

# Co-Designing Womunity

Exploring the Design Space of Guided Online Peer Support for  
Women Recovering from Gynecological Cancer



Master Thesis in Information Science

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May 2019



# Acknowledgements

I would like to express my gratitude to my advisors Frode Guribye and Eivind Flobak, for introducing me to the INTROMAT project. Thank you for your guidance, encouragement and support. I appreciate all feedback and advice I have received during the master thesis work.

I would also like to thank all collaborators in the INTROMAT project. A special thanks to Ragnhild Sekse, for your expertise, help and encouragement.

Thank you to all participants in this study for your cooperation, and for your time and effort.

Thank you to my fellow peer, Oda Elise Nordberg, for your invaluable support.

Thank you Lovise and Eline for your loving support.



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# Chapter 1

## Introduction

Women recovering from gynecological cancer face demanding challenges after treatment, living in a changed body, where they have to adapt to new ways of living. For many gynecological cancer survivors, the journey after treatment is a constant battle between life courage and life anxiety. The women may face challenges such as depression, a changed sexual life, fear of recurrence, and fatigue, which can reduce their quality of life and deteriorate their psychosocial health (Hodgkinson et al., 2007; Sekse, Raaheim, Blaaka, & Gjengedal, 2009).

The journey of survival can for many be a lonesome process, where they may need help and guidance on how to manage the side effects of cancer (Sekse, Raaheim, Blaaka, & Gjengedal, 2010). There is an increasing number of survivors from gynecological cancer due to a better understanding of the disease and improved treatment methods (Kreftregisteret, 2018). Consequently, there is today an increased focus on side effects of cancer and improving the survivors' psychosocial health (Helse- og omsorgsdepartementet, 2013, 2018; Helsedirektoratet, 2017). After treatment, however, many women are discharged from the hospital with little to no information regarding the side effects of cancer treatment. As a result of the lack of information there may be a build-up of psychosocial needs (Sekse, Raaheim, Blaaka, & Gjengedal, 2010).

It is recognized that cancer survivors are uninformed regarding side effects of cancer treatment, and that their psychosocial needs are not adequately met in the current cancer trajectory (Orre, 2018). The INTROMAT (INTROducing Mental health through Adaptive Technology) project aim to develop internet-delivered treatments that will provide psychosocial support to women who have recently been treated for gynecological cancer. The study presented in this thesis is situated within INTROMAT's case study on providing psychosocial support to these women.

The study presented in this thesis has explored the design space of online guided peer support in a planned internet-delivered learning and coping program for women recovering from

gynecological cancer. Peers are people who have experienced similar experiences, have similar interests, or abilities. Research shows how peers can offer a higher level of understanding, empathy and support than other people can (Mead & MacNeil, 2004).

The peer support prototype, Womunity was designed through a research through design process. Womunity facilitates text-based communication between women who have recently been treated for gynecological cancer. Womunity is designed to arrange for emotional and empathetic support between the peers. This study is placed within the HCI research field, and it extends our knowledge of online peer support by exploring this topic through a participatory design process with women who have recovered from gynecological cancer and expert participants. The expert participants consist of one domain expert with a PhD in nursing specialized in gynecological cancer survivors, two gestalt therapists, and one HCI researcher.

Gynecological cancer survivors have expressed the need for someone who would listen to them and ask how they are doing, where it can be difficult for the women to seek this help (Sekse et al., 2010). Online resource may reduce barriers to ask for help, considering the taboo-topics related to the reproductive organs, sexuality and intimacy, because of the possibility of anonymity and accessibility.

This thesis includes a thematic analysis of the co-design workshops with women who have recovered from gynecological cancer. They expressed their perspectives toward existing peer support applications, and from the analysis it was found how the women perceive current application to not be adequately moderated. They suggest that such applications should at least provide guidelines for how to behave and what should be allowed to discuss to promote a safe communicative environment. The women perceived peers to be valuable, discussing how peer may understand their situation at a deeper level, and make them feel less alone.

The contribution of this thesis is two-fold:

1. A peer support prototype that has been co-designed with five gynecological cancer survivors and four expert participants.
2. A set of design implications based on the design process of the prototype and the thematic analysis. The design implications are meant to aid practitioners and researchers in future designs of online peer support.

## 1.1 Research Questions

**RQ1:** What needs do women recovering from gynecological cancer have for online peer support?

**RQ2:** How can we design online guided peer support for women recovering from gynecological cancer?

To explore the research questions a literature review concerning the side effects of cancer treatment, including the psychosocial needs of gynecological cancer survivors, and health-related peer support applications was conducted. To explore the design space of peer support, an empirical study including design workshops with five survivors of gynecological cancer and four expert participants was arranged. The study was conducted in order to analyze how existing peer support applications are perceived by the survivors and what should be considered when designing online peer support for these women. The design workshops with the five survivors were thematically analyzed.

Through a research through design process, a prototype named Womunity was co-designed with survivors of gynecological cancer and the expert participants. Womunity has been designed to be a part of INTROMATs learning and coping program, which has the aim of meeting gynecological cancer survivors' psychosocial needs after treatment.

## 1.2 Structure of Thesis

The following list presents the structure of the thesis:

**Chapter 1** introduces the problem space, research motivation, and research questions of this study.

**Chapter 2** presents literature and existing applications relevant to this study.

**Chapter 3** describes the methods used in this study.

**Chapter 4** documents the design process of the prototype, Womunity.

**Chapter 5** presents the thematic analysis of the design workshops with gynecological cancer survivors.

**Chapter 6** discusses the results from the analysis and previous research in relation to the research questions and presents the design implications.

**Chapter 7** concludes the thesis with a summary of the study and presents future work.

# Chapter 2

## Background

This chapter presents relevant fields and studies concerning the unmet psychosocial needs of gynecological cancer survivors with a focus on existing peer support applications and how online peer support can possibly meet the unmet needs. A description of the fields of human-computer interaction and user experience is provided in this chapter.

### 2.1 Human-Computer Interaction

Human-Computer Interaction (HCI) is an area of research and practice that studies how people interact with computers. The HCI field emerged in the 1980s, formerly there were mostly engineers or computer scientists that had access to or knew how to operate computers. By the 1980s the computers moved from secure and locked spaces, to people's desks and homes. The new computers were both powerful and could be used by anyone, which made interaction an issue (MacKenzie, 2013).

There are numerous ideas and disciplines that contribute to HCI research, some disciplines the field encompasses are psychology (particularly cognitive psychology and experimental psychology), cognitive science, sociology, computer science, anthropology, and linguistics (MacKenzie, 2013). According to Grudin (2017) the HCI field covers major threads of research and development in four disciplines: computer science, information systems, information science and human factors. Human factors is both a science and a field of engineering, which concerns human capabilities, performance, and limitations, and with the design of systems that are safe, efficient, comfortable, and enjoyable for humans who use them (MacKenzie, 2013).

MacKenzie (2013) emphasizes that despite better designs and products being the end game in HCI research, the focus in HCI research is on ideas – ideas for new and improved user interfaces or interaction techniques. He stresses the importance of researching in iterations, where the idea

must be implemented, refined, tested, refined again, tested again, and so on. He underlines that testing is key in this process.

Oulasvirta and Hornbæk (2016) aim to describe HCI research as problem-solving, where they argue that there are three types of HCI research problems, these are empirical, conceptual, and constructive research problems. Empirical research is defined as “creating and elaborating descriptions of real-world phenomena related to human use of computing” (2016, p. 4958). Conceptual problems are non-empirical, where conceptual research “is aimed at explaining previously unconnected phenomena occurring in interaction.” (2016, p. 4958). These two types of research problems are based on Laudan's (1978) philosophy of science, who developed problem and solution as the foundational concept of science. Oulasvirta and Hornbæk extend the typology of problems by adding a third type, constructive problems. It is defined as followed: “Constructive research is aimed at producing understanding about the construction of an interactive artefact for some purpose in human use of computing.” (Oulasvirta & Hornbæk, 2016, p. 4958).

Oulasvirta and Hornbæk (2016) argue that their problem-solving view helps researchers to confront the grand conceptual problems of current HCI research, which includes what HCI research is (problem-solving), what good HCI research is (solutions that increase problem-solving capacity), and how to move the HCI field forward (bridge the empirical and the constructive). The problem-solving perspective urges to ask how the research solutions help us solve important problems in human use of computers, instead of asking whether or not the research is ‘valid’ or follows the ‘right’ approach. The problem-solving perspective offers a less discipline-oriented approach to HCI research. It does not necessarily apply to all HCI research or can solve all problems, but they believe the perspective can provide a good starting point for research papers and research programs in HCI by asking questions such as “Which problems does it tackle, and how does it increase our capacity to solve them?” (Oulasvirta & Hornbæk, 2016, p. 4965). The research in this study is both constructive and empirical, as well as problem-solving following a research through design approach further described in chapter 3.

HCI research is associated with the term user experience. HCI research concerns how humans interact with computers, where human abilities are emphasized, while user experience concerns the experience in which the human has with a particular product. How we interact with



computers and how we experience this interaction is highly related. User experience emphasizes the enjoyment and engagement of the whole interactive experience (Benyon, 2019).

### **2.1.1 User experience**

The user experience encompasses all aspects of the users' interaction with a product. It revolves around how people feel about a product and their level of pleasure and satisfaction while using it (Preece, Rogers, & Sharp, 2015). Norman stresses how "It is not enough that we build products that function, that are understandable and usable, we also need to build joy and excitement, pleasure and fun, and yes, beauty to people's lives." (2004, p. 312).

Hassenzahl and Tractinsky (2006) explain how user experience is a consequence of a users' internal state (e.g. expectations, needs, motivation), the characteristics of the designed system (e.g. its' complexity, purpose, usability), and the context or environment within which the interaction occurs (e.g. social setting, voluntariness of use, meaningfulness). One of the main objectives for HCI in the future is to contribute by designing for pleasure rather than absence of pain, according to Hassenzahl and Tractinsky (2006).

Designing for user experience involves understanding the role of emotions in peoples' lives. Emotions often influence the decisions we make, as much as the outcome of our decisions can influence the emotions we experience (Schwarz, 2000). Desmet, Overbeeke, and Tax (2001) stress the importance of designing products that 'fit' the emotions of the users, which means products that draw out the emotions the user would like to experience. The designer would then need to know the intended users' specific concerns in order to meet these emotional needs.

There is no unifying theory or framework on how to design for user experience. There are, however, numerous conceptual frameworks, guidelines, and relevant research findings that contribute to how to design for user experience. McCarthy and Wright (2004) define experience in terms of four threads: the sensual, the emotional, the compositional, and the spatio-temporal thread. They recognize that these are not fundamental elements to experience, but they are ideas to help us think more clearly about technology as experience. The sensual thread concerns our sensory engagement with a situation, which is related to the level of absorption people have with technological devices and applications. The emotional thread involves an understanding or sense-making process, the meaning assigned to an object or person because of their goals,

values, and desires. The compositional thread is concerned with the relationship between the parts and the whole of an experience, which relates to the internal thinking we do during our experiences. The spatio-temporal thread refers to the space and time in which our experiences take place and their effect upon those experiences. This pragmatic approach can provide designers with ideas of how to think and talk more clearly and concretely about the relationship between technology and experience (McCarthy & Wright, 2004).

McCarthy and Wright (2004) offer a way of viewing experience with technology that is creative, open and relational. They argue that only by seeing technology as participating in the *felt experience* we can understand the fullness of the technology's potential. The felt experience refers to the sensual and emotional quality of experience. In order to understand the wide range of influences technology has in our lives we should interpret the relationship between people and technology in terms of the felt life, that is life as lived, sensed and experienced, and the felt or emotional quality of action and interaction (McCarthy & Wright, 2004).

Understanding the potential users' current situation, their felt life, and their emotions is vital to design for the desired user experience. In this case understanding gynecological cancer survivors felt life and their experiences, emotions and current situation can potentially aid the design for the desired user experience.

### **2.1.2 Participatory design**

Participatory design is a set of theories, practices, and principles which encourage and support the direct involvement of all stakeholders in co-designing products. In the participatory design process, the tools and techniques include design workshops where the participants work collaboratively to envision future ideas and products, and use other methods such as scenarios, personas, iterative prototyping to ground their design conversations (Robertson & Simonsen, 2012). The field draws on other fields such as user-centered design, graphic design, software engineering, psychology, and communication studies (Muller, 2009). Robertson and Simonsen defines participatory design as the process in which the participants "investigate, reflect upon, understand, establish, develop, and support mutual learning processes as they unfold between participants in collective "reflection-in-action" during the design process." (2012, p. 5).

The mutual learning in the design process provides all participants with increased knowledge and understanding, according to Robertson and Simonsen (2012). They further elaborate by defining two roles in participatory design, the users and the designers. The designer aim to learn the realities of the users' situation, while the users strive to articulate their desired aims as well as learn appropriate technological means to obtain these aims.

Ehn (2008) argues that the strongest motivation for applying participatory design is the existing skills that can be made a resource, where the participants 'tacit knowledge' can be employed in the design process. The participants in the study presented in this thesis is described in section 3.2. The participants included expert participants and gynecological cancer survivors.

Gynecological cancer survivors face psychological and physical challenges, where they often have psychosocial needs that are unmet by health professionals (Hodgkinson et al., 2007). The challenges the women can encounter is further described in section 2.2. An explanation of what is meant by psychosocial support in terms of gynecological cancer with a focus on online peer support is provided in section 2.3.

## 2.2 Gynecological Cancer

Gynecological cancer is the generic term for malignant tumors developed in the female reproductive organs. In Norway there are about 1500 new cases of gynecological cancer each year (Great Norwegian Encyclopedia, 2016). The most common forms of gynecological cancer are cervical, ovarian, and uterine cancer (Norwegian Cancer Society, 2018a).

**Cervical cancer** is a malignant tumor formed from the mucosal in the uterus, which is caused by the sexual transmissible virus human papillomavirus (HPV).

**Ovarian cancer** is cancer developed in the ovaries and can be difficult to discover because the symptoms can appear late and are uncharacteristic.

**Uterine cancer** is tumors formed from the mucosal in the uterine cavity. (Norwegian Cancer Society, 2018a).

There is a growing number of survivors of gynecological cancer due to a better understanding of the disease and improved treatment methods (Kreftregisteret, 2018). The challenges

gynecological cancer survivors face in living a normal life again, with an emphasis on psychological changes, are presented in the next section.

### **2.2.1 Life after cancer**

Women who have gone through gynecological cancer treatment have experienced a life-changing event. For many survivors there is a constant battle living between life courage and life anxiety, as well as living between existential loneliness and relational caring (Sekse, Raaheim, Blaaka, & Gjengedal, 2009). This constant battle can result in great adjustments in their everyday life, and for some, their survival has made them put aspects of their life into perspective. For others, it is a struggle to get through each new day, and the journey is often lonesome. Several studies show how these women can experience many levels of change both in terms of physical and psychological changes after treatment. These women have to adapt to new ways of living and get to know their own body all over again. They face demanding challenges, but can also encounter enriching experiences (Sekse, Raaheim, Blaaka, & Gjengedal, 2010).

Studies have shown how numerous women are challenged with psychological changes after gynecological cancer treatment. Anxiety, depression, post-traumatic stress disorder (PTSD), are only a few of the issues the women can experience (Hodgkinson et al., 2007; Matulonis et al., 2008; Park et al., 2007; Sekse et al., 2009; Sekse, Gjengedal, & Råheim, 2013; Wenzel et al., 2002). The physical changes in their body, such as fatigue, treatment-related menopause, general pain, and sexual problems, can have a strong correlation to their mental state (Liavaag, Dørum, Fosså, Tropé, & Dahl, 2007; Molassiotis, Chan, Yam, Chan, & Lam, 2002; L. B. Wenzel et al., 2002). Sekse et al. (2009) describe that although they are now long-term survivors, a bodily change, pain or irregularity in the body, could trigger the feeling of distress and preparedness. This bodily alertness for recurrence could intensify the movement between life joy and life anxiety. The women in their study felt this anxiety was something they had to live with, because many aspects of life can trigger these feelings (Sekse et al., 2009). Some patients can experience changes right after treatment, while others might experience it years after, up to 20 to 30 years after (Norwegian Cancer Society, 2018c). A dominant factor from several studies is the feeling of fear. Fear of pain and discomfort during intercourse, fear of losing control over their body, fear of recurrence, fear of death, which is caused by the distress over the disease (Hodgkinson et al., 2007; Matulonis et al., 2008; Molassiotis et al., 2002; Sekse

et al., 2013). Sekse et al. (2013) found that many of the women no longer trusted their own body, where they had an unhomelike feeling with themselves.

Sekse et al., (2010) identified that going through cancer seemed to be a lonesome process, where they were vulnerable in their encounters with themselves and others. The women in their study experienced the feeling of being left alone, with little information and guidance through their journey. They expressed the need for help and information from committed health care professionals at an early stage. They were, however, well informed regarding the practical circumstances around surgery and treatment. The issue they raised was the lack of information about side effects and the long-term consequences after surgery and how to manage them. Some mentioned that getting the unpleasant menopause symptoms was shocking, which revealed the need for more information.

Not only the lack of information was expressed, but also the lack of someone to talk to, someone asking “How do you feel?” They voiced the need for someone taking their time talking to and listening to them, to not be left alone with their own thoughts. The women described the difference it would make to have someone to talk to. They expressed that the guidance and information is so important that it determines whether you feel okay or not afterwards, otherwise you would float around in uncertainty. They further added “This is the time, after cancer, when essential choices are made.” (Sekse et al., 2010, p. 804).

A need for better and more comprehensive supervision after cancer is also recognized by Wenzel et al., (2002), Wenzel et al., (2005), and Hodgkinson et al., (2007). These studies show that there is not only a need for medical informational, but also supportive care in terms of spirituality, and the meaning of life. This being said, it could be difficult for the health care professionals to spot these life phenomena challenges, such as existential loneliness, vulnerability, and life anxiety the women are in the midst of. As well as it could be difficult for the women to verbalize their inner thoughts and feelings (Sekse et al., 2009).

Gynecological cancer concerns private and intimate parts of the body, which is understandably difficult to talk about. Auchincloss (1995) discusses how cancer is correlated to social stigma, this is something that can leave the women with a strong sense of loneliness. They would often keep their feelings and issues to themselves. In the short consultations with their physicians there was not much room for elaborating around topics the women considered secondary or

embarrassing to discuss, such as sexuality. After all the main focus was to recover from the disease. Some women expressed that they would like this topic to be suggested by the health professional, by giving them information and offer the chance to discuss this topic (Sekse et al., 2010). Likewise, the health professionals would prefer the patients to raise these issues. Katz (2005) explains that health professionals has to initiate a discussion of this topic in order to offer patient-centered care. Hodgkinson et al., (2007) found in their study that significant psychosocial morbidity may occur many years after treatment, which leads to elevated supportive care needs. They suggest assessment and intervention efforts that are specifically targeted the survivor's issues. Molassiotis et al., (2002) suggest a similar solution for these women. They state that long-term psychosocial care may help them to adapt better to the demands of the illness.

A study by Park et al., (2007) report significantly poorer body image after having gone through gynecologic cancer treatment than before cancer. The decreased body image can play a role in sexual issues the women may encounter. They found that a group of women who received radiotherapy had “persistent anxiety about sexual performance, and vaginal changes.” (Park et al., 2007, p. 2722). Many can also lose the desire for sex, which can make them concerned over the relationship with their significant other (Sekse et al., 2010).

After gynecological cancer it is common for the woman to have lost her reproductive organs or that she has become infertile. For women that are past their child-bearing years the infertility does usually not make much difference in their life. However, many women under 40 years of age can be diagnosed with gynecological cancer and also lose their ability to bear children. It is a dramatic change for these women if they want children in the future (Sekse et al., 2010).

The women in Sekse's (2013) study explained how they had the feeling of emptiness in the womb immediately after surgery, and some of them described their feelings of loss and incompleteness. Stewart et al., (2001) presents that 19.5% of the women in their study reported a moderate to great sense of loss of reproductive potential. The results referred mostly to women under the age of 55. Wenzel et al., (2005) reasonably hypothesize that cervical cancer survivors that has become infertile may experience long-term diminished quality of life (QOL) if they wanted to bear children in the future. Auchincloss (1995) elaborates the issues a younger gynecological cancer survivor face, such as the possibility of rejection in the dating scene, hearing of others' pregnancies, and other social implications. This being said, many of the

women in Sekse's (2010) study expressed that the loss of their reproductive organs did not seem as a threat to their female identity. Their main project was to recover and to survive, where they had to get rid of these organs to save their lives.

Certain studies show that many of these long-term gynecological cancer survivors experience a good QOL, surrounding their satisfaction with life, hopefulness, supportive relationship and so on, in comparison to other survivors (Wenzel et al., 2002). They can experience positive changes after the disease such as the realization that life is precious, treasuring their families, and being more sensitive to other's needs (Molassiotis et al., 2002). For some the realization that their lives were at stake lead to personal growth. Their experiences made them feel more "alive", and feel a sense of closeness to other people, their surroundings, and their own lives, on a deeper level (Sekse et al., 2010).

In the study by Sekse et al., (2010) their focus was on whether experiencing such a life-threatening disease would change their lives in terms of superficiality, to perhaps live a more authentic life. In Heidegger's terms, to exchange from living an inauthentic life to a more authentic life, and further being empowered to be the person they truly are or ought to be. The anxiety of death and to not be offers the opportunity of living a more authentic life. To be confronted with death one can experience existential loneliness that can make one become aware of what is really important in life (Blattner, 2006; Fløistad, 1993). Most of the women in Sekse's study seemed to have exchanged after being confronted with their mortality. They explain that "the crisis offered an opportunity to find a deeper meaning in life." (Blattner, 2006; Sekse et al., 2010, p. 804). They further add that the deeper meaning in life does not necessarily mean that they are ready for fundamental changes, but that they no longer take life for granted. The common denominator for the women was the gratitude for life itself, where Sekse et al., (2010) suggested that this gratitude helped them balance the challenges they faced.

The gynecological cancer survivors can experience many levels of change both in terms of physical and psychological changes after treatment. These changes and challenges may deteriorate their psychosocial health. In section 2.3 psychosocial support is described with a focus on cancer patients and survivors' unmet psychosocial needs.

## 2.3 Psychosocial Support

The psychosocial health of an individual encompasses their mental, emotional, social, and spiritual state (Donatelle & Davis, 2011). An example of a psychosocially healthy person is a person that feels good about themselves, is able to meet the demands of life, maintains a positive outlook in life, and can appreciate and respect nature. The psychosocial health of an individual can deteriorate when he or she encounter traumatic events, stress, loneliness, is in an abusive relationship, or is having physical problems (Donatelle & Davis, 2011). When the psychosocial health of an individual is decreased, they may be in need of support in order to live a healthier and happier life. Some examples of support that can be provided include mental health counseling, spiritual support, and group or peer support (American Cancer Society, 2018).

People suffering from cancer or that have recovered from cancer are often in need for psychosocial support, due to their condition and the psychological wounds cancer has created (Hodgkinson et al., 2007). The rising number of long-term cancer survivors has made the need and importance of psychosocial support increasingly evident (B. E. Miller, Pittman, Case, & McQuellon, 2002). Many cancer survivors suffer from mental issues such as, anxiety, depression, or physical issues including fatigue, after being declared healthy. Mental issues can occur many years after their illness. (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Hodgkinson et al., 2007). They have experienced an illness that has taken up most of their time and energy, many aspects of their lives may have shifted, and it can be challenging to return to normal.

Several studies highlight the need cancer survivors have for psychosocial support, cancer in general and breast cancer (Hodgkinson et al., 2007; Mehnert & Koch, 2008; Söllner et al., 2001) and gynecologic cancer survivors specifically (Auchincloss, 1995; Molassiotis, Chan, Yam, Chan, & Lam, 2002; Urbaniec, Collins, Denson, & Whitford, 2011; Wenzel et al., 2005). Hodgkinson did a self-report questionnaire to assess the psychosocial needs and outcomes for long-term survivors. From this questionnaire almost 90% reported supportive care needs, and many of them were unmet by health professionals (Hodgkinson et al., 2007). Hodgkinson et al., (2007) explain how an improved understanding of the supportive care needs cancer survivors have, is the first step to improve the psychosocial support services which can in turn guide the survivors through the challenges they face. It is important to notice that people do



have different needs and seek different ways of solving their problems (Miller & Mangan, 1983), which should be taken into consideration when designing a support program.

Psychotherapy is one way of dealing with the psychosocial needs of patients. In psychotherapy a psychologist helps the patients work out their psychological issues. Through applying scientifically validated procedures the psychologist guide people to live a healthier and more productive life. Psychologists operate with different therapy procedures in order to provide the most appropriate treatment for their patients. Examples of psychotherapy include cognitive behavioral therapy, existential-phenomenological therapy, and gestalt therapy (American Psychological Association, 2019). Another way of facilitating psychosocial support is through peer support, which refers to people with similar experiences or backgrounds that can provide support to each other. It differs from psychotherapy because peers are either included in the support process as a support group, or is the only source of support, meaning no professional involvement in the process. Peer support is further explained in a later section.

Table 2.1: Dimensions of psychosocial support.

	<b>Online</b>	<b>Face-to-face</b>
<b>Peer</b>	Online psychosocial peer support (Facebook Groups)	Physical psychosocial peer support
<b>Professionals</b>	Online professional psychosocial support (Internet interventions)	Physical psychosocial support (Traditional psychotherapy)
<b>Both peer and professionals</b>	Online professionally moderated psychosocial peer support	Physical professionally moderated psychosocial support (A.A meeting)

Psychosocial support can be provided in different settings both online and face to face, and by professionals, peers or both. The dimensions of psychosocial support are presented in the coming sections. The research presented in this study concerns online psychosocial support between peers that is professionally moderated (Table 2.1).

### **2.3.1 Online psychosocial support**

Psychosocial support can be facilitated in person through traditional therapy appointments with a psychologist, and support group meetings with peers, or it can be carried out online in different settings for various psychosocial needs.

Bouma et al., (2015) conducted a literature review on online psychosocial support programs for cancer patients, where they analyzed the effect these programs have on cancer patients. They analyzed results from 16 studies including 13 different support programs. None of the reviewed studies involved cancer survivors. The results showed positive effects from all programs, mainly for social support and quality of life for cancer patients. Two programs from their review will be presented, The Comprehensive Health Enhancement Support System (CHESS), and GyneGals. CHESS was chosen because it is extensively researched through four distinct studies and it targets women. GyneGals was chosen because it was the only support program that targets gynecological cancer patients.

CHESS was an interactive computer system for people affected by breast cancer, including both the patient and their partners. Chess provided information, social support and problem-solving tools for the users (McTavish et al., 1995). The social support component of the system included a discussion group where the women could communicate anonymously with other people affected by breast cancer. The system was developed with inputs from potential users through needs-assessment surveys and field testing. The participants of the pilot study of CHESS used most of their time in the social components of the system. CHESS was well received by the participants, and they experienced feelings of acceptance, motivation, understanding and relief after interacting with it. McTavish et al., concluded that “CHESS can help ease the load of doctors and patient advocates, while allowing women to take back control of their lives.” (1995, p. 602).

GyneGals was developed in order to address the psychosocial impact of gynecologic cancer focusing on sexual distress (Classen et al., 2012). The program was a 12-week web-based support group intervention. It was hosted on two web pages, one included psychoeducational information, and the second included a discussion forum. The forum was moderated by a psychologist that had experience in facilitating different kinds of support groups. The results from this 12-week program showed that a professional moderated web-based support group

addressing sexual distress among gynecological cancer patients was well received and could potentially benefit the population (Classen et al., 2012).

#### *Possible benefits and challenges of online psychosocial support*

Transferring psychosocial support online may offer benefits. As explained by Tate and Zabinski (2004), participants often have the opportunity to be anonymous in an online setting, where social markers such as gender, age, and ethnicity are erased. The anonymity can make it easier for participants to achieve bonds at a safe distance, where they can explore difficult emotions. Allowing participants to access information and support in the comfort of their own home can reduce barriers that could have prevented them from seeking necessary help. These barriers could be shame and embarrassment over the sensitive topic of their condition, or a lack of time to seek help, or if they feel pressure to act a certain way in a face-to-face setting, or the lack of services in their area where it can be difficult to find people with similar disorders. Internet and computer-based support can offer novel solutions to overcome these geographical or physical barriers. This type of support is not time dependent, where support can be accessed at any time and when needed by the users. The constant availability and anonymity can make online psychosocial support more attractive (Tate & Zabinski, 2004).

Despite these benefits, challenges may also arise by transferring psychosocial support to an online environment. The challenges include, the lack of any visual cues during communication, which may lead to misunderstandings and confusion. The possibility of interpreting the emotional tone or intent of other users may cause issues. The challenge of interpretation can, however, be tackled by displaying emoticons, or periodic assessment of mood, or other non-verbal cues in the user interface. Implementing visual cues may increase a sense of human connection between the participants in the group (Owen, Bantum, & Golant, 2009). The lack of audio and visual contact can also be viewed as an enhancement of the experience by promoting emotional safety and emotional expression, according to Stephen et al. (2013).

There is a chance to encounter technical problems in an online environment, such as poor Internet connection, the application stops loading, and plug-ins that will not function properly etc. The less computer-literate may face other technical problems in participating in online support, where the use of technical language or acronyms may cause confusion, e.g. “BRB” which is an acronym for “be right back”. The variability of typing speed may result in several inconclusive discussion threads, which can be confusing for all participants, and especially the

less computer-literate (Owen et al., 2009). Women recovering from gynecological cancer may be elderly, where the average age at diagnosis for certain gynecological cancer types is at the age of 60 (Kreftlex.no, 2017). These women may be less computer-literate, which can result in difficulties utilizing support programs online.

Psychosocial support is vital for people after traumatic events like experiencing cancer. The support can be provided either in traditional psychotherapy appointments with a professional psychologist or in an online intervention program. The psychosocial support programs, CHES and GyneGals also included peer support components. Both programs include the possibility to talk with other people in the program that are in similar situations, through forums and support groups. Peer support may be a part of a psychosocial program, which is described in section 2.4.

## **2.4 Peer Support**

We have always been dependent on each other, where interaction and communication are vital for us in most aspects of life. We often find ourselves with people similar to us, which is commonly called peers. Peers refer to people with similar backgrounds, experiences, interests, abilities, and so forth (Mead & MacNeil, 2004). Peer support is one way of facilitating psychosocial support, where it has been defined as “a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful” (Mead, David, & Curtis, 2001).

Peer support is provided in order to bring about a desired social or personal change (Gartner & Riessman, 1982). Through offering support, empathy, sharing, companionship, and assistance, feelings such as loneliness, frustration, rejection, and discrimination are countered and dealt with (Stroul, 1993). Mead and MacNeil (2004) argue that people that have gone through similar experiences are more likely to relate better to their peers and can consequently offer a more authentic empathy and validation. Peers can offer practical advice and suggestions for coping strategies to deal with their issues that health professionals might be unaware of (Mead & MacNeil, 2004).

Hartzler and Pratt (2011) conducted a study concerning what patients can offer each other in terms of expertise. They analyzed content in online forums, where they compared the topic, form, and style of expertise shared in sources of patient expertise against sources of clinician expertise. They found that patients are offering other patients with substantial expertise that differs significantly from the expertise offered by health professionals. The patients are providing valuable emotional support, but they are also offering personal health guidance based on their own experience managing their health condition, from practical know-how to other coping strategies in their everyday life. Patients offered “strategies for coping with day-to-day personal health issues gained through trial and error of the lived experience.”(Hartzler & Pratt, 2011, p. 2). The patients told personal stories with actionable advice about managing responsibilities and activities associated with friends, family, and work surrounding the illness. By providing help to their peers they are not only guiding others through difficult times, but they are also helping themselves. The results of acting as a supporter can build social skills and occupational functioning, and reduce dependence on other resources (O’Leary, Schueller, Wobbrock, & Pratt, 2018; Salzer et al., 2013).

The traditional form of peer support is face-to-face, an example of this form is Alcoholics Anonymous (A.A.) meetings which emerged in the middle of the 20<sup>th</sup> century, and made support groups more common (Barak, Boniel-Nissim, & Suler, 2008). A.A. is a fellowship of both men and women who share their experience, strengths and hopes, to help each other overcome their common problem and recover from alcoholism (The AA Grapevine, 2013). These groups are based on the simple premise of people who share similar experiences, difficulties, misery, disease, or distress may understand one another better and can offer mutual emotional support (Barak et al., 2008). In these meetings there are usually a group of peers, with one or more people acting as moderators or facilitators. Their job is typically to engage the conversation and make sure the participants stick to appropriate topics. Support groups can also be found in an online environment, which makes it more accessible for people all over the world and gives the possibility to be anonymous in terms of appearance, age and other factors (Sharf, 1997). Based on several studies it is often preferable for people with mental health conditions to go online for support because of the potential benefits of anonymity, empowerment, and access (Houston, Lisa, Cooper, Daniel, & Ford, 2002; Melling & Houguet-Pincham, 2011; Poole, Smith, & Simpson, 2015). There is a plethora of web pages, support groups, online communities, social media, chats, forums, and such, people can seek in order to

help themselves in their current health condition, where they can potentially find peers to talk with.

Peers can potentially offer empathy and understanding at a different level than other people can, which may be the psychosocial support needed by people in challenging situations. Many people seek psychosocial support online, because of its' availability and anonymity, therefore two distinct online peer support tools are presented in the coming sections, forums and chats. Health related forums and chats are brought up with a focus on gynecological cancer and cancer in general. The potential benefits and challenges of online psychosocial support in subsection 2.3.1 also applies to online peer support applications, and additional potential benefits and challenges for forums and chats are presented in the coming sections.

#### **2.4.1 Online discussion forums**

Online discussion forums are widely used as peer support tools. Forums can also be referred to as online message boards or bulletin boards. It will be referred to as discussion forums or just forums in the thesis. They are used for a variety of issues and concerns by people all over the world. Forums facilitates asynchronous communication, which is characterized by messages between people that do not take place simultaneously (Tate & Zabinski, 2004), in contrast to synchronous communication where the users can view the messages written in real-time. Both GyneGals and CHESS made use of discussion forums in their studies. Discussion forums are websites that allow people to come together and discuss different topics. It is a place that is used for debates in which anyone can participate. There is essentially no limit to which topics that can be discussed on forums all over the Internet, there are categories for practically anything. Many discussion forum websites do, however, have some sort of restraint over certain topics that are inappropriate, violent, or mean-spirited, where the content may be moderated by forum moderators and terms of service (MedHelp.org, 2017).

A discussion forum is often categorized into topics and subtopics, which is often an identifiable feature of forums. The categorization can make the forums easier to navigate through. A health-related forum, for example, can be categorized in different health concerns, such as, cancer, and the subtopic ovarian cancer (Figure 2.1). Within the subtopic one can find a list of people, often patients with ovarian cancer or relatives of these patients, who ask a specific question in order to get advice from their peers, or by someone that might have appropriate answers. It does not

necessarily mean they are guaranteed any appropriate answers, but it is usually their goal after asking a question. A potential pitfall of these forums is therefore the possibility everyone has to answer where there is no guarantee for helpful answers.

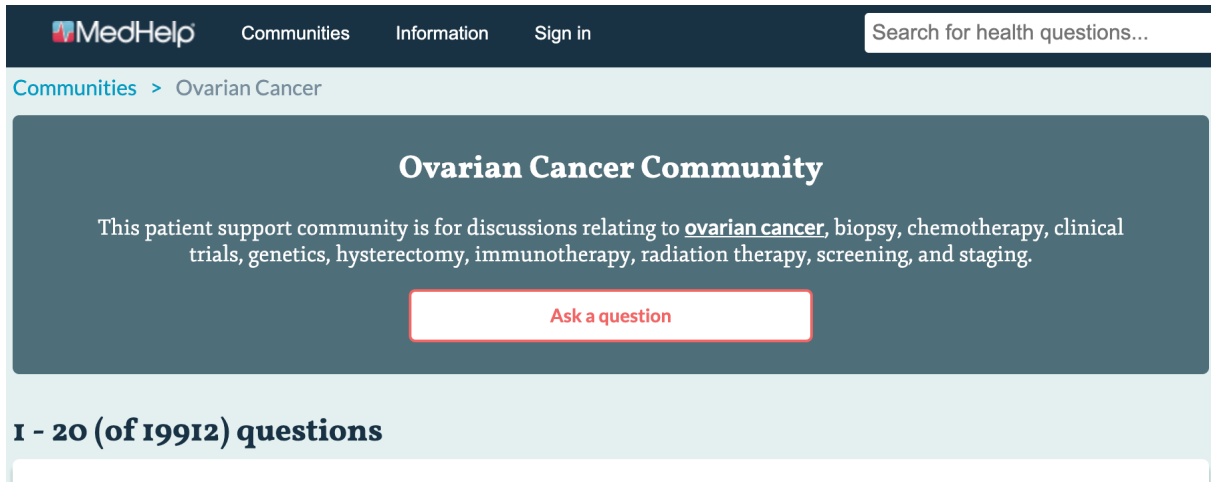


Figure 2.1: Ovarian cancer section in medhelp.org.

The users of forums do not have to be patients or relatives, but it could also be someone that has taken an interest for that certain topic that is being discussed. A forum conversation, or a forum thread, is initiated by someone, commonly called a thread starter who is asking a question or addressing a specific concern they want other views and opinions on from the users of the forum. To be able to post anything on forums one usually has to make an account with that specific forum service. The users can still be anonymous to some degree, but they might have to create a username that is displayed for other users in the forum. The thread starter asks a question and the question is typically put on the top of the web page, and a new page is generated for that specific post. Other users of the forum can add their answers or views underneath the main question.

#### *Health related peer support forum services*

Many health-related forum services offer health professionals advice in addition to regular users, but the forum is not intended to substitute professional medical advice, treatment or diagnosis (MedHelp.org, 2017). MedHelp is an example of a forum that provides health professional's advice. MedHelp is categorized into health-related topics and subtopics and is widely used in the United States with thousands of conversations posted daily (Figure 2.1).

There are millions of participants in this forum community, where they receive guidance, motivation, and support from their peers and experts (MedHelp.org, n.d.).

Gill and Whisnant (2012) conducted a study to illustrate the role online communities play in helping patients and their families to deal with ovarian cancer. They reviewed the ovarian cancer section of MedHelp.org to gain insight over the structure of the community, the reasons why people participate, which roles different users play, and the process that underlies the communication. They found that thread starters are looking for an answer and that something was desired from the others in the community by the thread starter. Information seekers were driven to participate in the forum by looking for answers regarding, self-management, trust, and support. Support is the basis of the MedHelp forum, which makes both support and trust clear drivers to participation. Since the participants did not know each other in person the finding of desire to seek self-management support and technical knowledge from the other users suggested that there is value placed on the experience of unqualified people. Information providers, however, were often seeking something as well; an opportunity to be a part of a community, provide empathy, and search for catharsis (Gill & Whisnant, 2012).

#### *Possible benefits and challenges of forums*

Forums and asynchronous communication offers the opportunity to compose a carefully constructed message in a particular manner, which can reduce the chance of confusion and avoid proliferation of misinformation (Tate & Zabinski, 2004). These carefully constructed messages may increase the quality of the support (Walther & Boyd, 2002). Several studies show that forums facilitate in collective knowledge-building and knowledge management (Beuchot & Bullen, 2005; Chalkiti & Sigala, 2008). Adler and Adler (2008), however, discovered that online discussion forums go beyond the boundaries of an information source, it can also serve as a support community. Zhang, Cho, and Zhai, (2014) explain how forums are valuable because they contain first hand experiences, which often have richer content than what can be offered by a single expert. A participant of a forum can also request or offer support at any time; however, they might not get any answers straight away. Forums may also allow for larger groups than synchronous chat groups, because of their asynchronous nature, where there is more time to read through the messages before new ones appear (Stephen et al., 2013).

A challenge in asynchronous communication is the possible time lag, which means that one might not get an answer when they need it. A new page is generated for each new thread which



may decrease the possibility of getting an answer at all because other users might overlook it, in contrast to synchronous communication where the user will see the question straight away. There is also a possibility for the responders to lack sufficient knowledge where they are unequipped to provide helpful answers, which may result in dissemination of misinformation or a lack of answers (Tate & Zabinski, 2004).

### **2.4.2 Online chat**

Online Chat is another communication form that can facilitate peer support. Chats can be referred to as instant messaging, synchronous chat, live chat, or just chat which will be the term used to here. Chats are often characterized as synchronous communication tools, although their nature is usually quasi-synchronous. Quasi-synchronous means that the participants cannot see what the others are typing as they are typing, but when they post their constructed message. If they were to observe while the other was typing, it would be called synchronous communication (Haake, 2006).

In a study conducted by O’Leary et al., (2018) the participants communicated in a truly synchronous way, using Google Docs as a chat room. These are documents people can use to write, edit, and collaborate, wherever they are in real time (Google, n.d.). In this case they were used as a communication tool. The chat tool was structured similar to a spreadsheet with boxes of information as prompts in the middle, as well as boxes to type in for both participants on either side of the prompts. In this way both participants as well as the facilitator could view the production of messages (Figure 2.2). The constructed chat tool was not similar to a typical chat in the sense of how messages were not underneath each other but rather side by side, and there was no typical send button. The fact that the participants could view the production of messages from the other conversation partner does not mimic typical chats, where this is hidden until the sender press the send button.

Follow the prompts together. **Type at the same time.** Move your cursor down when you're ready to move to the next prompt. **\*Wait\*** for each other and stay together, there's no rush.

Study ID: P95 Enter the start time: 7:30pm	Prompts	Study ID: P86
7	Rate how troubled you feel from 1 to 10. 1=not troubled; 10=very troubled.	5
I am worried about a letter that I sent to my ex girlf	Share a concern that is causing stress, anxiety, or low mood. Then, use the skills page to find your <b>main concern</b> and paste it.	I am not making it working just online jobs, but cannot
	"Wait" until they finish typing. Read their concern, and reply: <b>"You're concerned about..."</b>	
	Read their reply. <u>Underline things they said that resonate</u>	

Figure 2.2: Guided chat tool using Google Docs (O’Leary et al., 2018, p. 3).

A chat usually occurs quasi-synchronously where two or more participants communicate with each other. The communication form is mostly text-based, but many chat services offer video and microphone support as well (e.g. Skype, Facebook Messenger, WhatsApp). A chat conversation generally consists of short messages in order for the respondent to answer quickly. This rapid delivery between participants makes the chat feel more like a spoken conversation than asynchronous communication. This rapidness is one of the main differences between chat and forum. There is typically a box at the bottom of the chat where participants can type in their message and click a send button when they are ready for the receiver to view the message.

There is a plethora of chat services online, as well as forum services, for all kinds of people, issues, cases and needs. The most frequently used chat services are generally used to connect with friends and family, or between colleagues in a work setting, and they are not specific to a health issue like cancer. These can also be used as peer support tools, but they do not facilitate any health specific topics, guidelines, moderators or actual peers without finding them by oneself (e.g. Skype, Facebook Messenger, WhatsApp).

#### *Health related peer support chat services*

Peer support chat services that are specific to health issues do exist, where GRYT (previously Stupid Cancer) is one example. GRYT is a mobile application that is specifically designed for people with cancer, survivors, and their caregivers. The GRYT application was founded by

young adult cancer survivors and is also the target audience for the application. The application can, however, be used by people at any age. The purpose of the application is to connect people affected by cancer to others with similar experiences. Their mission is to “Help provide patients, survivors, and caregivers achieve personal triumph by providing the information and human connections that empower them to make choices that are right for them – based on their personal values and lifestyles” (GRYT, 2018).

Once a profile is made in GRYT the user will be paired up with people similar in age and diagnosis, and it is possible to talk directly with these people one-on-one in a chat (Figure 2.3). GRYT also offers the possibility of joining chat support groups, which means that several people can join in a collective chat and talk about certain topics. These support groups or chat rooms are vaguely categorized into topics, and the chats are often timed in order for people to be online at the same time. The chat room usually consist of many conversation threads with several different participants talking to each other at the same time, usually discussing cancer related topics. There are several program directors in the chat rooms, who function as moderators or facilitators of the conversation. The program directors can chime in on the conversation and give pointers to what to talk about to all participants. They ask questions to everyone to try to start the conversation or to keep it moving and provide practical information about upcoming chat events. The program directors do, however, not seem to have a large role in the chat room. They use the chat room much like the other participants, where they are also people affected by cancer (GRYT, 2018).

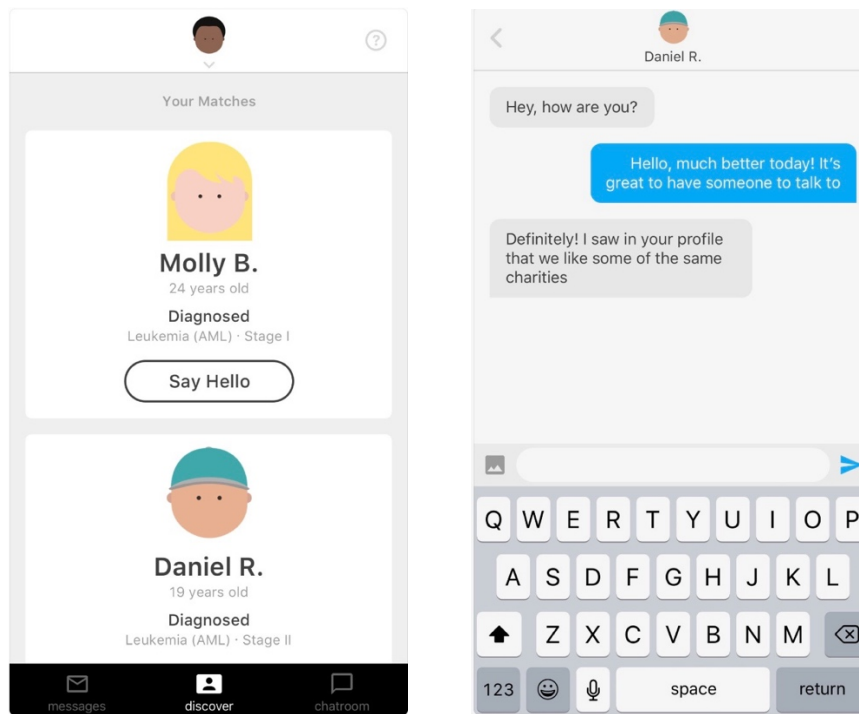


Figure 2.3: GRYT health cancer community.

The Norwegian Gynecological Cancer Association (Gynkreftforeningen, n.d.) also provide a peer support chat through a web application, where trained peers are online at certain hours to talk with peers. To answer incoming questions in the peer support chat one has to go through training, however, everyone can ask questions. The peers are not answering any health care related questions that require health professionals; however, they are there to share their experience with cancer and life after cancer. When the chat is closed, meaning no peers available at that time, it is still possible to send a message about their concern to a peer. This communication form is similar to an e-mail. They are providing both synchronous and asynchronous peer communication through this service.

#### *Possible benefits and challenges with chats*

Chats offer an interactive nature where the participants can both receive and provide immediate support and feedback. It facilitates the opportunity to clarify any misunderstandings or questions straight away because of the immediacy and the iterative way of typing (Tate & Zabinski, 2004). Chats allows for discussion and practice of skills, such as cognitive restructuring or role playing. According to Tate and Zabinski (2004) this form of practice can be highly helpful in achieving therapeutic goals. Stephen et al., (2017) found in their study of young breast cancer patients using online support groups, that synchronous chat was

challenging, however, by providing technical coaching and structure, set topics, and facilitation by professionals, the participants found their conversation to be focused and meaningful. They “were able to forge bonds and feel less alone, learn new ways of coping with cancer sequelae, and gain perspective and insight” (Stephen et al., 2017, p. 2293). This finding applies to online chat support groups with a professional facilitator.

Chat support groups require the participants to be available at the same time, which can result in scheduling issues (Stephen et al., 2013). If the participants are not there at the same time the communication is essentially asynchronous. A challenge one might face in a chat support group is related to discussion focus and pace, according to professional facilitators (Owen et al., 2009). Stephen et al., (2013) explained how their participants experienced the rapid pace as a challenge in order to follow the conversation. There were often two or more conversation threads which resulted in disjointed discussions and could cause confusion. “The rapid pace made it challenging to keep up, complete an idea, or get the wording right to convey depth of meaning” (Stephen et al., 2013 p. 183). Tate and Zabinski (2004) found that the typing speed of the participants can affect the flow of the conversation and the level of involvement by participants. Stephen et al. (2013) assume that these challenges can be overcome by ensuring that the groups are not too large, they found 6 to 8 members to be optimal and 10 as a maximum in a chat, and by employing trained facilitators. Stephen et al. (2010) explain how trained facilitators can keep track of the several discussion threads and weave them into coherent, inclusive and meaningful conversations.

Haake (2006) argues that the quasi-synchronous nature of chats may lead to multiple discussion threads in a single chat conversation, which can result in incoherent discussions. She did, however, explain how chat users use different techniques to avoid confusion in multiple discussion threads, as they “use devices such as naming, use of similar utterances and repetition to direct a comment to a specific previous chat message” (Haake, 2006, p. 135). Some chat services also allow people to link to previous messages in order refer directly to it in an orderly and clear manner.

Despite these possible challenges of group chats, early evidence suggests that participants in group chat studies yield positive results. Lieberman et al., (2001) found that the cancer patients in their study reduced depression and increased emotional control after participating in a support group. Male, Fergus, and Stephen (2017) find synchronous online support groups as a

promising psychosocial resource, because they offer many of the same therapeutic factors as face-to-face groups including other unique benefits as well, such as anonymity and convenience. Rains and Young (2009) expects that participants having access to both synchronous and asynchronous communication in internet interventions are more likely to achieve stronger benefits from participating than if just having access to one of the communication forms.

### **2.4.3 Other online peer support applications**

Services that offer communication tools can be used for peer support as well by regular people. Facebook Groups is an example of such an communication tool, where Facebook allow the users to assemble their own private groups. There are countless of groups for any kind of interests, where cancer and specifically gynecological cancer groups also exists. These are normally led by regular users and not by health professionals. The communication form in Facebook Groups is essentially asynchronous, similar to forums, however, they do offer quasi-synchronous chats within the group as well (Facebook, n.d.).

Peer support communication can be facilitated online in different ways. In this study, peer support tools like forums (medhelp.org), chats (GRYT), and Facebook groups have been researched. These applications include either synchronous forums, where the users can carefully construct their messages, or quasi-synchronous chats, where the users can get immediate emotional support from other people in similar situations. In asynchronous forums there is a possible time lag where the users may experience waiting to receive answers, if they receive any at all. In quasi-synchronous chats, the rapid typing speed and many conversations threads within a conversation may cause confusion. The next section describes the level of moderation in these peer support applications.

## **2.5 Moderated and Guided Peer Support Conversations**

Online peer support conversations vary in how they are moderated, both in terms of who is moderating, if anyone, and in what way they are moderated, if any moderation. Moderation in peer support conversations can guide the participants in their conversations and ensure a safe environment by deleting inappropriate content. The level of moderation scale from strictly

moderated by a professional facilitator at any time of the conversation to a free-flowing conversation with no moderation or guidance of any kind. Figure 2.4 illustrates the level of moderation in relevant applications and studies researched in this study.



Figure 2.4: Level of moderation in existing peer support services.

Table 2.2 lists the type of moderation that is found in the relevant applications and studies. The types of moderations that is described further is professional moderator, meaning a physical person moderating content online, guidelines, and terms of service.

Table 2.2: Type of moderation in existing peer support services.

Peer Support	Type of Moderation
Facebook Groups	Terms of service, report content
MedHelp.org	Terms of service, moderators and health professionals (rarely involved)
GRYT	Terms of service, program directors (moderators)
A.A. Meeting	Physical professional moderator (no way to 'delete' what someone has said)
(O'Leary et al., 2018)	Strict guidelines
(Owen et al., 2009; Stephen et al., 2013)	Professional moderator guiding the conversation

### *Professional Moderator*

A facilitator or moderators role is often to keep the conversation on appropriate topics, provide direction, deepening conversations, maintain a safe and focused environment, keep participants active, avoid misunderstandings, and make the participants feel comfortable (O'Grady, Bender,

Urowitz, Wiljer, & Jadad, 2010; Stephen et al., 2013). Stephen et al., (2013) explain that professional facilitators have an important role in group support chats, and participants satisfaction was due to the quality of the facilitation. The participants in their study described how “facilitators provided direction and depth to the chat, guided topic choice, maintained focus, and summarized discussion” (Stephen et al., 2013 p. 179). The facilitators acted as a “safety-net”, which helped the participants open up emotionally as well as understand each other better (Stephen et al., 2013).

The findings from the study by Stephen et al., (2013) show that professionally-led synchronous support group chats provided psychosocial benefits by facilitating meaningful conversations and the creation of social bonds. Male et al., (2017) point out in peer-led groups, which means no interference by professional moderators, establishing appropriate duration and content for the conversations can take excessive amounts of time, which thereby can detract from meaningful interactions. They further state that there is much greater probability that less dominant participants will hesitate to express themselves in the conversation, or that they might be disregarded by others.

### *Guidelines*

Moderation in a peer support conversations can also be represented as guidelines with psychotherapy- or conversation techniques. O’Leary et al., (2018) explain how providing guidance to peers could improve the quality, scalability, and efficacy of online interventions among peers. In reference to O’Leary et al.’s (2018) study where the participants chatted synchronously in Google Docs, they studied how to design guidance for people experiencing mental illnesses that is useful, appropriate, and effective. Two types of synchronous chats were arranged, where one was unguided and the other guided. The unguided chats were a free-flowing chat with no prompts or guide on conversation topics, other than the opening line of “Have a supportive chat about concerns, worry, stress, or low mood” (O’Leary et al., 2018, p. 3). The guided chats included prompts to the peer that was based on evidence-based psychotherapy skills to address emotional concerns. They based the prompts on a problem-solving framework, similar to problem-solving therapy and cognitive behavioral therapy. The reason behind choosing this approach was “because it involves the use of specific psychotherapy skills for identifying and reflecting on thoughts and feelings, which have strong evidence in treating a range of mental illnesses.” (O’Leary et al., 2018, p. 3). They based the



guidance on skills with broad applicability because they wanted the chats to serve a diverse set of users.

Both the guided and unguided chats in O’Leary’s study were between two participants, one-on-one anonymous conversations, where they were paired up with the same partner in several chat sessions. The prompts in the guided chats were aligned in the middle of the page where the participants could type in their own box on either side of the prompts (Figure 2.2, p. 24). All the prompts throughout the conversation were displayed at all times. The guide featured six expressive prompts and six reflective prompts. The expressive prompts instructed to help the participants open up about a problem, delve into problematic thoughts and feelings, and move toward solutions at the end. The reflective prompts guided the users to reflect their understanding of their chat partners thoughts and feelings (O’Leary et al., 2018).

O’Leary et al. point out that the prompts in the guided chats helped the participants express their thoughts and feelings by using cognitive and emotional skills which are well-established in talk therapy. The guided chats promoted deep discussions that lead to self-insight. The perceived depth of the conversation in these chats was increased because of the ability to both give and receive valuable advice according to the participants. Even when the guided chats were perceived as deep, the participants could have experienced increased distress by talking about troubling issues, according to O’Leary et al. (2018).

The unguided chats offered the participants to discuss openly about shared interests and experiences, which promoted a sense of personal connection that in turn contributed to smoothness in the conversation. The participants in the unguided chats tended to focus on pleasant topics that distracted them from their issues. This being said, the lack of guidance made it burdensome to initiate, maintain and end conversations. The participants fear of feelings such as being intrusive and oversharing increased by the issues in initiating the conversation (O’Leary et al., 2018).

O’Leary et al. (2018) found that by providing guidance helped ease the tension for the participants in seeking emotional support for sensitive disclosures. Both the guided and unguided chats in different ways reduced average symptoms of anxiety. The guided chats were perceived by the participants as “valuable for generating solutions to problems and promoting mutual awareness of chat partners’ concerns, whereas unguided chats were perceived as

pleasant distractions from troubles.” (O’Leary et al., 2018, p. 1). The participants did, however, suggest a balance between depth and smoothness in peer support chats. They expressed how the chats need less structure than the guided chat but should provide more instruction than the unguided chat.

Terms of service can be viewed as a form of low-level moderation, where the terms include a set of rules or guidelines in how to behave within a specific application. Most applications provide the user with terms of service before entering (e.g. Facebook), however, the terms are usually not displayed while using the application. Facebook also offers the opportunity to report any alarming behavior, in groups and anywhere else on the platform, which can also be viewed as a form of low-level moderation (Figure 2.5).

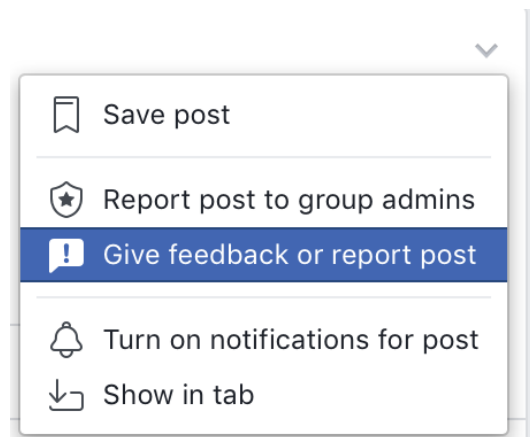


Figure 2.5: Give feedback or report post in Facebook Groups.

Peer support is one way of facilitating psychosocial support, where the support can be facilitated online in both forums, chats and other similar applications. Peer support applications vary in how they are moderated, by a professional moderator or through guidelines that can guide the peers in their conversations. Survivors of gynecological cancer face demanding challenges and changes in their body throughout their survival journey, meaning the life after cancer treatment, where the INTROMAT research team has recognized these challenges and their unmet psychosocial needs.

## **2.6 Psychosocial Support for Women Recovering from Gynecological Cancer**

The INTROMAT research team (2018) is currently developing an internet-delivered learning and coping program for women recovering from gynecological cancer. The research team recognize the psychosocial needs of gynecological cancer patients and survivors, and that these needs are not sufficiently met in the current cancer trajectory with recurrence-centered follow-ups. They therefore see a necessity for alternative and more holistic follow-ups, where internet-delivered technology can reach and aid a higher number of cancer patients than by physical appointments with health professionals. The goal of developing this program is to prepare and educate the women regarding both physical and psychological changes that are common after cancer treatment. The program is a web-based psychoeducational platform that consists of 6 modules that surrounds different aspects of life after treatment, including female identity, sexuality, changed body, fear of recurrence, among others. The program will be referred to as the psychoeducational platform in this thesis. The program consists of information about the changes they may experience, including advice on how to tackle the changes, and exercises, such as writing and mindfulness exercises. The platform will perform as a source of reliable content and a support service provided by health professionals. Womunity was designed to be a part of this psychoeducational platform.

## **2.7 Chapter Summary**

This chapter presented fields and studies, including existing applications, relevant to this study. HCI and user experience concerning how people interact with technology, and the felt life and felt experience with technology. Gynecological cancer survivors' unmet psychosocial needs, their psychological challenges after treatment, have been presented to obtain a thorough understanding of the target group. Online psychosocial support, including peer support, may offer novel possibilities and challenges to alternative psychosocial help. Forums and chats can facilitate psychosocial peer support where people can find others with similar experiences, either through structured forums or immediate support chatgroups. Through these services peers can potentially receive and provide a mutual understanding and respect. Health related peer support applications offers people the opportunity to find others with similar health issues,

diseases, and conditions, however, they often lack moderation or clear guidelines in how to talk to each other or what is allowed to post.

# Chapter 3

## Methodology

The research questions (as introduced in section 1.1) of this study are:

**RQ1:** What needs do women recovering from gynecological cancer have for online peer support?

**RQ2:** How can we design online guided peer support for women recovering from gynecological cancer?

This chapter presents an overview of the research methodology applied in the study to explore the outlined research questions. This study was conducted as a research through design process, where the participants in the study co-designed the prototype through attending design workshops. A persona and scenario were designed to make the prototype more explicit. The prototyped and evaluated by the participants. Lastly a thematic analysis was conducted of the design workshops with gynecological cancer survivors.

### 3.1 Research Through Design

Zimmerman, Forlizzi, and Evenson (2007) propose the model research through design (RtD) for how interaction designers can contribute to HCI research by producing novel integrations of HCI research, which is artifacts of significant invention, by attempting to make the *right* thing. According to Zimmerman et al. (2007) the HCI community can benefit from the added perspective of design thinking in a collaborative research environment. Design thinking is a solution-based methodology that takes a holistic approach to addressing complex or undefined problems (Dam & Siang, 2019).

This study was conducted using the RtD framework because it explored under-researched subjects constructively, as well as it offers problem-solving capacity to constructive research contributions.

RtD engage in “wicked problems”, which refers to problems that are complex and hard to define. These problems cannot be accurately modeled and cannot be addressed using the approaches of science and engineering (Zimmerman et al., 2007). These problems have no optimal solutions in the sense of any definitive and objective answers (Rittel & Webber, 1973).

By following the RtD approach design researchers will focus on producing the *right* thing which are “artifacts intended to transform the world from the current state to a preferred state” (Zimmerman et al., 2007, p. 497). The design researchers will continuously reframe the problem while attempting to make the *right* thing through an active research process of ideating, iterating, and critiquing potential solutions. The final result of this process is a concrete problem framing and articulation of the preferred state, as well as a set of artifacts – products, models, prototypes, and documentation of the design process. The artifacts produced will provide appropriate pathways for the research findings to transfer to the HCI research community (Zimmerman et al., 2007).

Designing a solution for women recovering from gynecological cancer to meet their psychosocial needs is a wicked problem, because there are no definitive or objectively correct solution. There is a desire to transform the world from the current state to a preferred state in producing the *right* thing for these women. Providing gynecological cancer survivors with appropriate tools throughout the challenging survival journey is a problem worth solving through a RtD process.

Zimmerman et al. (2007) provides a set of criteria for evaluating the quality of an interaction design research contribution:

**Process** – The design researcher must provide sufficient detail and documentation about the process they employed, enabling the reproduction of the process. There is, however, no guarantee that the same process will produce the same results.

**Invention** – The research contribution must constitute a significant invention. The designer must be able to demonstrate that they have produced of a novel integration of distinct matters to address the specific situation.

**Relevance** – The design contribution must be framed within the real world, and the designer must also be able to articulate the preferred state their design attempts to achieve and argue why the community should consider this state to be preferred.

**Extensibility** – The design research contribution must be described and documented in a way that the community can use the knowledge derived from the work and build on the resulting outcome.

## 3.2 The Participatory Design Process

The empirical study presented in this thesis was conducted as a participatory design process. Both cancer survivors and expert participants have co-designed Womunity by exploring the design space of online peer support. The study has been approved by the data protection official at Haukeland University Hospital as part of the INTROMAT study on developing internet-delivered psychosocial interventions.

Five women that have recovered from gynecological cancer represented the users in this study, and they are referred to as the user representatives in this thesis. The women were recruited through the INTROMAT gynecological cancer study at Haukeland University Hospital. These five women represented the potential users and offered first-hand experiences and knowledge about life after cancer which proved to be highly valuable for the design process. They participated in three design workshops that were arranged by the INTROMAT research team. The women were actively making decisions on how to design online peer support in collaboration with the other participants.

The expert participants consisted of one domain expert with a PhD in nursing specialized in gynecological cancer survivors, two gestalt therapists, and one HCI researcher. The experts functioned as a source of health professionals and HCI professionals to aid the design process of the prototype with their expertise. They participated in three design workshops throughout the design process and evaluated the prototype during each iteration.

The participatory design process was applied with the aim of researching the possibilities with peer support for gynecological cancer survivors. Throughout this study, design workshops with the participants have been conducted in order to reflect upon and investigate the possibilities with peer support for this specific target group. The participatory design process was applied because it gave the survivors the possibility to offer the accounts of their lived experience with gynecological cancer, where they were in a unique position to aid the design process. By involving survivors their ‘tacit knowledge’ of having gone through the survival journey was valuable in the design process. Figure 3.1 illustrates the two participant groups and the corresponding activities they attended.

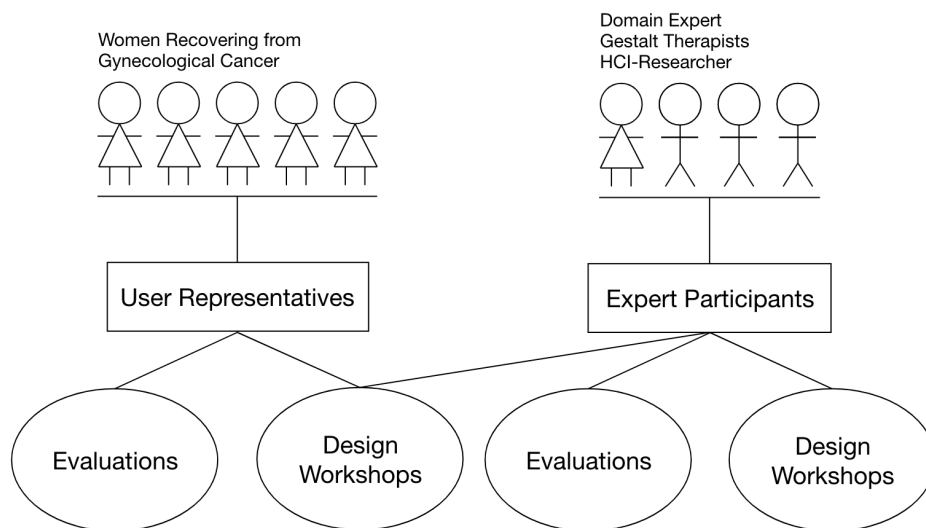


Figure 3.1: Participants with corresponding activities.

### 3.2.1 Design workshops

During this study six design workshops were conducted with the study participants. The workshops in this study were held at Haukeland University Hospital in 2018 and 2019. Involving stakeholders in the research process to work actively with the research results during workshops is a way for them to feel a sense of ownership and engagement in the project. Design workshops or brainstorming sessions bring people together to discuss problems, imagine new ideas and consider solutions (Esser & Mortensen, 2018).



### *Design workshops with user representatives*

Three design workshops were conducted with the user representatives. The workshops were arranged in order to understand their experiences with online peer support, and to obtain their perspective on online peer support for women that have recently gone through treatment for gynecological cancer. We worked collaboratively to discuss the problem space and imagine ideas in the design process. Three user representatives attended the first workshop, with two facilitators from the expert participants. Four user representatives attended the second workshop, with two facilitators from the expert participants. Three user representatives attended the third workshop, with one facilitator from the expert participants.

This method was applied because it allowed the women to be in a position to express their views in a collaborative manner with their peers, and collectively make decisions with the other participants in the study. The workshops produced fruitful discussions, where the women were encouraged to talk to each other by exchanging anecdotes and comment on each other's responses, in their own words. The outcomes of the design workshops with the user representatives have been thematically analyzed and is presented in chapter 5.

### *Design workshops with the expert participants*

During this study three design workshops were conducted with the expert participants. The workshops lasted from 30 minutes to 1 hour. The first two workshops were conducted in order to obtain a shared understanding of the project and to acquire the experts' view on different aspects surrounding online peer support for this specific target group. Ideas surrounding moderation and guidance in online peer support specifically for these women were shared between the participants.

In the third design workshop concrete guidance in the Womunity was the topic of discussion. There was a discussion on how to guide the women into having helpful conversations with their peers. The persona and her concerns (Subsections 4.2.1 and 4.2.2), displayed as a forum question, were used during the workshop for all participants to understand how gynecological cancer survivors may feel after treatment and how they may communicate online about their issues. New ideas and solutions on guidance were shared and discussed between the participants in the workshops. The outcomes of the design workshops are presented in subsections 4.1.1, 4.1.5 and 4.4.2.

Table 4.1 (p. 45) lists all design workshops, with the attended participants, conducted in this study.

### **3.2.2 Prototyping**

Prototypes were used in this study to visualize ideas onto physical objects, and to communicate the ideas to the participants in the study. Buchenau and Suri defines prototypes as “representations of a design made before final artifacts exists” (2000, p. 424). Houde and Hill emphasizes how “everyone has different expectations of what a prototype is” (1997, p. 368). A prototype can take many forms, and they can range from a low-fidelity paper-based storyboard to a high-fidelity complex piece of software. A low-fidelity prototype is a representation of the design in its simplest form, it does not necessarily look like the final product, nor have the same functionality. A high-fidelity prototype on the other hand looks like and functions close to the final product (Preece et al., 2015).

Prototypes serve a variety of purposes, for example to clarify requirements among team members, or to test the technical feasibility of an idea, or to do user testing and evaluate ideas to design better prototypes and end products. Prototypes can be viewed as a communication device between team members, this is because they are often used when discussing or evaluating ideas with stakeholders (Preece et al., 2015).

The first prototypes made for this study were sketches drawn on paper, as the design process progressed the prototypes were made using digital interactive prototyping tools. Adobe Experience Design (Adobe XD) was used to design an interactive prototype and display the conceptual functionalities. Ideas were physically drawn out for the participants to view them in context, in order for them to understand the intention of the potential product and to understand what is meant by the different concepts discussed. The feedback received from displaying the prototypes to the participants was valuable because it formed a basis for how to continue improving future prototypes by attaining new perspectives on ideas and current designs.

### **3.2.3 Persona**

A persona was created for this study to mimic a potential real user. Persona is an interaction design technique, which is a description of a hypothetical archetype of an actual user and his or her goals (Cooper, 2004).

Pruitt and Grudin (2003) argues that while personas alone can aid design, they are more powerful in complementing other methods, where they can amplify their effectiveness. The greatest value in personas are the way they can provide a shared basis of communication for the whole team, and not just the designers and the clients. Personas can guide designers through making assumptions about the target audience more explicit. The method helps to establish who is and who is not being designed for (Pruitt & Grudin, 2003).

The persona for this study created a shared understanding of the target group between all participants and made the context of the prototype more explicit. The persona is based on literature about women that have recovered from gynecological cancer (Sekse, 2011). The persona was used in the prototype for the participants to understand the context of Womunity when displaying it. The persona is illustrated in figure 4.2 and further elaborated in subsection 4.2.1.

### **3.2.4 Scenario**

The scenario in this study describes the personas everyday challenges and her needs after treatment. A scenario was applied for the expert participants to better relate to the target group by understanding the gynecological cancer survivors' struggles in everyday life.

Carroll describes scenarios as “informal narrative descriptions” (2000, p. 41). Scenarios are stories about human activity, which allows for exploration and discussion of requirements, contexts, and needs. Scenarios revolve around telling a story to emphasize the potential user's activity and daily tasks. Bødker (2000) illustrates how scenarios provide important means to making the iterative development process possible, and that they offer a basis for communication between users, designers and other stakeholders.

The scenario in this study was applied for the prototype to be more coherent. It formed the basis of a forum thread which was used to discuss guidance during a design workshop with the expert participants. The scenario is outlined in subsection 4.2.2. The persona and its' corresponding scenario complemented the other methods applied in the study by making the context of the prototype more explicit.

### **3.2.5 Evaluation**

Iterative design processes require continuous evaluations to collect data about how the product is perceived by both the users and team members which will validate the knowledge created. This data will function as a rationale to continue the design process and improve future prototypes. In each iteration of the design process (documented in chapter 4), the prototype was evaluated by the expert participants. The domain expert attended each evaluation and offered in-depth knowledge about women recovering from gynecological cancer. The gestalt therapists offered their expertise on guidance in health-related conversations. In the third iteration the prototype was evaluated by the user representatives.

Obtaining domain experts' evaluation is highly valuable during design process because they can offer their expertise within a project. The expert evaluations were conducted at the end of each iteration, the paper-based low-fidelity prototype and the interactive high-fidelity prototypes were evaluated. Each prototype was displayed to the evaluators and key components were discussed.

Acquiring users' opinions and ideas during the design process is useful because they are offering first-hand experiences and background knowledge. The user representatives evaluated the interactive prototype in the third iteration. Three representatives and the domain expert attended, where key components were discussed.

## **3.3 Thematic Analysis**

The design workshops with the user representatives were recorded with an audio recording device. 4 hours and 30 minutes of recordings were transcribed. The transcriptions were

thematically analyzed. The following question guided the analysis: “What should be considered when designing online peer support for women recovering from gynecological cancer?”

Thematic analysis was applied to analyze the qualitative data from the design workshops with the user representatives in order to search for thematic patterns. This approach was chosen because it provides flexibility and it is applicable to various types of data, where it can potentially yield detailed and rich reports of data. Thematic analysis is a qualitative analysis method, which is defined by Braun and Clarke as “a method for identifying, analyzing and reporting patterns (themes) within data” (2006, p. 79). Braun and Clarke’s step-by-step guide to thematic analysis was followed to analyze the data material.

By both attending the design workshops and transcribing the data, I obtained a thorough understanding of the data. The transcription was written in the participants own dialect in Norwegian to capture the authenticity of the data material. The transcribed data was analyzed in Norwegian, and later translated to English in the phase of identifying themes. The analysis was performed using an inductive, bottom up approach, meaning a data-driven analysis without any preexisting coding frame. The transcribed data was read and re-read where initial ideas of interesting aspects of the data were noted. Data extracts from the transcribed data were coded and collated to find thematic patterns within the data set. After coding and collating all the data extracts, four themes were identified. The codes and data extracts within each theme were reviewed and organized to ensure they fit the particular theme. The themes were refined to ensure they describe the essence of the data extracts in each theme. Lastly the data extracts were translated to English. The thematic analysis is presented in chapter 5.

### **3.4 Chapter Summary**

This chapter presented the research methodology applied in this study. The research through design process was applied in order to explore the research questions of this study. Methods of how the participants were involved in the design process was described, including a description of how the prototype was iteratively evaluated and how the qualitative data obtained was analyzed.



# Chapter 4

## The Design Process

This chapter presents the design process of the peer support prototype Womunity. Each design iteration is explained in detail chronologically from a low-fidelity prototype to a high-fidelity prototype. Design workshops with the expert participants and with the user representatives, evaluations, and design choices in the prototype is presented in this chapter. An overview of the meetings arranged in this study is displayed in table 4.1.

Table 4.1: Overview of meetings arranged in this study.

Design Phase	Meeting Type	UR <sup>1</sup>	EP <sup>2</sup>	Purpose
1 <sup>st</sup> iteration	Design Workshop	-	2	Introduction to gynecological cancer case study. Share ideas of peer support.
1 <sup>st</sup> iteration	Design Workshop	3	2	Obtain UR's views on online peer support.
1 <sup>st</sup> iteration	Design Workshop	-	4	Obtain shared understanding of peer support and evaluating the lo-fi prototype.
2 <sup>nd</sup> iteration	Expert Evaluation	-	4	Evaluation of hi-fi prototype.
3 <sup>rd</sup> iteration	Domain Expert Evaluation	-	1	Design critique of hi-fi prototype.
3 <sup>rd</sup> iteration	User Evaluation Design Workshop	3	1	Feedback on hi-fi prototype. URs making design decisions.
4 <sup>th</sup> iteration	Design Workshop	-	3	Develop content in the guidebar. <i>Acknowledge, normalize, concretize</i>

<sup>1</sup> User Representatives

<sup>2</sup> Expert Participants

## **4.1 First Iteration**

The first iteration began with a design workshop with two of the expert participants. This workshop was arranged in order to obtain a shared understanding of the project and the target group of women recovering from gynecological cancer. A design workshop was conducted with the user representatives to obtain their perspective on peer support. Based on these activities, initial user experience goals were established, and a low-fidelity prototype was designed. A second design workshop was arranged with the all of the expert participants, where the prototype was displayed, and ideas were shared between the participants. The prototype was evaluated by the expert participants at the end of the first iteration.

### **4.1.1 Design workshop with expert participants**

To initiate the project a design workshop was arranged with two of the expert participants, the domain expert and the HCI researcher. The workshop was held in order to be introduced to the psychosocial support for gynecological cancer survivors-project. We discussed the target group including their cancer experience and their potential challenges after treatment. The domain expert introduced the psychoeducational platform, where she explained the aim of the project and its' current status. The aim of the project is to provide psychosocial support and reliable information regarding side effects of cancer treatment, to women after they had gone through treatment. The INTRMAT research team was at that time developing the modules the psychoeducational program would consist of.

We further considered the possibilities with peer support communication for these women and specifically how it could fit within the psychoeducational platform. We came to an agreement about peer support being highly relevant for these women, where online peer support could potentially function as a community.

### **4.1.2 Design workshop with user representatives**

Early in the interaction design process a design workshop with three women from the user representatives-group was conducted, the domain expert and the HCI researcher also attended



this meeting. The topic peer support was explained in order for the participants to understand what is meant by the term, this entailed presenting examples of existing technologies that provides peer support. The examples presented were Facebook Groups, MedHelp.org and GRYT (Figure 2.1, p. 21 and 2.3, p. 26).

The goal of the design workshop was to obtain the user representatives perspective on existing online peer support applications and their experiences with it. They offered their experiences and expressed their views regarding moderation within these peer support services. The outcomes of the workshop were thematically analyzed, and the analysis is presented in chapter 5.

### 4.1.3 User experience goals

A set of desirable user experience goals were established after reviewing literature about the target group, specifically concerning how they experience life after cancer, and after the first design workshop with the user representatives. These goals cover a range of emotions and felt experiences. Table 4.2 displays the user experience goals of Womunity.

Table 4.2: User experience goals

User Experience Goals
<ul style="list-style-type: none"><li>• Womunity should give the users a feeling of safety and security.</li><li>• Womunity should enhance sociability.</li><li>• Womunity should guide the users into having emotionally fulfilling conversation.</li></ul>

Considering the sensitive topics that may be discussed, Womunity should make the users feel safe and secure while using it, by knowing that their information will be kept confidential. Womunity is designed for communication which is why it should enhance sociability between the users. The intention of Womunity is to arrange for emotional support which is why it should guide the users into having emotionally fulfilling conversations.

#### 4.1.4 Low-fidelity prototype

**Womunity:** A web application that allows for text-based communication between women that have recently been treated for gynecological cancer. The women will be guided by the application somehow in order for them to help each other and themselves in the process of communicating and providing support.

After the preliminary activities with the participants and the establishment of initial user experience goals a low-fidelity was designed. The process began by sketching out ideas on paper and considering different solutions by taking the participants ideas and opinions into consideration, as well as acknowledging existing applications and literature.

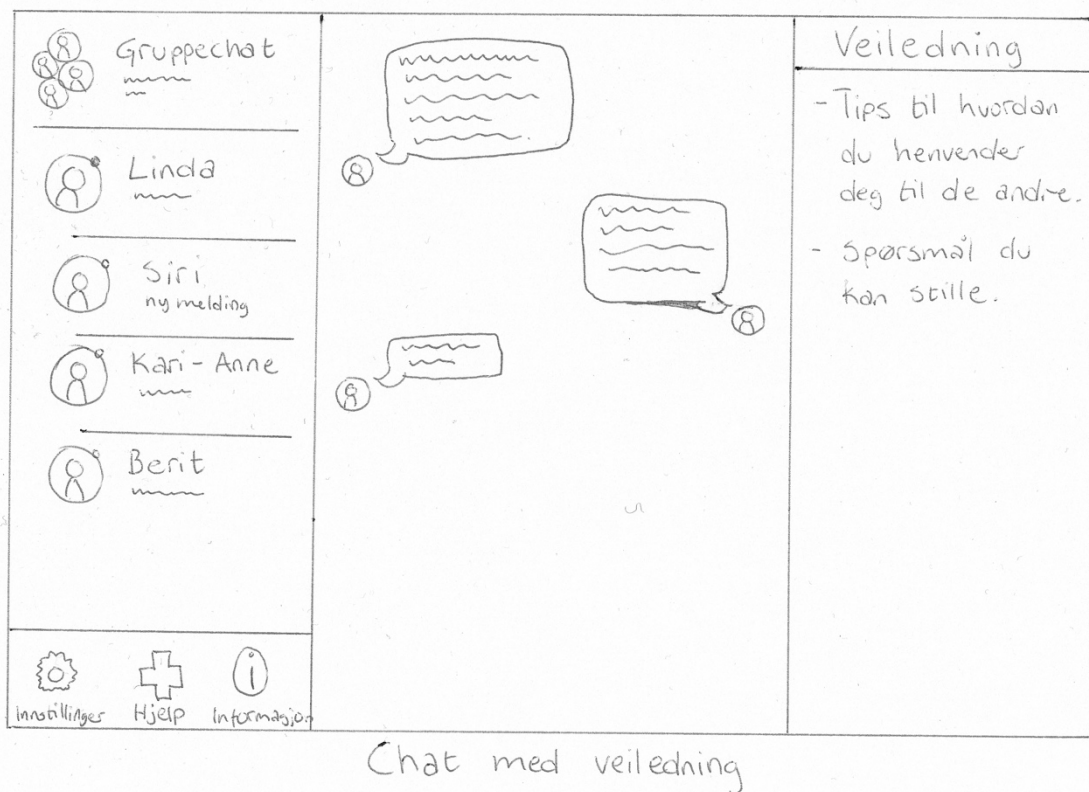


Figure 4.1: Sketch of the low-fidelity prototype.

A paper-based low-fidelity prototype was designed after sketching out initial ideas. Figure 4.1 illustrates the prototype that was later displayed in the design workshop and evaluated by the expert participants in subsection 4.1.5.

To the left in figure 4.1 there is a list of other users to speak with within Womunity. The users can choose between a group chat at the top left or individual chats underneath. The chat is displayed in the middle of the website, and a form of guidance is provided at the right side of the website. The latter will be referred to as the Guidebar in the thesis. This structure is similar to the web application for Facebook Messenger or Slack with three columns. At the bottom left a menu is displayed, where the users can edit settings, or report alarming behavior and ask for help, as well as find more information regarding the application.

The idea of guidance in the prototype came from several sources. From literature, where O’Leary et al. (2018) researched how guidance is perceived in mental health conversations. Guidance was well received by the participants in O’Leary et al.’s study (Section 2.5 *guidelines*). The user representatives noted how many women have no filter to what they share online and that this frightened them, hence the need of some form of guidance that gives the women pointers as of what to speak about and how to answer the other users (Analysis in chapter 5). Exactly how this guide should appear within Womunity was not certain at that time. Guidance was the topic of discussion with the expert participants in the upcoming design workshops.

The intention of the Guidebar was to provide the users with appropriate guidelines in how to utilize the application in order to establish a safe environment for the users. At this time the content in the Guidebar was not determined, however, based on the preliminary activities ideas of content included: advice on how the users should speak to each other, and the possibility to contact health professionals with medical queries.

#### **4.1.5 Design workshop and evaluation with expert participants**

A design workshop with the expert participants was arranged in order obtain a shared understanding between all participants of how peer support can have potential within the psychoeducational platform (Section 2.6). In the workshop, ideas were shared about different aspects of peer support, such as guidance, forum, chat, and anonymity. These aspects were

discussed as a result of reviewing existing applications and literature about peer support. The user representatives' views about peer support from the first design workshop was addressed to the expert participants. Later the preliminary user experience goals for Womunity was discussed with the experts.

An expert evaluation of the concept, including the low-fidelity prototype, was also arranged with the expert participants at this time. The prototype was displayed to the experts and where key components were examined.

There was a mutual agreement over the considerable potential online peer support has in this case, where they all supported the concept and idea. The experts emphasized the importance of using a clear tone of voice throughout the application to inform the users about what the intention of the application is and how they can utilize it. They supported the idea of guiding the users to give them a clear vision of its' purpose. A question that arouse was whether there would be a physical moderator that could view and delete content. We concluded to try to avoid being constrained to a physical moderator, and rather create appropriate guidelines for the users. The experts agreed that guidance should be something offered to the users, both because it can moderate the conversation without the need of a physical health professional, and it offers the users a guide to self-help. The guidelines should be made in such a manner that the users know how to speak to one another and help themselves and others in the process of communicating.

An idea we discussed was to categorize the content, either through channels, (e.g. Slack) or through categories and subcategories, similar to what forums offer. Categorization was discussed because it can organize the content in the forum which can make it easier to find specific information.

The second iteration of the design process was initiated after evaluative feedback was received. The knowledge and the accounts of the lived experiences from the user representatives obtained from the design workshop, the feedback and design decisions from the evaluation, guided the improvement of the next prototype.

## 4.2 Second Iteration

In the second iteration a persona and scenario were created and displayed within the prototype as the ‘user’ of Womunity. The prototype was at this time designed using Adobe XD. The prototype evolved into an interactive and more realistic prototype in regard to a potential end-product. Lastly the prototype was evaluated by the expert participants at the end of the second iteration.

### 4.2.1 Persona

The persona was added to the prototype as the ‘user’ to illustrate a typical user of Womunity (Figure 4.2). The personas’ concerns are raised within the prototype as a forum-thread (Figure 4.3). The persona was used in the design process to communicate with the rest of the team a typical user and to better understand the context of Womunity.

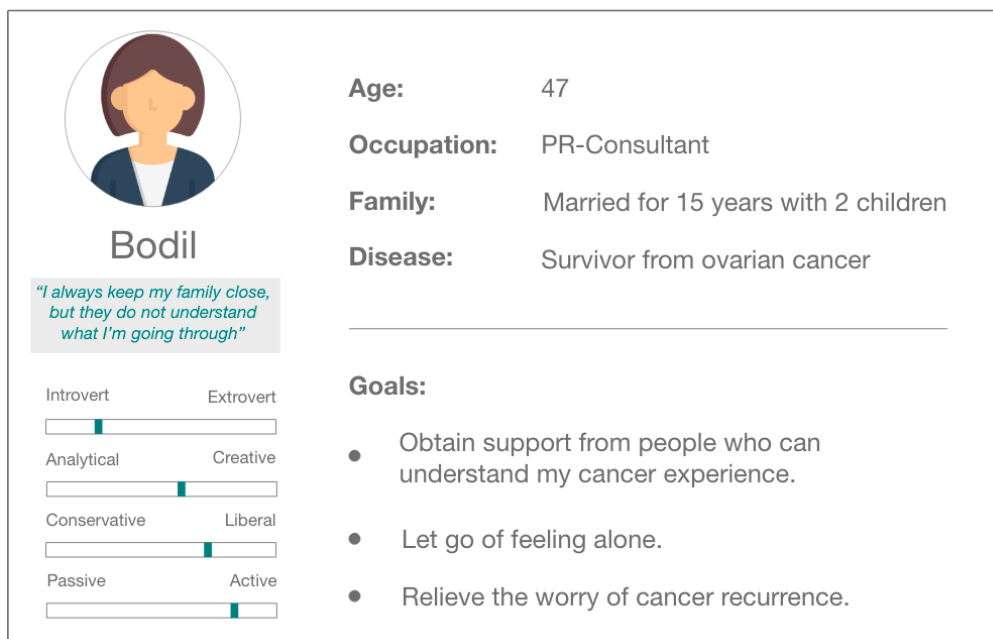


Figure 4.2: Persona illustrating a typical user of the application.

### 4.2.2 Scenario

Following is a scenario of an aspect of the personas' life after cancer. The scenario was made in collaboration with the HCI researcher. Some of the personas every day challenges, struggles, and needs, associated with the cancer experience, are described:

Bodil has battled ovarian cancer and has now been declared free from cancer, she was discharged from the hospital three weeks ago. She is relieved to have survived this battle, and grateful for the life she has, however, she is constantly worried that the cancer will recur. She loves her family and always keeps them close. Bodil loves to be active where she would go for long walks with her dog every day, but during and after cancer she has been too tired to do anything remotely active. She is afraid that the cancer might have come back since she had a similar experience with fatigue when she was diagnosed with ovarian cancer. Her family tries to understand her struggles and help wherever they can. Even though Bodil keeps her family close, she feels alone with her issues and does not know of anyone to talk to who will understand what she is going through.

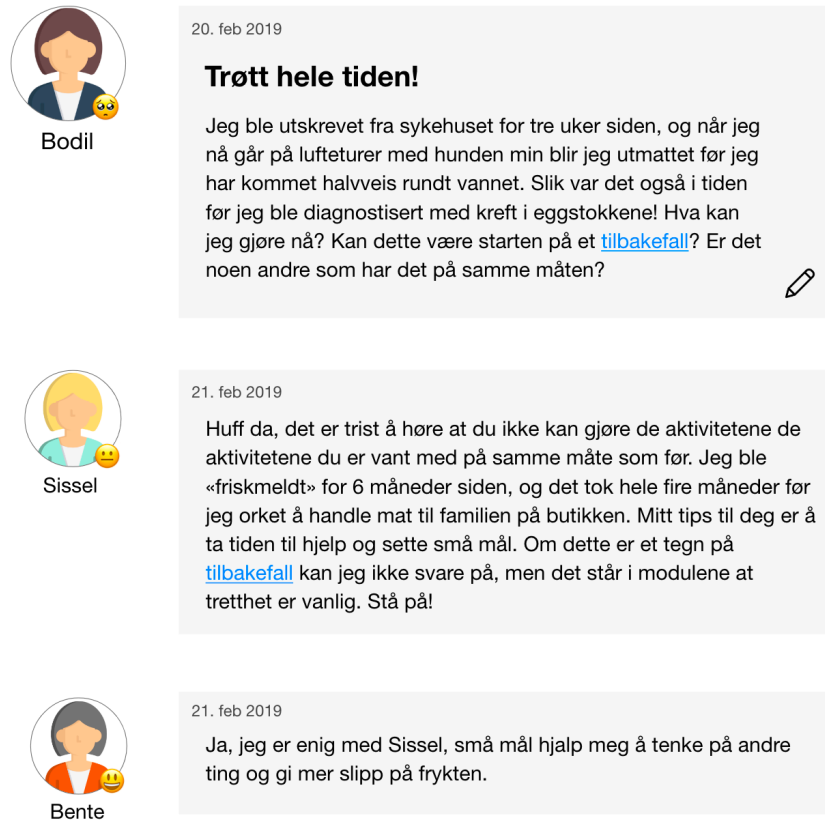


Figure 4.3: The personas concerns raised in the forum with answers (in Norwegian).

Figure 4.3 displays the personas concerns raised within the forum at the top of the forum thread. Bodil explains her current struggles and seeks advice from the other users. Two other hypothetical users have answered her, and they are trying to help her by telling their stories or by providing practical advice.

### 4.2.3 Design choices

The prototype evolved from sketches to an interactive high-fidelity prototype made using Adobe XD (Figure 4.4.). After reviewing literature about peer support and examining existing applications, both an asynchronous forum and a quasi-synchronous chat was added to the prototype. Both communication forms offer potential benefits to the users. The forum offers a more structured conversation which is less fast-paced than chats, considering the less computer-literate who may utilize the application (Owen et al., 2009). The chat can feel more like a spoken conversation where the users may offer and receive immediate support. The chat also offers the possibility to clarify misunderstandings and questions straight away (Tate & Zabinski, 2004).

The forum was structured by the then four modules the psychoeducational platform consisted of (Section 2.6) It was categorized by the modules because there was a desire to organize it somehow, similar to existing forums, in order for the users to find content easier.

Figure 4.4 illustrates the interactive prototype where it displays three sections with information. The left section displays links to the chatroom at the top, and to all forum categories underneath. The middle section displays the chat- or forum-conversation. The right section displays the Guidebar. The content in the Guidebar at this time was made in collaboration with the HCI researcher. The content would be further discussed with the expert participants and literature would be reviewed to add appropriate advice in the Guidebar.

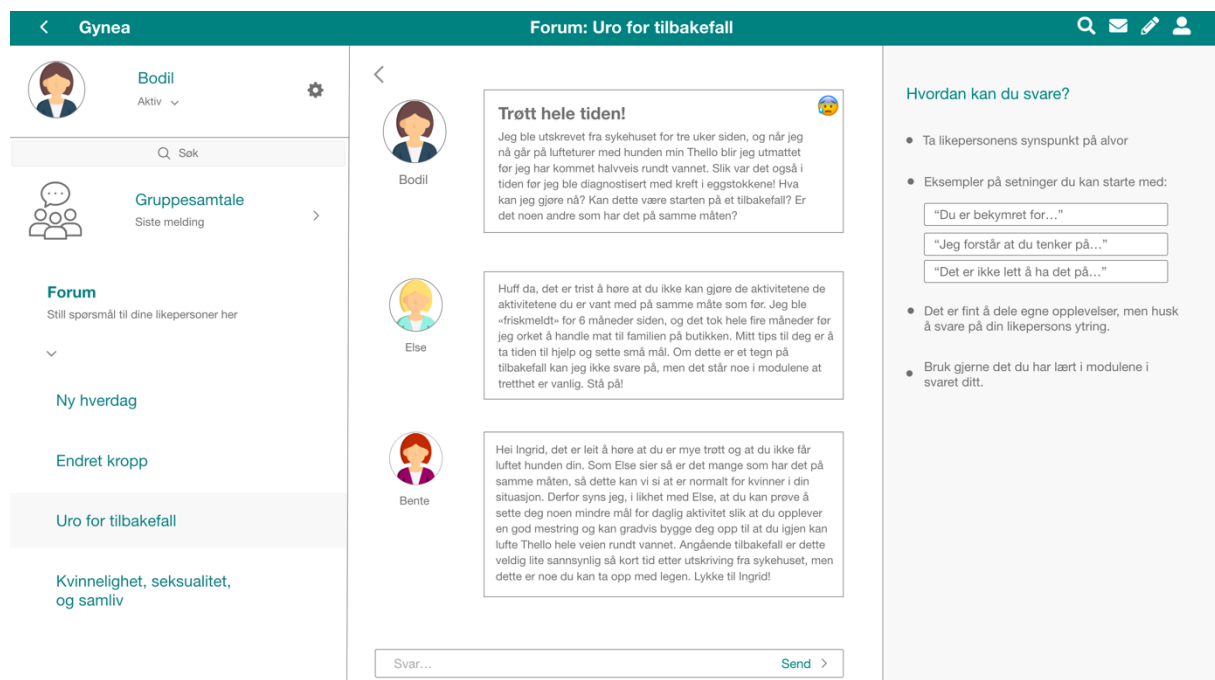


Figure 4.4: High-fidelity interactive prototype.

#### 4.2.4 Evaluation by the expert participants

The high-fidelity prototype was evaluated by the expert participants. During the evaluation it was evident how the distinction between forum and chat should be more apparent. The experts pointed out that it was difficult to understand the difference between the two communication forms, where they questioned if the users would be able to separate them. They also questioned if both communication forms were necessary, where it may confuse the users.



The experts were puzzled over the categories in the forum. It was found to be illogical to categorize the forum by the modules because the participants in the psychoeducational program may not be in the same modules at the same time. This could have resulted in less answers in each category, according to the experts. New ways of organizing the forum was considered.

There was an agreement over the idea of guiding the women through their conversations, as well as before they enter the application, in order to make its' intention clear. The experts mentioned how the Guidebar is a suitable way of guiding the women through their conversations, because it can perform as a reminder for the women on how to behave respectfully and guide them into helping their fellow peers. The Guidebar should, however, include more general advice on how to behave and speak to one another, according to the expert participants. The experts recommended Falk (2016) concerning how to communicate with people who are distressed or afflicted by any life crisis or disease. Falk (2016) provides clear guidelines and hands-on strategies on how to help people in need, by communicating.

### **4.3 Third Iteration**

The prototype evolved based on the feedback received from the previous iteration. After reviewing literature and editing the prototype, a domain expert evaluation was conducted. An evaluative design workshop with the user representatives was arranged at this time, where valuable views were obtained in order to move forward in the design process.

#### **4.3.1 Design choices**

The distinction between forum and chat in the prototype was unclear according to the expert participants. There was therefore an attempt to make a clear distinction between the two by separating them instead of displaying them in the same section. There are advantages of both communication forms, which was why both still were included. There was also a desire to ask the user representatives about both forum and chat to get their perspective on the matter.

General advice was added to the Guidebar in the prototype. The advice was based on Falk (2016) about the helping conversation with distressed patients. In a previous design workshop with the expert participants this book was introduced as a result of discussing how to guide

cancer survivors into having helpful conversation. Falk (2016) presents the perspective of a health professional to patient conversation, and not peer to peer. Many of the advice given in this book may be transferrable to a peer to peer conversation as well, because it provides advice on how to speak with or help distressed people. Following is an excerpt of the general advice in the Guidebar.

Table 4.3: General advice in the Guidebar.

<b>Advice</b>
<ul style="list-style-type: none"><li>• Be aware and listen.</li><li>• Make room for emotions in the conversation.</li><li>• You cannot always provide solutions for her, but you can always offer empathy and life experience.</li></ul>

The advice “Be aware and listen” revolves around the women allowing others to speak and listen to them before telling their own story, this may keep the conversation organized by staying on topic, and it can reduce the chance of multiple discussion threads. Emotions have a large role in peoples’ lives, and especially when experiencing traumatic events such as cancer. “Make room for emotions in the conversation” was therefore added as an advice in the Guidebar. It is important to recognize and allow for emotions when talking about difficult topics, according to Falk (2016). The last advice signifies how the peers do not necessarily hold solutions for the other women, but they can always offer their own experiences, and provide empathy towards their peers.

The advice was further discussed and refined with the expert participants in the fourth iteration to fit these women and their experiences and considering this being online support conversations (subsection 4.4.2).

### **4.3.2 Evaluation by the domain expert**

After reviewing literature and editing the prototype in Adobe XD, it was displayed to and evaluated by the domain expert. Key components and concepts were shown and questioned during the evaluation. The key components and concepts included the content in the Guidebar, forum and chat, categories and contact health professionals.

The domain expert expressed that more general advice should be added to the Guidebar. The guidance was, however, something we agreed to discuss further with the rest of the expert participants, because they could provide valuable therapeutic perspectives to the matter, according to the domain expert. She emphasized that there should not be excessive amounts of information displayed on the website, where it may be disturbing and overwhelming for the women, considering what they have recently gone through.

The expert argued that the chat offers more free-flowing in the moment conversations, as opposed to forums which may perform as question-and-answer page. She recognized the former to be more suitable considering the target group and the intention of the application, that rather hints towards emotional support than a solution-based question-and-answer page. The question concerning which communication form would fit best for online peer support was something we agreed to ask the user representatives their opinion of.

She stressed the importance of adding the possibility for the users to contact health professionals if they come across any alarming behavior or have any questions in need of health professionals' expertise. This possibility may prevent people from asking for medical advice to unqualified people, and it can promote seeking professional help.

We agreed that the application should be designed with good visibility and transparency because of the potentially elderly users, as well as considering what these women recently have gone through. Many of the survivors may struggle with memory loss and have concentration issues after treatment, which is why the application should offer clarity (Norwegian Cancer Society, 2018b).

### **4.3.3 Evaluative design workshop with the user representatives**

An evaluative design workshop with the user representatives was arranged to familiarize with their perspectives on certain concepts of Womunity, including chat and forum, categorization, and guidance in online peer support. Questions that arose from the domain expert evaluation was discussed during this workshop. The outcomes from the first workshop with the user representatives and this evaluative workshop was thematically analyzed and is presented in chapter 5.

## 4.4 Fourth Iteration

The fourth iteration was initiated after receiving evaluative feedback from the user representatives in the design workshop. Changes were made to the prototype based on the two previous evaluations. Later a design workshop concerning how to guide the women into providing emotional support to their peers, was arranged with the expert participants. The persona and scenario were used in the design workshop to discuss guidance.

### 4.4.1 Design choices

During the fourth iteration a clearer distinction between forum and chat was added to the prototype. The forum was separated from the chat where it was moved to the bottom menu. The categorization was changed from following each module to a search-bar with frequently mentioned topics underneath. Figure 4.5 illustrates the search-bar with topics underneath. This categorization design choice was proposed by the user representatives in the evaluative design workshop. In this way the user can simply search for the topics they want to discuss or read others' experiences concerning particular topics. When the users are searching for a specific topic all content will be visible for that particular searched topic, except for content from private conversations that the users are not a part of.

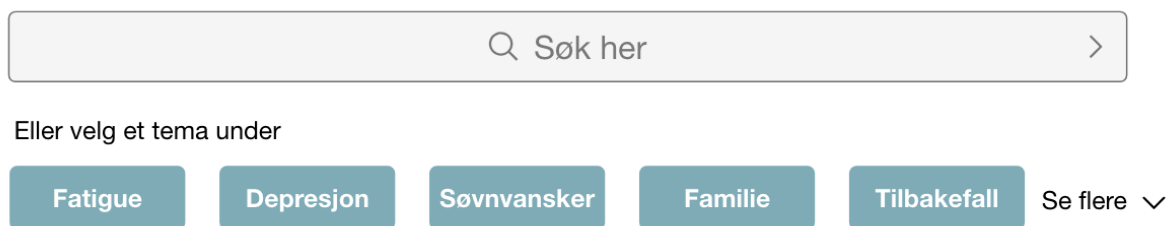


Figure 4.5: Categories in the forum.

Clear terms of service were formed concerning confidentiality and mutual respect to inform the users of what the intention of the application is. The possibility to contact health professionals was emphasized and promoted to avoid proliferation of misinformation. The text and icons were made more visible considering the possible wide range of users.

#### 4.4.2 Design workshop with the expert participants

One of the essential ideas surrounding online peer support in this case is guidance, which was why there was a need to assess how to design a guide for these women. The expert participants attended this design workshop. The general advice derived from Falk (2016) was displayed to them and they gave suggestions on alternative more explicit wording. Later the persona with the corresponding forum post (figure 4.3) was presented and the experts gave their suggestions on how to guide a peer to answer the forum starter in a helpful manner.

The participants expressed that the issues raised in the forum post was recognizable and familiar. Three main guidance principles were identified in the workshop, *acknowledge*, *normalize*, and *concretize*. To acknowledge means that the peers should show empathy towards and acknowledge their conversation partners. They should show understanding towards what their peers are going through and allow for and recognize feelings in the conversation. The peers should be guided to be good listeners by being aware in the conversation and not run over the other person by telling their own story straight away.

From the forum post (figure 4.3) the woman wondered if her issues were normal, which they clearly were, according to the expert participants. Advice concerning normalization around the cancer experience should therefore be considered. To normalize the peers' issues, the respondents may provide responses such as: "It is normal to be anxious", "You have been through a challenging treatment", "It is natural and common to feel like that".

The peers may help each other through concretizing what they are experiencing by asking questions such as: "How often are you feeling this way?", "When did you feel it first?" The peers may also concretize by providing practical advice, however, they should be careful by not contributing with any unqualified information, according to the experts. Expressed by the experts, practical advice may include recommending their peers to contact their doctor, if they are asking for medical advice, or telling them to give it more time and try to sense any changes in their body. It is important, however, for the responses from the peers to not be perceived as accusations which can be the case when providing advice e.g. "You just have to do this!".

The experts emphasized the importance of guiding the peers to not provide any medical advice and make it clear to their peers that their task is not to produce solutions but provide empathy

and support through communicating. The experts found the advice of “offer your life experience” to be contradictory when the women should listen to each other and not just jump to their own story (table 4.5). The term *life experience* should be changed to *support*, according to the experts. The peers should rather strengthen each other to find the answers and solutions within themselves because everyone’s experiences are different, and they should not be compared, according to the experts. The expert participants expressed how the guide should not include too many restrictions where the peers would not dare to say a word, it should simply guide the users through having supportive conversations.

The outcomes of the design workshop surrounding the guidance was considered and refined within the Guidebar.

#### **4.4.3 Design choices in the Guidebar**

After receiving feedback from the expert participants, the Guidebar was refined and edited based on the design proposals by the experts. The guidance principles were separated into three topics: acknowledge, normalize and concretize. The initial acknowledge-principle was derived from Falk (2016), but the normalize and the concretize was ideas from the expert participants. The first advice within acknowledgement: “be aware and listen” was still viewed as appropriate. The second advice was changed to “acknowledge emotions” as well, based on ideas from the experts. The experts emphasized how the women should not provide solutions, at least not if they are medicinal solutions, which is why the third advice was changed to the task is not to provide solutions, but empathy and support can always be offered. In the normalize and concretize principles, there are displayed examples of what the peers can tell each other, “It is normal to be worried”, “Give it some time and feel for any changes” (Table 4.3).

Table 4.4: Guidance in the Guidebar.

<b>Acknowledge</b>	<b>Normalize</b>	<b>Concretize</b>
Be aware and listen	Remember that it is normal to feel changes in the body after cancer treatment	You can recommend this to your peer:
Make room for and acknowledge emotions in the conversation	“It is normal to be worried”	“Give it some time and feel for any changes”
Your task is not to provide solutions, but you can always offer empathy and support	“You have been through a challenging treatment”	“Maybe you should contact your doctor”

The Guidebar also included the important statement of how it is not allowed to discuss topics that require health professionals. This message was displayed at the top of the Guidebar because it is vital for the safety for the users to not provide any unqualified advice. The user representatives expressed how there could be links to become a better conversationalist within the Guidebar, which is why a link was added at the bottom of the Guidebar (Figure 4.6).

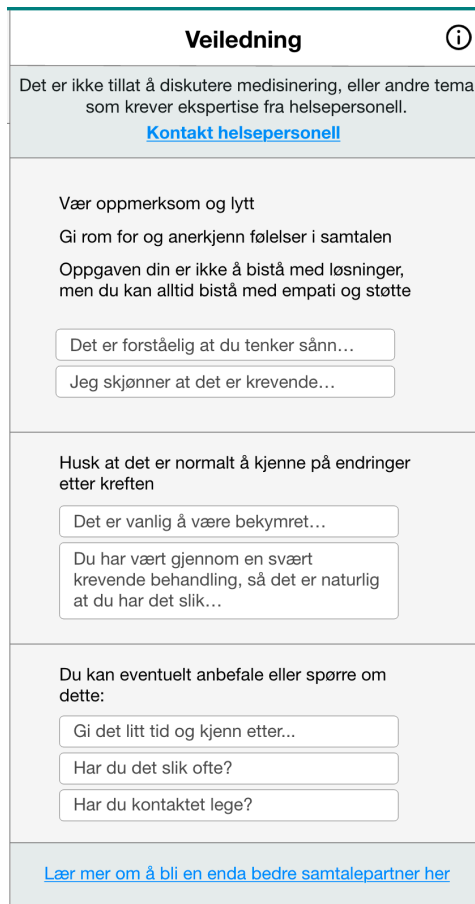


Figure 4.6: The Guidebar.

Figure 4.6 displays the final Guidebar with advice concerning how to support someone in need, and tips on how the users can potentially answer their peers. See appendix A for a screenshot of the fourth iteration prototype.

## 4.5 Chapter Summary

This chapter has described the design process of the prototype, Womunity, an online guided peer support application for women recovering from gynecological cancer. In four distinct iterations the prototype was co-designed with five former patients and four experts in the fields of gynecological cancer, gestalt therapy, and HCI.

Following is a thematic analysis of the design workshops with the user representatives who participated in this study. The results are presented in chapter 5 and discussed in chapter 6 in relation to former research described in chapter 2 with a focus on the research questions for this thesis.



# Chapter 5

## Thematic Analysis

This chapter presents the results from the thematic analysis of the transcribed design workshops with the user representatives. The following question guided the analysis: “What should be considered when designing online peer support for women recovering from gynecological cancer?” All names mentioned are pseudonyms, and all quotes are translated from Norwegian. The Norwegian quotes are found in appendix B.

Topics discussed during these workshops concerned existing peer support applications, such as Facebook Groups, GRYT and forums, and moderation in these applications. The prototype, Womunity from iteration three, was presented to the user representatives. Topics such as forum and chat, anonymity, categorization, moderation and confidentiality in relation to online peer support, were discussed to obtain their perspectives on these matters. Four themes were identified in the analysis.

### 5.1 “No one told me anything”: The Lack of Information and Resources After Treatment

The user representatives identified the lack of information and resources after treatment as an issue when recovering from gynecological cancer. Berit explained how many gynecological cancer survivors are not aware of the gynecological cancer society and that it is possible to get help after treatment, because of the lack of information provided to the patient regarding the topic.

Berit: That [the lack of information] is maybe what is so sad when you for example are in a vulnerable situation. When you have finished treatment and you are about to be discharged from the hospital, then there may not be anyone that takes their time to tell you «take a trip down to the swimming hall, you can find help there» right?

Dagny: That was exactly what happened to me, no one told me anything.

Berit explained how the lack of information and knowledge of resources available may result in the build-up of problems and sorrow after treatment, because it can take time to get the help that you need. According to the user representatives, it is unfortunate that people do not get the information they need. Berit stated how some women may need a push to seek the help they need, by providing the women with reliable information and informing them about the possibilities to receive help. Dagny responded how she did not receive any information after treatment.

Dagny: I think a group like this [an online discussion forum tailored for women recovering from gynecological cancer] could be very good for people that are quite ill. They may be able to participate in a [support] group. If they find someone they can talk with, that could be nice. At the hospital you have less and less resources to sit down and talk to people.

Dagny suggested how an online peer support group could be highly valuable for people that are ill, because the hospitals do not provide the patients with the information they need. An online support group would therefore be an alternative and perhaps a more efficient choice that can aid the survivors at the comfort of their own home, according to Dagny.

## **5.2 Shared Understanding and Mutual Support Between Peers**

Talking with and receiving support from other people through recovery was valued to the user representatives. That someone would be interested in what you are saying and show empathy towards what you are going through would be highly appreciated. To receive support from other women who have gone through similar experiences was recognized as beneficial as well by the user representatives. Peers can understand you in a different way than other people can, because they may have gone through the same or similar emotions, according to Berit.

Berit: It [support from peers] can help to clarify that what you are feeling is similar to what others are experiencing as well, and kind

of that you are not alone or that you are not... That the vulnerability or the way you feel becomes clear together with fellow sister or something.

Talking with peers can guide you through difficult emotions by knowing that you are not alone, where other people are experiencing similar emotions and go through similar issues. Berit classified the peers as fellow sisters when discussing how peers can provide empathy and mutual support to each other. Dagny extends Berit's thought by describing her own experience:

Dagny: Yes, absolutely Berit. Totally agree, I was completely alone, [I] had no one. And it was very difficult, I can tell you that. I remember one time I expressed that this was difficult for me [to non-cancer survivors]. «I have so much sorrow. » «Sorrow? You have survived! »

Dagny expressed how her feelings were not well received by other people who had not gone through cancer. They did not understand how she could feel sorrow even though she had survived cancer. She was in their words "lucky to be alive". Berit recognized this experience by adding how other people do not know what to say or how to answer someone that have gone through this. Some survivors of gynecological cancer do not want to speak about the subject because of its' sensitive nature. Berit explains how the topic may be taboo for some people.

Berit: Because it [gynecological cancer] is a bit taboo, but people [gynecological cancer survivors] need someone to air their thoughts to and then they don't know where to go.

Berit explained how an online peer support group may fit people who are too frightened to bring up the topic offline in front of people they know. Both the anonymity aspect and peer aspect could be attractive to many gynecological cancer survivors, according to Berit. Anonymity may make it easier to speak up when you do not have to show your identity, according to the user representatives.

Dagny: It is nice if two people can meet online and talk together, right?

Dagny highlights that it could be helpful for two people to meet online and talk together about these topics because it can relieve the psychological pain and uncertainty after treatment. The user representatives were positive to an online community where peers can provide and receive support, as long as the community was controlled by health professionals.

### **5.3 Promoting a Safe Online Environment**

The user representatives shared their knowledge and experiences with existing online peer support services. They were familiar with Facebook groups and other forums used by gynecological cancer patients and survivors. Their experiences indicate an assumption of how these services were used mostly by the younger generation of survivors. A few of the user representatives did, however, express that they were currently members of gynecological cancer Facebook groups. The account of their experiences and perspectives suggested that many existing online peer support services are not professionally led or moderated, where it is unsafe to trust them.

Dagny: They [the diagnosed women] come up with questions that are very difficult to answer. Because you [everyone] have different experiences, and it is often very ill people, well they are sick... they have so many... they have so many problems that they need [health] professionals.

Dagny emphasized how the questions asked by the women in these support groups and forums are challenging to answer because everyone has different experiences with cancer. According to Dagny the experiences should not be compared, and inexperienced or unprofessional advice should not be provided. The user representatives find how some of the women posting these questions to be very ill and that they require health professionals who can provide reliable information and practical help to deal with their physical or psychological issues. Berit exemplifies how someone may ask for advice, which can lead to dangerous health risks:

Berit: «Yes well now my body is like this [acting a certain way] and what can I take? Which medicines have you tried? » right? And this is something we [cancer survivors] can't help each other with because we are not qualified, right?

She underlined how they as cancer survivors and peers are not equipped to answer, therefore they should not provide any medical advice. The user representatives stressed how users of these services disclose sensitive and personal information to strangers online, for example about where they live, or post intimate disease related pictures. The uncensored disclosure made the user representatives worried for the women using these services because you never know where the information can end up.

Dagny: These groups that exists, I have looked a bit, I get a bit like a bit scared for these women. I'm thinking, oh my... No there is no guidance on these, there is no guidance on what you can or can't speak about, or no boundaries.

Many online peer support services do not offer any form of guidance or moderation as of what is allowed to discuss or post, according the user representatives, and the lack of moderation worried them. They assumed that the users of these services, are too frightened to ask for help by health professionals, where the users would rather seek help online. They expressed how the women are desperate and need help and guidance on how to resolve their issues. The user representatives are not including themselves in this statement, where they are talking about "these women" as other gynecological cancer survivors.

Berit: People are changing, and less people are signing up for [cancer] societies because there is so much alternative help to get, and online [resources] are so easy to seek out when you are young right? When it is more young people that get it [cancer] than elderly so I think it is timely.

Berit explained how she believes there is an abundance of alternative help online which is why people may not join cancer societies. People can find the help they want anonymously online, which may reduce the barriers of asking for help. According to the user representatives, seeking help online is typical for the younger generation, where resources are often more accessible.

Cecilie: They [peer support groups] haven't given me anything the groups I have been a member of. It [peer support groups] is not used for what it probably was meant for.

...

Berit: [I am] very critical to this type of communication online when it's not controlled.

Cecilie pointed out how the peer support groups she was a member of did not help her in any way after treatment, she therefore considered leaving the groups. Considering there is a lack of moderation or guidance in many of these websites the user representatives expressed how they are critical to this type of communication and that these groups and forums are misused by the users.

Dagny: There has to be a guide there [in a peer support group], someone who sorts out that this is a problem, and then you have to go there, then you have to go there.

Berit: An administrator kind of.

Dagny: Simply someone who refer you to responsible entities.

Berit: Yes, and deletes when it [the conversation] is inappropriate.

Berit and Dagny agreed that if health professionals were behind such a service and were moderating the content, by not only deleting, but also referring the users to appropriate sources, it may be helpful for the women because you avoid proliferation of misinformation between the users. The user representatives expressed how the users would receive reliable information and help anonymously with a form of moderation.

Dagny: But a group with, I mean a structured group.

Berit: Yes, with, I was about to say, precautions. There is a set of rules that, and if you don't follow them you will be kicked out.

Cecilie: It can be very clear that it [rules] exists.

Clear guidelines of what is not allowed to discuss, and how to behave should be implemented as rules and should be clearly visible to the users, according to the user representatives. They

further added how the users of peer support applications should sign a confidentiality agreement before entering with an emphasis on clear terms of use to promote a safe environment. Berit explained how receiving help on when to seek and where to get medical help is an appropriate and positive form of help. In this way the users would receive emotional support from their peers as well as reliable information regarding their issues or who to contact if they have medical questions.

Else: Then [with visible terms of service] it would also be when you start that you are more aware of it, that you don't, that you treat the information there [in the peer support application] confidential.

Else suggested to display terms of service with the confidentiality agreement before the users enter an online peer support application. In this way the users would be aware of treating the other peers with respect and that it is not allowed to proliferate any personal information from this application. Berit added how a visible confidentiality agreement could be displayed at any time while using the application, which could remind the users of the importance of the agreement.

Cecilie: As you said earlier that it is good to protect each other in the conversation, and it is not always so that you are aware of it. So, there could be a link to «here are some tips about how to talk about difficult things» ... In this way you learn a lot yourself, right? And to become a good conversationalist.

In a helping conversation people are not always aware of how to speak to one another and how to guide someone through difficult times in a helpful manner. Cecilie points out how there should be links to pages that provide tips on how to become a good conversationalist. Such tips would make the peers aware of how they should speak to help each other, as well as it can be helpful for themselves to read the tips and become a good conversationalist, according to Cecilie.

## 5.4 The Need for Structure in Fast-Paced Online Conversations

Else argued how a structured forum could be more useful in this case as opposed to an unstructured fast-paced chat.

Else: I believe that there has to be something apart from the chat-dialogue, because it [chat] is so incredibly fast-paced, if you don't have... If you go in to the group chat then it is very unorganized, which can be nice, but it is much more organized in the forum if you can read about topics or specific questions and look more at that. Because if you at a point enter late into the group chat then there are hundreds of messages that you have to [read through].

Else explained how a conversation in a chat can be difficult to follow or read through because of its' unorganized and unstructured nature. The rapid chat-conversations with multiple discussion threads may confuse the users, according to Else. She believes that a discussion forum or something similar to it should be implemented in a peer support application, because it can provide the reader or responder with more time to read and construct messages. She further adds, however, the difficulty of categorizing questions that you want answers to or different perspectives on.

Else: Well I am bit uncertain about that [how the forum should be categorized], because if you... sometimes it can be difficult to define the questions you are asking, where there are several things you are wondering about... it then gets difficult to define where you should put in the question because it goes a bit under this and a bit under that.

Else explained that it is often difficult to define or categorize what you want answers to and maybe the question does not fit within any of the categories. Cecilie suggested to categorize the content automatically by showing topics that are most talked about, where you can click on a particular topic and read the posts that says something about that topic. In this way the questions asked could be automatically tagged with keywords the post includes, according to Cecilie. She also suggested adding a search-function if you cannot find the topic you want to discuss, where the users can search throughout the forum for particular topics or keywords. In this way the



users do not have to be dependent on any set categories to find what they are looking for. Berit suggested adding links or boxes of information, concerning topics discussed by the users such as fatigue, within the forum in order to provide reliable information as well as the possibility to read others' experiences. This would in a way categorize the content in the forum, according to Cecilie.

## **5.5 Chapter Summary**

This chapter has presented the results from the thematic analysis of the transcribed data from the design workshops with the user representatives. There is a lack of information after treatment and some survivors may experience a lonesome survival journey, according to the user representatives. They expressed how there is value in having someone to talk to, and who will listen to you, after the potentially traumatizing event of cancer, and they recognized how peers can understand you at a higher level than non-cancer survivors can. The user representatives also recognized how there is a lack of moderation or guidelines, as of what is allowed to post, in existing peer support applications. They find fast-paced chats to be unstructured and difficult to follow, where they would rather prefer a categorized and structured forum in online peer support.



# Chapter 6

## Discussion

This chapter provides a critical discussion reflecting on the research questions:

**RQ1:** What needs do women recovering from gynecological cancer have for online peer support?

**RQ2:** How can we design online guided peer support for women recovering from gynecological cancer?

To explore the research questions, a prototype, Womunity, was co-designed with the user representatives and the expert participants, using the methods described in chapter 3, drawing on previous research and existing health-related peer support applications presented in chapter 2. The research questions are discussed in relation to the iterative design process of the prototype, documented in chapter 4, and the thematically analyzed design workshops with the user representatives, presented in chapter 5.

The chapter concludes with a list of design implications elicited from the discussion where each implication address aspects of the research questions.

### 6.1 The Value of Peers Sharing Lived Experiences

Gynecological cancer survivors can experience the time after treatment to be lonesome, where there is a lack of information and support. Both the user representatives in this study and literature recognize peers as a valuable source of emotional support. Mead and MacNeil (2004) argue how peers are more likely to relate to each other and can consequently offer more authentic empathy and validation than other people can. Similarly, the user representatives expressed how peers provide kinship through the sharing of experiences that relates to one's

own lived experience. The user representatives emphasized how peers can offer shared understanding, empathy, and mutual support. The expert participants explained that peers should strengthen each other to find solutions within themselves rather than adopt their peers' solutions because of the differences in their experiences. Peers do, however, have the similarity in how they have gone through gynecological cancer treatment, but their emotions and life situations may differ.

### *Design implications*

Peers have the ability to offer shared understanding and can provide mutual emotional support. Online peer support that is tailored for women recovering from gynecological cancer should facilitate for the sharing of lived experiences and emotional support between peers.

## **6.2 Guiding Peers to Promote a Safe Online Environment**

In open forums anyone can register for an account and answer forum posts. The users in these forums do not know the background of other users and whether the other users have gone through similar experiences. This uncertainty challenges the legitimacy of such forums. The user representatives expressed how they find it difficult to trust such forums because of the uncertainty of the reliability of the information provided through these forums. The user representatives find many of these forums to be unmoderated or provide no set of guidelines in how to behave. It is therefore important to consider designing guidelines in how to utilize the application, when designing online peer support for women recovering from gynecological cancer, in order to promote a safe environment. According to all participants in this study it is vital for the environment in which peers communicate is safe, which means that any health-related advice provided by unqualified people is avoided and sensitive information is not proliferated.

Presenting visible guidelines to the users on how to behave and how to answer each other, as well as what is not allowed to post is necessary because it may prevent users from disclosing sensitive information. The expert participants argued how such guidelines could perform as reminders because of the visibility while using the application. Similarly, the user representatives suggested that clear guidelines, including a confidentiality agreement, should be made visible to the users. In a study by O'Leary et al. (2018) the guidelines that guided the

online conversations was clearly visible throughout the conversation, where it had a positive effect and helped the participants in seeking emotional support for sensitive topics. The intention of Womunity is to arrange for emotional support where guidance therefore is an appropriate form of moderation for gynecological cancer survivors considering the sensitive topics. The participants in O'Leary et al.'s (2018) study expressed that the conversations should not be strictly guided at the level of turn-taking between participants in the conversation (Figure 2.2, p. 24). The guide designed in this study offers clearly visible general guidelines in how to answer someone who needs support, rather than guiding for specific messages.

### *Design Implication*

Users of online peer support should be guided through general guidelines on how they respond to their peers. Proliferation of unqualified advice and sensitive information may be avoided with appropriate visible guidelines.

## **6.3 Acknowledge, Normalize and Concretize Each Other in Peer Support**

The guidelines, named the Guidebar, in Womunity were co-designed with the expert participants and the user representatives, as well as based on literature, in particular Falk (2016). The user representatives suggested that they would want online peer support to be guided or moderated in order to maintain a safe environment with boundaries of what to talk about and how to talk to each other.

The expert participants suggested three overarching principles to guide the women into having emotionally supportive conversations: *acknowledge*, *normalize*, and *concretize*.

To *acknowledge* pinpoints the intention of Womunity, which is to arrange for emotional support and empathy. It is vital to acknowledge and allow for emotions in the conversation especially considering the sensitive topics and the gynecological cancer survivors recent experiences. To acknowledge someone or what someone has said refers to listening to what they have to say, and to be aware of emotions in the conversation. This means that you should listen to provide the support the other person needs, and answer accordingly, before addressing your own issues without acknowledging the other persons feelings and their needs first.

To *normalize* refers to easing the concern of their peer, if they are worried when experiencing changes in their body after cancer treatment. When the experts discussed the need to normalize what a person is experiencing this was a response to what a particular forum-post concerned. In this particular forum post the issues she was experiencing were normal, according to the experts (forum post in figure 4.3, p. 53). Whether their concerns are normal may not always be the case. If the peers should normalize their experiences would therefore depend on what the person is actually saying or asking about. However, to *normalize* is by all means necessary to potentially relieve feelings of distress and fear surrounding their bodily changes.

To *concretize* means to clarify what the person in need of support is going through to understand the underlying issues, which may potentially make it easier for the women to deal with their issues. One way of concretizing may be to ask how often they are feeling a certain way, and to provide practical advice such as referring them to their doctor or gynecologist, or to tell them to feel for any irregularities in the body.

#### *Design Implication*

Guidance in peer support should be founded on a set of principles. The three overarching guidance principles *acknowledge*, *normalize*, and *concretize* are well-suited for guiding peer support conversations for women recovering from gynecological cancer.

## **6.4 Involving Gynecological Cancer Survivors in the Design Process**

This study involved five gynecological cancer survivors in the design process. The women provided the perspective of having gone through cancer treatment and gone through the recovery phase after treatment.

Involving these women made the design process more practical and concrete in comparison to being limited to literature about the side effects of gynecological cancer. Obtaining their perspectives on how they perceive online peer support was valuable. Talking with them about these topics made the survivorship more comprehensible. If we were to work with women that recently had gone through cancer treatment, they would not only be in a vulnerable state, but

they would also not know how they are going to experience their survival journey. The women in this study, however, did know how they felt at that time, where they might be better equipped to describe their felt life and their needs at that time, than women that may be in a disoriented phase of recovery. It might, however, be challenging to look back at a difficult time in their life and tell you “this is what I would have wanted”. The time after treatment might have been a blur of emotions, where the user representatives stated how their memory of that period is now impaired.

The women provided accounts of their experiences of how it is to talk about the sensitive topics of the reproductive organs and sexuality with health-professionals, non-cancer survivors, and peers, which may differ from other types of cancer. If gynecological cancer survivors were not involved in the design process these valuable insights would have been unexplored.

#### *Design Implication*

Women who have been treated for gynecological cancer are experts by experience. They provide valuable insights about the felt life after treatment. They should be included in the design process of services that target their situation and needs.

## **6.5 Summary of Design Implications for Online Peer Support for Women Recovering from Gynecological Cancer**

Through collaboratively exploring the design space of online peer support with gynecological cancer survivors and expert participants a prototype, Womunity, was designed with the intention of arranging for emotional support between peers. Following are four design implications elicited from the discussion regarding future research on how to design online peer support for women recovering from gynecological cancer.

1. Facilitate sharing of lived experiences and emotional support between peers.
2. Users of online peer support should be guided on how they respond to their peers because proliferation of unqualified advice and sensitive information may be avoided.
3. Guidance in peer support should be founded on a set of principles. The three guidance principles *acknowledge*, *normalize*, and *concretize* are well-suited for guiding peer support conversations for women recovering from gynecological cancer.

4. The gynecological cancer survivors as experts by experience should be involved in the design process of online peer support that target their situation and needs, because they provide valuable insights about the felt life after treatment.

The three guidance principles may be used to guide any peers to help others through challenging emotions and help people in need of psychological support. The first principle *acknowledge* is based on Falk (2016) which concerns how to communicate with people who are distressed or afflicted by any life crisis or disease, which is why the principle should be transferrable. Considering the design workshops with the nurse and gestalt therapists concerned guidance in emotionally supportive conversations between peers the four design implications may be transferrable to peer support applications for mental health in general.

## 6.6 Limitations

Three design workshops were arranged with the user representatives during this study. Additional workshops could have been conducted to obtain and identify further ideas and perspectives on online peer support for women recovering from gynecological cancer. The lack of time in each design workshop was a limitation of this study, the five women had a lot of great ideas which may have been explored further with either additional workshops or more time in each session. However, rich data material from the design workshops were collected and carefully analyzed, which formed a good foundation to explore the research questions of this thesis.

The study presented in this thesis was limited to five gynecological cancer survivors; however, more survivors may have been included to achieve a broader vision of gynecological cancer survivors' perspectives on online peer support.

The participants in this study could have been more actively involved in sketching out ideas on paper, where their visions and ideas might have been communicated clearer.



## **6.7 Chapter Summary**

This chapter has presented a discussion on aspects of the research questions in regard to the design of Womunity and the process of co-designing with the study participants. Four design implications were presented to guide future research on how to design online peer support for women recovering from gynecological cancer. The limitations of the study has been presented in this chapter.



# Chapter 7

## Conclusion

The research presented in this thesis has explored the design space of online peer support for women recovering from gynecological cancer to meet some of their psychosocial needs after treatment. The motivation to conduct this study was the increasing number of gynecological cancer survivors, where their psychosocial needs after treatment are often unmet by the current cancer-trajectory.

Through applying a research through design process, the prototype, Womunity, was co-designed with gynecological cancer survivors and expert participants who contributed with their experience, knowledge and expertise. The prototype is the first research contribution of this study. Womunity is designed to be a web-based peer support application for women that have recently been treated for gynecological cancer. The prototype is designed to facilitate communication between the women to possibly both offer and receive emotional support after the potentially traumatizing event of cancer. Womunity is designed to guide the women through their conversations in order to maintain a safe environment and support each other in the survival journey. Womunity offers a guide in how to support each other through *acknowledging* what the other person is saying, potentially *normalize* what they are experiencing, and *concretizing* by referring to appropriate sources.

The second research contribution of this study is four design implications regarding future research on how to design online peer support for women recovering from gynecological cancer. The implications may be transferrable to online peer support for mental health in general based on how the design workshops were conducted with a nurse and two gestalt therapists. The presented research shows the importance of guiding people when they are discussing health-related topics to avoid proliferation of unreliable information, or unqualified advice.

By exploring the design space, the research presented here contributes to the knowledge on what needs gynecological cancer survivors have in relation to online peer support and about how to design online peer support.

## **7.1 Future Work**

In future research the guidance in Womunity could be evaluated by two participants communicating through a chat with the Guidebar visible to both. Existing chat services like Slack could be used to perform this evaluation and the guide would be sent to the participants as a document. The participants could be told to communicate about concerns causing stress or worry and use the guide as much as possible in the conversation. The participants could be interviewed about how they experienced the guide and how actively they used it in the conversation, after each chat-session. The evaluation should be conducted with several sets of conversations and with multiple participants

The guidance in Womunity could also be evaluated through a Wizard of Oz (WoZ) trial in future research, to evaluate the concept of guidance in peer support applications for gynecological cancer survivors. The guide could be designed to dynamically adapt to what the peers are saying to each other. The general guidance principles would still be the foundation of the guide, but message-specific tips of how to answer could be changed by a person acting as the application, who reads through the conversation and changes the guide accordingly.

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# Appendix A

## Womunity Screenshot 4<sup>th</sup> Iteration

**Gynea** Forum

**Velkommen til forumet.** Her kan du stille spørsmål til kvinner som er i lignende situasjon som deg. Du kan også søke etter tema du ønsker snakke om eller lese andres erfaringer. Husk å bruk veiledningen til høyre.

Søk etter tema her

Eller velg et tema under

Fatigue Depresjon Søvnvansker Familie Tilbakefall Se flere

**Siste innlegg**

26. feb 2019 **Bente**  
**Smerter i kroppen. Er kreften tilbake?**  
Jeg har den siste uka hatt smerter i kroppen som jeg ikke vet hva kommer av. Sliter med å konsentrere pga av denne smerten...

25. feb 2019 **Bocil**  
**Trott hele tiden!**  
Jeg ble utskrevet fra sykehuset for tre uker siden, og når jeg nå går på luftetur med hunden min blir jeg utmatet før jeg har kommet halvveis rundt vannet...

25. feb 2019 **Sissel**  
**Vanskelig å stå opp**  
Jeg finner ikke motivasjon til å stå opp om dagene og er konstant urolig for at noe er galt med kroppen min. Jeg sliter med å skape en god rutine i hverdagen etter sykdommen...

**Gruppesamtale**  
Bodil: Ja jeg har opplevd noe lignende...

**Sissel**  
Du: Det er ikke godt å høre at du...

**Bente**  
Bente: Takk for støtten...

**Elise**  
Snakk med Elise privat her.

**Vera**  
Snakk med Vera privat her.

**Lag egen gruppe**  
Velg de du vil snakke med i gruppe her

Min profil Forum Kontakt helsepersonell Hjelp

**Veiledning**

Det er ikke tillat å diskutere medisiner, eller andre tema som krever ekspertise fra helsepersonell.  
[Kontakt helsepersonell](#)

Vær oppmerksom og lytt

Gi rom for og anerkjenn følelser i samtalen

Oppgaven din er ikke å bistå med løsninger, men du kan alltid bistå med empati og støtte

Det er forståelig at du tenker sånn...

Jeg skjønner at det er krevende...

Husk at det er normalt å kjempe på endringer etter kreften

Det er vanlig å være bekymret...

Du har vært gjennom en svært krevende behandling, så det er naturlig at du har det slik...

Du kan eventuelt anbefale eller spørre om dette:

Gi det litt tid og kjenn etter...

Har du det slik ofte?

Har du kontaktet lege?

[Lær mer om å bli en enda bedre samtalepartner her](#)

# Appendix B

## Quotes from Analysis in Norwegian

Norwegian:	English:
Berit: «Ja altså no er kroppen min sånn og sånn ka kan eg ta? Ka medisina har du prøvd?» sant, og dette er jo ting som ikkje vi skal hjelpe hverandre i for vi ekkje kvalifisert sant.	Berit: «Yes well now my body is like this [acting a certain way] and what can I take? Which medicines have you tried? » right? And this is something we [cancer survivors] can't help each other with because we are not qualified, right?
Dagny: De gruppene som eksisterer, så har eg sett littegranne, får littegranne sånn litt redd for disse damene. Eg tenke uffameg.	Dagny: These groups that exists, I have looked a bit, I get a bit like a bit scared for these women. I'm thinking, oh my.
Dagny: Ingen, det er ingen som rettleiar på disse her, det er ingen rettleiing på ka du kan ta opp eller ikkje nokke grensesetting.	Dagny: No there is no guidance on these, there is no guidance on what you can or can't speak about, or no boundaries.
Cecilie: De har i alle fall ikkje gitt meg noe i de gruppene som eg har vært med i. Det er værtfall ikkje brukt til det det sikkert var tenkt til.	Cecilie: They [peer support groups] haven't given me anything the groups I have been a member of. It [peer support groups] is not used for what it probably was meant for.
Berit: Veldig kritisk til sånn type kommunikasjon på nettet da, når det ikkje blir passa på.	Berit: [I am] very critical to this type of communication online when it's not controlled.
Berit: Det er det som kanskje er litt leit når du for eksempel er i en sårbar situasjon, du er ferdigbehandlet og du skal skrives ut av sykehuset, så er det kanskje ikkje nokken som tar seg tid til å fortelle «ta deg en tur ned på badesenteret, der er det hjelp å få» sant.	Berit: That [lack of information] is maybe what is so sad when you for example are in a vulnerable situation, you have finished treatment and you are about to be discharged from the hospital, then there may not be anyone that takes their time to tell you «take a trip down to the swimming hall, you can find help there» right?
Dagny: Da var akkurat det samme med meg, ingen fortalte nokken ting.	Dagny: That was exactly what happened to me, no one told me anything.
Dagny: Så eg tenke ei sånn gruppa kan være veldig god akkurat for det der, for de som e ganske syke kanskje klare å sitte i ei gruppe, hvis de finne då nokken de kan prate med, så kunne det være godt, på sykehuset så har man jo mindre og mindre ressurser på å sitte seg ned å prata med folk.	Dagny: So I think a group like this [online discussion forum tailored for women recovering from gynecological cancer] could be very good for that, for people are pretty ill may be able to be in a group, if they find someone they can talk with, that could be good, at the hospital you have less and less resources to sit down and talk to people.
Berit: Det kan være med å sitte fingeren på at det du tenker sånn har de andre det og på en måte at ikkje du e aleine eller du ikkje, at den sårbarheten eller bare sånn du føle blir tydelig sammen med medsøstre da eller sånn.	Berit: It [support from peers] can help to clarify what you are thinking is what others are experiencing as well and kind of that you are not alone or that you are not, that the vulnerability or the way you feel becomes clear together with fellow sister or something.
Dagny: Det er godt hvis to treffes på nettet og kunne prata i lag, sant?	Dagny: It is nice if two people can meet online and talk together, right?
Dagny: Det må være en veileder gjerne, som sortere ut og ditte er et problem og da må du henvende seg der, da må du henvende deg der. Berit: En administrator på en måte. Dagny: Rett og slett noen som henviser til ansvarshavande instants. Berit: Ja og slett når det er upassande.	Dagny: There has to be a guide there [in a peer support group], someone who sorts out that this is a problem, and then you have to go there, then you have to go there. Berit: An administrator kind of. Dagny: Simply someone who refer you to responsible entities. Berit: Yes, and deletes when it [the conversation] is inappropriate.



<p>Dagny: Men sånn gruppe med sånn der, strukturert gruppe tenker eg.</p> <p>Berit: Ja også en del forhåndsregler holdt e på å si. Det er et reglement som, og følger du ikkje det så blir du kastet ut.</p> <p>Cecilie: Det kan jo og være veldig synlig at det eksisterar.</p>	<p>Dagny: But a group with, I mean a structured group.</p> <p>Berit: Yes, with, I was about to say, precautions. There is a set of rules that, and if you don't follow them you will be kicked out.</p> <p>Cecilie: It can be very clear that it [rules] exists.</p>
<p>Else: Nei jeg tenker egentlig, at det må være ett eller annet som er annerledes enn bare den chat-dialogen, fordi den er så utrolig fortløpende, hvis ikke du har, hvis du skal gå inn å se i gruppechatten så er det uoversiktlig, det kan være fint, det er mye mer oversiktlig på forumet hvis du skal lese om problemstillinger eller noen spørsmål og se litt mer på det. For hvis du på ett eller annet tidspunkt kommer for seint inn i gruppechatten så er det jo hundrevis og drøsevis med meldinger som du må..</p>	<p>Else: No I believe that there has to be something apart from the chat-dialogue, because it [chat] is so incredibly fast-paced, if you don't have, if you go in to the group chat then it is very unorganized, that can be nice, but it is much more organized in the forum if you can read about topics or specific questions and look more at that. Because if you at a point enter late into the group chat then there are hundreds and tons of messages that you have to [read through].</p>
<p>Else: Ja altså det er jeg litt sånn usikker på fordi hvis man, av og til kan det være vanskelig å definere hva man skal spør om, flere ting man lurar på om det da blir vanskelig og når den, å definere hvor man eventuelt skal legge inn spørsmål fordi det går litt på det og litt på det.</p>	<p>Else: Yes, well I am bit uncertain about that [if the forum should be categorized by the modules], because if you, sometimes it can be difficult to define the questions you are asking, several things you are wondering about if, it then gets difficult and then to define where you should put in the question because it goes a bit under this and a bit under that.</p>
<p>Else: Folk må gjør som de vil.</p> <p>...</p> <p>Berit: Da har folk valgmuligheter og da tror eg at det er lettere å være åpen og.</p>	<p>Else: People can do whatever they wantt</p> <p>Berit: Then [when creating your own group conversation] people have options and then I think it's easier to be open as well.</p>
<p>Berit: For ellers så er det jo lett at en eller annen lesar at Bente Olsen hon sa sånn og sånn sant også Googler folk det sant også. Folk blir hengt ut for de har ment nokke eller sagt nokke.</p> <p>Else: Man kan jo velge å lage seg en oppdikta identitet.</p>	<p>Berit: Because otherwise [if the user could not be anonymous] it would be easy for someone to read that Bente Olsen [fictitious name] she said this and that right? And then people can Google it right? People can be disclosed and bullied online because they have a certain opinion or have said something.</p> <p>E: You can just choose to make a fictitious identity though.</p>
<p>Else: Så burde det være, så vil det jo også være i det du starter at man har ekstra oppmerksomhet på det, at man ikke, man behandler de opplysningene der om andre konfidensielt.</p>	<p>Else: Then [with visible terms of service] it would also be when you start that you are more aware of it, that you don't, that you treat the information there [in the peer support application] confidential.</p>
<p>Cecilie: Som du sa noe i sted at det er greit å ivareta hverandre i samtalen. Og det er ikkje alltid man er klar over det. Så det kunne jo gjerne vært en liten link til, her er noen tips om kordan man skal snakke sammen om vanskelige ting ... På den måten så lærer man mye sjøl og sant det å være en god samtalepartner.</p>	<p>Cecilie: As you said something about earlier that it is good to protect each other in the conversation, and it is not always so that you are aware of it. So, there could be a link to «here are some tips about how to talk about difficult things» ... In this way you learn a lot yourself, right? And to be a good conversationalist.</p>

# Appendix C

## NORSRII Abstract Submission

*Norsrii abstract submission*

### **Participatory Design of a Guided Peer Support Application for Women Recovering from Gynecological Cancer**

Ingvild Fiskerstrand, Eivind Flobak, Ragnhild Sekse, Frode Guribye, Tine Nordgreen

This study reports on the participatory process of designing online peer support for women recovering from gynecological cancer. The online peer support is designed as an addition to and integrated part of a psycho-educative internet intervention that provides psychosocial support for this group as many cancer survivors struggle to deal with psychological and bodily changes following cancer treatment. The main aim of the design is to guide the women to having helpful and meaningful conversations with each other about the topics raised in the psycho-educative intervention.

The participatory design process has included domain experts and two focus groups with women recovering from gynecological cancer. In these focus groups we have found that the women do not currently use any form of online support groups, much because they are not professionally moderated, and that they do not trust the information provided in the support groups. The focus groups also served as a basis for establishing requirements to our design and a low-fidelity prototype was developed and evaluated by the domain experts.

In the next iterations of design and evaluation we will identify guidelines for the conversations inspired by phenomenology and gestalt therapy. These guidelines will consist of examples of how to initiate the conversation on a given topic, and general advice for having a respectful and constructive dialog with your peers. In the final evaluation we will focus on how the different conversation topics, conversation guidelines and suggestions for helpful comments are perceived and experienced by the participants.

# Appendix D

## NORSRII Poster

### Participatory Design of a Guided Peer Support Application for Women Recovering from Gynecological Cancer

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NORSRII May 14th 2019, Bergen, Norway  
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**Research Question:**  
 How can we design a guided peer support application for women recovering from gynecological cancer?

#### Why?

Gynecological cancer survivors' unmet psychosocial needs. Anxiety, distress, loneliness  
 Lack of professionally moderated support services

**What?**  
 Designing a web-based peer support application in collaboration with Gynea  
 Designing a guide on how to help each other

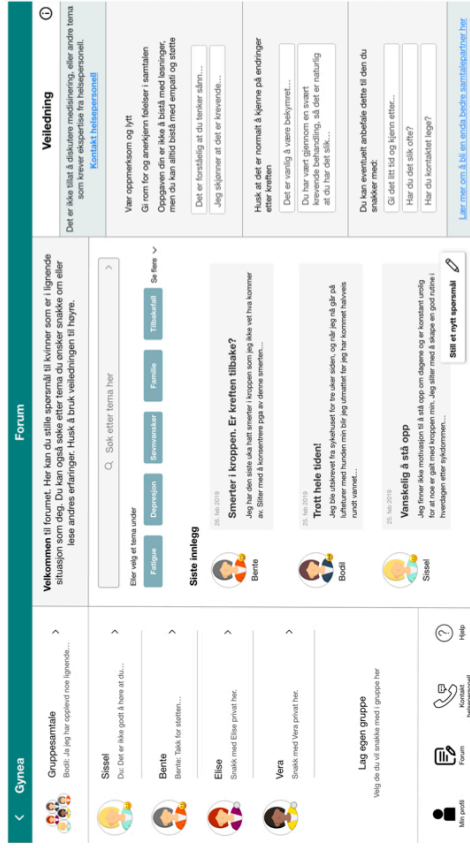
#### How?

Research through design approach  
 Focus groups with former patients  
 Design workshops with therapists and domain experts  
 Thematic analysis of focus groups

**Results**  
 Lack of information after treatment  
 Common to ask medical questions to non-professionals online  
 Alternative, anonymous and more accessible help online  
 Value in support from peers

#### Future Work

Implementation of complete design  
 Trial and testing of the application



The forum-page in the application with guidance to the right