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# Gynecological Cancer Survivors’ Experiences and Desire for Follow-up After Recent Treatment

## A Phenomenological Hermeneutic Study

### KEY WORDS

Cancer follow-up  
Cancer rehabilitation  
Cancer survivorship  
Coping after cancer  
Fear of cancer recurrence  
Gynecological cancer  
Information needs

**Background:** Gynecological cancer survivors experience a variety of challenges after discharge from hospital treatment. Cancer support and rehabilitation are recognized as significant facilitators for quality of life in survivorship but are reported to be insufficient by gynecological cancer survivors. **Objective:** To describe the lived experiences of gynecological cancer survivors and how their needs for follow-up should be met following recently completed treatment. **Method:** This study used a phenomenological hermeneutic design with individual in-depth interviews with 20 women after recently completed cancer treatment. Transcribed interviews were analyzed with the Lindseth and Norberg phenomenological hermeneutic method. **Results:** Four themes were identified: “a brutal transition to life after cancer,” “fear of recurrence overshadowing the existence,” “a need for professional support,” and “information is not given unless asked for.” **Conclusion:** After completing gynecological cancer treatment, the fear of cancer recurrence is dominating, regardless of prognosis and diagnosis. At the same time, information and support from healthcare professionals are described as lacking. Participants expressed a need to be contacted directly as a formal routine by healthcare professionals after cancer treatment with cancer-specific information as this may alleviate the existential

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R.J.T.S. has been the project leader for the development of the Gynea intervention (where the participants are recruited from) and has also been a supervisor for some of the women who have been through the intervention. After completing the intervention, a telephone message was sent out asking to participate in the interview, which had been asked once before, when the women consented to the study. SMS was used as this was deemed to be less

intrusive and would make it easier on the women to notify the authors should they not want to participate.

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suffering that the cancer experience brings. **Implications for clinical practice:** A person-centered, systematic follow-up rehabilitation is needed as a continuation of the care provided during cancer treatment. Future research is needed to explore the impact on women's quality of life when gynecologic-specific information is given in advance of hospital discharge after completing treatment.

Although cancer rehabilitation and survivorship support have been recognized to reduce the symptom burden and increase quality of life in cancer survivors,<sup>1</sup> gynecological cancer survivors worldwide are experiencing deficiency in current rehabilitation and follow-up.<sup>2-5</sup> It is necessary to understand women's needs and preferences in follow-up to enhance their quality of life, thus improving rehabilitation.<sup>2</sup>

## ■ Background

Gynecological cancers are cancers located in the female genitalia. The 3 most common forms are ovarian cancer, cervical cancer, and endometrium cancer.<sup>6</sup> The number of gynecological cancer cases differs greatly, depending on geographic localization, and it is the most frequent female cancer type in Africa,<sup>7</sup> whereas its frequency is lower in Europe.<sup>8</sup> In 2021, 1777 women were diagnosed with gynecological cancer in Norway, representing the fourth most common cancer in women.<sup>9</sup> The success of cancer treatment depends on diagnosis and staging, consisting of surgery, chemotherapy, and radiation, given alone or in combination. Early detection and improved cancer treatment have gradually led to an increase in the number of women surviving cancer.<sup>6</sup> After illness and treatment, most women suffer from 1 or more changes and challenges related to physical, psychosocial, and/or existential areas.<sup>2,4,5,10-13</sup> Examples are menopausal symptoms, sexual difficulties, urinary and intestinal complications, lymphedema and pain, and fear of recurrence.<sup>4</sup> Cancer recurrence varies, depending on diagnosis and stage of disease and is not always symptomatic. However, the most common symptoms of recurrence reported are pain and vaginal bleeding.<sup>14</sup> In several studies, women have reported a lack of information concerning consequences and complications after cancer diagnosis and its treatment.<sup>4,15-18</sup> In comparison to breast cancer survivors, patients with gynecological cancer have reported being less informed in many areas related to the disease, especially regarding psychological support, and experience lower quality of life and emotional functioning.<sup>15</sup>

Even though cancer illness and treatment entail a range of physical challenges, the unfulfilled needs that have been highlighted in previous research relate to comprehensive care needs and psychosocial support.<sup>2,3,16,17,19,20</sup> Lack of psychological support after gynecological cancer treatment has been related to increased anxiety and depression, and difficulties in coping with cancer, physical changes, and treatment.<sup>21</sup> Another study also found a higher prevalence of distress with a negative impact on partner relationship, emotional problems, appearance, memory and concentration, pain, sexual

function, sleep, and more, when psychosocial needs were unfulfilled.<sup>10</sup> Despite the well-known positive effects of rehabilitation, follow-up for patients with gynecological cancer seems to be overlooked or postponed.<sup>5,11,19,22</sup> Rehabilitation includes assistance as well as guidance on psychosocial needs and what the patient can do to improve her situation after cancer treatment.<sup>23</sup>

Empirical recommendations for follow-up after gynecological cancer put forward an individual approach from health professionals<sup>4,13,19</sup> and a focus on physical challenges, as well as sexual health and existential issues.<sup>2,5,13</sup> Although the unmet needs and the desire for more care for gynecological cancer survivors are well described in recent empirical studies, there are few descriptions of how these support needs should be met in practice. There is a need for more knowledge to develop optimal information and care in follow-up for gynecological cancer survivors. This study aimed to explore women's lived experiences of follow-up after recent treatment for gynecological cancer and how they retrospectively wish their care needs had been met.

## ■ Methodology

Merleau-Ponty's<sup>24</sup> phenomenology of the body is applicable for our understanding of the lived experiences in the lifeworld. What we experience with our bodies determines our perception of our life. We cannot understand a bodily experience without living it. This understanding supports the research design, in which a lived life experience must be gained from what Todres et al<sup>25</sup> call an insider perspective. To provide care, that is caring, it is important to understand "what it is like" for the ones who experience the lived embodied experience. This is the strength of qualitative research.<sup>26</sup>

## ■ Research Design

We chose a phenomenological hermeneutical design as we wanted to understand the lived experience. The purpose of phenomenological hermeneutics is to disclose the essential meaning of being in the lifeworld.<sup>27</sup> The data presented in this study are part of a larger data sample. All informants in this study had, at the time of the interviews, participated in a digital rehabilitation program called Gynea, which at the time of recruiting was running as a pilot. Participation in Gynea consisted of a 6-week internet-delivered course, where the women worked independently with educational content and mindfulness exercises, related to themes that were found to be relevant for life after gynecological cancer. Once a week, participants received professional

guidance by telephone from an experienced nurse.<sup>28</sup> The data in this study focus on the lived experiences from the period when the women were discharged from hospital treatment and until they were enrolled into the digital rehabilitation program.

## ■ Selection of Research Participants


We used purposive sampling as all informants were recruited from the aforementioned study that piloted Gynea. After completing the rehabilitation program, 25 participants were asked to take part in qualitative interviews, and 22 women accepted. Two participants withdrew before the interviews started because of deteriorating health. Informants to the pilot were recruited on invitation, through social media, relevant patient organizations, and marketing in printed and digital media. Brochures with information were sent to hospitals and cancer coordinators in the municipalities. Inclusion criteria were as follows: completed primary treatment for gynecological cancer, age older than 18 years, and Norwegian speaking. Exclusion criteria were as follows: cancer recurrence, present and history of severe mental health disorders, insufficient cognitive or language skills, or no curative intent of the treatment.

## ■ Informant Characteristics

The mean age of participants in this study was 53 years. The severity of cancer illness and range of treatment varied. All the participants except one, a retiree, worked at the time they were diagnosed. Fifteen women had a career position requiring a university degree, and the remaining 5 had a high school degree. Five of the informants did not have children. Cancer was the reason of one woman for not having children. The sample characteristics are shown in the Table.

## ■ Data Collection

Data were collected between January 2021 and February 2022. We chose to explore the phenomenon by using semistructured individual interviews, with the intent to facilitate the informants in sharing their experience of follow-up after recent cancer treatment and how they would like their care needs to be met. At the time of the interviews, 5 to 18 months had passed since the participants had completed cancer treatment. All the interviews were conducted digitally on Zoom<sup>29</sup> and were audio recorded for transcription. The participants were at home (in their time off work) during the interviews, except for one woman who was at her workplace. The interviews were initiated by asking the informant to share her experiences of what it was like to go through cancer illness and treatment. When the researcher expressed interest in the stories regarding the research aim of this study, with either comments or visual expressions, many informants elaborated on the experience. The informants were asked, “What was it like to have completed treatment?” and “What was it like to be at home after discharge from the hospital?” and “How did you experience the follow-up after treatment?” The researcher used

 **Table •** Participants' Illness and Treatment Characteristics (N = 20)

Age, y	
30–39	4
40–49	2
50–59	11
60–69	2
70–79	1
Marital status	
Married/living with partners	15
Single	5
Children	
None	5
1 or 2	11
≥3	4
Occupational activity before cancer	
Working	19
Retired	1
Occupational activity after cancer	
Working as before cancer	1
Working less than before cancer	10
100% Sick leave	7
Unemployed	1
Retired	1
Diagnosis	
Cervical cancer	6
Uterine cancer	7
Ovarian cancer	7
Type of treatment	
Surgery	8
Surgery and chemotherapy	7
Surgery and/or radiotherapy	5

exploratory and affirmative follow-up questions to develop a deeper understanding of the women's experiences. As an example, one of the informants said she would have had a greater ability to cope with the challenges after treatment if she had been better prepared, and the researcher asked the informant to elaborate more specifically on what and how she thought she could have been better prepared. The women's desire for follow-up and how they wished it would be approached emerged toward the end of the interviews when the informants had told their stories and reflected upon their experiences. The interviews lasted between 60 and 150 minutes, and only the interviewer and informant were present. Immediately after each interview, a summary was written. All interviews and transcriptions were done by the first author. The first 4 interviews were discussed among the authors to evaluate the interviewing process. Data saturation was reached at 16 interviews as similar themes and experiences were described. Four more interviews were done, which confirmed the themes and added to the depth of data. The informants were given pseudonyms alphabetically, in the order of enrollment in the study.

## ■ Analysis

The interviews were analyzed with the Lindseth and Norberg<sup>27</sup> phenomenological hermeneutical analysis. The

analysis followed 3 steps: naive understanding, structural analysis, and comprehensive understanding.

## Naive Understanding

The text was read several times with a phenomenological attitude trying to grasp the whole of the text. A naive understanding of each individual informant's experience of follow-up and care needs was written. Before working on the structural analysis, we formulated one naive understanding that represented the lived experience of cancer treatment and desire for follow-up, for all the informants, with its variations.

## Structural Analysis

The structural analysis involved a thematic description. The transcribed text was read again, and meaning units were identified. The meaning units were then condensed to express the content as concisely as possible. Themes were identified. This was a dialectical process that led to overlapping findings, which lead to a restructuring of the themes. A deeper understanding evolved. The structural analysis validated the naive understanding.

## Comprehensive Understanding

Reflection on themes comprises this step regarding the research questions, context, and in discourse with appropriate literature, to revise, widen, and deepen the understanding. The comprehensive understanding was merged with the discussion.

## Ethical Considerations

The study was approved by the Norwegian Research ethical committee, number 2019/491 and assessed by the Norwegian Center for Research Data with reference number 446602. The participants gave informed consent to participate in qualitative interviews at enrollment in Gynea, and a new informed consent was signed ahead of the interviews. The women were asked again by SMS if they would like to participate in the interview shortly after the completion of Gynea. We used SMS as this was deemed to be less intrusive and would make it easier for the women to notify us should they not want to participate. Each consent was based on information about the study and its purpose, together with information on data security procedures in line with relevant ethical guidelines.

Audiotaped recordings and transcribed interviews were stored on the research server of the responsible institution, and data that might identify participants were omitted from the transcriptions. We used COREQ (Consolidated Criteria for Reporting Qualitative Research) to support the research process and to reassure transparency of our research work.<sup>30</sup> Rigor in the research was obtained through the systematic and in-depth work that is described through the methodology.

## Results

### Naive Understanding

After discharge from gynecological cancer treatment, many women experienced being left to themselves and felt lonely in their cancer experiences. These experiences were related to being alone with unfamiliar bodily changes, alone about having had cancer, and alone with the uncertainty surrounding the future. Feeling alone and living with uncertainty made most of the women develop a deep fear for their existence, and for some, that was more than they could handle on their own. In the period between discharge from treatment and the first checkup 3 months after treatment, women reported experiencing the greatest distress and wanting healthcare personnel to be available to reach out to them when they did not seek help on their own. Most women experienced illness- and treatment-related changes that affected their existence beyond the bodily changes, resulting in an emotional vulnerability. Several women did not experience the anticipated joy and relief upon completing treatment, but rather emptiness and a feeling of being in what was described as an emotional vacuum. The illness and treatment had caused changes that deprived them of the feeling of being healthy. The women wanted to focus on the future, and many took personal measures to regain health on their own, that is, exercising, looking for support online, and pushing themselves to go back to work. However, life after cancer treatment was an unknown territory, and they lacked experience as well as knowledge and understanding. The women expressed a need for care that addressed their altered self and that could guide them in regaining a meaningful daily life.

### Structural Analysis

The lived experience of follow-up after recent treatment for gynecological cancer and the desired care approach afterward are described in the themes "a brutal transition to life after cancer," "fear of recurrence overshadowing the existence," "a need for professional support," and "information is not given unless asked for."

#### A BRUTAL TRANSITION TO LIFE AFTER TREATMENT

Most participants described hospitalization and treatment as good experiences, with caring healthcare personnel, and the hospital as a safe place to be. To be discharged from the hospital was described as a disruptive and sudden event where the women felt that they were left to themselves with bodily and psychological changes that had consequences for their daily life. Metaphors such as "being thrown off a train at speed" or "to be left hanging in the air" depict a brutal transition to life "after treatment." Anne (50 years old), who had treatment consisting of surgery followed by 6 weeks of chemotherapy, described the transition from hospital to home: "It goes so fast during treatment. You don't know what happens to the body, how you will react, things like that, who to ask and then you are suddenly left hanging in the air."

Many women experienced being left to themselves, like Sarah (55 years old), who described that she suddenly came home from the hospital and had to provide further care on her own. She experienced a need for contact in follow-up and said, "I think it was a little strange, that it was up to me to contact a general practitioner, cancer coordinator and others. You must figure it out for yourself somehow. Is that how it should be? I felt empty and thought, now I am completely left to myself." When discharged from the hospital, the women were told "Just give us a call" if they had questions or needed help. The women felt uncertain as to whether the questions they had qualified for making a call and whether what they experienced was normal. When the women accepted the invitation to call, this also had its limitations. Torunn (50 years) described the communication challenges with healthcare services: "The general practitioner (GP) asked me to call the hospital to talk to the specialist. But when I called, I only reached a secretary who contacted the doctor, and then the secretary called me back again. I never did get to talk to a doctor." Although the GP was responsible for the follow-up, several of the women experienced that the GP had little knowledge about the disease and its consequences or little knowledge about the individual woman and her situation. Even though the women had close family or friends who were supportive and caring, they were unable to alleviate the feeling of loneliness after cancer illness and treatment. The women also described how they chose to hide their fear and suffering from their close relatives, instead striving to maintain the appearance of an unchanged everyday life. This was done to spare the family from worries, but also to avoid the suffering of seeing their loved ones worried or sad.

## FEAR OF RECURRENCE OVERSHADOWING THE EXISTENCE

The time until the first follow-up at the hospital, 3 months after treatment, was described as particularly challenging. Regardless of whether the women had a good prognosis or advanced disease with a high risk of recurrence, this was a challenging period. Particularly demanding was the profound fear of cancer recurrence or that the treatment had failed, which dominated the existence of many women. Elisabeth (30 years old), who had gone through surgery for early-stage cancer, said, "After surgery, I was so scared that the cancer would come back, and I thought to myself that this is not a dignified life if I have to spend the rest of my life being as worried as I am now." The women were not informed or forewarned of the physical changes resulting from the cancer and treatment and described psychological reactions related to these unexpected changes. The lack of information and preparation made the women associate the physical changes with cancer recurrence or failed cancer treatment, which resulted in existential fear. Ursula (55 years old), who was treated with surgery for early-stage cancer, said: "After 6 months, the anxiety came back strongly. The fear of cancer recurrence was there all the time but peaked when I developed some minor ailments. Pain in the upper abdomen, hips and back. I called the hospital and was allowed to come in for an extra examination. They said everything was fine, but I did not settle for that. I went to the GP and was referred for a CT at another hospital." Some women

reported both emergency hospitalizations and referrals to psychiatric health services due to anxiety when they experienced the changed body they were not prepared for. Frida (50 years old) said: "I'm not sure if I would have needed a psychiatric admission if someone had just called me and told me that what I was struggling with was normal. I know that now, but when you are in the middle of it all, you're unable to think that it is just normal."

Follow-up for the women consisted of a routine checkup at the hospital every third month in the beginning. The women reported that the routine checkup had a 1-sided focus on checking for recurrence of cancer. Despite the lack of a holistic approach, the confirmation that there was no cancer recurrence held a great value for the women's perspective on the future and their quality of life. One woman said that when the checkup confirmed that she was cancer-free, she went back to work the very next day. Prior to this, she was on sick leave because of her feelings of uncertainty regarding the future. Several women described feeling cancer-free for the first months after the checkup, until they received the letter of appointment for a new checkup. Some women said that they did not consider themselves cancer-free until the checkup could confirm it. Although most women experienced the checkup as stressful, none of them would consider being without it. One woman said that she loved the checkups because then she felt that she was being cared for and respected. Her experience was somewhat different from the several women who experienced the checkup to be without empathy and a person-centered approach. Nevertheless, the checkup was important to all participants in that it decided whether they would live on or not.

## A NEED FOR PROFESSIONAL SUPPORT

After treatment, the women longed for professionals who would offer individual and holistic support in the aftermath of cancer, an aftermath encompassing psychological, physical, social, and existential challenges. Several women expressed a need for being contacted directly by healthcare personnel with a formal responsibility for them as patients, rather than initiating contact themselves. The women described a concrete desire to be contacted by phone regularly, for example, once a week. This need was also expressed as "being sought out" as a routine after having completed cancer treatment. Many women shared that they did not see what they needed after the treatment. They would have been unable to ask for help, even if it were available. Marie (55 years old) described it as: "During the crisis, when I got cancer, it was difficult to deal with my own feelings. When I stood in the middle of everything, I was no longer my own master. Although I was responsible for myself, I needed support from others who could empower me."

One woman described a very satisfactory follow-up, entailing just that contact from the specialist health service that many participants desired. She was called regularly by a compassionate nurse during the first 3 months after discharge from the hospital and before the first checkup. The nurse asked her how she was doing, and she was able to voice any thoughts or questions she may have. After the first checkup confirmed that she was cancer-free, she felt she did not need the weekly conversations any longer.

The need to be contacted by healthcare professionals was also referred to as an opportunity to break the existential loneliness. Sarah (60) described it as: "I had many people around me, both friends and professionals, but I was still alone in my life. With all my existential thoughts. No one can get in there completely. But you need to share some of them with someone who's listening to you."

The informants in this study emphasized that the person who would "seek them out" should be someone with experience with and professional knowledge about gynecological cancer. It was also important that the person was caring and a good listener and could withstand their suffering without being personally affected by it. Some women feared the latter could be challenging with peer support. Three women had peer-support experience, which was described as increasing their existential distress. One peer support had cancer recurrence, which scared the woman. Another woman said she felt embarrassed about her own way of coping in comparison with the peer support.

Wendy (55 years old) said that she needed to talk to an experienced nurse who had worked in the field for many years. She needed someone who could talk to her about the emotional aspects of her life, but also about all the practical things that might help her cope with everyday challenges. When health professionals or friends downplayed or simplified the cancer experience, this would work against the feeling of coping and lead to a feeling of failure or of not being taken seriously.

#### INFORMATION IS NOT GIVEN UNLESS ASKED FOR

Many of the women experienced that information was not given unless they asked for it specifically. A doctor told one participant that other women did not have the same need for information as she did. Another woman was told by a hospital nurse that they did not give information about everything that could possibly happen after cancer treatment because then it might happen. Some women said that they were informed about specific possible challenges but experienced completely different challenges that were more comprehensive and inhibitory to the quality of life than expected.

The women wished they had received written information to prepare them for life after treatment, to use as a reference work when questions arose. Menopausal symptoms, lack of energy, sleep difficulties, intimacy problems, change in digestion, pain, concentration difficulties, and anxiety were some of the specific issues the women spoke of. In the absence of information, many women used the internet in search of answers. This included a risk of finding information that might be psychologically destructive, which made the women more careful in their search for information, despite the great need to know more. Theresa (50 years old) described the lack of knowledge as: "I did not receive any information from the hospital when I returned home. Nothing about the rest of my life, only information about the medication I should use, and how often I should go in for a checkup. I had a thousand questions. I tried to ask but got no answer. There was no real conversation about what would happen next to me because of the treatment and what I had been through. There was nothing – I missed it and it was overwhelming."

Some of the women started exercising to strengthen their bodies but were unsure of how much to do. Some participants experienced pushing the body more than may be wise, such as the woman who experienced vaginal bleeding after an abdominal fitness exercise, 2 weeks after surgery.

The general description of an ideal follow-up was with a focus on the individual and the multifaceted challenges following the illness, which was more than a routine checkup provided. Cecilie (50 years old) described the absence of a holistic approach when she was discharged from the hospital: "It was all about the surgery, what they had done, and what they had removed. No one talked to me about what it was like to be me in my situation and who I am now. I had many questions, and I felt a lump inside my chest all the time. And what should I do? I felt so left to myself." Most women said they had needed guidance when trying to regain their health after treatment. Rebecca (60 years old) said she needed someone to tell her what to do: "I was thinking to myself, that I have to manage this. I must get through this. But I needed someone who could tell me what to do. I wanted to do all I could, to help myself through this." The women consistently expressed a need for more information and knowledge, so that they could gain a deeper understanding of themselves after the illness and enter the rehabilitation process.

#### Comprehensive Understanding and Discussion

This study reveals that after gynecological cancer treatment women frequently perceive being left to themselves and that they often feel lonely when dealing with the multifaceted challenges that the cancer experience had brought. The bodily experiences were expressed through loneliness, emptiness, fear, and an existential vulnerability. The findings indicate that gynecological cancer survivors need to be consulted by healthcare professionals after treatment, as a continuation of the cancer trajectory. There is a need to share the lived experiences that, if remaining unspoken, manifest as existential suffering and create a basis for destructive pondering. Many women were offered to contact the healthcare service after discharge from treatment. However, follow-up was experienced as nonexistent because of no formal responsibility from the healthcare service. Most women expressed a need to be contacted by healthcare professionals, as the life-threatening situation they were in made it difficult to seek help.

Other studies<sup>5,11,30</sup> have also identified the challenge in seeking support after gynecological cancer treatment as the patients did not know what to ask for and it was unclear to the patients what problems they could address. What the women in this study found logical and reasonable retrospectively was not clear to them when they needed support. We can understand this phenomenon in the perspective of Merleau-Ponty<sup>24</sup> thinking. According to Merleau-Ponty, we know our bodies better than our minds, and so the body experience comes first. Our thoughts are the result of our embodied experiences and may only be comprehended after the passing of time.<sup>24</sup> The women in our study experienced a variety of challenges of which psychological distress and existential thoughts were prominent. To go into the unknown, without any previous knowledge and without

anyone who could confirm their experiences, made them feel left to themselves. This finding is similar to previous studies<sup>11,13,31,32</sup> where women experienced loneliness and uncertainty related to bodily symptoms that were not confirmed by others, an experience they described as a lack of psychosocial support. Another study<sup>16</sup> found that missing psychosocial support was correlated to higher levels of anxiety and depression in gynecological cancer survivors, a finding that underscores our findings. The women who missed psychosocial support also reported a great deal of anxiety.

The women in our study described unexpected physical changes associated with the fear of cancer recurrence. There may be a close connection between fear of cancer recurrence and psychological distress. The findings are in line with Mawardika et al<sup>33</sup> and Galica et al,<sup>5</sup> who found that psychological challenges after cancer treatment, such as anxiety, depression, fear of relapse, and uncertainty about the future, were related to the degree of physical challenges; the more physical symptoms, the greater distress.

According to Merleau-Ponty,<sup>24(pp90-91)</sup> what happens to the body affects the whole human being. Any “somatic” change opens a psychological disturbance that again manifests in the body. The women in this study express their existence through the experiences of the lived body with an existential expression such as the feeling of loneliness and existential suffering. For some women, being alone with existential suffering and anxiety led to emergency psychiatric admissions when the anxiety emerged to a level they were unable to manage on their own. This relates to the findings from a review that women who failed to process the cancer experience, either alone or with others, also struggled the most.<sup>4</sup> There seems to be a great need to address the cancer experience and the challenges following illness and treatment to reduce the overarching anxiety. A holistic approach that encourages addressing all aspects of the illness has proved to reduce anxiety and depression in gynecological cancer survivors.<sup>34,35</sup> Several of the women in our study believed that they might have avoided or reduced their anxiety and distress if healthcare professionals had sought them out and confirmed the challenges they experienced, with knowledge and understanding. A recent study<sup>36</sup> supports this belief, and a significant direct association was found between social support and emotional well-being in cancer survivors who had someone to talk to about their health issues. In addition to the need to be contacted and confirmed, the informants in our study also believed that information given ahead of the challenges they experienced could have made their distress less worse. A review that explored the relationship between information provision and quality of life in cancer survivorship<sup>37</sup> found that patients who had fulfilled their information needs had higher health-related quality of life and lower levels of depression and anxiety. However, the outcomes were dependent on the quality of the information given, whereas general information without specific focus had no or little influence on health-related quality of life, anxiety, and depression in the patients.

In our findings, information and knowledge sharing from the healthcare service was experienced as completely absent or deficient, which left the women unprepared for the challenges that

came. Several studies report unfulfilled information needs in the patient group.<sup>4,5,31,38,39</sup> For the women in our study, the lack of information was perceived as detrimental to their recovery and increased existential suffering. Fundamental changes and challenges such as sexuality, existential issues, bodily changes, and adverse effects were not addressed or discussed by healthcare personnel. The women longed for someone to inform them about what to expect after discharge from treatment and provide them with written information. Merleau-Ponty<sup>24(pp340-341,364)</sup> says that it is through the relationship with others and things that we know ourselves. The perception of others’ response and behavior is interpreted with our own inner experience. When there is no relation to others, perception of the bodied experience is based on previous understanding. A bodily change may then, as experienced by the women in our study, become associated with the cancer illness.

In our findings, some women believed that information was being deliberately withheld so as not to make them fear what might come. Recent studies have found that information needs turn out to be less fulfilled in women with gynecological cancer in comparison with other cancer groups.<sup>14-16</sup> Could this mean that survivors of gynecological cancer receive less information than other groups of survivors? Healthcare personnel in previous studies related to gynecological cancer confirm that they avoided providing information because they did not want to scare the women with information about recurrence and potential health challenges,<sup>19</sup> with their intent being to help patients focus on improving their quality of life. Healthcare personnel in another study also confirm the lack of information and state that the main reason for this is a lack of time and support tools to assess the women’s needs.<sup>22</sup> In another study involving survivors of gynecological cancer, survivors described being told by healthcare personnel they were fortunate because they had been cured and faced a low risk of recurrence.<sup>11</sup> This contradicted the women’s experiences as they struggled with physical and sexual challenges. To be labeled fortunate made it even more difficult for the women to seek help for their challenges. The women in our study who received information about possible challenges found that these were not the challenges they in fact experienced. This may underscore the individual approach that is emphasized as ideal in several previous studies<sup>4,5,13,19</sup> and by the informants in our study. The women wanted to be prepared for what might come. This demands a more general approach that includes the variety of potential outcomes for the entire patient group.

Previous research emphasizes the life-affirming importance of the routine checkup, when it verifies that the women are cancer-free and their future is not threatened by illness.<sup>20,31</sup> A 20-minute checkup that can confirm that there is no recurrence gave the women a more optimistic future perspective up until the arrival of the invitation to the next routine checkup. The woman in our study who returned to work the day after a positive checkup is an example of the impact such a checkup can have on daily life and social economic factors.

However, although the checkup provided the highly appreciated confirmation that the cancer was gone, the checkup was described as lacking a holistic approach to address the complexity of

the illness. Women in previous studies also expressed the need for follow-up to enhance self-management and coping with survivorship.<sup>5,31,40</sup> The women in our study experienced that there was no time in the checkup for holistic care, which has also been found in previous research.<sup>5,22,40</sup> Some women reported that checking for symptoms on their own was helpful, whereas some women said they did not know that they had cancer before they had acute symptoms. They were thus dependent on the confirmation from a specialist and felt they could not trust their own body on this.

All the informants in our study were women who had participated in a psychoeducational intervention, which most of them had found on their own as they felt they lacked knowledge and professional support. The informants, except one, were all highly educated and were working full time when they received the cancer diagnosis. A previous study found that higher education was associated with higher needs for psychosocial support in women with gynecological cancer.<sup>16</sup> Thus, one might think that this category of participants may also be represented in our study. Patients with psychological challenges are more likely to use the internet to search for information, and those with the highest education were more willing to use the internet for health information.<sup>41</sup> On the other hand, people with lower education were more likely to follow the interventions as recommended.<sup>42</sup> Women in Norway receive the same follow-up across levels of education and social background/demographics. Another question is whether less resourceful women also have more difficulty seeking help, and if so, the women in this study may act as spokeswomen for their fellow cancer survivors.

## Methodological Strengths and Weaknesses

A limitation of this study is that it includes a sample of gynecological cancer survivors who looked to the internet for help and support when they experienced a lack of support, which indicates that this group was dissatisfied with their follow-up. We do not know if we would have the same results from a random selection of gynecological cancer survivors. All participants in this study had participated in a digital rehabilitation program, which may have influenced their experiences retrospectively. Thus, there is an unknown self-selection bias based on the recruitment from Gynea. The participation in Gynea may have influenced the women's stories through raised awareness of life after illness and speaking of the cancer experience. The latter may also influence their willingness to share their experiences, which is a strength of this study. The sample is also heterogeneous when it comes to educational background and career. In our sample, 75% had a career requiring a higher education, whereas in national statistics 38% of Norwegian women have a higher education.<sup>43</sup>

A strength of the study may be that the first and third authors have a clinical background from work in the field of gynecological nursing, thus understanding the clinical problem and building trust in the interviews. The interviewer had no previous relationship with the informants, and before each interview, she explained that she had not been part of the intervention development or implementation. She also informed the participants that she had a clinical background from work-

ing in the field. Data analysis was done in collaboration with the third author, who had read the transcripts of each interview. The third author provided feedback throughout the whole analysis process. During interviews and analysis, all 3 authors met and reflected and discussed the collected data.

## Implications for Practice

There seems to be a strong need for a cancer pathway home in which the routine care in hospitals is extended through systematic follow-up by healthcare professionals after discharge. Essential, but easy to overlook, is that it must be healthcare professionals with knowledge and experience with gynecological cancer survivorship who make contact, as initiating and making contact is a challenging task for women shortly after treatment for cancer. Healthcare professionals must be aware that family and friends are not equal to existential support that is needed after cancer treatment.

## Conclusion

This study describes how survivors of gynecological cancer experienced follow-up after treatment regarding their needs, and the care they wanted. After treatment, the women experience a lack of information and support from the healthcare service. The fear of cancer recurrence is overarching after discharge, and the women believed that information and support from healthcare professionals could have prevented some of this suffering, a belief supported by previous research.<sup>16,37</sup> This study provides insight into the importance of customized information along with a holistic approach in future interventions that aim at total recovery after gynecological cancer diagnosis and treatment. There is a need for further research on the impact of cancer survivorship information when given in advance. There is also a need to reassess the checkup and its content with the aim to provide women with tools that not only can improve life skills but also can preserve life-affirming advantages.

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