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Redefining sexual health after gynaecological cancer: Lived experiences from Gynea, a digital rehabilitation programme

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Abstract

Background: Gynaecological cancer illness and treatment have a significant impact on women's sexual health and concerns regarding sexual health are known to be an unmet need in survivors. The digital support programme Gynea was designed to enhance women's health, including sexual health, after gynaecological cancer treatment. This study aimed to explore how cancer survivors experienced participation in Gynea. Methodology: This is a phenomenological hermeneutic study. Individual, in-depth semi-structured interviews were conducted to explore lived experiences. Twenty women were interviewed after completing the Gynea programme. The transcripts were analysed using Lindseth and Norberg's phenomenological hermeneutic method. Findings: Three main themes (with subthemes) emerged from the analysis: (1) A silent existential trauma; (2) Redefining sexual health; (3) Communicating with a partner about sexuality. The women redefined sexual health rather than just being sexual intercourse, being a rediscovery of the body. The women's increased awareness and understanding of their own sexual health empowered their communication about their sexuality with their partners. This was important for regaining sexual health and intimacy in their relationships.

Conclusion: Participation in Gynea helped to strengthen the women's sexual integrity. Knowledge and support empowered them to take care of their sexual needs and communicate these with their partners.

Implications for Patient Care: Healthcare services and nurses need to be aware that sexual health is an existential state of being, in which good sexual health does not necessarily equate to sexual function, but rather to sexual empowerment. Digital support with nurse guidance can support women in caring for their sexual health after cancer illness by thematizing sexual health with a holistic approach and should be part of the medical treatment.

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Patient or Public Contribution: Twenty gynaecological cancer survivors contributed by sharing their experiences from the sexual health module in Gynea.

KEYWORDS

digital rehabilitation, gynaecological cancer, nurse support, sexual empowerment, sexual health, women's health

1 | INTRODUCTION

After diagnosis and treatment for gynaecological cancer, women suffer from a range of challenges. In particular, sexual health and relationships represent significant concerns, as indicated by several studies (Hubbs et al., 2019; Roussin et al., 2023; Sears et al., 2018; Sekse et al., 2019). Furthermore, the literature highlights that challenges related to sexual health have also been among the most frequently reported unmet needs in gynaecological cancer survivors (Ashmore et al., 2020; Beesley et al., 2017; Faller et al., 2019; Galica et al., 2021; McCallum et al., 2017; Roussin et al., 2021; Sekse et al., 2019; Vermeer et al., 2016). However, the sexual health challenges that follow gynaecological cancers are complex. Previous research underscores the multifaceted impact of cancer on women's sexual health and identity, encompassing physical, emotional and psychosocial dimensions (de Souza et al., 2021; Roussin et al., 2021, 2023; Sears et al., 2018). The multidimensional aspects of sexual health are also addressed by the World Health Organization (WHO, 2017), which defines sexual health as physical, emotional, psychological and social wellbeing and not merely the absence of disease, dysfunction or infirmity. Good sexual health herby demands bodily integrity, privacy, personal autonomy and the option to decide whether and when to be sexually active.

To support women in achieving good sexual health the provision of professional support is essential. The WHO (2017) further emphasises the importance of information, resources, health services and support to reach good sexual health. Identifying challenges and providing helpful information regarding sexual health is a task for healthcare professionals with higher education, such as nurses (The Norwegian directorate of health and care services, 2018). Hence, sexual health support after cancer treatment is a crucial part of cancer rehabilitation.

Unfortunately, cancer patients have found that rehabilitation in general is regarded as low priority (Lie et al., 2019), and that sexual health in cancer rehabilitation is under-communicated by healthcare professionals (Chowdhury et al., 2020; The Norwegian directorate of health and care services, 2018). However, the opportunity to provide cancer rehabilitation through digital health services has been recognised as cost- and resource-effective (WHO, 2016), also in providing psychosexual support to cancer survivors (Kang et al., 2018). Reviews on sexual health support for women after cancer have highlighted digital media as a preferred means because of the privacy and convenience it brings (Benedict et al., 2022; Febrina et al., 2022).

Nevertheless, many interventions have their main focus on improving sexual function and quality of life for women. These interventions rely on measuring outcomes by sexual function scales (Rosen, 2000; Roussin et al., 2021; Sears et al., 2018). This approach

What insights does this paper contribute to the wider global clinical community?

- Sexual health after gynaecological cancer is strongly negatively affected by existential trauma following cancer.
- Women suffer from guilt and worry about not being able to satisfy their partner after gynaecological cancer and the risk of losing intimacy in their relationships.
- Nurses can support women's sexual integrity by thematizing sexual health as an existential situation rather than function alone.

does not provide a holistic understanding of personal sexuality and fails to consider the full complexity of women's sexuality after gynae-cological cancer (Abbott-Anderson et al., 2012; Olesen et al., 2023). Therefore, adopting an exploration of lived experience in our study could offer a comprehensive perspective to women's sexuality in rehabilitation after gynaecological cancer.

2 | BACKGROUND

Efforts to support women's sexual health are directed towards the women's challenge. However, these challenges are multifaceted, encompassing physical, psychological and existential dimensions. Physical changes that make sexual activity more challenging after gynaecological cancer are closely linked to treatment consisting of surgery, chemotherapy and radiotherapy, alone or in combination (Sears et al., 2018). Removal of the ovaries causes a sudden drop in sex-steroid hormone levels results in vaginal dryness, lack of sexual desire and other menopausal symptoms. Surgery can cause vaginal shortening, changes in vulvo-vaginal and clitoral structure, vaginal atrophy and damage to pelvic nerves (Sears et al., 2018) (Olesen et al., 2023). Radiation therapy is known to cause soreness and tissue stiffness in the vagina, and women may also experience a lack of sensation due to peripheral neuropathy. Additionally, treatment can further give rise to lymphedema and symptoms related to induced menopause (Roussin et al., 2021).

Besides the physical dimension, gynaecological cancer impacts women's overall quality of life. Research (Olesen et al., 2023; Roussin et al., 2023; Wilson et al., 2020) has shown its impact on female identity, psychosexual wellbeing and partner relationships and their sense of womanhood (Fischer et al., 2019; Vermeer

et al., 2016). Gynaecological cancer is experienced as an existential crisis in women's lives with many women struggling with pain, anxiety, worries about the future (Bal et al., 2013; de Souza et al., 2021) and a changed body image. All of these struggles have a profound impact on these women's sexual health (Fischer et al., 2019; Wilson et al., 2020).

There has been a surge of interventions for addressing women's sexual health concerns following cancer treatment (Benedict et al., 2022; Candy et al., 2016; Febrina et al., 2022; Sears et al., 2018). Medical pharmaceutical interventions, such as oestrogen treatment, lubrication supplements, vaginal dilatation regimes, physiotherapy, etc., focus on compensating or supporting physical ailments (Candy et al., 2016; Sears et al., 2018). Psychosocial and mind-body interventions focus on educational content, cognitive behavioural therapy, mindfulness training (Candy et al., 2016; Chow et al., 2016; Sears et al., 2018) and psychological support (Chow et al., 2016). Nevertheless, there is limited evidence on interventions that significantly improve sexual function following gynaecological cancer (Chow et al., 2016). Research studies on digital sexual rehabilitation interventions following gynaecological cancer are particularly scarce. One review on digital interventions addressing breast and gynaecologic cancer patients' sexual health (van Lankveld, 2016) included two studies specific to gynaecological patients, which consisted of psychoeducational content. Both studies measured a positive effect on patient's sexual health, but in the one study that incorporated nurse guidance, there was a statistically stronger positive effect (Schover et al., 2013). Another digital self-help intervention, which aimed at 100% self-help, had high attrition, but for those who completed the programme, their sexual function measurements and use of sexual aids improved (Schover et al., 2020). Considering this background, the research suggests that there is a potential for digital interventions to provide sexual health support, however the existing research remains relatively limited.

3 | THE STUDY

Despite increased knowledge about women's sexual health concerns after gynaecological cancer treatment, it is unclear how women experience digital sexual support interventions. This knowledge gap is important to fill, because of the complexity of sexual difficulties after gynaecological cancer, together with the growth of digital support interventions. In this study, we aim to explore women's experiences of a nurse-supported digital programme, Gynea, which targeted sexual health following gynaecological cancer treatment.

3.1 | The Gynea programme

Gynea is an internet delivered digital rehabilitation programme developed to enhance women's quality of life following gynaecological cancer treatment (Sekse et al., 2021). The inclusion criteria for participation in Gynea were as follows: completed primary

treatment for gynaecological cancer, age over 18 years and fluency in Norwegian. The exclusion criteria were known cancer recurrence, presence or history of severe mental health disorders, insufficient cognitive or Norwegian language skills and no curative intent of the treatment. The programme is presented as a website consisting of six different thematic modules that have been identified in research as being relevant for life after cancer (Sekse et al., 2019). Of these modules, 'sexual health' is the one at the centre of this study. The other modules were 'Everyday life after illness, A changed female body, Fatigue, Fear of recurrence and Summary'. For the sexual health module, the participants worked on the content for about a week, working at their own pace with reading informational texts, listening to informative audio files and doing reflection work through writings tasks, written into digital textboxes. By the end of the week, the participants received telephone support from an experienced nurse which had read their written texts. The sexual health module aims to educate and support women in addressing sexual health challenges after gynaecological cancer, with a focus on rediscovering sexuality, improving communication and self-efficacy through self-support, self-care and mindfulness practice using educational activities and mindfulness training. This approach emphasises sexuality as affecting wellness and pleasure of the entire body (Sekse et al., 2021). Throughout the module, three constructed characters, developed from previous research (Sekse et al., 2012), share their experiences with sexual health following cancer and explain how they communicated about sexuality with their partners (Sekse et al., 2021). The information and educational content are specifically tailored to women with gynaecological cancer, which makes the interaction with the nurse and the personal writing assignments person-centred.

4 | METHODS

4.1 | Design

We used a phenomenological hermeneutic design to explore women's lived experiences of a digital rehabilitation programme targeting sexual health after gynaecological cancer. Semi-structured interviews constituted the data for interpretive text analysis. Phenomenology as a research method aims towards people's descriptions of a phenomenon which they have experienced, while hermeneutics aims towards unfolding the deeper meaning in a text through interpretation and reflection regarding its context (Ricoeur et al., 1999, p. 68). In phenomenological hermeneutics, we aim to create a universal understanding of the phenomenon being studied (Lindseth & Norberg, 2021), a phenomenon that the reader can, for example, recognise as being useful for healthcare.

4.2 | Setting and participants

The participants in this study were 20 women who participated in the Gynea digital rehabilitation programme between 4 and

Theme	Subtheme
A silent existential trauma	An existential trauma Thematizing sexual health after cancer
Redefining sexual health	Rediscovering the body Living in the tension between self-care and care for the relationship
Communicating with partner about sexuality	Game changing conversations Towards a common understanding

TABLE 1 Themes and subthemes from the structural analysis.

15 months after completing primary treatment for gynaecological cancer. The nurse who facilitated the programme recruited the participants for this study. So requests to participate would be less intrusive, they were made via the short message service (SMS). Twenty-two women were invited, all of whom agreed to be interviewed, but two women withdrew their consent before the interviews, due to deteriorating health. Information about the study was given both verbally and in writing, and the participants gave their informed consent.

The mean age of the participants in the study was 53 years. There was an even distribution of cancer types, stages and treatments received. Fifteen of the 20 women were in a relationship at the time of the interviews. Of the five women without a partner, one was recently widowed, and one was newly divorced.

4.3 | Data collection

Individual in-depth interviews were conducted digitally on zoom between January 2021 and February 2022, except for two participants who requested telephone interviews. The participants were in their homes during the interviews, as was the interviewer. The interviews were carried out by the first author, following a semi-structured interview guide. The participants were asked about their experiences with the Gynea programme, their experiences with follow-up and, more specifically, how they experienced working on the theme of sexual health in Gynea. The results from the latter question were analysed for this study.

Some participants elaborated on their experiences with sexual health and Gynea without encouragement, while others gave short answers. Explorative follow-up questions were asked to gain an in-depth description of their experiences. For example, one informant said she experienced the sexual health module as game changing for her partner relationship, while another said she found it unimportant. Both these answers were followed up by explorative questions asking the informants to elaborate their answers, such as, 'Can you elaborate on that? In what way did you experience it as game changing? Or why did you find it unimportant?'

Audiotaped interviews lasted between 60 and 150 min and were transcribed by the first author shortly after the interviews.

4.4 | Analysis

The transcripts were analysed according to the Lindseth and Norberg (2021) phenomenological hermeneutical method, which forms a hermeneutical circle aimed at uncovering a universal meaning of the phenomenon being studied. This method consists of three steps: naïve understanding, structural analysis and comprehensive understanding.

Naïve understanding is a first reading of the text with a phenomenological attitude, which means putting judgements and presupposed understanding aside (Lindseth & Norberg, 2021). Due to the complexity of each participant's experience, we composed a naïve understanding of each individual interview before writing a naïve understanding of all the interviews.

To validate the naïve understanding, we performed a structural analysis with the purpose of avoiding any one-sided views or opinions and prejudices (Lindseth & Norberg, 2021).

In the structural analysis, meaning units from the original transcripts are structured based on themes and then condensed to present a precise expression of their meaning. Various themes and subthemes surfaced throughout this work and were carefully considered in their entirety, with them intertwining to form an objective understanding supported by representative citations. An iterative process of rewriting and rephrasing the themes and realigning the meaning content was undertaken until there was a consistent connection between the naïve understanding and the structural analysis.

In the final stage of the analysis—referred to as the comprehensive understanding stage—we reflected critically on the findings and discussed them in light of previous research and theory that could contribute to a universal meaning of the phenomena as a way of participating in life (Lindseth & Norberg, 2021). Thus, a comprehensive understanding is presented as a discussion in this article.

4.5 | Ethical considerations

The study has been approved by the Norwegian Research ethical committee, number 2019/491 and has been assessed by the Norwegian Centre for Research Data with reference number 446602. The participants gave informed consent to participate in the qualitative interviews. Each consent form was based upon information about the study and its purpose, together with information on data security procedures in line with relevant ethical guidelines.

4.6 | Rigour and reflexivity

To ensure the study's rigour, we employed the CORQ Checklist (COnsolidated criteria for REporting Qualitative research) (Supplementary File 1), as outlined by Tong et al. (2007).

5 | RESULTS

We explored how women experienced participation in the Gynea digital rehabilitation programme, targeting sexual health after gynaecological cancer treatment. The themes and subthemes are presented in Table 1.

5.1 | Naïve understanding

Working with sexual health in a digital rehabilitation programme varied from being the most important theme for some to being unimportant for others. Common was that the cancer had made an impact on the women's life and remained a trauma in their bodies. For some. relief was experienced when sexual health was thematized, as sexual health had been an unspoken topic during and after treatment, which had led to loneliness and a negatively altered state of sexual health. Prior to participating in Gynea, many women understood sexual health as the activity of intercourse. Through new insights, an individual-oriented sexuality was incorporated with awareness of one's own needs, wants and readiness at its core. When penetrative sex became absent in their relationships, many women lost intimacy and closeness with their partner, expressed as a great sense of longing. By gaining an understanding of how illness and treatment had affected their sexual health, the women's communication about sexuality with their partners improved. For some of the women, sexuality, for various reasons, was such a difficult topic which made sexual health unimportant to them. Sexual health was something that had to wait or that was determined to not have a place in their lives.

5.2 | Structural analysis

5.2.1 | A silent existential trauma

After treatment, most women said that they were not well informed about how the illness and its treatment would affect their sexual health and that sexuality was not a theme that was spoken of by healthcare personnel before or after treatment. Along with physical changes, such as shortened vagina, vaginal dryness and soreness,

pain, discomfort during intercourse and lack of sexual desire, the women found themselves existentially shaken by the illness and experience the treatment as a traumatic event. By identifying and recognising their challenges through the educational content in the programme, the women gained insight into and understanding of the physical and psychosocial changes concerning their sexual health. This understanding also opened up the sharing of their concerns and worries about sexuality.

An existential trauma

The cancer illness was described as a traumatic event which was manifested in bodily and emotional expressions for a disrupted life. Cecilie (50) said, 'My life has been taken away from me, even if the cancer is over', and Rebecca (60) said, 'The person that I was, is actually dead', describing how cancer had brutally affected her life. The cancer and the impact of the treatment on their existential experience of life was a bodily trauma for the women that gave associations to feelings of violation. Mary (60), who had been treated with surgery and chemotherapy for ovarian cancer, said, 'When I left the hospital I said to my husband, the way that I feel now must be something similar to what those who have been raped feel'. After treatment, several women said that they experienced a bodily resistance to intimate touch, which was expressed by the tension of pelvic muscles and, for some, a stiffened body. In the interview, some women stretched out their hands to show how they experienced resentment to touch, a resentment that would be accompanied by utterances such as 'Don't touch me', 'I feel like I am suffocating, I cannot breathe', 'Leave me alone' and 'I do not know if I'm going to feel sick, but it's unpleasant'. Hannah (30), who appreciated intimacy with her partner, described it this way: 'So much has happened, my body has been ravaged. As soon as he strokes my back and especially my stomach, I go into defensive mode'. For most women, bodily tension was related to touch from a partner, especially on the stomach, while Frida said that if someone gave her a friendly hug her pelvic muscles would tense and she would feel like she was suffocating.

For the women who had to use dilators after treatment to keep the vagina open, usually after external or internal radiation treatment, this process was experienced as 'assaulting themselves'. Olivia (60) had to dilate daily; she chose to dilate every morning before getting out of bed. After dilating, she showered because she felt dirty and disgusting. She said, 'In the beginning, I threw up every time I used it. I felt I was doing abuse towards myself. I also think that it kills my sex drive. It has become a part of my life, and I hate it.' Linda (40) talked about a distant relationship with her genitals and said that dilating was out of the question even though she was advised to do it. When discharged from treatment at the hospital, the women received simple instructions for use of the dilators but were still unsure if they were doing it correctly. At the follow-up 3 months after discharge, the women received feedback and more detailed instructions from the gynaecologist that adjusted how they should use the dilator. Dilator use was something that these women wished had been a topic in Gynea, so that the emotional challenge

and experience of dilator use could have been discussed. As Olivia (60) said, 'It can't be only me who find it so emotionally difficult'.

Thematizing sexual health after cancer

Sexual health was, for the most part, an unspoken topic in encounters with healthcare personnel, both during and after treatment. For many, the Gynea programme was the first time sexual health was addressed after the women received the cancer diagnosis. Ursula (50), who had been treated with surgery for uterine cancer, said the following: 'No one talked to me about these things. When I got sick, I was in a relationship, and I suddenly entered menopause. One of the things I thought was that I would never be able to have sex again. And I still do not know if I can. I've felt completely destroyed afterwards...()... I miss my sexual life. And I feel it is under-communicated'. Through the narrative characters in Gynea, several women recognised their own challenges and were comforted by knowing that it was normal to have these experiences after illness and treatment. The insight gained into their own challenges also gave the women hope that their sexual life was not over forever, even if it was difficult now. This hope was connected to the new insight from the programme that it was possible to resume sexual activity and to have a sexual life without penetrative sex. Several of the women alleged that it was good to talk about concerns about altered sexual health and guilt for not being an active sexual partner in the relationship. These were concerns about which they had been alone. For some, the insight gained confirmed that lack of desire and interest in sex, as well as resentment towards touching, were not caused by declining feelings towards their partner, but rather by illness and treatment.

5.2.2 | Redefining sexual health

Prior to working with the programme, many women understood sexual health as synonymous with having penetrative sex with a partner. After participating in Gynea, a new meaning was given to sexual health by the women, being redefined and more than intercourse, incorporating a good relationship with oneself and one's partner. Sexual health also incorporated awareness of one's own body and the need for self-care. This redefining of sexual health opened up a new dimension of sexuality in the women's relationships. However, it also presented a dilemma for some women, as it was challenging for them to care for their own sexual boundaries at the same time as caring for their partners sexual desire.

Rediscovering the body

A growing awareness of bodily expressions and the importance of asking questions about what they needed to feel good, was highlighted by some women as an important benefit from the programme. Hannah (30) spoke of 'rediscovering the body' through some of the exercises in the programme, for which she stroked herself and focused on how this made her feel. Diana (40) described the exercises in detail, for which self-care and being good to herself

were central. She said, 'There was something in the program that made me start to reflect on my own sexuality. What do I want, and what do I need? Before, I have not really shown what I was feeling on the inside and rather been the person that I thought others wanted me to be.' Diana (40) also talked about a changed awareness and stronger contact with her own body after working with the programme, something which she also found helped her experience a new orgasm that she felt throughout her whole body. A different perspective on their bodies with a focus on self-care and kindness to oneself was referred to by several women, a perspective opposed to frustration and anger towards a body that did not respond the way it used to. The need for closeness and intimacy with a partner, albeit without intercourse, was something several of the women longed for. Several descriptions retrieved from the programme talked about how one could be close to a partner without intercourse and described such intercourse as a gateway to intimacy.

Living in the tension between self-care and care for one's relationship

Although many women said that sexual activity was not important to them anymore, it was still important to their partners. Several of the women who were in a relationship said that they were conscious of not doing anything they did not want to do, with the belief that it could be harmful for both their relationship and their own selfesteem. While the women found it important to listen to their own needs, they also experienced fear of being abandoned by their partner and felt guilt for not satisfying their partner's needs. To avoid arousing desire in their partner, some women avoided closeness, which also deprived them of intimacy. Mary (60) said, 'I cuddle with my husband and hold my arms around him, but I'm terrified that he'll get aroused, because then I feel that I have to... (have sex). That is my experience, that I then invite him to have sex. ... Now it's been a long time without, and I feel so sorry for him, because he still wants to...()...but I don't know what to do to make it happen... It's not that I don't like him, or that I don't think that he's handsome. It's about me and my body.'

To 'let go of' having sexual intercourse was something that several women said they would be happy with, but at the same time, they recognised that they had a need for intimacy and closeness. Jane (50), had completed treatment a year and a half ago, and she felt a loss of intimacy with her spouse due to the absence of sex. She said, 'We don't have a sexual relationship, but I would like this. But now, it is completely blocked. Nothing works. It's been a long time since I've dared to try, so I don't know what it is like now. Sex gives me closeness, which you should have in a partnership'.

Refraining from sexual intercourse they did not feel ready for nor wanted appeared to be important to several of the women and resulted in them not having sexual intercourse with their partners. The need for support and acceptance of their choice of not having an active sex life was expressed by some women. Wendy (60) said that she had a common understanding with her husband that their sex life was over, but felt it was unacceptable in society to have a good relationship without sex. She said, 'I wish it was even clear in

Gynea that it is perfectly fine not to have sex. That you shouldn't push yourself like that, to things you don't really want to do'. Some women talked about a perceived social pressure where intercourse was portrayed as decisive for a good couple's relationship. This was difficult for the women when they did not manage it.

5.2.3 | Communicating with partner about sexuality

One of the main benefits from participating in Gynea was the support in communicating with partners. Sexual health had been an unspoken topic between most couples, which the women explained was due to a feeling of being unsure about how to describe the challenges thereof and a fear that their partner would feel rejected.

Game-changing conversations

Their altered sexual health also altered the women's relationships with their partners, an alteration which for most was negative and caused sorrow and worries. When the participants read about how the three narrative characters in Gynea talked to their partners about their sexual challenges, they understood how they themselves could talk to their partners. Elisabeth (30) referred to the story of Guri with whom she identified herself in the programme and said: 'Guri in the program, had such a clarifying conversation, where she shared her feelings and perceptions of the situation and got to talk about them. For me, it was to explain that I am not quite ready for sex yet'.

Hannah (30) used the word 'game changing' when she described how she learned how to talk about sexuality with her partner. She said, 'It led us to have a proper conversation about our expectations, both his and mine. And I talked about my fears. We talked about cuddling and caressing, and the whole understanding of what sexuality is, and that was the key. We are not there yet, but that was the key to getting us started'.

Decisive for communicating and sharing knowledge with partners was that the women gained insight into the challenges they faced along with a vocabulary to address them through the fictive characters in Gynea.

Towards a common understanding

Sharing the information in Gynea with their partner was expressed by several participants as important for their partner to understand their challenges. Torunn (60), who had surgery for cervical cancer, felt vaginal discomfort and a foreign sensation when she and her partner had sex with penetration. Through Gynea, she learned that the vagina became shorter after surgery, which explained the discomfort she had experienced. She said, 'When I started reading about it, I got him to read it too, and then he understood why I didn't want to and why it was painful for me.' For some women, it was easier to show the information in Gynea than to talk about it themselves.

In some of the couples, the women said that they already had a common understanding with their partner that penetrative sex

was a part of their relationship that was finished. Olivia (60) says it this way: 'We haven't had sex since I got cancer. I cannot bear the thought of it, and that's okay. I hope it comes back, but it's not the worst because it is enough if we lie close to each other in bed and he holds his arms around me...he doesn't push me to do anything else. And we agree that this is how it should be now.'

The women who said they had a common understanding of sexuality in their relationship also had less concern and challenges with regard to their altered sexual health.

Some women said that they had a negative history of sexual activity before they became ill and had lived without an active sexual life. Anne (60) said, 'I was raped when I was in my early teen years, and since then I have experienced that some brakes were put on. My husband and I found a great way to be together where closeness has been the most important thing.'

For some, sexual health was a matter of readiness. Frida (50), who had surgery for ovarian cancer over a year ago, said that she had printed out the content of Gynea for later reference. She said, 'I have to land all these other issues first... It feels a bit unimportant right now. I do not know any other way to explain it. I want control over my body first. I am on my way to getting some of that back, and then I must sort out what's important here and now...' For Frida and most others, this was related to the aftermath of a cancer, such as bodily pain, fear of recurrence and fatigue, which made sexual health less important.

6 | DISCUSSION

This study set out to explore how women experienced participating in a nurse-supported digital rehabilitation programme after gynaecological cancer treatment. To the best of our knowledge, this is the first study that addresses lived experiences from using a digital sexual health rehabilitation programme after gynaecological cancer. In this discussion, we present a comprehensive understanding, first of how the *traumatic experience* of cancer impacted the women's sexuality and how participating in the rehabilitation programme was meaningful for them. Second, we discuss how *redefining sexuality* impacted the women's lives, and third, the meaning of *communicating sexuality with partners*.

Multidimensional challenges to sexuality following gynaecological cancer are found throughout our study, underscoring sexual health to be an existential part of life and much more than just a physical activity. Prominent in our findings are the women's descriptions of a persistent existential trauma from the cancer illness, a trauma which negatively impacted their sexual lives. Some of the women found the illness trauma to be reactivated through touching sensations, especially in the stomach area, which led to pelvic muscle tensions and resistance to intimate touching. Some women compared this resistance to what they presumed sexual assault would feel like. We can help understand this phenomenon through Merleau Ponty's body phenomenology, which says that our body holds a consciousness of all lived experiences. We live our lives through our bodies,

as the body is not something we have-rather, we are our bodies (Merleau-Ponty, 1994). Even if we do not consciously remember or intentionally keep a memory, the body retains knowledge of the memory, even though we may not consciously remember it. When attention is given to a particular area of our body and the aspects of our life it concerns, sensory messages or memories are consciously grasped (Merleau-Ponty, 2012, p. 165). Although cancer treatment is not an assault, the illness of cancer and its treatment are invasive to the body. The reaction of the women in this study to intimate touch can possibly be understood as their bodies reacting to previous experience remembered in their bodies. Some of the women in our interviews said that being touched intimately created a bodily resistance over which they felt they had no control. Theories on handling sexual traumas, such as assault, say that flashbacks can be triggered by sex as well as sensations from within the body (Stephanie Buehler, 2017, p. 191). In recovery of sexual problems after trauma, it is recommended that survivors empower themselves to say no if they do not want to engage in sexual activity or if they feel pressured. It is also important to check in internally to discover what it is they really want (Stephanie Buehler, 2017, p. 191). The approach to recovery from sexual trauma resembles the redefined understanding of sexuality for the women in our study, an understanding that incorporates bodily integrity and caring for one's own sexual health. The WHO (2017) definition of good sexual health, to have personal autonomy and to choose when and whether to have sex, is also consistent with the women's redefined understanding. Even though the women in our study expressed a conscious awareness of not pressuring themselves into unwanted sexual activity, the guilt for rejecting their partners' sexual needs simultaneously put their own need for closeness at stake. Previous studies confirm that women experience guilt when they have difficulties engaging in sexual activity following gynaecological cancer (Roussin et al., 2021, 2023; Vermeer et al., 2016). Unfortunately, having sex as an obligation can deprive women of sexual enjoyment and is associated with negative sexual and relational outcomes (Georgieva et al., 2023). Women in another study who had obligational sex also developed anger towards themselves and their partner, an anger which they struggled to speak with their partner (Traeen, 2008). Another study highlights how personal wanting seems to be important, as having sex when wanting to please the other, as opposed to feeling obligated to have sex, is shown in the study to not have a negative impact on relational measures (Georgieva et al., 2023). To be aware of and true to one's own sexual needs is, then, an act of caring for one's own sexual health. Although redefining sexual health was important in the sexual health recovery of the women in our study, it also represented a loss. In addition to losing a sexual life they had enjoyed but seemed impossible to retain, some women also lost the closeness they had with their partner. McGuirk (2019, p. 166) refers to psychologist Goldstein when saying that the reconstitution of what is lost comes at the cost of additional suffering. It is possible to regain a new normal by reorientating, such as the women did by redefining sexual health, but at the root it is disclosive—there is also mourning over what is lost (McGuirk, 2019).

Thematizing sexual health following gynaecological cancer in Gynea relieved the participants of some of their concerns and the guilt they had for not satisfying their partners' sexual needs. Most women did not feel ready for sexual activity, but thematizing it was highly appreciated, as it had been an unspoken topic for most women. The silence around sexual health following gynaecological cancer has been well documented in previous research (Ashmore et al., 2020; Wilson et al., 2020). Women want healthcare professionals to address sexuality (Abbott-Anderson et al., 2020; Bal et al., 2013; Chapman et al., 2019; Sekse et al., 2019; Vermeer et al., 2016), while nurses and health professionals see sexuality as a private and taboo matter, thus avoiding the subject unless it is raised by the patient (Annerstedt & Glasdam, 2019; Klaeson et al., 2017). Another problem is that sexual health challenges have often been regarded as medical issues, by both patients and health professionals, rather than existential issues (Annerstedt & Glasdam, 2019). Previous research has shown that nurses are considered good communication partners regarding sexuality (Roussin et al., 2023). To receive information and talk about challenges is experienced to help allay concerns about sexual life and manage sexual problems (Chow et al., 2016), something that was experienced by the women in this study. For some women, thematizing sexual health also led to hope that it was possible to have a sexual life following cancer.

In fear of encouraging their partners' desire for penetrative sex, the women in our study avoided intimacy. Lack of communication encouraged this cycle, which led several of the women to be deprived of closeness they had in their relationship prior to cancer. Similar experiences are found in another study (Fischer et al., 2019), where intimate touching was avoided for fear that it led to sexual intercourse. Many couples struggle with communication about sexuality, but this communication can be supported and encouraged by healthcare professionals (Benedict et al., 2022; de Souza et al., 2021). In another study that found cancer patients renegotiated sexual intimacy beyond penetrative sex, effective communication between partners was regarded as the primary factor for change (Ussher et al., 2013). The guidance regarding how to communicate about sexuality in our study was experienced as valuable to the participants. This communication was two dimensional. First, it was to communicate personal experiences with a changed sexual health, and second, it was to share any information learned in Gynea to gain a mutual understanding of sexuality in the relationship. Crucial for communicating about sexuality was that the women first had a conscious understanding of their own sexuality after treatment of the cancer. It also seemed appeared that women needed to legitimate their lack of sexual desire and not have penetrative sex. The women suggested Gynea be even clearer in its content, saying that it is okay not to have sex if you do not want to.

A substantial part of the women in our study described sexual health as unimportant to them while struggling to cope with side effects and their illness as an existential matter. Still, they expressed a great need to be supported in coping with sexual health challenges. The greatest challenge seemed to concern sexuality for the women in a relationship where the partner had a sexual desire. The ill body is

experienced through its loss (Carel, 2018, p. 73), contrasting with the way the body used to be prior to illness. But if there is no experience of a deficit, here as of a good sexual life, there is also less experience of loss. This is also related to cultural values. If a value does not exist or carry the same significance, the loss of it will not be experienced (Carel, 2018, p. 45). Some women in our study also said that they experienced a society that considered sexual activity essential in a good relationship. Social pressure to be sexuality active, in terms of penetrative sex, has also been reported in previous research, in which a successful sexual life has been presented to include frequent sexual intercourse (Traeen, 2008). This pressure made the women in our study feel that they were inadequate partners when sexual penetration and intimacy seemed impossible. This pressure made the women in our study feel that they were inadequate partners when sexual penetration and intimacy seemed impossible.

The participants in our study did not describe an improvement in the physical aspect of their sexual challenges but rather a strengthened sexual integrity with conscious awareness of their own wellbeing in their own body, self-care and their sexual wants after participation in the programme. This development can be considered sexual empowerment. Sexual empowerment is a continuous multidimensional process that refers to the individual's power over their own body, to an individual's feelings and sexual interaction. Attaining sexual empowerment can take considerable time, but it can also be attained from transformative moments in which a certain event or moment proves decisive (Peterson, 2010). Sexual empowerment seems important, as sexual function is altered negatively after illness, putting women's sexual integrity and self-esteem at risk.

Some women experienced that sexual health had been an unimportant part of their life because of previous negative sexual experiences, such as childhood abuse and rape. As 27% of Norwegian women report experiencing violence one or more time in their life (World Economic Forum, 2022), there needs to be awareness of this problem when addressing sexuality following cancer, with an understanding that the cancer itself is not the cause of all challenges women experience following gynaecological cancer.

6.1 | Strengths and limitations

A strength of this study is the research method, which provides rich descriptions and in-depth descriptions of the women's sexual health challenges and how these are met through a nurse-led digital rehabilitation programme. The interpretation of the women's experiences considering their situation and context helps to understand their challenge as a complex matter, calling for a holistic and open approach to healthcare service. Another strength is the variations of age, diagnosis and the relationship status of the women, a variation that provides a broader perspective to the study.

A limitation of this study is that the phenomenon is not generalisable to a wider population, and that it is only the specific programme of Gynae that has been evaluated. Thus, we do not know

the experiences of women who did not participate in this programme or the utility that could be derived from other interventions. It is also a clear limitation that cancer survivors' experiences are in a Norwegian context, where cancer survivors with other ethnic background, socio- economic and cultural status are excluded. Norway is known for having one of the highest levels of gender equality in the world and has a robust socio-economic status (World Economic Forum, 2022). Inclusion of cancer survivors with different demographic and ethnic background is relevant for future research.

6.2 Recommendations for further research

Recent research has found that how emotional intimacy in a relationship is experienced to be gender specific, with emotional intimacy being correlated to frequency of sexual intercourse for men but not for women (Štulhofer et al., 2020). We have only interviewed women who took part in the study and not their partners, so we do not know the partners view on how participation in the digital programme affected the relationships. Although the women benefited from communicating about their difficulties about their sexuality and their readiness for sexual activity, we do not know how their partners experienced these difficulties. These considerations could be considered by future research.

6.3 | Implications for policy and practice

It is important that nurses and healthcare providers who address sexuality in cancer rehabilitation are aware of sexual health as an existential phenomenon which must be understood in relation to individual women's lives, rather than being limited to dysfunction. Nurses and doctors can support women in caring for their sexual health after cancer illness by thematizing sexuality, allowing for individual women's concerns and challenges to be identified and discovered. Acceptance and normalisation of sexual challenges can open up new understandings and rediscovering of intimate relations. The digital format is a cost-efficient means for healthcare support and also allows women to read and work at their own pace. Nurse support is of great importance for listening and creating acceptance and hope regarding women's sexual health concerns following cancer.

7 | CONCLUSION

This study describes how women experienced participating in a sexual health module in a nurse-supported rehabilitation programme following gynaecological cancer. The existential trauma from cancer illness and treatment had a deep impact on the women's sexual health. Thematizing sexual health in a digital programme, together with nurse support, gave the women an understanding of some of the changes and challenges they were facing, and relieved them of some of the worries, guilt and emotional struggles resulting from an

altered sexual health. The women gained a new understanding of sexual health as more than penetrative sex, giving hope for retaining intimacy and a sexual life in the future. Participation did not lead to an increase in the women's sexual function but rather a sexual empowerment as embracing their relation to their bodies and feelings as part of their sexual health. Thematizing and redefining sexual health empowered the participants to communicate their needs for intimacy and closeness and their readiness for sex, as well as to create a common understanding of sexuality with their partners. Participation in Gynea supported the women in caring for their own sexual needs, helping them to enhance their bodily integrity when recovering from cancer. For some women, focus on sexual health had to wait as the women struggled to cope with daily challenges following cancer, and some had had a distant relation to sexual health prior to cancer. We further suggest exploring the experiences of women from other ethnic, socioeconomic and cultural contexts regarding the topic. We also recommend that future research includes both women and their partners.

AUTHOR CONTRIBUTIONS

Sigrund Breistig had no previous relationship with the informants or part of the development team of the Gynea project, a fact which was explained to the women prior to the interviews. Data analysis was done in collaboration with Kari Marie Thorkildsen and Ragnhild Johanne Tveit Sekse, who read the transcripts and gave feedback throughout the analysis process. Henrica Maria Johanna Werner and Tine Nordgreen gave thorough feedback throughout the writing and discussion.

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CONFLICT OF INTEREST STATEMENT

The fifth (last) author has been the project leader for the development of the Gynea intervention and has also given nurse guidance to some of the participants in this study. After completing the Gynea programme, 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 for the women to notify us should they not want to participate. The third and fourth authors have also been part of the development team of Gynea but have not had any personal contact with the informants.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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BREISTIG ET AL.

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