatika-behandling, hvor mange perioder?
- Hvor lenge er det siden dere mottok siste behandling?

Hoveddel:

Det er viktig at diskusjonene er åpne nok til at deltakerne kan utveksle erfaringer og kommentere hverandres synspunkter. Den som intervjuer skifter tema når det virker som om deltakerne har snakket seg tomme eller gjentar seg selv.

- Hvordan er det å leve med erfaringene dere har fått etter å ha vært gjennom behandling for kreft i eggstokk?
    - Diagnostisering, symptomer.
- Hvordan er en typisk dag for dere?
- Hvis dere ser tilbake til tiden dere ble diagnostisert, før behandlingen startet, er det noe dere opplever helsepersonell burde spurt dere om?
- Hadde dere behov underveis i utredning og behandling som ikke ble tatt opp med lege eller sykepleier?
    - Hvorfor ikke?
- Hvis dere husker tilbake til den tiden dere fikk diagnosen.
    - Er det noe dere erfarte manglet av informasjon?
- Hvordan opplevde dere samtalene med sykepleier og lege underveis i behandlingen
    - Opplevde dere å kunne være ærlig med lege og sykepleier?
    - Opplevde dere at legen var ærlig med deg mtp behandling og prognose?

- Livskvalitet er et utfallsmål innen all kreftbehandling, på lik linje som overlevelse, og måles ved hjelp av livskvalitetsskjema med nummerering og kvantifisering – ulempen er manglende dybde og innsikt i hvilken livskvalitet som faktisk blir erfart.
    - Har dere erfaringer med bruk av livskvalitetsskjema?
    - Hadde dere mulighet for å si noe «personlig» underveis i behandlingen om hvordan dere hadde det?
- Kreftutredning og kreftbehandling påvirker familien og den kreftsyke sitt sosiale liv.
    - Hvordan og hvilke familiære og sosiale utfordringer ble mest fremtredende for dere?
- Kreftbehandling gir kroppslige bivirkninger i ulik grad og påvirker kroppsbildet.
    - Hvis dere ser tilbake på behandlingen dere har mottatt, hvordan kroppen har endret seg og endringer det har medført i relasjon til familie og sosialt liv – var dere forberedt?
    - Hva ville dere eventuelt endret?
    - Hvordan kunne endringene blitt erfart bedre?
- Med deres erfaring; Har dere funnet noe som kan være hjelpsomt til det å mestre å leve med kreft i eggstokk?
- Hvilke utfordringer har dere hatt som følge av behandlingen dere har gjennomgått?
- Har dere noen råd for kvinner som skal gjennomgå behandlingen dere har gjennomgått?
- Hvordan vil dere definere diagnosen *kreft i eggstokk*?
    - Hvilken betydning har diagnosen hatt for dere?
- Hvordan har deres erfaringer med pakkeforløp for kreft vært?
- Vi planlegger å utføre intervjuer på ulike tidspunkter i utredning og behandling.
    - På hvilket tidspunkt i utredning, - og behandlingsforløpet mener dere kvinnene selv har behov/ overskudd til å bli intervjuet?

Avsluttende:

- Er det noe annet dere vil dele meg, om deres erfaring med å ha fått diagnosen kreft i eggstokk og å ha mottatt behandling for kreft i eggstokk?

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