Meaningful Engagement with Digital Health Interventions

Experience, Participation and Design

Eivind Flobak

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

This thesis has been written as part of my Ph.D. studies at the Department of Information Science and Media Studies, University of Bergen. The university funded my position at the department for a four-year position, including one year of teaching.

This thesis presents research undertaken in a Norwegian research and innovation project called INTROducing Mental health through Adaptive Technology (INTROMAT). The Research Council of Norway funded the project under Grant 259293/o70.

The INTROMAT project was a multidisciplinary research project with health researchers (clinical psychologists, nurses, and medical doctors), computer science researchers, and industrial partners. The project's main aim was to improve public mental health by integrating psychological treatments and technology.

In the project, I worked within work package 2, titled "Patient treatment modules," aimed at designing treatment modules for mental health care. My thesis relates to how we can design digital health interventions as treatment modules by involving people with relevant experiences in the process and how we can design interventions that facilitate meaningful engagement.

Professor Frode Guribye at the Department of Information Science and Media Studies, University of Bergen, was my primary supervisor. Professor Oskar Juhlin at the Department of Computing and Systems Sciences, Stockholm University, was co-supervisor.

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Abstract

This thesis explores meaningful engagement with digital health interventions (DHI). By this, the thesis aims to expand upon the engagement concept from an experiential perspective, in particular in how people construct meaning from their interactions with DHIs.

A further aim of this thesis is to understand how we can design for meaningful engagement and how user involvement can be configured when creating DHIs for the mental health domain. The thesis consists of three papers, each exploring participatory design of different DHIs, including empirical studies of people's experiences with the design prototypes.

The first paper explores how adolescents can contribute to the design of virtual reality (VR) exposure therapy as co-designers in a participatory design workshop. By using their lived experience of being high school students, the adolescents designed realistic and authentic VR scenarios that provided a view of the settings in which fear of public speaking can occur for adolescents.

The second paper explores how existing qualitative studies of illness can be used with the input from experts by experience to inform the design of DHIs. In collaboration with former gynecological cancer patients, we designed audiovisual narratives that support survivors of cancer in reflecting on their experiences. The empirical study describes how former cancer patients experienced the narratives as relevant to their lived experience and meaningful when reflecting on their own experiences.

The third paper presents a participatory design process of designing video vignettes for a DHI that supports adults with ADHD in managing everyday life. A comprehensive evaluation study of the DHI that used these videos described how people with ADHD related to the characters and their situations, finding comfort and inspiration in seeing others struggle and cope with everyday life situations.

The studies form the empirical underpinning of the thesis' contributions to Human-Computer Interaction (HCI) and DHI research. A key contribution of this thesis is the introduction of meaningful engagement as a conceptual lens to further understand engagement with DHIs. The concept is made up by its three interconnected dimensions: *purposeful interaction*, *felt experience*, and *sense-making*. I make a further contribution by showing how experience and narrative can be used as resources for design to help facilitate meaningful engagement with DHIs.

The thesis concludes that a participatory approach to designing DHIs that involves people with the lived experience of illness can provide a unique, experiential perspective in the design process that can facilitate personally relevant and authentic experiences with DHIs.

Preface

The following thesis is article-based and is divided into two main parts. The first part summarizes the research, including a detailed description of the methods and a broad discussion of the findings. The second part consists of the three papers that serve as the basis for this Ph.D. thesis.

The first part of this thesis, the summary, is my writing alone. The second part, consisting of Papers I-III, was written in collaboration with my colleagues as co-authors. I was involved in all stages of the research of Paper I-II. In the research presented in Paper III, I did not take part in the design process of making the video vignettes for the intervention. The process was facilitated mainly by the paper's second author, Emilie Sektnan Nordby, who planned it in collaboration with the third author Frode Guribye and last author Astri Lundervold. For that study, I was involved in preparing the intervention for the clinical trial and conducted the empirical study and analysis in collaboration with my colleagues.

List of publications

Paper I Eivind Flobak, Jo D. Wake, Joakim Vindenes, Smiti Kahlon, Tine Nordgreen, and Frode Guribye. 2019. Participatory design of VR scenarios for exposure therapy. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, New York, New York, USA, 1–12. `https://doi.org/10.1145/3290605.3300799`

Paper II Eivind Flobak, Oda Elise Nordberg, Frode Guribye, Tine Nordgreen, and Ragnhild Johanne Tveit Sekse. 2021. "This is the story of me": Designing audiovisual narratives to support reflection on cancer journeys. In *Designing Interactive Systems Conference 2021*. ACM, New York, NY, USA, 1031–1045. `https://doi.org/10.1145/3461778.3462005`

Paper III Eivind Flobak, Emilie Sektnan Nordby, Frode Guribye, Robin Kenter, Tine Nordgreen, and Astri Lundervold. 2021. Designing Videos With and for Adults With ADHD for an Online Intervention: Participatory Design Study and Thematic Analysis of Evaluation. *JMIR Mental Health* 8, 9 (sep 2021), e309292. `https://doi.org/10.2196/30292`

Additional publications

1. **Eivind Flobak**, Daniel A. Jensen, Astri J. Lundervold, Tine Nordgreen, Li-Hsuan Chen, and Frode Guribye. 2018. Towards Technology-Based Interventions for Improving Emotional and Cognitive Control. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems (CHI EA '18).* Association for Computing Machinery, New York, NY, USA, Paper LBW049, 1–6. `https://doi.org/10.1145/3170427.3188603`
2. Robin Håvik, Jo D. Wake, **Eivind Flobak**, Astri Lundervold, and Frode Guribye. 2018. A Conversational Interface for Self-screening for ADHD in Adults. In *International workshop on Chatbot research and design.* INSCI 2018. Lecture Notes in Computer Science, vol 11551. Springer, Cham, 133–144. `https://doi.org/10.1007/978-3-030-17705-8_12`
3. **Eivind Flobak** and Frode Guribye. 2019. LARPing into the Virtual: Participatory Design of VR. In *Workshop: Larping (Live Action Role Playing) as an Embodied Design Research Method.* At DIS 2019, San Diego, California, USA.
4. Ragnhild Johanne Tveit Sekse, Tine Nordgreen, **Eivind Flobak**, Morten Lystrup, Espen Braathen, and Henrica MJ Werner. 2021. Development of a framework and the content for a psychoeducational internet-delivered intervention for women after treatment for gynecological cancer. In *Nursing Reports* 11, 3, MDPI, 640–651. `https://doi.org/10.3390/nursrep11030061`
5. Tine Nordgreen, Emilie Nordby Sektnan, Sunniva Burok Myklebost, **Eivind Flobak**, and Smiti Kahlon. 2021. In Case of an Emergency: The Development and Effects of a Digital Intervention for Coping With Distress in Norway During the COVID-19 Pandemic. In *Frontiers in Psychology.* `https://doi.org/10.3389/fpsyg.2021.705383`
6. Tine Nordgreen, Fazle Rabbi, Jim Tørresen, et al.[1] 2021. Challenges and possible solutions in cross-disciplinary and cross-sectorial research teams within the domain of e-mental health. In *Journal of Enabling Technologies* `https://doi.org/10.1108/JET-03-2021-0013`
7. Yngve Lamo, Suresh K Mukhiya, Fazle Rabbi, et al.[2] 2022. Towards adaptive technology in routine mental health care. In *Digital Health.* `https://doi.org/10.1177/20552076221128678`

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[1] 23 authors

[2] 25 authors

Contents

Abbreviations

ACTS Accelerated Creation-to-Sustainment

ADHD Attention Deficit Hyperactivity Disorder

CBT Cognitive Behavioral Therapy

DHI Digital Health Intervention

GMT Goal Management Training

HCI Human-Computer Interaction

HMD Head-mounted Display

PBA Person-based Approach

PD Participatory Design

PPI Patient and Public Involvement

RCT Randomized Controlled Trial

REK The Regional Committee for Medical Research Ethics of Western Norway

RQ Research question

RtD Research through Design

UCD User-centered Design

UX User Experience

VR Virtual Reality

Part I

The summary

Chapter 1.

Introduction

Mental health care is undergoing a significant transformation, influenced by new channels for communication, shifting cultural norms, and evolving societal attitudes. On social media platforms, users are directly involved in creating and sharing content about health that drives engagement with these platforms. For example, Instagram is used by people with experience of mental illness to convey narrative accounts of illness in everyday life (Feuston and Piper, 2019). On TikTok, trained therapists provide recommendations for managing mental health using creative visual and audio elements that align with popular trends and patterns (i.e., the memes and tropes) of social media that are common on this algorithmically controlled new media platform (Avella, 2023).

One common feature of these platforms, which are used for health communication, is the strong engagement from people who personally identify with the content and its creators. Engagement with the content on these platforms is algorithmically fueled based on impressions, clicks, and responses that in turn lead to *viral* engagement (Avella, 2023). However, we cannot know whether the recommendations shared on these platforms about mental health are clinically sound or evidence-based. While users may engage strongly with this content, we should consider the reliability and credibility of the sources.

Engagement with evidence-based Digital Health Interventions (DHIs), on the other hand, varies greatly with each implementation of these interventions (Yeager and Benight, 2018), and is the focus of much research on DHIs (Perski and Short, 2021; Borghouts et al., 2021; Torous et al., 2020). DHIs are specifically designed to support and promote healthy behaviors (Murray et al., 2016), and are built from an evidence-based perspective (Blandford et al., 2018). These technologies are provided for a broad range of illnesses and conditions and have successfully provided effective treatments for mental health and somatic problems (Barak and Grohol, 2011; Andersson and Titov, 2014). DHIs are expected to increase the availability of help for many health challenges, especially because of their scalability and cost-effectiveness.

One popular approach for delivering DHIs is through web-based interventions, which aim to provide educational resources and self-management tools to support and improve individuals' health and well-being. The aims of these interventions are to "create positive change [and enhance] knowledge, awareness, and understanding via the provision of sound health-related material and use of interactive web-based components" (Barak et al., 2009, p. 2). These interventions can be accessed with a web browser and are often structured as modular, self-guided courses provided as interactive websites. Other approaches and techniques for delivering DHIs include virtual reality (VR), wearable devices such as smartwatches, and smartphone applications.

The use of self-guided DHIs are becoming increasingly popular as a tool to support people in nationalized healthcare services, particularly in the mental health field where sensitive topics are often involved. These new self-guided services are forming new experiences and ways of interacting with technology in healthcare. There is an opportunity to explore how we can leverage the narrative style and experiential expertise of social media posts (Hartzler and Pratt, 2011) in designing engaging, evidence-based DHIs.

This thesis aims to: (1) explore how people experience engagement with DHIs as meaningful, and (2) understand how we can design DHIs for the mental health domain that involves people's relevant experiences with a participatory approach.

Engagement with DHIs To understand how people use DHIs, research has primarily concentrated on the notion of *engagement*. Engagement is typically understood as a psychological construct that models a person's use of a DHI from a behavioral, cognitive, and affective perspective (Kelders et al., 2020a). In research on DHIs, engagement is often seen as an end in itself, and seen as conducive to other means as it is argued that engagement can lead to improved health outcomes (Donkin et al., 2011; Gan et al., 2021).

Similarly to how engagement is measured and informs social media algorithms, engagement with DHIs is typically measured by usage data, such as the number of log-ins, clicks, and completion rates. However, these quantitative measures of engagement do not necessarily capture the way in which the engagement is personally meaningful and relevant. For example, just because a user logs in to a DHI multiple times and click through a range of pages does not mean that they are engaged in improving their health or find the intervention meaningful.

The more general *experience* of using a DHI has received limited interest in research on DHIs (Søvold and Solbakken, 2022; Stawarz et al., 2018). Experience is a broader concept that includes engagement but also encompasses other aspects of DHI use such as the user's perception of the technology, their emotional response to it, and how it fits into their daily life (McCarthy and Wright, 2007).

By addressing engagement from the broader perspective of experience, we may better understand how DHIs influence people's sense of identity and values, and how they form new experiences from their interactions. In this thesis, I argue that engagement with DHIs can fundamentally be understood as an experience. McCarthy and Wright's (2007) notion of *technology as experience* is used as a backdrop in this thesis to understand how engagement with DHIs is a lived and embodied experience. Through the lens of experience, engagement with DHIs can be further understood as personally meaningful. I suggest 'meaningful engagement' as a conceptual lens to better understand how people interact with DHIs, based on the empirical the empriical studies of Paper I-III included in this thesis.

User involvement The development of DHIs is often led by a clinical perspective, grounded in evidence-based medical research, in which expert clinicians are predominantly the decision-makers in terms of content and format of delivery (O'Cathain et al., 2019b). In routine care, calls for person-centered care argue for emphasizing the experiential perspective of illness in everyday contexts, to value the whole person behind the illness (Ekman et al., 2011). For designing DHIs, user-centered design approaches have been adopted, in which representatives of end-users are consulted to improve the acceptability of the DHI for intended target populations (Yardley et al., 2015).

Although there are established processes for consulting end-users in the design of evidence-based DHIs (Yardley et al., 2015), the perspectives of those that have the experience of illness may be overlooked or ignored in theory-based, expert-led processes (Blandford et al., 2018). By Norwegian law, citizens' participation in healthcare is regulated on three different levels: the individual level, the service level, and the institutional level. At the service level, the regulations regarding quality enhancement of health services are clearly worded: "make sure to use patients', users' and relatives' experiences in the improvement of services" (Norwegian Institute of Public Health, 2019, *my translation*). Moreover, the Directorate of e-health (2019a) in Norway stressed the importance of user involvement as a priority area in their strategic commitment to “healthcare in new ways”:

> User involvement is relevant to safeguard the citizens’ perspective in strategic management, development of national solutions, and concrete service provision. The citizen perspective puts important topics on the agenda. In the wake of increased technological possibilities, questions of principle arise related to developing the welfare society’s roles and power relations, prioritization, privacy, and social differences. Efforts in this area will help to strengthen and facilitate citizens’ involvement and increase the relevance of various initiatives. Participation can take a direct or indirect form. Indirect in that solution development is based on a rich and up-to-date knowledge base about citizens in relation to e-health. Directly through involvement in expert groups and lay people’s panels in developing concrete services. (Directorate of e-health, 2019b, p. 21, *my translation*)

The direct participation of people concerned with a DHI may bring topics to the table that could otherwise have been neglected. In the Norwegian government’s vision for digital health services, user involvement is a democratic principle that they expect will increase the relevance of digital health initiatives. There is, however, little guidance on *how* citizens’ perspectives can be elicited and effectively included in the design of DHIs.

Participatory methods in HCI offer opportunities for involving concerned parties directly in the design of DHIs. Participatory design (PD) is a participatory method for systems development that was originally motivated by directly involving workers’ knowledge in the design of new technology (Ehn, 2008). The research conducted for this thesis has aimed to understand how people’s first-hand knowledge and experience of illness can be used as a resource for design when shaping DHIs for the mental health domain. This thesis documents how people with relevant experiences took part in participatory methods to design content for DHIs that target fear of public speaking in adolescence, recovery after surviving gynecological cancer, and a self-help program for supporting adults with attention deficit hyperactivity disorder (ADHD) in everyday life.

1.1 Research questions

This thesis explores the following research question: *How can participatory methods be used to shape Digital Health Interventions (DHIs) that facilitate meaningful engagement in the mental health domain?*

To break up the parts of the above question, the following research questions (RQs) are provided:

RQ1. *What is meaningful engagement with DHIs?*

RQ2. *How can we design for meaningful engagement with DHIs?*

RQ3. *How can we configure user involvement in participatory design of DHIs?*

1.2 Contribution statement

This thesis makes three main contributions to the field of HCI and research on DHIs. First, by suggesting meaningful engagement as a conceptual lens to further understand interaction with DHIs, this thesis aims to make a conceptual contribution to understanding engagement in research on DHIs. Understanding how engagement with DHIs can be personally meaningful can help us to better understand the effects of DHIs. 'Meaningful engagement' is here comprised by the dimensions *purposeful interaction*, *felt experience*, and *sense-making*. This conceptual contribution is underpinned by the empirical research presented in this thesis. Secondly, this thesis makes a contribution to our knowledge of how to design for facilitating meaningful engagement with DHIs. This contribution is developed in two approaches: (1) using experience as a resource when designing DHIs, and (2) employing narratives to convey lived experience of illness. Thirdly, the thesis contributes to how we involve people with relevant experiences to facilitate citizens' involvement in the design process of developing DHIs. Furthermore, the thesis provides a set of suggestions on how user involvement can be configured for designing DHIs for the mental health domain.

1.3 Thesis structure

The first part of this thesis consists of eight chapters. Following this introduction, the second chapter provides an overview of the theory and concepts relevant to this thesis. In the third chapter, the methodological approach of this thesis is presented and discussed. The fourth chapter presents a summary of each paper. Chapter 5-7 discusses the findings of the studies against the research questions. The summary is ended with a chapter that provides a conclusion to the thesis and limitations.

The second part of this thesis includes the full texts of Paper I-III, which are presented as individual chapters following the conclusion of the first part.

Chapter 2.
Background

In this chapter, I present concepts and theories relevant to this thesis. I begin with an account of how the concept of experience has been treated in HCI research. Following this account, I give an overview of how engagement is understood in both DHI and HCI literature. The latter part of this chapter focuses on user involvement. First, I give an overview and background to how user involvement is understood within HCI research, then I provide an overview of approaches to designing and developing DHIs.

2.1 Experience in HCI

Interactive technology has permeated and mediated our everyday lives for decades. Our everyday experiences are constructed in interaction with technology. To understand interaction, it is meaningful to consider the experience of interaction with technology in everyday life.

Building on Houde and Hill's (1997) notion of the *look and feel* of a system, Buchenau and Suri (2000) characterized experience as a dynamic and subjective phenomenon that describes our sensory experience of interactive technology, its contextual factors, and the role of interactive systems in users' lives. In Buchenau and Suri's (2000) view, a focus on experience in interaction design entails an attitude to design that can help us design technology that are shaped to fit and transform everyday life.

The developments in considering experience in HCI research align with Bødker's (2006; 2015) characterization of the third wave of HCI research, which broadened the view of HCI to include new elements of "the human," such as experience, emotion, and culture. Third-wave HCI continued the break from the original cognitivist paradigm (Bannon, 1991) that HCI is founded upon, one that bore a strong task-oriented conceptualization of interaction. Over the years, a large strand of the HCI research community has steered toward a more interpretivist tradition, emphasizing the individual and drawing attention to reflexivity in understanding key concepts of HCI.

The discussion of emotions and aesthetics in HCI research, which are closely related to the concept of experience, emerged in the early 2000s concurrently with the discourse on experience. According to Norman (2002, 2004), the way we experience technology emotionally is affected by the aesthetic appeal of technology: “Good design means that beauty and usability are in balance. An object that is beautiful to the core is no better than one that is only pretty if they both lack usability.” (Norman, 2002, p. 42). With this view, the experience of aesthetics in technology is condensed into a traditional information-processing model of cognition, suggesting that usability and aesthetics are properties of the technology. In a contrasting account, more in line with third-wave HCI research, Boehner et al. (2005) argued that emotion is experienced as a dynamic phenomenon depending on social and cultural factors. In their view, the experience of emotion is negotiated through one’s interactions, and thus cannot be separated from the context in which it occurs. From this perspective, the concepts of emotion and experience are viewed as products of interactional processes that are constantly changing (Höök, 2013).

The interest in experience as a concept has increasingly impacted the software industry, known by the term “user experience” (normally shortened to UX). The term has been attributed to the computer company Apple in the 1990s (Norman et al., 1995). More recently, Hassenzahl (2008) defined user experience as “a momentary, primarily evaluative feeling (good-bad) while interacting with a product or service” (Hassenzahl, 2008, p. 12, italics removed). In this view, user experience is built and unfolds directly from the interaction and “self-talk” (Forlizzi and Battarbee, 2004) that occurs when interaction with technology. The definition emphasizes a performative, user-centered view on *product quality*, here seen as interactively constructed. Today, the term UX is used within the software industry to refer to interaction design as a practice, user-centered design as an approach to product development, the users’ evaluative feeling of a product, and product quality from a user-centered point of view. Thus, a conceptual gap exists between how experience is commonly understood within HCI research as a reflexive concept and the evaluative concept of product quality, as conceptualized under the term ’user experience’ in the software industry.

Related to the quality of user experience, Mekler and Hornbæk (2019) developed a framework for unpacking the experience of meaning in interaction. Rooted in positive psychology, it is argued by Mekler and Hornbæk (2019) that the experience of meaningfulness in HCI promotes well-being. Their framework conceptualizes meaning from five components: connectedness, purpose, coherence, resonance, and significance. With connectedness, the way the immediate experience of interaction relates to aspects of the self and others is emphasized. Purpose is the sense of direction when interacting, and understanding how one's current activities are linked to future events and long-term goals. Coherence concerns the sense-making of the experience in relation to one's life as a whole. Resonance "denote[s] the immediate, unreflected experience of something making sense" (Mekler and Hornbæk, 2019, p. 6), typically in a profound way that immediately feels *right*. Lastly, significance refers to how interaction is valued, e.g., as important or trivial.

This thesis is grounded in an interactional view of experience, in line with those of Boehner et al. (2005) and Höök (2013) above, in which experience and meaning are negotiated interactionally spanning the individual, social, and cultural spheres of human life. A pragmatist, holistic view of the experience of technology has been developed in McCarthy and Wright's (2007) theoretical framework for unpacking interaction as an experience further on individual, collective, and cultural levels.

2.1.1 A pragmatist view on the experience of interaction

McCarthy and Wright's (2007) *Technology as Experience* presented a conceptual foundation for understanding the experience of technology use. Their framework can be used to develop an account of how people's experiences and sense-making form through interactions with technology, situated within social and cultural contexts.

With *felt experience*, Wright and McCarthy emphasize that "lived experience is an embodied experience" (2010, p. 13). This embodiment is situated in time and space and is the consequence of past experiences also situated in time and space. And because experiences take place in one's body, the experience is thus *felt*. Building upon this view of felt experience as lived and embodied, one cannot divide experience into Cartesian terms of mind and body and their subcategories. Instead, we must understand experience holistically as "the interplay between sensation, emotion, intellect and action situated in a particular place and time" (Wright and McCarthy, 2010, p. 14). And, in its complexity and situatedness lies the paradox of felt experience: It is difficult to develop an account of experience because one cannot "step out of experience and look at it in a detached way" (McCarthy and Wright, 2007, p. 15). Therefore, some degree of reduction in experience is inevitable when studying this phenomenon.

McCarthy and Wright's framework of technology as experience follows from Dewey's

(1934) *Art as Experience*. To Dewey, *aesthetic experience* is profound and distinct from the *humdrum* we experience in the everyday. It is argued that aesthetic experience can be understood as an all-encompassing engagement, wherein one is fully involved and conscious. The aesthetic experience is what Dewey refers to as *an* experience, related to Mekler and Hornbæk's (2019) notion of resonance in experience as something that makes immediate sense in a profound way.

In the pragmatist philosophy of Dewey, experience results from the relationship between self and an object as it is formed by human action. Action is, to Dewey, always situated and creative, and this composition is what gives meaning to experience. An aesthetic experience is therefore something that is contingent on the person's context and is therefore personal and subjective. In other words, the qualities of an experience are found within the process of interacting with the world, not as attributes or properties of some isolated object.

Following this perspective on felt experience and sense-making, an experience cannot be guaranteed in art and design; it can only be designed for. Thus, it is the responsibility of designers to create designs that can be experienced aesthetically.

Next, I will provide a comparative analysis of the various perspectives on experience in HCI, highlighting the main characteristics of each.

2.1.2 Comparison of perspectives on experience in HCI

In this section, I have described how the concept of experience has been treated within HCI research. Table 2.1 provides a summary of the major perspectives on the concept of experience in HCI discussed in this chapter, including their defining characteristics and theoretical backgrounds.

I have chosen to include aesthetics, emotion, and meaning in addition to experience in this section as they are closely related to each other. In my view, they all ultimately address the experience of technology, and I will thus refer to these phenomena by the collective term *experience*.

The perspectives on experience in HCI discussed in this thesis can be broadly categorized as dialogical (Hassenzahl, 2008; McCarthy and Wright, 2007; Boehner et al., 2005), phenomenological (Buchenau and Suri, 2000), and psychological (Norman, 2004; Mekler and Hornbæk, 2019). The main contrasts between these perspectives are found in how the phenomena of user experiences are created. In the dialogical perspectives, experience is seen most fundamentally as interactionally negotiated between the self and an interactive object, but also through the interaction with others in social and cultural spheres. The phenomenological account, here represented by Buchenau and Suri (2000), sees experience as unfolding directly in the first-person point of view. Other detailed accounts of experience from a phenomenological perspectives exist in HCI (Svanæs, 2000; Dourish, 2001; Höök, 2018) but are not described or discussed further in this thesis about DHIs. Lastly, the psychological perspectives on experience provide an individualistic view of how experiences are formed through interactions with technology. Together, the perspectives provide a backdrop for discussing the experiences of interacting with DHIs.

Table 2.1: Overview of experience and closely related phenomena in HCI literature

Name & author(s)	Characteristics	Theoretical background
User experience (Hassenzahl, 2008)	Evaluative feeling of product quality as either good or bad	Dialogical: “Self-talk” (Forlizzi and Battarbee, 2004)
Technology as experience (McCarthy and Wright, 2007)	Felt experience of technology as lived and embodied	Dialogical, pragmatist philosophy (Dewey, 1934)
Affect as interactively experienced (Boehner et al., 2005)	Emotion as dynamic and reflexively negotiated in interaction influenced by personal, social, and cultural factors	Dialogical: Linguistics as socially shared practice (Wittgenstein, 1953)
Experience Prototyping (Buchenau and Suri, 2000)	Immediate sensory experience of interaction, contextual factors, and role of interactive system	Phenomenological: Look and feel of interactive systems (Houde and Hill, 1997)
Emotional design (Norman, 2004)	Balance of aesthetic appeal and usability in an interactive system	Cognitive psychology
Experience of meaning in interaction (Mekler and Hornbæk, 2019)	Meaningful experience conceptualized from the components connectedness, purpose, coherence, resonance, and significance	Positive psychology

This thesis is based on an understanding of experience from a pragmatic and dialogical perspective, in line with McCarthy and Wright (2007). By unpacking the ways we experience technology, we can understand how we find meaning in everyday technology use and make sense of interactions. A perspective on the lived and embodied use of DHIs may offer new insights into how the interaction and engagement with DHIs can be meaningful to people.

2.2 Engagement with DHIs

Engagement describes interactions with a DHI. Engagement is a term in DHI research that differs to the treatment of experience in HCI. In contrast to how experience has been described in the past few pages, engagement describes a more direct relationship between the use of an interactive system and a specific goal or outcome. This outcome can be associated with hedonic qualities such as enjoyment, or pragmatic qualities such as the fulfillment of some goal. For DHIs, the goal of engagement is attaining improved health outcomes.

Based in a systematic review of works in the ACM Digital Library that include the word ‘engagement’, Doherty and Doherty (2019) broadly described how engagement with technology is presented as part of a process that leads to certain outcomes in technology use:

> Engagement is frequently adopted not just as an outcome in itself but as conducive to other aims. It is both an end and a means to an end. Engagement is popular in educational research, for example, due to the assumption that greater engagement with a system for e-learning is likely to support improved learning outcomes and, in well-being research, behavioral outcomes. Engagement is seen as contributing to a larger goal, such as well-being, happiness, learning, or task efficacy. This mediating relationship is one of the advantages of engagement over the concept of experience. It supports a reasoned connection to other valued concepts. (p. 27).

With a view of engagement as a mediator to larger goals, engagement is construed as a functional component of technology use, contrasting how experience is commonly understood in HCI.

2.2.1 Psychological and experiential models on engagement

Current debates in the literature discuss engagement with DHIs as: (1) a psychological construct explaining the use of technology and adherence to the treatment program; (2) as a quality of user experience, or; (3) as a combination of the former two models.

In research on DHIs, engagement is closely related to the concept of adherence (Eysenbach, 2005). The adherence to an intervention describes, in plain words, the user’s obedience to the prescribed procedure (Donkin et al., 2011). In this sense, adherence describes the “right” kind of engagement (Sieverink et al., 2017), completing each of the intervention’s modules by reading material, doing exercises, and other intended activities.

Engagement with DHIs is seen as a precondition and a mediator for the effectiveness of interventions (Yardley et al., 2016). Therefore, engagement with DHIs can be seen as an end in itself and has been viewed as a measurable metric of intervention use. The level of adherence to the intervention program, duration of use, frequency, and other usage statistics are measured and aggregated to give a view of a person’s level of engagement with a DHI (Edney et al., 2019; Short et al., 2018). In this psychological conceptualization, engagement is an exclusively behavioral construct that can be modeled and measured from usage data.

In a recent study of engagement with a cognitive behavioral therapy (CBT) for symptoms of depression and anxiety, the engagement was defined from two types: whether a user logged in within a given week, and whether the user opened a specific module in that week (Chien et al., 2020). Engagement types were further classified as patterns by a machine learning algorithm based on median time spent interacting with the DHI. Chien et al. (2020) analysis of interaction data showed that there was a relation between frequency of use and positive health outcomes in their study. A limitation of these usage-based approaches to modeling engagement, however, is that they do not unpack the meaning of interaction and engagement and how it can be meaningful to the people interacting with the DHI, further facilitating positive health outcomes.

A purely behaviorist model of engagement can lead to a “dose-response” assumption of the relation between technology use and improved health outcomes (McVay et al., 2019), similar to pharmacological studies. Thus, the details of what the user experiences while engaged, and how the content facilitates the delivery of a treatment program may be lost to researchers examining the effects of DHIs. A review of engagement’s effect on mental health outcomes (Gan et al., 2021) did demonstrate a “dose-response” relationship in which more DHI use led to more positive health outcomes (Gan et al., 2021; Donkin et al., 2011). This effect, however, has been disputed by other studies that do not find the same relationship between frequency of use and therapeutic outcomes (Donkin et al., 2013; Kelders and Kip, 2019). Engagement with DHIs, however, is a complex concept lacking a clear conceptualization in the literature (Ng et al., 2019; Yeager and Benight, 2018). Accoring to Ng et al. (2019), because engagement is not consistently conceptualized between studies, measurements of the phenomenon vary and cannot be compared in a meaningful way.

In a more detailed conceptualization by Kelders et al. (2020b), people's engagement with DHIs can be viewed as a psychological construct in three components: behavioral, cognitive, and affective. The behavioral component of engagement can be understood as the existence of a routine for DHI use, and the level of use seen in relation to the needs from a therapeutic point of view. The cognitive component denotes motivation and support for reaching relevant goals. The affective component of engagement refers to people's emotional response (or lack of) to their progression in a DHI, and the felt enjoyment of using DHI technology, and even a sense of identity that can occur with the use of a DHI. Furthermore, Kelders et al. (2020b) distinguishes engagement on two levels: engagement with the technology itself and engagement with the intended health behavior promoted by the technology.

Yardley et al. (2016) suggested "effective engagement" as a way of measuring engagement in relation to the intended outcomes of interventions. In their view, engagement can be distinguished into micro- and macro-level when investigating the relationships between experience, use, and behavior change. Micro-level engagement refers to the concrete use of a DHI (e.g., the number of tasks completed) and the experience of it, whereas macro-level engagement refers to the motivation for following an intervention and is linked to high-level behavioral goals.

In the psychological models of engagement, the concept is interpreted on the individual level, missing the larger social dimension of engagement. The socio-cultural context of engagement could involve family members and broader cultural settings, as briefly introduced in Yardley et al. (2016)'s model of effective engagement.

A focus on the facilitation of effective engagement with DHIs may lead to better outcomes for the people that use DHIs to better their health. To understand engagement more broadly, and *how* it is facilitated or obstructed, a more comprehensive approach to the experience of DHI use may be warranted.

In HCI, engagement with interactive technology has been construed as a quality of user experience by O'Brien and Toms (2008):

> Engagement is a quality of user experiences with technology that is characterized by challenge, aesthetic and sensory appeal, feedback, novelty, interactivity, perceived control and time, awareness, motivation, interest, and affect. (p. 941)

In O'Brien and Toms's (2008) definition, engagement is seen as a fluctuating, temporal, and passing phenomenon that describes the experience. This is in contrast to the views in DHI research detailed above, in which engagement is understood primarily as conducive to other means. This conceptualization of engagement can be seen in relation to the concept of *flow* (Csikszentmihalyi, 2009) where one's mental state is fully focused and immersed in the situation at hand, which has been used to describe experiences of sustained engagement with interactive technology (Zhou, 2013).

The underpinnings of O'Brien and Toms's (2008) conceptualization, in which engagement is closer to how *user experience* is understood, are starting to gain ground within the DHI literature. For example, Balaskas et al. (2022) analyzed which factors that affected the user experience of a DHI for anxiety management, based in qualitative analysis of app reviews and interviews with users. Graham et al. (2021) demonstrated that people who experience a DHI as easy to use and satisfying had better outcome measures, leading them to conclude that the subjective experience of DHI design may be a mechanism for change. Furthermore, a recent review of engagement definitions synthesized an integrated definition of this phenomenon (Perski et al., 2017). Perski et al.'s (2017) definition integrates a behavioral view on engagement with subjective experience, characterized by attention, interest, and affect, as a dimension in engagement. In this framework, people's experiences with DHIs are given weight in determining what contributes to or deters engagement.

2.2.2 Comparison of models of engagement

Engagement with DHIs is a multidimensional concept that spans behavioral, cognitive, affective, and experiential dimensions. Table 2.2 provides an overview of the models of engagement discussed in this section of the chapter.

Research of usage and efficacy of DHIs often subscribe to a purely behaviorist model of engagement, in which use is seen as engagement and in turn associated with DHI participants' health outcomes from the intervention. In the models described in Table 2.2, the behaviorist model of engagement is supplemented by other components of psychology such as cognition and affect (Kelders et al., 2012), subjective experience (Yardley et al., 2016; Perski et al., 2017), and design and usability (Short et al., 2015).

Missing from these models of engagement with DHIs that include experience are clear recommendations on how understanding the experience of DHI participants can be used to understand engagement and have implications for design. The models of engagement presented here are primarily interested in measuring the level of engagement and establishing a reasoned connection between use and health outcomes. What these models lack is an interest in the meaning of the engagement with a DHI and how a qualitative understanding of the engagement can help us improve the delivery of DHIs.

Table 2.2: Overview of definitions of engagement

Authors	Short description	Method
Doherty and Doherty (2019)	Engagement with technology describes a mediating relationship, and is seen as conductive to other aims, such as behavioral outcomes	Systematic review of research papers on engagement in the ACM Digital Library
O'Brien and Toms (2008)	Engagement as a quality of user experience described by "challenge, aesthetic and sensory appeal, feedback, novelty, interactivity, perceived control and time, awareness, motivation, interest, and affect" (p. 941)	Semi-structured interviews of users that have engaged in online shopping, Web searching, educational Webcasting, and video games
Yardley et al. (2016)	Engagement on a micro-level (usage and experience) and macro-level (adherence to the intervention program)	Expert consensus of DHI researchers
Kelders et al. (2020b)	Engagement as a psychological construct in three components: behavioral, cognitive, and affective	Systematic scoping review of research papers on engagement with DHIs from medical research databases and ACM Digital Library
Perski et al. (2017)	Engagement as a behavioral construct integrated with 'subjective experience' as a dimension in describing engagement with DHIs	Systematic review using critical interpretive synthesis of medical research databases
Short et al. (2015)	Model of user engagement with DHIs comprising of environmental factors, individual factors, and design characteristics of persuasive design and usability	Literature review of systematic reviews and meta-analyses of engagement with DHIs

The challenges of quantifying engagement are clear, as it encompasses not just the time spent using a DHI, but also the depth and quality of these interactions. A perspective on the quality of engagement means that assessing engagement cannot be boiled down to a collection of metrics. Instead, we need to consider both behavioral and experiential elements. In the next section, the methods, both quantitative and qualitative, used to evaluate the engagement with DHIs are described.

2.2.3 Evaluation of use and engagement with DHIs

Evaluations of DHIs are commonly designed to capture measures of efficacy (Blandford et al., 2018) and are conceptualized by medical language such as “active ingredients” (Dombrowski et al., 2016) and the aforementioned “dose-response” relationship (Donkin et al., 2011). Therefore, evaluations of DHIs assess technology use in terms of how it enhances health behavior change in a long-term process. Such evaluations are decisive in understanding the usefulness and cost-effectiveness of novel DHIs.

To properly analyze the clinical effects of DHIs, randomized controlled trial (RCT) studies are designed to provide evidence of the effects. In the medical literature, RCT is considered the “gold standard” for clinical trials, which emphasizes the reliability of the results of these trials. When assessing the effectiveness of a DHI, the RCT design is used to ascertain whether the interventions will likely improve health outcomes for its intended population. This type of summative evaluation is needed to ensure that the DHI can be safely deployed and effective in helping people. However, the RCT design may not be suitable or optimal in evaluating how a certain DHI facilitates engagement due to the complexity of the engagement process.

The richness of people’s experiences from interacting with DHIs could be argued to be overlooked in how engagement is understood today. DHIs are usually evaluated in large-scale summative assessments after the RCT standard (Inal et al., 2020), in which interaction and health behaviors are represented by quantitative measures. Thus, the design of DHIs and its impact on people’s engagement can be viewed as a “black box” when evaluated, meaning that the processes by which the design influences engagement are not understood.

Since the health benefits of DHIs are often prevented by non-use, exploring how people experience and engage with these technologies can reveal facilitators and barriers to DHI use. One should consider the limitations associated with the RCT design in regard to understanding people’s experience of DHIs. Formative evaluations can be used to understand how the design of a DHI facilitates engagement before doing the final summative evaluation. Focusing on experience in clinical trials can illuminate how design influences engagement with DHIs, demystifying the “black box” of design and engagement.

In interaction design, designers favor formative evaluations for iterative refinement of the design process (Blandford, 2019). Experience-based evaluations (Buchenau and Suri, 2000) can be used to explore how people experience a design, and how it pertains to the experience of meaning. Understanding engagement with DHIs in formative evaluations does not elicit clinical implications but implications for how we design the presentation of DHIs.

Within HCI research, Klasnja et al. (2011) argued that DHI evaluations should be zoomed in on a micro-level of (1) estimating the efficacy of specific behavior change techniques within a DHI, and (2) people's experiences with health technology. For building a "deep understanding" (p. 3069) of people's experiences with technology, Klasnja et al. suggested that "qualitative studies that focus on people's experiences with the technology [can] help researchers understand why and how their system is working" (2011, p. 3063). By better understanding how people experience DHIs, we can design DHIs that are informed by people's needs for DHIs as a form of delivery for health treatments.

To better understand and design for these experiences, researchers have suggested a range of qualitative methods for assessing engagement. In an overview of qualitative approaches to assessing engagement, Short et al. (2018) suggest semistructured interviews, think-aloud and focus groups as methods for assessing people's engagement with a DHI. For example, Jardine et al. (2020) provided a longitudinal, qualitative study of how people experienced a DHI built on CBT principles using open-ended survey data from an RCT. They found that the DHI was experienced as a support in the participants' lifestyles over a longer period of time, rather than a short-term treatment that would restore health. Positive experiences of using DHIs included "feeling supported, validated, reassured, relieved and empowered, and more pragmatic experiences of gaining self-awareness and insight, behavioral change and crucially, seeing an improvement in mood or a reduction in symptoms" (Jardine et al., 2020, p. 3). In designing for engagement it may be important to plan for sustained use over time, in which the intervention can be used to motivate people to attain self-awareness and insight that may better their lives.

An important aspect of enhancing engagement with DHIs is ensuring the interaction's meaningfulness and relevance to the individual. The design of DHIs can impact users' engagement, with the provision and presentation of psychoeducative material being one such example. Learning, through the provision of psychoeducative material, is seen as a cognitive process that leads to an improved understanding of one's mental health condition (Yeager and Benight, 2018). A study by Zhang et al. (2019) focused on DHIs, used a combination of qualitative and quantitative methods to explore which interactions were clinically meaningful toward intended outcomes related to depression and anxiety. Three clusters of user interaction were identified and associated with reductions in depression symptoms: learning, goal setting, and self-tracking. In the interactions that contributed toward learning, viewing and listening to psychoeducative content were identified (Zhang et al., 2019). Although learning in itself may not directly produce health outcomes, it is understood as a mediator to improvements in health from subsequent mechanisms of action (Yeager and Benight, 2018). Therefore, the design and inclusion of meaningful, relevant psychoeducative material in a DHI can enhance user engagement, thereby potentially improving health outcomes.

2.3 Designing for engagement

The way an intervention is designed can be key in facilitating engagement. On the other hand, design elements may also constitute barriers to engagement. Borghouts et al. (2021) presented a review of barriers to and facilitators for user engagement with DHIs for mental health care, and found that the support system for an intervention and the design of intervention content was important for facilitating engagement:

> Engagement with [DHIs] was facilitated if participants liked the type of content; they perceived a [DHI] to be a good fit for them and perceived it to be useful; there was a level of guidance on how to use it, it facilitated social connectedness, and it had a positive impact, such as improvement of symptoms. (Borghouts et al., 2021, p. 14).

Content in DHIs is thus important to facilitate engagement. In designing content for improving engagement with web-based DHIs, Doherty et al. (2012) suggested a strategy of providing a personal experience, tailoring content to users' needs, and providing them with a sense of control over how they progress through the intervention.

In examining barriers to engagement, Borghouts et al. (2021) named three factors as the key causes of disengagement: poor usability (Torous et al., 2018), a lack of motivation to persist with self-guided intervention (Wilhelmsen et al., 2013; Baumeister et al., 2014), and the perceived relevance of the information provided within the DHI (Feng and Campbell, 2011).

In the following, I present these three factors and the opportunities they present for further research on DHIs.

Usability DHIs are accessed through consumer products such as smartphones and PCs, and their use qualities are therefore reliant on the user interface that delivers the intervention. Torous et al. (2018) found that DHI interfaces can be difficult to use and have faults in the design. Similarly, Borghouts et al. (2021) found that technical issues and usability issues were major barriers to engagement with DHIs. Examples of usability issues include "difficulty [in] finding information in an intervention, a time-consuming process to log in to an intervention, and difficulty navigating within an intervention" (Borghouts et al., 2021, p. 12).

Motivation Social interaction with supporters has been found to be the primary contributor to sustained engagement with DHIs (Chikersal et al., 2020). An obvious solution to the challenges of motivation in self-guided interventions is to rather develop interventions guided by therapists. However, developing a DHI as a guided intervention is not always feasible. Support from clinicians or coaches demands labor and resources, which can be hard to acquire for people or groups with limited access to health care services (May et al., 2009).

The lack of guidance from a supporter in using the intervention (e.g., to regularly access and use the intervention through an app or website) is a barrier to engagement with DHIs (Borghouts et al., 2021). Reminders sent by text messages and e-mails have been used to mitigate this issue. In unguided or self-guided interventions, special attention is thus required to design for the experience of use due to the absence of a relationship between client and supporter (e.g., a therapist-patient relationship).

Relevance and credibility It has long been recognized that the perspective of the target groups of DHIs when designing intervention content is key in ensuring that the intervention is seen as relevant and consistent with their values (Eysenbach, 2005). According to Short et al. (2015), when there is a match between the intervention content and the user's demographic, psychosocial, and behavioral characteristics, the content may be perceived as personally relevant to the user and thus motivate the user to engage with the intervention. Therefore, intervention designers should generate content that is relevant to people that share characteristics such as illness, demographics, and values, rather than a one-size-fits-all approach (Borghouts et al., 2021). Factors facilitating engagement include seeing examples of other people that have similar experiences to the user, and whether the intervention made efforts to normalize experiences of illness (*ibid*). Perhaps unsurprisingly, high satisfaction with content, and the type of content, increase engagement with DHIs (*ibid*).

In summary, an important factor in successful DHIs regards whether the intervention content is seen as relevant and credible to the people who use them (Borghouts et al., 2021). Short et al. (2015) point to DHI development approaches as being too reliant on the theory and behavioral change techniques, and thus failing to incorporate content that can inspire and motivate people to use the DHI.

There has been a call for more attention to the design of content that fits with the characteristics of intended users. The PBA by Yardley et al. (2015) was designed to be such an approach, taking an aim to “ground the development of behavior change interventions in a profound understanding of the perspective and psychosocial context of the people who will use them, gained through iterative in-depth qualitative research” (Yardley et al., 2015, p. 2). However, in generating the content, it is up to the intervention developer through rigorous qualitative inquiry to determine its form and function.

Blandford et al. (2018) discuss a set of contrasts in practice between the research communities of HCI and health sciences. In the health sciences, expert knowledge is valued and prioritized, with their efforts focused on identifying behavior change mechanisms – hence, design requirements are identified by health experts, as is the case with PBA. Conversely, HCI-informed processes for designing interactive systems are, virtually by default, motivated by an “implicit assumption that the user is the expert in what they do and what they need” (Blandford et al., 2016, p. 7).

In improving the designs of DHIs to meet the challenges of disengagement, there are lessons to be learned from the developments of methods and theory in HCI to increase the relevance of content, enhance people’s motivation with DHIs, improve usability, and design for richer experiences.

2.4 Design and user involvement in HCI

The HCI research community holds a long history of studying the design of interactive systems from the user’s perspective. In this section, I give a background to how design and user involvement is treated in HCI research. I end the section by presenting three approaches to human-centered design.

2.4.1 Historical context

HCI emerged as a cognitive science in the early 1980’s studying the human factors engineering of computing (Card et al., 1983; Bannon, 1991; Bødker, 2015). Early developments of HCI were concerned with developing models of interaction for which human use of interactive systems could be accurately predicted (Newell and Card, 1985).

As computer technology became more present in the workplace, there was a need for knowledge of how computers can support work practices. In a critique of the first generation's focus on cognitive aspects of interaction, Bannon (1989) argued for a shift "from human factors to human actors," in what has since been coined *the second wave* of HCI research (Bødker, 2006).

To Bannon (1991), a focus on actors that collaborate with the use of interactive technology constituted a move away from the laboratory where one would study users in controlled environments: "Understanding people as actors in situations, with a set of skills and shared practices based on work experience with others, requires us to seek new ways of understanding the relationship between people, technology, work requirements and organizational constraints in work settings" (p. 25). These notions signified a conceptual expansion of HCI from the task-oriented cognitive paradigm. This made way for the incorporation of social science research in the study of interaction. A few years prior to Bannon's musings on the human as the central element in HCI, Suchman (1987) called for a situated view of HCI, incorporating how interaction is dependant on the setting in which it occurs.

The move towards a socially situated view of interaction lay the foundation for a pragmatic view of HCI. With a focus on people's practices in HCI research, the importance of design in HCI was highlighted. This focus on design entailed seeing interaction design knowledge as acquired by practice and example, thus as experiential knowledge, not always explicit or formal (Rogers, 2012). According to Carroll (1997), HCI was then transformed from "merely applied psychology" (p. 62), towards a design-oriented field of research.

2.4.2 HCI as a design-oriented field of research

HCI research does not conform to one single approach, one field of research, or a family of methods. In fact, there are a plethora of fields and methods associated with HCI. The fields associated with HCI are informed by the theoretical perspectives of the social sciences, cognitive science, psychology, philosophy, and many more. However, if we look closely at the types of contributions made by the research community, HCI has emerged as a distinct *design-oriented* field of research (Fallman, 2003) over the past four decades.

In HCI research, we explore how people interact with and through the means of computing technology, often by designing research prototypes to imagine new ways of interacting. Fallman (2003) sought to conceptualize the role of design in HCI to differentiate our field from the established social and natural sciences in how we understand “design”:

> In design-oriented research, the knowledge that comes from studying the designed artifact in use or from the process of bringing the product into being is the contribution, while the resulting artifact is considered more a means than an end. (Fallman, 2003, p. 231)

Fallman (2003) drew out two types of contributions that can be made in design-oriented research: empirical studies of interactive artifacts, and studies of how we design interactive artifacts. Wobbrock and Kientz (2016) identified empirical contributions and artifact contributions as the most common papers accepted for publication in the CHI[1] conference proceedings. In Wobbrock and Kientz (2016) view, “knowledge is embedded in and manifested by artifacts and the supporting materials that describe them” (p. 40), and is thus focused on the new possibilities for interaction afforded by the artifact. Appraising design-oriented artifact contributions as scientific knowledge, however, could require criteria for assessing rigor and accountability. Partly in response to stated needs for quality criteria for design-oriented HCI research, *research through design* (Zimmerman et al., 2007) was developed as a method for conducting interaction design as an integral part of research. Notably, Gaver (2012) disagreed that design-oriented knowledge needed rigor and accountability, and argued that such criteria could hamper the creativity of research through design.

HCI has been criticized for a lack of a unifying and coherent theory (Oulasvirta and Hornbæk, 2016) and a lack of “motor themes” (Kostakos, 2015). Building on *problem-solving capacity* (see Laudan, 1978), Oulasvirta and Hornbæk (2016) suggested using performative measures of efficiency and effectiveness to evaluate research. More broadly than Fallman (2003), they conceptualized all of HCI research as problem-solving, with its contributions being formulations of solutions to said problems:

> A research problem in HCI is a stated lack of understanding about some phenomenon in human use of computing, or stated inability to con-

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[1] CHI (pronounced ’kai’) is short for Conference on Human Factors in Computing Systems, the flagship conference of ACM’s SIGCHI (Association for Computing Machinery’s Special Interest Group on Computer–Human Interaction).

> struct interactive technology to address that phenomenon for desired ends. (Oulasvirta and Hornbæk, 2016, p. 4960)

In Oulasvirta and Hornbæk's (2016) view, HCI research is oriented towards "solving problems related to the human use of technology" (p. 4695). This concept of HCI research can be a helpful aid in thinking about which phenomena related to computing are "worthy" of research in terms of significance and effectiveness. Furthermore, it is a concept that fits well with a pragmatic view of design-oriented research. However, such a solutionist view on HCI, reducing scientific inquiry to formulating problems and their solutions, can be problematic. Computing technology has long since entered our everyday lives through mobile devices and embedded in our homes through voice assistants, robot vacuum cleaners, and the like. As such, technology has become entangled with our social lives and personal identities, and as a result more challenging to disentangle from each other (Frauenberger, 2020). If the problem-solving capacity of HCI research is the merit on which we judge its quality, we may fail to see what problems we ought to be "solving" or those who are negatively affected by our "solutions." HCI research may just as well be about conceptualizing problems as it may be about solving them.

2.4.3 Human-centered approaches to design

Concurrently with the shifts in the thinking about theory in HCI, human-centered approaches to designing interactive systems emerged. In the following, three approaches to human-centered design are considered. First, I will provide some background with Norman and Draper's (1986) user-centered system design, from which user-centered design (UCD) evolved. Secondly, PD is presented as a design approach that directly includes future users in decision-making. And lastly, experience-centered design (Wright and McCarthy, 2010) was introduced as a humanistic approach to designing for meaningful experiences.

User-centered design (UCD) is an approach to designing interactive systems that put emphasis on understanding users' goals and from there modeling the technical requirements necessary to fulfill user needs (Norman and Draper, 1986). As the user requirements of a UCD process become clear, the iterative process of design, evaluation, and redesign begins. Central to the approach is the fulfillment of usability goals, which can be summarized as objective criteria that the task performance of users is measured against.

A wide array of methods facilitate the UCD process. Task analysis involves users completing prescribed tasks in controlled environments, where a usability engineer records actions and performance to understand how a specific interaction workflow can be improved (Diaper and Stanton, 2003). Heuristic evaluation is performed by experts who judge the quality of interactive systems against usability principles (Nielsen and Molich, 1990). In think-aloud evaluations, the user is tasked to perform "self-talk" while using the interactive system, whereas the usability engineer records the actions that are taken, and the comments the user makes (Boren and Ramey, 2000).

Participatory design (PD) is an approach to designing interactive systems that involve a strong commitment to future users (Greenbaum and Kyng, 1991; Muller, 2002; Schuler and Namioka, 1993; Ehn, 2008; Robertson and Wagner, 2012). Similar to other approaches to design, such as user-centered design (Norman and Draper, 1986) and contextual design (Beyer and Holtzblatt, 1999), PD tries to anticipate use before use (Redström, 2008; Bratteteig, 2021). What is special to PD, however, is its commitment to people as participants in co-design activities at all stages of development (Bratteteig and Wagner, 2012).

Central to participatory design's theoretical foundation is the belief that people are experts in their own everyday life and practices, be it work, leisure, or other spheres in which a person ventures. Participatory design seeks to make the knowledge that people possess explicit and accessible for a design purpose. Ehn (2008) views the motivations for using participatory design methods from two distinct values:

> One is the social and rational idea of democracy as a value that leads to considerations of conditions for proper and legitimate user participation. The other value might be described as the importance of making the participants['] "tacit knowledge" come into play in the design process, not only their formal and explicit competence. (Ehn, 2008, p. 94)

The first value refers to the democratic principle that people have a right to influence their own future. The early developments of PD are rooted in Scandinavian labor movements' political struggles of maintaining power in the introduction of technological advancements such as automation machinery for iron workers (Nygård and Terje Bergo, 1975) and later evolved to encompass personal computing technology such as the application of artificial intelligence in newspaper editing[2] (Bødker, 1987; Ehn, 1988). In

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[2] See the American documentary film *Computers in Context* for a historical document of participatory design practices in the Norwegian Bankworkers Union, The UTOPIA project at Swedish newspaper Expressen, and Scandinavian Airlines: https://archive.org/details/computers_in_context

these developments, PD was used to give workers a stake in designing their future work applications. In the UTOPIA project, focused on tools for graphic workers in the Scandinavian newspaper industry (Bødker, 1987; Ehn, 1988; Sundblad, 2011), PD enhanced the design results by emphasizing the workers' skills in design processes.

Direct participation of workers in design activities gave way to what Ehn (2008) described as making tacit knowledge "come into play in the design process", which is the second value in the above quote. With this perspective on PD, mutual learning is achieved between design researchers and participants in the design process, allowing designs that reflect the skills and practices of people. Mutual learning means that the design researchers learn from the participants and *vice versa*.

The two values presented by Ehn can be seen in relation to Frauenberger et al. (2015) who "see a wide spectrum of philosophies driving PD processes, possibly best described as ranging from pragmatic to idealistic" (2015, p. 93). Comparing the two, Ehn's value of democracy can be seen as idealistic, whereas the value concerning mutual learning of tacit knowledge aligns with a pragmatic philosophy. Ehn (1988) developed PD as a pragmatic method, using Wittgenstein's philosophy of language games as a concept for describing how stakeholders use design as a boundary object for navigating the design space. Bratteteig and Wagner (2016a) further see design in PD as pragmatic, using Schön's (1983) notion of "design move" to describe how designers work: "a 'move experiment' (or 'design move') includes the designer's evaluation of a situation, a move to change it, and an evaluation of the move" (Bratteteig and Wagner, 2016a, p. 433-434). In this view, participatory design is seen in line with Schön's concept of reflective practice, in which design moves are reflection-in-action – actions that are both a result of, and subject to, continuous reflection and refinement in the relation between a designer and the world.

Central to participatory design activities is the workshop (Muller, 2002). In a workshop, different stakeholders (e.g., patients, doctors, project managers, software developers, and interaction designers) come together to communicate and commit to shared goals. Moreover, workshops are often used to collaborate on constructive efforts in imagining future designs. To Muller (2002), the PD workshop constitutes a hybrid "third space" converging two spaces: the world of technology designers and the world of end-users. In *future workshops*, stakeholders strive to achieve future designs by critiquing the present, envisioning the future, and implementing the future (Kensing and Madsen, 1992). In implementing the future, design methods are used, such as idea generation activities and low-fidelity prototyping (Houde and Hill, 1997). Commonly, one person leads the workshop in the role as a facilitator.

Provided participatory design's roots in Scandinavian labor movements, it is not surprising to find examples of participatory design within health care services in the Scandinavian welfare states. Dahl and Svanæs (2020) explored how the facilitator role in participatory design activities in healthcare contexts plays an important role in balancing different stakeholders' power in decision-making. According to Dahl and Svanæs (2020), the work of a facilitator is highly delicate: different stakeholders' actions influence who has a say in subtle and often unforeseen ways. In health care, the asymmetrical power relations between different roles are well known (e.g., between the roles of patients, doctors, and nurses). Dahl and Svanæs (2020) suggested the facilitator role as a reflective practice that attempts to balance out different perspectives in future workshops of PD. With a view to Muller's (2002) notion of a third space, a PD workshop in the health care domain is a political struggle in which the facilitator plays a role of balancing the different worlds (that of the clinicians and that of the patients) attempt at colonizing the other.

Experience-centered design aligns with a humanist agenda for the design of technology (Wright and McCarthy, 2010). In this holistic approach to design, the whole person behind the user is valued, seeing the person as a concerned agent.

This approach to design works from McCarthy and Wright's (2007) framework of *technology as experience*. In emphasizing interactive technology as lived and embodied, experience-centered design seeks to highlight that experience is co-created between the user and designer. At the core of this approach lies a commitment to building empathic relationships and understanding to the people one designs for and collaborates with (Wright and McCarthy, 2008).

Storytelling and narrative are central to the foundation of experience-centered design. The stories we tell about our lives and experiences are embedded with meanings and values, providing an externalization of the experience. In order to understand experience, then, a dialogical perspective on sense-making can be suitable to unpack people's experiences through stories. Wright and McCarthy (2010) see ethnography, interviews, focus groups, role-play, and probes, among others, as suitable methods for constructing stories that people tell of their experiences with technology. All of these methods are dialogical, providing a more discursive approach than the analytical detachment of UCD methods; dialogue is reliant on involvement that goes beyond the passivity of "capturing" research data.

In relation to the emphasis on constructing stories to unpack experience, Balaam et al. (2019) argued for the use of existing narrative accounts when these are available to designers. Doing dialogical qualitative research in sensitive settings, such as health care, can become emotional work which participants and designers/researchers may be ill-prepared or not equipped to deal with.

With experience-centered design, there is an emphasis on the moral and ethical effects of design, as the approach “can and should attempt to impact people’s lived experience in ways that are socially, politically, and personally meaningful” (2010, p. 9). As such, this approach can be seen as a furthering of the humanist agenda of UCD to emphasize the user and as a reinforcement of the political and social agenda of PD, but moving the primary focus of design from the collective towards the individual, experiential, and emotional.

Having introduced three approaches to human-centered design, we could think of them as existing on a continuum between usability and experience in terms of the extent to which these methods embody these two concepts. On the usability side, we find user-centered design with its emphasis on tasks and efficiency, although it should be noted that it too touches upon *context* which connotes to experience. Somewhere in-between the two, we find participatory design which methods situate the design work within the practices and knowledge held by the participants. Then, placed at the experience end of the continuum, is experience-centered design, a humanistic vision of design that seeks to enhance people’s experience of meaning and sense-making with technology.

The design of DHIs comes from a somewhat different angle, where HCI approaches to design are appropriated to align with the needs and values of medical sciences.

2.5 Design and development of DHIs

The design and development of DHIs are often carried out in multidisciplinary teams represented by health clinicians and researchers, computer science specialists and researchers, and sometimes representatives of the target population. To guide this work, a variety of approaches have been made to steer the development of complex interventions. DHIs touch upon multiple theories and models of behavior change, involve interactive systems to mediate the intervention, and present content to users to aid them in enhancing their health.

In this section of the chapter, I present approaches to the development of DHIs and in particular how they involve users in the process. A further interest to this thesis is how the approaches relate to methods of HCI.

2.5.1 Systematic approaches to developing interventions

O'Cathain et al. (2019b) provide a systematic methods overview of existing approaches to developing complex interventions. In essence, approaches can be theory-based and evidence-based (e.g., the Medical Research Council guidance on developing complex interventions (Craig et al., 2008)), target population-centered (e.g., the person-based approach (PBA) (Yardley et al., 2015)), implementation-based (i.e., with a focus on how an intervention can be designed to sustain and fit with the existing regime of health institutions (Mohr et al., 2017)), or made in partnership with future users of the interventions (O'Cathain et al., 2019b).

In the following, I present two approaches (Table 2.3) to developing DHIs: The PBA (Yardley et al., 2015) and the Accelerated Creation-to-Sustainment (ACTS) model (Mohr et al., 2017). There are many other development approaches for DHIs out there. It is not, however, within the scope of this thesis to document development approaches. These two approaches provide a diverse view of state-of-the-art development approaches in the DHI literature. Here, I provide a description of each approach, with special attention to characteristics of the approach that relates to design process, user involvement, and how experience is treated.

Table 2.3: Development approaches to DHI

Approach	Focus
Person-based approach (Yardley et al., 2015)	Systematic and rigorous qualitative research of an intervention's target population's needs and perspective, combined with theory-based and evidence-based approaches to intervention development
Accelerated Creation-to-Sustainment model (Mohr et al., 2017)	Design and implementation approach to digital mental health interventions that integrates HCI methods and intervention science, viewing DHIs as sociotechnical systems that necessitates a contextual and situated perspective on design and implementation

Person-based approach The PBA is motivated by a commitment to ground "the development of behavior change interventions in a profound understanding of the perspective and psychosocial context of the people who will use them, gained through iterative in-depth qualitative research" (Yardley et al., 2015, p. 2). Grounding the development in the users' perspectives are seen as decisive in ensuring the acceptability of DHIs, which is necessary for the intervention to be used in everyday life. The approach is presented as compatible with HCI approaches to design, with an emphasis on UCD. The PBA consists of four stages: "planning, design, development, and evaluation of acceptability and feasibility, and implementation and trialing" (Yardley et al., 2015).

In the planning stage, key behavioral issues, needs, and challenges are identified to establish the intervention. A qualitative synthesis of previous studies that detail similar interventions and qualitative research to elicit user views guide this phase. These activities are balanced with the modeling of intervention mapping based on theory and evidence. In the design phase, *guiding principles* are created to summarize features of the intervention that are seen as central to the success of intervention objectives. Here, the creation of personas, scenarios, and use cases associated with user-centered design can be done to exemplify the guiding principles in a wider context. In the development and evaluation phase, components of the intervention are evaluated and refined. Here, qualitative research is again undertaken to "elicit, observe and analyze user reactions to every intervention element (e.g., using think-aloud techniques), iteratively modifying [the] intervention to optimize from [the] user's perspective" (Yardley et al., 2015, p. 3). Finally, the DHI is moved into implementation and trial where the intervention is evaluated in a real-world context.

Yardley et al. (2015) stress the importance of making design choices from rigorous use of qualitative methods, claiming that "qualitative research or expert and user consultation [...] is often somewhat ad hoc, piecemeal, and not well articulated" (Yardley et al., 2015, p. 4). It is, however, unclear what qualifies as a high-quality use of qualitative methods in the PBA. Regarding the qualitative inquiry, the PBA suggests open-ended questions that allow participants flexibility in how they answer, and select participants from purposive sampling that targets a diverse set of participants representing different characteristics such as gender, cultural background, and experiences. By this, the PBA puts an emphasis on understanding user representatives' perspectives in the development of DHIs. Even though the PBA asserts rigorous qualitative research to ground design choices in reliable data, it is unclear how such choices are then grounded in the qualitative inquiry. The authors claim that design choices in the PBA are elicited through "systematic means of addressing the user experience of intended behavior change techniques” (Yardley et al., 2015, p. 1). A description of how design choices in PBA are made, then, remains an under-explored area of PBA practice.

In summary, the PBA is founded upon a commitment to user involvement for improving DHIs acceptability, by addressing user needs through qualitative research. In involving users’ perspectives, the intervention developer using PBA makes design choices based on a qualitative inquiry into their needs and perspectives.

Accelerated Creation-to-Sustainment model The ACTS model is a design and implementation framework specialized for mental health intervention that integrates methods from HCI and implementation science (Mohr et al., 2017). A central premise for the model is the belief that digital interventions require some human support to obtain and sustain benefits. Thus, DHIs are sociotechnical systems that must be designed in the context of the settings where they are to be deployed. Although this can be seen as limiting the ACTS model in scope to guided DHIs involving social support, the model is nevertheless interesting for its integration of HCI design methods.

In the ACTS model, design and evaluation are two iterative functions that are applied to the phases *create*, *optimization*, and *sustainment*. In the create phase, user-centered design, or related approaches to systems design such as participatory design and contextual design, are used in “recogni[tion] that the success and adoption of technology depend on people’s experiences and the ecosystem’s support of that technology” (Mohr et al., 2017, p. 6). As such, this framework employs a pragmatic design approach in which the process is adapted to users’ needs and their contexts. The goal of the create phase is to arrive at a set of technologies that are functionally reliable.

In the second phase, optimization, the intervention (and associated implementation strategies) are evaluated with regards to clinical goals (Mohr et al., 2017). Here, the create phase is extended by continuously redesigning as iterative evaluations are undertaken. A central part of optimization is to evaluate for effectiveness to provide evidence that the intended outcomes are achieved. A central goal of this phase is to support ongoing learning by adapting and improving the design while evaluation trials are ongoing.

In the third phase, sustainment, the research support of the intervention is detached. In this phase, the intervention should be sustained by a health care system that can offer the intervention to people in need and continuously improve the intervention based on its results (Mohr et al., 2017).

2.5.2 User involvement in intervention design and development

User involvement in designing interventions is expected to improve quality and can be used to identify priorities, and build an understanding of the intervention from a unique position (O'Cathain et al., 2019b).

User involvement in the design and development of DHIs can take many forms. Consultation with users can be done as a one-off meeting, or several meetings, where they are invited to share their experiences, voice their opinions or provide feedback to intervention designers. Alternatively, a more hands-on approach can be taken where the users are given a role as co-designers in the process of designing interventions.

According to O'Cathain et al., user involvement in the development of complex interventions "can help to identify priorities, understand the problem and help find solutions that may make a difference to future implementation in the real world" (2019a, p.5). Since DHIs are provided through interactive technology, one could, from an HCI perspective, expect that user involvement can make even more of a difference in the resulting intervention, given that the DHIs are often used in everyday contexts (e.g., in the home, while commuting, etc.). In this section, I discuss how user involvement is integrated in the PBA and the ACTS model.

User involvement in PBA has been described earlier as central to the approach, enacted through rigorous qualitative research. In this approach, design choices are made at the discretion of the intervention designer after some kind of synthesis of qualitative research or original qualitative inquiry. Regarding the active involvement of user representatives as co-designers, the PBA takes a firm position in opposition to such activities:

> It is important to note that this process is different from co-design with members of the target population. Sometimes developers seek the opinions of users concerning what elements and characteristics they believe the intervention should include. A potential problem with this approach is that it encourages users to try to anticipate the needs of others, which they are unlikely to do well, rather than simply reporting their own experience and views, which they do very well. We find that users are naturally expert at telling us what they like or dislike about our intervention, but most users are understandably less able to generate effective behavior change techniques or good design solutions. (Yardley et al., 2015, p. 7)

The argument from Yardley et al. (2015) is essentially that users should not be asked to anticipate others' needs, only intervention developers should. The user involvement in PBA is thus reduced to an inquiry into users' experiences and evaluative remarks of the intervention, not lending them agency in the design of the intervention. This notion that users cannot participate directly in the design and development of interventions can be seen in relation to the above quote on page 30 where user consultation in previous works of DHIs is described as "ad hoc, piecemeal, and not well articulated." In the PBA, a systematic and rigorous process is emphasized over pragmatic approaches to design.

In a more recent publication, the PBA is extended with the inclusion of citizens in design (Muller et al., 2019), contrary to the quote above. In this work, Patient and Public Involvement (PPI) is described as research "being carried out *with* or *by* members of the public rather than *to*, *about*, or *for* them" and that contributors may be "patients, members of the public, carers, people who use health and social care services, or members of organisations representing service users" (Muller et al., 2019, p. 2). Here, co-design is described as a valuable contribution to intervention design with the proper facilitation: "There may be a risk that this approach to developing complex interventions can lead to an over-reliance on 'PPI preference' as justification for including aspects of an intervention, rather than including theory and evidence to inform intervention development in addition to PPI" (Muller et al., 2019, p. 3). Finding the balance between co-design and sound theory is emphasized, but at the same time the authors acknowledge that the involvement of users can help set the agenda in the design process. As such, including users directly in the PBA necessitates a careful balancing between the preferences of users, on the one hand, and the theory and evidence that informs the therapeutic rationale of the intervention, on the other hand.

The ACTS model is in particular motivated by a stated lack of bottom-up design processes for developing interventions (Mohr et al., 2017). Here, co-design is promoted as a way for deepening the understanding of useful design elements in the intervention:

> [C]o-design workshops bring together the researchers and stakeholders to help representative end-users begin designing their own solutions that address their needs. [...] The role of the researcher is to help participants translate these solutions into effective design constructs (Spinuzzi, 2005). At the core of the co-design concept is the idea that stakeholders themselves are best positioned to articulate these solutions. (Mohr et al., 2017, p. 6)

As such, the ACTS model is based upon theories and methods in HCI that promotes a situated understanding of the context one is designing for, and the benefit of incorporating co-design methods to learn from the users' perspective.

The two approaches take different positions on the importance of and how user involvement is performed. In PBA, the perspective and needs of the target population are central to ensuring the acceptability of interventions and include users through rigorous qualitative inquiry to reflect their values and experiences in design. The ACTS model takes a pragmatic and contextually situated position on how to design DHIs with the aid of user involvement. In this approach, the users are seen as "best positioned" to identify and articulate design choices.

2.5.3 Designing for mental health and well-being in HCI

A body of work in HCI research over the past two decades concerns the broader topics of designing for well-being and mental health in HCI. Most research has focused on mental health and well-being on an individual level, while some have called for efforts to improve health on a community level (Stowell et al., 2018; Lattie et al., 2020). Stawarz et al. (2015) saw mobile technology as an opportunity to support habit formation in behavior change interventions. In grounding HCI research on behavior change in theory, Hekler et al. (2013) argued for taking behavioral science into account in HCI research. Nunes et al. (2015) focused on patients' everyday life experiences when designing self-care technologies.

For designing mental health care technologies, Doherty et al. (2010) presented a set of guidelines for the design process, design element factors, and evaluation. For the design process, Doherty et al. (2010) recommended using PD method *future workshops* and the overall adoption of the UCD process of iterative design to a mental health care context. Further, the use of role-play as a design method was emphasized as a way of collectively engaging in designing technology and was particularly emphasized because therapists in the mental health care setting are often used to this way of working from their practices.

In a review of HCI research on affective disorders (e.g., depression, anxiety, bipolar disorder), Sanches et al. (2019) argued that there is potential for HCI research to innovate technology that supports new therapeutic methods. In generating new ways of intervening in people's mental health, Sanches et al. (2019) argued for new design methods that strengthened researchers' empathy with vulnerable groups and stressed the importance of safeguarding technological innovations from being appropriated into harmful use.

Regardless of the seemingly great possibilities for innovation within mental health care, the road from a working research prototype to implementation in a health care context is not straightforward. For example, implementing new technology in a complex work context can provide new pragmatic difficulties in handling everyday work-life challenges with the add-on of technical difficulties (Thieme et al., 2016). Therefore, a broader framework to guide the implementation of technology, such as the ACTS model (Mohr et al., 2017), may be warranted when evaluating an HCI research prototype in-the-wild.

Concerns for ethical measures in designing mental health care contexts have been raised in HCI research, for example, in how everyday wisdom (*phronesis*) can supplement clinical knowledge and technical know-how in design processes (Barry et al., 2017). When designing technology in a mental health care context, Barry et al. (2017) recommended a diversity in the people that provide feedback on designs to include diverse perspectives on well-being, including those of the project researchers, clinical staff, mental health researchers, and those with the lived experience of mental health problems. Furthermore, adopting a pluralist approach to ethics can help recognize shared universal values yet acknowledge the cultural differences embedded in participants' value systems. In particular, disciplinary differences between different strands of research (e.g., HCI, medical practice, psychology) have implications for those whose values are embedded in the design and need careful consideration in design to balance different stakeholders' perspectives (Barry et al., 2017).

The design of technology to support mental health in HCI has concerned a wide array of diagnoses, from common mental health issues, such as depression, anxiety, and psychological well-being, and designs for severe mental illnesses, such as psychosis intervention, self-harm, bipolar disorder. In an alternative take on designing for mental well-being, Feuston and Piper (2019) challenged the allegedly shared notion in the HCI research community of aligning mental illness with deviance from societal norms. Instead, it is argued that people who share their experiences of mental illness on social media do so by contextualizing their experiences as everyday stories, thus emphasizing how their illness is salient within everyday life. This practice of sharing illness as an integrated part of everyday life contrasts what could be argued as solutionist perspectives from a neurotypical viewpoint in much of HCI research (Spiel et al., 2022). In Feuston and Piper's (2019) view, technological solutions to mental illness often fail to contextualize illness and therefore sensationalize components of illness from the holistic experience.

Scholars of Critical Disability Studies have raised concern with how people with disabilities and mental health issues have been treated and given agency in HCI research (Dalton, 2013; Frauenberger, 2015; Ymous et al., 2020). A critical review of HCI and computing research has examined how technology research privileges neuro-normative health outcomes (Spiel et al., 2022). The review argued that technology is designed to mitigate the experience of ADHD because it disturbs neurotypical standards of behavior and that participants with ADHD are rarely consulted in the design processes (Spiel et al., 2022). In a review of autistic children's agency in technology research, Spiel et al. (2019) found that efforts in designing technology to support autistic children rarely align with the children's stated needs, desires, and interests. Instead, technology in this realm is intended to correct behavior, failing to include the children in defining the technology's goals on their own terms (Spiel et al., 2019).

2.5.4 Participation in mental health care research in HCI

Involving participants with a relevant background and experience is central to human-centered approaches to design. For example, participants that have the lived experience of mental illness and an interest in participating in designing technology can provide value to include otherwise hard-to-reach perspectives.

However, in mental health care and well-being research, access to participants can be limited in an HCI context (Matthews and Doherty, 2009). Furthermore, the inclusion of participants that experience distress has been argued to be ethically problematic (Doherty et al., 2010).

Including "peer users" that match the designated target group in age, social background, and interests may help align designs with the target group's psychosocial factors (Doherty et al., 2010).

Formerly receivers of psychological treatments or that otherwise have a relevant lived experience of what is being designed for can be used as experts by experience in design processes for mental health care technologies (Honary et al., 2018). These participants can be given the role of co-designers in a design process or evaluators in a panel of experts.

Lastly, clinicians can act as "proxies" to the target group by representing and communicating their interests as they see them from their clinical experience and knowledge (Doherty et al., 2010).

2.6 Concluding remarks

For this thesis, I have worked from an HCI-centric perspective on experience grounded in the pragmatic view of McCarthy and Wright (2007). By this, I have given attention to how users experience DHIs in their everyday lives. My attention has thus not been towards efficacy – the degree to which a DHI enhances a person's health. The effectiveness of DHIs is indeed important to investigate. However, I have chosen to explore the design of DHIs and how people make sense of these designs. In particular, this thesis explores how participatory design can be used to ensure user involvement in all design stages and to explore the qualities this approach contributes to DHIs.

Chapter 3.
Methods

This thesis summarizes three HCI research studies that share a common approach to design and design research, qualitative research, and theoretical assumptions about experience. In this chapter of the thesis, I present the overall research approach and the methods used to explore the thesis research questions.

The following studies were conducted to explore the thesis research questions:

1. Participatory design of VR scenarios for exposure therapy
2. Design of audiovisual narratives for supporting reflections on cancer survival
3. Participatory design of video vignettes for an online intervention for supporting adults with ADHD

In each of these studies, prototypes were built and evaluated. Through the design and evaluation of the prototypes, these studies contribute knowledge of how we can involve users in the design of DHIs, what their involvement contributed in terms of qualities, and how the practice of designing interactive systems can be situated in the processes of developing DHIs.

3.1 Research approach

I align this thesis with the pragmatic perspective on design-oriented research as put forward by Fallman (2003). The research presented in this thesis has combined the methods of design research, participatory design, and qualitative research. In this section, I will present how these methods were used to construct knowledge. Beginning with design research, I give a background to how design research has been conceptualized as “research through design” in HCI, and the significance this method holds in the following work. Following design research, I describe how participatory design has been conceptualized and implemented in this research. Finally, I describe qualitative empirical research, and how qualitative methods are used to understand participants' experiences in this thesis.

3.1.1 Research through design

Related to the notion of a distinct methodology of design-oriented research, there is a body of methodological papers dedicated to defining the epistemology of design research, or perhaps more accessibly formulated as *designerly ways of knowing* (Cross, 1982).

Frayling (1993) challenged the assumption that art and design cannot be considered research, arguing that the roles of researcher and designer are often similar and sometimes indistinguishable. In an attempt to capture how designers can contribute to research, Frayling defined "research *through* design" as the practice of "for example, customising a piece of technology to do something no one had considered before, and communicating the results" (Frayling, 1993, p. 5). In HCI, the use of interaction design as a method for generating novel interactive artifacts that embed scientific knowledge has been conceptualized as research through design (RtD) (Zimmerman et al., 2007). In this section, I will give an overview of RtD and how the research in this thesis has used concepts of this method.

Designing interactive systems is about constructing things that are unique and particular, shaped in a given context by a specific designer or team of designers. The specificity of all the steps associated with designing goes to show the complexity involved in RtD (Stolterman, 2008).

> Design practice is about the creation of a desired reality manifested as an ultimate particular. The *ultimate particular* is a design concept of the same dignity and importance as truth in science. (Stolterman, 2008, p. 59)

If each exemplar of RtD is a unique invention, how can we build upon prior examples and produce scientific knowledge? Following Cross' (1982; 1999) notion that design knowledge is embedded in products, Zimmerman et al. (2007) view the artifacts produced through RtD as objects that embody design knowledge.

> The artifact reflects a specific framing of the problem, and situates itself in a constellation of other research artifacts that take on similar framings or use

> radically different framings to address the same problem. These research artifacts provide the catalyst and subject matter for discourse in the community, with each new artifact continuing the conversation. When several related research artifacts have been created, then researchers can use more traditional design research methods to analysis the artifacts and search for similar approaches designers have taken in addressing common problems. (Zimmerman et al., 2007, p. 498)

In making the design knowledge accessible to practitioners and researchers, the process the design researchers followed must be clearly communicated. Four lenses for evaluating RtD have been suggested: the reproducibility of the *process* (however, not the result); whether the contribution is a significant *invention*; the *relevance* of contribution to the community; and lastly, *extensibility*, the degree to which the knowledge contributions of the RtD can be sensibly leveraged by practitioners and researchers in the HCI community (Zimmerman et al., 2007).

The research studies I present in this thesis are inspired by RtD as a method in the way it has been described by Zimmerman et al. (2007). Central to that configuration of RtD is the view of the research prototype as a significant invention, and a quality of novelty in terms of interactivity. The way I think of RtD is more in line with Storni (2015)'s reasoning of RtD being "a resource for the production of knowledge," rather than the design artifacts from RtD being objects that embody knowledge. The research contributions of the papers presented in this thesis can be viewed as a hybrid between Wobbrock and Kientz's (2016) category of empirical contribution and artifact contribution.

In this thesis, a design-oriented approach has explored the design of DHIs and people's experiences with them constructively and exploratively. In the studies, prototypes and interactive artifacts have been produced that can be used, experienced, and interpreted by people. With this approach, this thesis presents knowledge on two levels: (1) how we can design DHIs, and (2) how people experience the DHIs.

In each of the studies presented in this thesis, a prototype was prepared through design iterations to integrate knowledge from different domains and participants. By designing prototypes, different concepts could be evaluated and the experiences people had from using them studied. In Paper I, the participants designed the prototypes. Through iteration, they refined their ideas of what could be a suitable VR scenario for capturing the experience of fear of public speaking. In Paper II, two prototypes were constructed through iteration in cooperation with clinicians, an artist, and participants: (1) a front-end for presenting a modular DHI for women after gynecological cancer (Appendix A); (2) three audiovisual narratives to support women in reflecting on their experiences of cancer survival. In Paper III, the front-end of the former study was adapted to the needs of a modular DHI for supporting adults with ADHD in managing everyday challenges. Twelve video vignettes were designed for use in the intervention in cooperation between clinicians, adults with ADHD, and a production company. In all of these studies, the knowledge produced through RtD was developed in the process of designing the artifacts and through empirical studies of people's experiences of using the artifacts.

The ethics of design is an ongoing debate in HCI (Bardzell and Bardzell, 2011; Bruckman, 2014; Friedman, 1996). All designs are embedded with values, and the question of ethics becomes what those values are, whose values they are, and for what purpose. In doing design-oriented research, I have sought to collaborate on constructively exploring new ways of presenting DHIs that support people in managing their health. A further goal was to build on people's experiences of managing their health in the design explorations. In keeping with these goals, participatory design was used to ensure a plurality in the values and perspectives that the research studies presented in this thesis encompass.

3.1.2 Participatory design

Two out of three studies in this thesis have been presented as examples of participatory design (PD) in their respective papers (Paper I and III). I argue, however, that the thesis project as a whole, including Paper II, has been motivated by the values and objectives of PD. In this section, I give a brief overview of PD and how I align my studies with this approach.

In the studies presented in this thesis, the use of PD has been motivated by both values of Ehn's (2008) dichotomy between PD as emancipatory, democratic practice and PD as mutual learning between participants of a design process (see page 25 for more on the motivations for PD according to Ehn (2008)).

Workshops In participatory design, one is designing a future of technology use in direct cooperation with future users (Bratteteig and Wagner, 2012). Thus, participatory design is more than "listening to what the user wants," or understanding their context, it is about involving them as active participants with a certain decision-making power in the design process. In the studies presented in this thesis, the participants have used their experiences and lifeworlds as a resource in design. In this way, their participation has surpassed merely sharing their preferences. They have, through their participation, suggested particular designs and made design choices reflected in the finished research prototypes. Their participation in the design processes has provided qualities to the DHIs which would not be possible without their knowledge from experience.

Table 3.1: Overview of participatory design activities

Study	Participants	Activities
1	Adolescents	Design workshop weekend
2	Women treated for gyn. cancer	Design critique committee
3	Adults with ADHD	Ideation workshops and movie script writing

Central design methods within participatory design are workshops and low-fidelity prototyping (Muller, 2002). In workshops, participants envision scenarios of how new technology could enhance their activities and what that technology could be. For an overview of the participatory activities part of this thesis, see Table 3.1.

In Paper I, adolescent participants recruited from public schools envisioned scenarios for VR exposure therapy by using low-fidelity prototyping tools and 360° cameras. The participants used their experience of taking part in everyday school activities to envision scenarios that could be appropriate in an exposure therapy scenario for fear of public speaking Figure 3.1. In Paper II, participants took part in a committee that was regularly consulted for design critiques of our designs for a web-based DHI for women recovering from gynecological cancer. In this study, the participants did not contribute to design directly by co-design, however, they did contribute to the decision-making by giving us feedback on what they saw as appropriate and inappropriate ways of addressing these sensitive topics. In Paper III, participants suggested ways of making information and coping techniques for adults with ADHD available in a DHI, and later the participants made scenarios and scripts in co-design workshops that depict everyday situations and challenges for adults with ADHD.

3.1.3 Reflections on participatory design

Participatory design engages with people as active co-designers, seeking to empower their values, positions, and experiences directly in design processes. Respect for participants is vital for engaging participants as co-designers in a constructive way. In the participatory design workshops and processes, extra care was taken to consider the participants' points of view, particularly their experiential knowledge of health.

Figure 3.1: A snapshot from the video observation footage captured for the first study, detailed in Paper I. The participants were discussing how someone entering the classroom while answering a question in class, in a VR scenario, would faze the speaker. The idea is referenced as "that door" in their discussion. The captions read: "And then you think like 'oh, okay, I got away from that one' and then you get a 'yes, please continue' [from the teacher] and you lose focus completely. So, I think that door would be wicked."

As an emancipatory approach to research, participatory design bears a commitment to upholding norms of democratic fairness in design (Robertson and Wagner, 2012). Given the healthcare context of the studies presented in this thesis, protecting the integrity of participatory design as an emancipatory approach to research was not straightforward. The healthcare sector is built upon expert knowledge, in which the clinician's expert knowledge and evidence-based theory are preferred. Bratteteig and Wagner (2012) argued that prototyping is a decision-making process that closes the "design space" as defined from an initial design vision based on values and concepts. In the cases that formed the research studies of this thesis, however, what constituted the design space was not clearly articulated or shared by all stakeholders. It should be mentioned here that participatory design is not only made up of facilitators and participants; many different parties (doctors, nurses, psychologists, and software developers) represented the stakeholders involved in the design processes presented in this thesis. Therefore, tensions arose when people of different backgrounds worked together to make decisions in prototyping. For example, views on health as represented by the participants' experiential knowledge and the clinicians' prescriptive knowledge would sometimes conflict. In these conflicts, clinicians' perspectives were typically given more weight, which could be seen as natural because they represent the expert knowledge the health care system is built upon. Referring to clinicians' perspectives as singular may give the impression that these were in unison; however, that was not always the case. Conducting participatory design studies in the health care context has required careful consideration in striking a balance between different perspectives and representing the participants' voices in design.

3.1.4 Qualitative research

I have used qualitative research methods to collect and analyze data on how participants work to design VR scenarios (Paper I) and how people experience the design artifacts (Paper I–III). For an overview of qualitative methods used in this thesis, see Table 3.2. In this section, I present the third leg of my research methodology: qualitative research.

Table 3.2: Overview of qualitative studies

Study	Method(s)	No. of participants
1	Participant observation and interviews	15 and 6
2	Think-aloud evaluations with interviews	10
3	Qualitative survey and interviews	109 and 6

Qualitative studies in HCI focus on the current and future use of technology (Blandford et al., 2016). Essentially, qualitative research can be described to be about meaning, sense-making, and experience. Third-wave HCI has seen a shift in focus from organizations and social use of computing (Bødker, 2006) towards the individual's experience of computing (McCarthy and Wright, 2004, 2007). With qualitative methods, researchers can construct rich descriptions of how people interact with technology, the experiences they shape, and the meanings that technology uses forms.

Since qualitative research is interested in meaning and does not seek to quantify phenomena and make statistical-probabilistic measures of outcomes, one could ask whether the number of participants or the amount of data is important within the qualitative paradigm. Including multiple informants in a qualitative study is important to ensure diversity in the collected data. However, there are no clear-cut recommendations on how many participants to include, although some specific methods, such as grounded theory, provide guidance for reaching *data saturation* (Saunders et al., 2018). In my studies, I have sought to include participants that give a varied picture of the phenomena under study, focusing on the variations found in the data material rather than the quantity of it.

Research is expected to produce knowledge, and as such, the knowledge produced needs to be transferable between different domains and contexts. Qualitative research offers generalizability by naturalistic generalizability, transferability, analytical generalizability, and intersection generalizability (Smith, 2018). The studies presented in this thesis provide transferability in that the analysis and contributions of the papers that present these studies can be valuable for other researchers and practitioners designing DHIs. Moreover, the papers may provide naturalistic generalizability in that the reader may recognize work processes and experiences presented in the paper and thus make inferences about their own practices as researchers or practitioners.

Knowledge constructed with qualitative research is closely linked to the researcher(s), as they shape how the data is collected and analyzed. The concept of *reflexivity* has been developed to show how the researcher's position contributes to the richness of the data. In contrast, in postpositivist research, *bias*, the degree to which the method or the use of the method puts disproportionate weight in favor or against an outcome is controlled for. When done from a non-positivist perspective, qualitative research does not recognize bias as detrimental to research but reflexively sees the researcher's values and position as part of the data analysis.

Concluding remarks on research approach

Having presented the overall research approach of this thesis, I will make a short conclusion to this part of the chapter. The methodology of this thesis has three legs: research through design (RtD), participatory design (PD), and qualitative research. Together, they form a whole that I have found coherent and helpful in exploring how DHIs can be designed with users involved. The first part, RtD, is perhaps the most distinct, as it presents interaction design as a part of scientific inquiry. By generating designs, I have been able to constructively explore how interaction design can be situated within the development of DHIs. The second part, PD, is related to the first but includes a commitment to involving end-users or representatives of these as co-designers in some capacity. The third, qualitative research, is an established family of methods for conducting research into people's experiences and is, within HCI, specialized in understanding current and future use of technology.

In the remainder of this chapter, I will give an overview of the participants included in the studies and a description of the methods that were used to gather and analyze data.

3.2 Participants

The studies presented in this thesis have included participants in each study's design activities and the evaluation of DHI prototypes. For an overview of all participants connected with these studies, see Table 3.3.

Table 3.3: Overview of participants

Paper	Description	Role	No.	Recruitment
1	Adolescents	Designers	15	Convenience, snowballing
1	Clinical psychologists	Evaluators	6	Convenience
2	Former cancer patients	Experts by experience	5	Convenience
2	Former cancer patients	Evaluators	5	Snowballing
3	Adults with ADHD	Experts by experience	3	Conveneince
3	Adult with ADHD	Co-designer	1	Purposive
3	Adults with ADHD	Co-designers	10	Convenience
3	Adults with ADHD	Evaluators	109	Social media, flyers, recruitment website
3	Adults with ADHD	Evaluators	6	Self-selection

In Table 3.3, the participants are listed per study and activity they took part in. For the column "Role," three types are given: *designer*, *evaluator*, and *expert by experience*. Participants that had a *designer* role took part in design activities in a constructive way by contributing to the design process with their ideas through design. *Evaluators* have contributed by assessing and evaluating prototypes. *Experts by experience* refer to participants that have had a part in a decision-making process as part of a committee. They are deemed *experts* by virtue of their experiences from having an illness or a psychiatric disorder.

Regarding the recruitment strategies, *convenience* refer to the strategy of including the most accessible participants (e.g., colleagues, students, family), and *snowballing* is a related strategy where one asks recruited participants to suggest participants they know (Blandford et al., 2016). *Purposive* recruitment is the strategy to select participants by how confident the researcher is that they would be "right" for the project and efficiently address the research question. *Self-selection* refers to eligible participants that choose to participate by submitting their contact information through any means of contact with the researcher.

In the first study, participants of the PD process were recruited from public high schools in the vicinity of Bergen, Norway, by convenience sampling. The participants were recruited with lenient inclusion criteria, with the primary being “an interest in technology.” The purpose of the PD workshop was to design exposure therapy in VR for adolescents’ fear of public speaking. For that purpose, we did not set out to recruit people that have a social anxiety disorder or personal experience of fear of public speaking – what was of interest to the study was that the participants had experience in the social milieu where adolescents can experience a fear of public speaking. To evaluate the VR scenarios produced by the adolescents, six clinical psychologists were recruited by convenience sampling. These participants were a mix of my colleagues and acquaintances with a degree in clinical psychology.

In the second study, participants were recruited by a co-researcher through the board of a local patient organization for gynecological cancer. The included participants had completed treatment for gynecological cancer and took part in a committee as experts by experience. For a think-aloud evaluation procedure, five additional participants were recruited through snowballing of the aforementioned experts.

In the third study, participants were recruited by a co-researcher by convenience through a local patient organization for people with ADHD. The three participants were recruited as experts by experience. The initial three participants contributed to the design process in meetings by voicing their opinions and making suggestions for what kind of content they preferred. Later, one of these three participants was purposely recruited for a video production to form a character and write a storyline for the video vignette.

Participants with an experience of illness or psychiatric diagnosis, here referred to as experts by experience were recruited through contact with patient organizations. In the second study, these were recruited from a local patient organization for women that have or have had gynecological cancer. In the third study, the participants were recruited from a local patient organization for adults with ADHD. The recruitment was not screened through inclusion and exclusion criteria; rather, we were interested in having motivated participants that self-selected their participation in our studies. These recruitment processes were handled by clinician co-researchers in charge of the intervention studies.

3.2.1 Institutional approval

HCI research deals with people, and the human experience of interaction. Research involving people should be considered in terms of balancing potential risks with potential benefits. Any action is associated with potential harm, and researchers indeed risk harming their subjects (Bruckman, 2014).

All three studies were granted “ethical clearance” by different bodies. In the first study, The Data Protection Official (Norwegian Social Science Data Services) appointed by the University of Bergen granted the collection of participant observation by video recording and interviews by audio recordings. In the second study, data collection was exempted from ethical approval by The Regional Committee for Medical Research Ethics of Western Norway (REK). Audio recordings of committee meetings and interviews were reported to and approved by the data protection officer at Haukeland University Hospital (2018/11263). In the third study, the audio recording of interviews and storing of participants’ responses to surveys was approved by REK (2020/90483).

Participants in the design phases of all three studies gave informed consent for participating in the research and innovation studies and signed confidentiality agreements.

3.3 Prototype evaluations

The three studies employed three strategies for evaluating DHIs: experience prototyping (Buchenau and Suri, 2000), think-aloud testing (Nørgaard and Hornbæk, 2006), and a clinical trial. In this section, I will first give a short background to discussions of evaluations of DHIs in HCI, followed by a presentation of the three studies’ evaluation procedures (overview available in Table 3.4), with a brief discussion of each evaluation method.

Table 3.4: Overview of evaluation methods

Study	Evaluation method
1	Experience prototyping
2	Think-aloud
3	Clinical trial

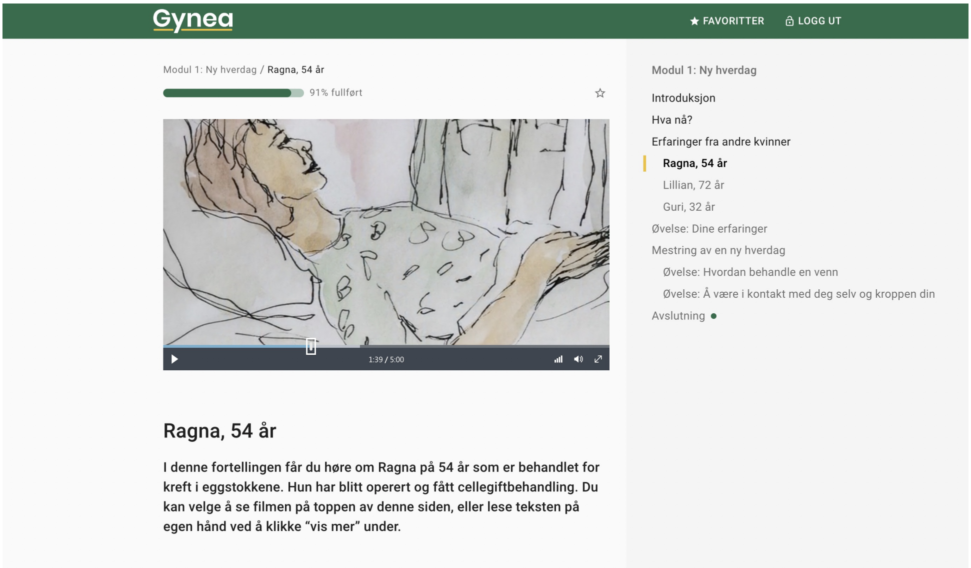
The evaluation of interactive systems is a major strand within HCI research. For DHIs, Klasnja et al. (2011) argue that limiting the evaluation of health behavior change technologies to efficacy – the degree to which the DHI contributes to intended behavior change outcome – is too limited for HCI research. Instead, an emphasis on the *how* and *why* of DHI use is recommended for HCI (Klasnja et al., 2011). Doherty et al. (2010) recommend evaluating prototypes in several stages. In early-stage evaluations, expert-led evaluations have been suggested, with an emphasis on uncovering usability

Figure 3.2: A participant evaluating a VR scenario with a head-mounted display.

issues and assuring a fit with clinical health theory. Following the early stages, when a more comprehensive prototype is ready, evaluation with non-clinical peer users or therapists as proxies to the intended target population is suggested to understand people's engagement with the DHI (Doherty et al., 2010). Regarding the focus of evaluation in HCI, Klasnja et al. (2011) sees people's experiences with prototypes as vital in understanding how we can design better DHIs that meet the diverse needs of healthcare users.

3.3.1 Experience prototyping – study one

In the first study, evaluation was done in two parts of the process: throughout the PD process as an integrated part of the design process; an expert evaluation of the PD outcomes performed by clinical psychologists. In this thesis, I view the type of evaluation done for study one as experience prototyping (Buchenau and Suri, 2000), similar to Houde and Hill's (1997) notion of "look and feel" prototypes. In experience prototyping, the look and feel is understood as the "sensory experience of using an artifact – what the user looks at, feels and hears" (Buchenau and Suri, 2000, p. 424). In the PD process, experience prototyping allowed the participants to experience their designs firsthand through a head-mounted display for viewing VR (Figure 3.2). Following the



Ragna, 54 år

I denne fortellingen får du høre om Ragna på 54 år som er behandlet for kreft i eggstokkene. Hun har blitt operert og fått cellegiftbehandling. Du kan velge å se filmen på toppen av denne siden, eller lese teksten på egen hånd ved å klikke “vis mer” under.

Figure 3.3: The website for the DHI *Gynea* in which the audiovisual narratives for the Paper II study were presented (Appendix A). Evaluators used this website, and watch three audiovisual narratives, one of which is shown here.

workshop, six clinical psychologists evaluated the three VR scenarios produced by the participants. They, too, got to experience the prototype firsthand and were asked to share their impressions of the scenarios. However, they also gave their expert opinion on how the scenarios or VR technology could be used in clinical practice. As such, the VR scenarios also functioned as role prototypes (Houde and Hill, 1997), which investigates what a prototype can do.

3.3.2 Think-aloud – study two

The evaluation of the audiovisual narratives in study two was modeled as a think-aloud protocol in accordance with recommendations of the PBA (Yardley et al., 2015). In traditional approaches to think-aloud evaluation (Boren and Ramey, 2000), users evaluate a prototype within a controlled environment. While interacting with the prototype, the user is tasked to articulate their impressions of the prototype as they go along with the evaluation. In this way, think-aloud protocols ”focus on the interaction with a particular interface, and so are well suited to identifying strengths and limitations of that interface as well as the ways that people undertake their tasks using the interface” (Blandford et al., 2016, p. 39). Although early think-aloud protocols recommend minimal interference with the user during evaluation, this is rarely the case in usability testing practice (Nørgaard and Hornbæk, 2006). In practice, evaluators ask the user questions while undergoing the think-aloud procedure. In the second study, we prepared a set of assignments to be carried out by the user (e.g., “open the first module and browse through the pages”). Before starting the evaluation, we instructed the user to “think aloud” and tell us about their impressions as they worked through the tasks (Figure 3.3). Parallel to the think-aloud tasks, we followed a semi-structured interview protocol and asked the user questions informally, making sure that all items on the interview protocol were completed by the end of the think-aloud sessions. On average, the sessions took about one and a half hours each to complete.

3.3.3 Clinical trial – study three

In the third study, the evaluation for gathering empirical data was part of a clinical trial. The DHI in study three was given to 109 participants to complete in an unguided intervention regimen over a period of six weeks, meaning the participants were to use the DHI as they saw fit. The data collected in this evaluation was done by providing the participants with short qualitative questionnaires during the six weeks and retrospective in-depth interviews post-trial.

The studies presented in this thesis have been evaluated at three distinct stages: early stage with non-clinical use, meant for experimentation with technology and exploring how to design for clinical health (study one); a concrete prototype mature for clinical use (study two); and, the stage of a full-fledged DHI ready for a clinical trial (study three).

3.4 Interviews

Conversations are a basic mode of interaction between people (Kvale, 2011). In using conversations as input for empirical data, *in-depth interviews* can be used to conduct a conversation with the purpose of building knowledge (Legard et al., 2003). Each of the studies in this thesis employed in-depth interviews as a technique for gathering empirical data from the evaluations.

The interviews conducted for these studies are best described as semi-structured, in-depth interviews; questions were pre-prepared ahead of the interview session and were planned to touch upon different topics related to the participant’s experiences of a design prototype.

Doing an interview as a researcher, or an interviewee for that matter is a reflective practice. You may have prepared a structure, or a series of prompts, in preparation for the interview. And as the interview unfolds, the participant's story unfolds. As an interviewer, I took part in that storytelling, giving cues and asking follow-up questions to further explore the participant's point of view. As Kvale (2007) pointed out, the interaction affects both the interviewee's and the researcher's understanding. While interviewing, ethical issues may surface for the researcher. Do I probe further into this matter? Is the participant comfortable? Does the participant want me to change the subject? Why am I bored with this participant? These are just a few examples of the kind of thoughts I have had in interview situations over the past years as a researcher conducting interviews.

When interviewing, I have tried to be respectful towards the interviewee, yet colloquial in tone and wording. Doing this has been my effort in creating a safe space for sharing experiences and reflections. When interviewing subjects about intimate subjects, such as gynecological cancer, it is my experience that the subjects may have a need to tell "their story". When this happened, we, as we were two interviewers in those interviews, let the interviewee speak freely of their experiences, and tried to emphatically listen and respond to their stories. Had it been for another "group" of participants, for example, adolescent school students or adults with ADHD, I may have tried to steer the conversation towards a more desired direction, that being my research objectives.

Maintaining emotional well-being as an interviewer in health research is something that requires practice and expertise (Wolters et al., 2017; Moncur, 2013). In an interview, the researcher is more or less the instrument; the interview transcripts are a result of the interaction that took place in the interview situation. The emotional strain the interview method can have on both the researcher and the interviewee has led to calls for alternative sources of experience such as pre-existing narrative accounts (Balaam et al., 2019) by HCI researchers. This was done in the second study, as we saw little benefit in conducting extensive qualitative research into the experience of cancer illness when one of our research members had extensive knowledge of and prior publications on the lived experience of gynecological cancer survival that could be appropriate for our study.

Ethical issues of the interview method go beyond the interview situation (Kvale, 2007). For example, any ethical issues that arose during the interviews could carry on to the next research stages of transcription, analysis, verification, and reporting. The analysis is particularly interesting from an ethical point of view: what does the subject mean when they report *this*, and how do I know that they do not really mean *that*? This thesis is aligned with an inductive and semantic understanding of interview data. That being, I have looked for meaning in the way the subjects use their language, analyzing their experiences for what they say about them.

3.5 Thematic analysis

After data gathering comes analysis, it is, however, not straightforward to separate the "data gathering" phase from the "data analysis" phase when doing qualitative research. In fact, these activities, although conceptualized as distinct, overlap and feed into each other. For example, as one follows through the interview situation, questions regarding the meaning of the interviewee's statements can be formed and asked *in vivo*. Moreover, as new perspectives unfold in the interview, the interviewer may think of the interviewee's statements in terms of how it relates to other interviewers' statement and how these statements together form analytical constructs.

In the studies presented in this thesis, I have used Braun and Clarke's (2006) framework for thematic analysis, and their many subsequent updates (Braun and Clarke, 2014, 2020, 2021, 2022; Braun et al., 2017), as the primary approach to analyzing qualitative data.

A *theme* in thematic analysis can be described as a "pattern of shared meaning" (Braun et al., 2019, p. 845) structured as an account of how a central organizing concept can capture the essence of meaning as it is understood from the analysis. Themes are analytical constructs, formed by a researcher in a process of analyzing qualitative data. Together, the themes form an answer to a research question that guides the analysis.

Thematic analysis can be described as an iterative and reflexive process and has been conceptualized as six steps by Braun and Clarke (2006, 2022):

1. Reading and re-reading the transcripts, familiarizing with the data.
2. Generating codes that describe data excerpts.
3. Arranging codes to develop overarching themes.
4. Reviewing whether themes are representative of their codes.
5. Naming and refining themes by comparison.
6. Producing the report detailing the analysis.

It should be noted that as the method is both iterative and reflexive, thematic analysis is flexible in that the steps are repeated and reworked out of sequence; themes are constructed in a dialogue between the interpretation of the shared meaning between parts of the data set and the research question.

3.5.1 Research questions for thematic analysis

Thematic analysis requires a research question to guide the researcher through exploring the data set for meaning. In the papers that are attached to this thesis, the following research questions for the thematic analysis are provided:

> **Paper I:** "How do the participants make sense of their design task, and how do they work when designing VR scenarios?"
>
> **Paper II:** "How do survivors of gynecological cancer engage with audiovisual narratives designed for an online intervention?"
>
> **Paper III:** "How do participants in the online intervention experience and make sense of video vignettes designed for the intervention?"

These research questions were subject to repeated refinements throughout the analysis process. Refining the research questions was done as the analytic focus was shifted between different aspects of the data material (e.g., experience, engagement, sense-making). Moreover, the research questions were refined in wording for precision.

These research questions guided the process of constructing themes that captured essential aspects of the data material that could contribute to the knowledge of how DHIs made in collaboration with users are experienced.

3.5.2 Coding practice

Within all the studies, the qualitative data were analyzed with a bottom-up, inductive approach, where transcripts were read, and excerpts were marked with codes representing each excerpt's meaning as they were understood. This approach to analyzing data is known as semantic and inductive: "With a semantic approach, the themes are identified within the explicit or surface meanings of the data, and the analyst is not looking for anything beyond what a participant has said or what has been written" (Braun and Clarke, 2006, p. 84). Data analysis was done by induction, meaning it followed a bottom-up approach in which codes are generated based on the coders' interpretation of data. This way of conducting thematic analysis does not map data to pre-determined concepts like a deductive analysis.

Although inductive thematic analysis may seem atheoretical, it is better seen as theoretically flexible (Braun and Clarke, 2021). The concepts of experience, engagement, and sense-making are used in the research questions for each study above. In analyzing the data, these concepts were understood pragmatically, in line with McCarthy and Wright (2007) and HCI scholars of the experiential turn (Buchenau and Suri, 2000; Boehner et al., 2005; Höök, 2013) in which experience is lived, embodied and situated in personal, social, and cultural contexts.

Coding the qualitative data in the first two papers was done in two iterations: first, by me in familizaring with the data, then in cooperation with co-authors to refine codes in areas of interest. Finally, I generated codes for the third paper, and the later stages of developing and adjusting themes were discussed and created with co-authors.

Specialized software for conducting qualitative analysis was used in each study, namely NVivo and Atlas.ti. Interview and observation video transcripts were entered. While reading the transcripts, excerpts were marked and labeled.

3.5.3 Theme construction

As described above, themes convey a pattern of shared meaning across a data set. To form these patterns, codes were arranged in groups by making connections between the codes. When refining the themes, these were discussed with co-authors of the papers for each study. Data excerpts were read out loud in discussion with co-authors, and together we discussed the meaning of these and how the themes related to each other.

Each theme for each paper tells a part of the overall story of the analysis. Sometimes, there was conceptual overlap between themes. For example, in the second paper, there were four themes, two of which related to the sense of authenticity of narrative characters. The first theme described how participants related to the characters, while the third focused on how participants perceived realism. As such, there is some conceptual overlap between the themes in how they both address authenticity in narrative characters. Regardless, the themes are separate analytical constructs that emphasize different nuances of the qualitative material. In the former example, the theme confirms that participants could relate to the characters and unpack how they could see themselves or others in the characters. In the latter theme, more consideration is given to how participants perceived the characters and their narratives as realistic.

Chapter 4.
Summary of papers

This thesis consists of this summary and three attached papers. In this chapter, I provide a short summary of each paper.

4.1 Paper I

In the first paper[1] , 360° videography was explored as a means for participatory design of VR scenarios. VR technology has a long history of use in exposure therapy for fear of public speaking within clinical psychology research. The design and implementation of such VR applications require technical skill, and therefore research on VR exposure therapy is typically concerned with pixels, sensory fidelity, and outcome measures. What may thus be overlooked in these applications is an authentic and realistic view of fear of public speaking, and how this experience is shaped in adolescents' everyday lives.

In an effort to produce scenarios that could be seen as relevant and realistic for adolescents that have challenges in giving public presentations, we devised a PD workshop to generate VR scenarios grounded in the experiences of participants. Fifteen adolescents were recruited to participate in a weekend workshop, where they, in teams of five participants, learned to produce VR scenarios using a design process including a 360° video camera. As they refined their scenario designs through iterations, the participants could view and experience their own 360° scenarios using a head-mounted display that provided an immersive view.

A thematic analysis of participant observation video recorded during the weekend

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[1] Full citation: Eivind Flobak, Jo D. Wake, Joakim Vindenes, Smiti Kahlon, Tine Nordgreen, and Frode Guribye. 2019. *Participatory Design of VR Scenarios for Exposure Therapy*. Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. Association for Computing Machinery, New York, NY, USA, Paper 569, 1–12. `https://doi.org/10.1145/3290605.3300799`

found that participants negotiated the task of making exposure therapy scenarios using their experiences. Following the workshop, six clinical psychologists experienced and evaluated the VR scenarios, sharing their views on how the scenarios could fit within clinical practice and their experience of being immersed in the scenarios.

4.2 Paper II

In the second paper[2], the design of audiovisual narratives as content for web-based interventions is explored.

The narratives were written from former qualitative studies by the paper's last author, in particular a typology of living through gynecological cancer (Sekse et al., 2012). In the narratives, three (fictional) women are presented who have had various gynecological cancers and different ways of coping with illness and life. The aim of including these narratives as content in an intervention was to provide users of the intervention with narratives that they may recognize themselves in and support them in reflecting on their own experiences of illness.

The DHI for which these narratives were designed (see Appendix A) was designed and implemented over a two-year period. During the design phase, we had regular meetings with a panel of five user representatives to discuss our designs. The representatives provided valuable feedback and helped us understand how seemingly small nuances in design could have a large impact on people's experience of a sensitive issue.

Think-aloud evaluations of the narratives with ten participants form the empirical material in this paper. In an analysis, the participants' experiences of the narratives are construed as meaningful experiences, focusing on how the narratives provided the participants with a sense of coherence, connectedness, and resonance. Based on this analysis, considerations for how to design audiovisual narratives for DHIs are considered.

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[2] Full citation: Eivind Flobak, Oda Elise Nordberg, Frode Guribye, Tine Nordgreen, and Ragnhild Johanne Tveit Sekse. 2021. *"This is the story of me": Designing audiovisual narratives to support reflection on cancer journeys*. In Designing Interactive Systems Conference 2021 (DIS '21). Association for Computing Machinery, New York, NY, USA, 1031–1045. DOI:`https://doi.org/10.1145/3461778.3462005`.

4.3 Paper III

The third paper[3], details a PD project involving adults with ADHD co-designing video vignettes for a web-based intervention. The intervention was designed with the PBA, modeling the core training principles of the self-guided intervention after Goal Management Training (GMT) (Figure 4.1) (Levine et al., 2000; Jensen et al., 2021). The choice for designing video vignettes was motivated by the need for an easy and engaging way to explain the principle of the GMT intervention and in response to the participants' request for video content with an experiential focus. A comprehensive evaluation study (n=109) of the video vignettes was done as part of a clinical trial examining the effects of the web-based intervention on adults with ADHD.

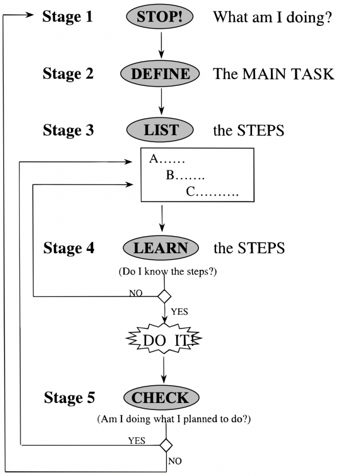

Figure 4.1: A high-level flowchart to illustrate the steps involved in the original GMT intervention. Figure adapted from Levine et al. (2000).

In the paper, both positive and negative experiences held by people with ADHD are discussed. ADHD is associated with a public stigma, leading to self-stigmatization in adults with ADHD that contributes to feelings of low self-worth and self-efficacy. However, disclosure of experiences associated with the illness on social media has challenged public stigma and empower people with mental health issues. The focus on the everyday experience of ADHD as it has been featured on social media inspired the use of video vignettes to support core training principles of the web-based intervention.

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[3] Full citation: Eivind Flobak, Emilie Sektnan Nordby, Frode Guribye, Robin Kenter, Tine Nordgreen, and Astri Lundervold. 2021. Designing Videos With and for Adults With ADHD for an Online Intervention: Participatory Design Study and Thematic Analysis of Evaluation. *JMIR Mental Health* 8, 9 (sep 2021), e309292. `https://doi.org/10.2196/30292`.

The video vignettes produced for this study were made in collaboration between clinical psychologists and adults with ADHD. The vignettes present characters that lead ordinary lives and provide a view of everyday experiences. For example, the characters show how they cope with their challenges related to ADHD by using techniques taught in the web-based intervention.

The evaluation of the video vignettes combines data collected from qualitative surveys issued to participants within the intervention and individual in-depth interviews with six participants after completing the web-based intervention. The analysis explores how the participants experienced and made sense of the video vignettes. The participants used the characters of the video vignettes as role models for change, related to the characters and their situations based on their experience of similar situations, and recognized their own experiences of ADHD in the vignettes. Based on the analysis, considerations for how authenticity can be retained in DHIs are developed. Moreover, the person-based approach (PBA) is discussed in relation to PD, and how the therapeutic aims of DHIs can be balanced against the experiential perspectives developed in a PD process.

Chapter 5.

Meaningful engagement

This is the first of three chapters addressing the overarching research question of this thesis: *How can participatory design be used to shape Digital Health Interventions (DHIs) that facilitate meaningful engagement in the mental health domain?* The discussion elaborates on the results of Paper I-III and focuses on the three research questions of this thesis.

In this chapter, I discuss the findings of this thesis project in regard to the first research question *What is meaningful engagement with DHIs?* First, based in the studies, I propose 'meaningful engagement' as a lens through which to explore engagement across its dimensions: *purposeful interaction*, *felt experience*, and *sense-making*. In the next section, the concept is applied in an analysis of the findings of Paper I-III. Lastly, I compare this concept to how experience is conceptualized in HCI research and how engagement is depicted in DHI research.

5.1 Meaningful engagement as a conceptual lens

What is meaningful engagement with DHIs? With this thesis, *meaningful engagement* is suggested as a conceptual lens for understanding the experiential qualities of engagement. This lens supports the current understanding of engagement by providing an experiential perspective on how engagement can be meaningful. Drawing on Mekler and Hornbæk's (2019) framework of the experience of meaning in interaction, I here translate this framework for meaningful engagement, seeing engagement as a quality of experience characterized by *connectedness, purpose, coherence, resonance, and significance*. Meaningful engagement with DHIs is here conceptualized as comprising three connected dimensions: (1) purposeful interaction: interaction with a DHI in pursuit of improving one's health, (2) felt experience: how the experience of purposeful interaction with a DHI is tied to a lived body shaped by past experiences, and (3) sense-making: how a person makes sense of the felt experience of purposeful interaction with DHI content and activities. These dimensions are not isolated elements but interconnected facets that together shape how a person engages meaningfully with a DHI. While they serve as useful analytical tools for study, the boundaries between them can often blur in real-world application.

5.1.1 Purposeful interaction

Engagement refers to purposeful interactions with technology (Doherty and Doherty, 2019). The main purpose of interacting with a DHI is to improve one's health (Yardley et al., 2016). From the perspective that engagement is linked to improved health outcomes, engagement can be understood as a clinical concept, associated with behaviors that impact health. The number of log-ins to the DHI, clicks, completion rates, and other user behavior are recorded to measure engagement. However, this way of measuring engagement does not capture to what extent DHIs are experienced as meaningful. In the conceptualization of meaningful engagement, interaction is termed 'purposeful' to signify that the interaction is in pursuit of a higher-level goal (i.e., improving one's health). This dimension connects to Mekler and Hornbæk's (2019) notion of *purpose* in interaction.

By valuing the purpose of the interaction, a focus is given to the DHI participants' intentions of interacting with the DHI. In this way, the concept of meaningful engagement seeks deeper into the motivations that lead to the overall goal of improving one's health by identifying purposes from the participant's perspective. The purposes of interaction may be to improve one's health, learn new coping strategies, or seek validation and identification with others to name a few. As a contrasting example, in clinical models of DHI use, the focus is often on adherence and compliance to gauge engagement and better understand its effects. Adherence and compliance can be viewed as purposeful interaction in the way they provide a reasoned connection to the goal of participating in health interventions: to improve health by following sound therapeutic procedures. In the conceptual lens of meaningful engagement, on the other hand, a focus is provided to what the participants of a DHI seek to achieve by interacting with the DHI.

5.1.2 Felt experience

A person's lived experiences can have consequences in the embodiment of new experiences (McCarthy and Wright, 2007). Embodied, lived experiences of illness, with its possible vulnerabilities, in the interaction with technology that concerns those very experiences will color the felt experience of using a DHI. For example, a person who has lived with the everyday challenges (Turgay et al., 2012; Franke et al., 2018) and stigma associated with ADHD (Holthe and Langvik, 2017; Hinshaw, 2018) could experience a DHI focused on supporting stress management for adults with ADHD as more relevant to their experiences than someone who has not had such experiences.

To understand engagement with DHIs in the mental health domain, it is necessary to understand participants' felt qualities of interacting with material that touches upon their vulnerabilities. A perspective on engagement as felt puts an emphasis engagements as it is tied to lived and embodied experience. The emphasis on the felt qualities of interaction provides a person-centered focus to DHI engagement. With this, the focus on engagement with DHIs is shifted from cohort studies of engagement to the individualized experience of engagement.

5.1.3 Sense-making

When interacting with technology, people actively construct meaning by making sense of their experience in a way that affects the lived experience of interaction itself (McCarthy and Wright, 2004). This reflexivity can be seen in line with the learning process involved in working through psychoeducative material in a DHI (Yeager and Benight, 2018). To make sense of the content in a DHI, a person using the DHI constructs meaning from the interaction with the material.

Participants in DHIs can experience a connection through their engagement with the material in that they find the material speaks to their current situation and past experiences. Coherence with one's life can be the notion that something in the DHI reflects their personal experience well (e.g., how a participant in the third study reported that the video vignettes reflected their own experiences of everyday challenges in self-regulating their ADHD symptoms when working a day job). Resonance is the immediate sense of something making sense from the interaction with a DHI (e.g., how a participant in the second study described that an audiovisual narrative showed the experience of cancer survival the way she had). In the context of engagement with DHIs, significance refers to the degree of importance an individual assigns to their interaction with the DHI, which can range from being perceived as personally relevant and important to trivial, depending on its perceived relevance and impact on their health or well-being.

Meaningful engagement provides a lens for exploring the experience of interacting with a DHI by viewing the interaction with technology as purposeful, understanding the experience of interaction as lived and embodied, and by providing the analytical tools for unpacking how people make sense of the experience and ascribe meaning to their use of a DHI. This focus can in turn provide new possibilities in designing DHIs and new directions for researching the effects of use in evaluations. The former is discussed in the next chapter on designing for meaningful engagement. The next section discusses how qualitative findings from evaluations of DHI use can be further unpacked with the lens of meaningful engagement.

5.2 Unpacking meaningful engagement

Paper I-III present the empirical studies that support this thesis' contributions. In this section, I further explore the findings of these papers with the conceptual lens of meaningful engagement for understanding use and interaction with the prototypes presented in these papers.

A prototype was designed and evaluated with participants for each of the papers presented in this thesis. The prototypes were structured around narrative content. In the first study, the narratives were in the form of 360° VR scenarios depicting situations in which one may experience a fear of public speaking. In the second study, three audiovisual narratives tell the story of fictional characters' onset of and survival from gynecological cancer. In the third study, video vignettes depicted situations with problems and resolutions in everyday life with an ADHD diagnosis. The analyses of the studies probed the participants' sense-making of their experiences.

5.2.1 Purposeful interaction

The prototypes evaluated in the research studies were all designed to support therapeutic activities in the mental health and wellbeing domains, the latter domain more relevant for the second study.

In the first study, the intended purpose of the design was to be exposed to a virtual public speaking situation in a secondary education context. The evaluators in this study engaged with the prototype and related to the purpose of interaction from a different point of view than of participants in a DHI. The evaluators focused their assessment of the prototypes on how they saw it as fit for therapy with adolescents, although they also experienced the prototypes first-hand, reporting their immediate sense of interacting with the prototypes.

In the second study, the audiovisual narratives were presented as part of a first module on coping with life after gynecological cancer in the intervention. The audiovisual narratives were followed by a reflection exercise where participants could reflect on their own experience of undergoing treatment for cancer. The designs were intended for provoking and eliciting reflections from participants with the lived experience of undergoing similar cancer treatment. In the evaluations, former gynecological cancer patients, some of which took part in the design process, evaluated the first module of the intervention including these audiovisual narratives. As they participated in a controlled think-aloud evaluation (subsection 3.3.2), their use of the DHI content and comments was solicited by us as researchers for the purpose of evaluating the content in preparing for a larger clinical trial of the DHI. Regardless of this structured approach, the participants' engagement with the DHI content was not merely a procedural response to our research methods. The participants saw their participation in the evaluation as important because they wanted to contribute to future gynecological cancer post-treatment procedures.

In the third study, the guiding principle (see paragraph 2.5.1) of the video vignettes was to support adults with ADHD in a DHI by providing examples and contexts to how to implement and address self-stigmatizing beliefs often held by adults with ADHD. For each module, participants viewed the video vignettes as a support in comprehending the featured coping techniques for handling everyday challenges. In a clinical trial of this DHI presented in Paper III, the participants interviewed after the trial related to their purpose of engaging with the DHI as their interests in learning more about ADHD as a diagnosis, how to cope with everyday challenges, and to learn about others that struggle with similar challenges as themselves. Specifically for the video vignettes, participants related this to their purpose of interacting with intervention, reporting how the videos supported their motivation of participating in the DHI. The vignettes showed protagonists that "struggles with the same things as me" and was related to as role models for change.

The grounds for discussing purposeful interaction are quite different between these three studies. In the first and second study, the evaluation was done within their respective design processes. As such, the purpose of interaction in these studies were facilitated in controlled settings. In the third study, the evaluation reported in Paper III took place in a clinical trial. The research design of this evaluation therefore provided us, as researchers, a view of how the designs were experienced in the everyday. Therefore, discussing the 'purposeful interaction' of participants in the first two studies may be somewhat forced when applied in this analysis. Regardless of the difference in controlled and uncontrolled settings of the evaluations, the participants did at some level relate to a purpose in their interactions as discussed above.

While purposeful interaction lays the groundwork for meaningful engagement, the essence of engagement extends beyond mere interaction. To better understand the impact of the prototypes in the studies, we need to consider the felt experience of interaction, the lived and embodied experience that unfolds during the interaction.

5.2.2 Felt experience

The design artifacts of Paper I-III was evaluated with participants that had lived experiences of gynecological cancer and ADHD, respectively. In the first paper, clinical psychologists were used as proxies for adolescents with a fear public speaking. We chose to use clinicians as proxies because evaluating with young people who have social phobias posed practical challenges for us that was seen as too inconvenient to work around for a set of experimental VR scenarios. The evaluators were proxies of the intended users, speculating in how the scenarios would work in a therapeutic context using their professional expertise and personal experience. The use of clinicians as proxies provided a pragmatic solution to evaluating the scenarios when access to the intended user group was limited.

In the first study, adolescent participants designed scenarios for a VR therapy intervention targeting public speaking anxiety using a 360° camera. The scenarios, depicting anxiety-inducing speaking situations, were subsequently evaluated by six clinical psychologists, who served as proxies for the intended clinical setting, in an experience-based evaluation (Buchenau and Suri, 2000). Still, they also used their personal, immediate experience of the designs when evaluating the prototypes, based on their experiences of public speaking and being students at different educational stages. One evaluator described the experience: “You can feel it coming. One step closer, one step closer. I could feel it in my body that there was an activation.” The evaluator used their immediate experience of the VR scenario, thus communicating the felt experience of interacting with the virtual environment. Furthermore, the evaluator supported their assessment by using clinical language, ‘activation’, referring to a behaviorist model of how one’s body is alerted of danger, which is a part of inhibitory learning in exposure therapy (Craske et al., 2012). Moreover, the psychologist evaluators emphasized how the adolescents felt like real classmates: “Although this is similar to my prior experiences with VR, where you are presenting, this is so much more ... realistic, down-to-earth. ... Because you have the adolescents, with their body language, which I think people with fear of public speaking will find quite disconcerting". Here, one evaluator compared the prototypes designed by adolescents to "off-the-shelf" VR exposure therapy apps, emphasizing the realistic view of the scenario provided by the adolescent participants' designs.

The participants in the second study had the experience of surviving gynecological cancer. Surviving this type of cancer has been associated with changes to the body such as fatigue and fear of cancer recurrence. In a phenomenological typology of living through gynecological cancer (Sekse et al., 2012), three types of survivors were identified: the emotional- and relationship-oriented, the activity-oriented, and the self-controlled. These types were reflected in how the evaluators reported their experience of the audiovisual narratives: some focused on the emotional burden of the characters, while others found similarities in how the characters practically coped with treatment. Regarding the felt experience of the audiovisual narratives, the immediate aesthetic experience of the narratives was discussed vividly by the evaluators. In particular, the tone and wording of the narratives were seen as both too gloomy and too upbeat in addressing the subject by different participants. The difference in how the evaluators experienced the narratives indicates that their felt experience of the audiovisual narratives' aesthetics indicates that their lived experience of going through gynecological cancer colored their experience of the narratives.

The participants in the clinical trial for the third study had both self-reported and clinically validated diagnoses of ADHD, associated with problems of self-regulation (Barkley, 2015) and everyday challenges (Turgay et al., 2012; Franke et al., 2018). ADHD is furthermore associated with a significant public stigma, characterized by unruly behavior and laziness among other attributes (Holthe and Langvik, 2017; Hinshaw, 2018). This stigmatization of ADHD is portrayed and reinforced by media and social institutions such as schools, and even the stigmatizing values sometimes embedded in technology (Spiel et al., 2022). The video vignettes were generally well-received by the participants in the clinical trial, citing how they addressed the experience of living with ADHD in a realistic way without being offensive: "[The videos] are done in a way that allows me to see my negative things without it becoming uncomfortable." The participants described the experience of watching the video vignettes as self-affirming in that they considered everyday challenges that they themselves regularly struggled with, while not sensationalizing those challenges.

5.2.3 Sense-making

In the first study, the clinicians made sense of the scenarios at a clinical level, assessing whether the VR scenarios could be a feasible tool for doing exposure therapy in therapeutic setting. However, the evaluators did make connections between their experiences of the scenarios and their own experiences of public speaking and student life.

In the second study, narrative content created an opportunity for the participants to connect the DHI to their own lived experiences. The participants described the narratives as realistic and discussed different ways in how they identified with the characters. These experiences were, in the paper, understood as meaningful in that the participants connected the narrative characters' traits and stories to their own lived experiences. For example, in response to one of the narratives, a participant commented "this is the story of me," indicating how the narrative was experienced as coherent with the participant's own experiences of surviving cancer. Experiencing coherence with narrative content means a perception of the narrative as coherent with their own lived experience. Resonance in this context means that the narratives immediately evoked a feeling of making sense - that something is just *right*. Former gynecological cancer patients in the second study described resonance with the narratives, immediately recognizing themselves in the story that most matched their characteristics. Participants resonated with specific lines in the narratives, such as "the disease has put an end to many of our dreams," and would use them as points of departure to tell their own stories to the evaluators. Through telling their own stories, the participants further described how the characters and narratives evoked feelings of coherence and connectedness.

In the third study, the participants' identification with the characters is particularly interesting. The video vignettes made for the DHI were colored by a lighthearted, sometimes self-deprecating sense of humor. Given the stigma associated with having ADHD, one could expect that these video vignettes would fall flat in engaging participants with ADHD in addressing self-stigmatizing beliefs and techniques for coping with ADHD. In the study with 109 participants, participants were cued to provide written feedback on the video vignettes in a survey. The participants responded well to the tone in the videos, identifying with the YouTube-inspired style of addressing one's experiences of having an ADHD diagnosis. For example, participants described experiences of identifying with the female character in the videos, and how she coped with balancing an active social life against mundane, everyday chores that were easily put off. The participants recognized the desensationalized view of ADHD in the videos, in how they depicted everyday, ordinary contexts of work, single life, and family life. As one participant put it: “It has actually been a huge relief to find out that there are others who have it just like you; you are not as unique as you thought!” Recognizing one’s own struggles of coping with everyday challenges and negative self-talk in the DHI content. The videos facilitated an experience of connectedness for participants, further engaging the participants in using the DHI with a sense of purpose.

In the sense-making of narrative content that features characters in DHIs, identification and resonance with both the character and their storyline were ways in which the participants constructed meaning from their interactions in the second and third study. Resonance refers to the immediate feeling of coherence with one’s life. Identification is a more evolved, contemplative quality that, in this context, aligns the character’s values or storyline with the participants’ past experiences.

Further experiential qualities of meaning from engaging with narrative content in DHIs include realism and authenticity. In the second study, former gynecological cancer patients described the characters and their stories as believable and realistic. In the third study, video vignettes showed actors who portrayed everyday life with an ADHD diagnosis. Regardless of the acting, participants in a clinical trial described the stories and characters featured in the video vignettes as realistic. Thus, it can be argued that even though the characters were portrayed by actors, the narratives felt authentic. The difference between realism and authenticity is subtle. Experiencing the interaction with narrative content as realistic means acknowledging and resonating with a feeling that the narrative was coherent with their own life. For the first paper, it meant that the scenarios could have happened in “real life.” On the other hand, authenticity means that the narratives are perceived as *true*, originating from someone’s actual lived experience. In the VR scenarios of the first paper, authenticity meant the authentic perspectives of adolescent participants as depicted in their prototypes and experienced by the evaluators.

5.3 Comparison to experience and engagement

Meaningful engagement draws on engagement as purposeful interaction (Doherty and Doherty, 2019; Yardley et al., 2016), dialogical perspectives on experience (McCarthy and Wright, 2007; Boehner et al., 2005), and sense-making of interaction and experience (Mekler and Hornbæk, 2019; McCarthy and Wright, 2007). As such, there is conceptual overlap against these perspectives and models. In essence, the proposed lens for understanding engagement lends from HCI and DHI research to provide an integrative view of what it means to engage meaningfully with a DHI. In this section, I provide a comparative analysis of meaningful engagement against the literature of experience in HCI and engagement with DHIs.

The main feature of meaningful engagement is the focus on the quality of interaction and experience. In the models of engagement discussed in section 2.2, frequency and duration of use are the defining characteristics of engagement. That is, the frequency of log-ins, clicks, completed task, and duration of each session and page view. With meaningful engagement as a lens, the focus is shifted towards the DHI participants experiences of the interactions, and how they make sense of the experience and ascribe meaning to it.

Yardley et al.'s (2016) model of engagement in the DHI literature is conceptualized to make inferences between use of DHIs and its effects on health outcomes. Similarly, 'meaningful engagement' draws inspiration from this model by emphasizing the purpose of interaction. This lens is, however, not concerned with the efficacy or effectiveness of engaging with a DHI to health and well-being. These effects are better understood by quantitative methods. Rather, 'meaningful engagement' focuses on the purposeful interaction, felt experience and sense-making of engaging with DHIs.

Certain existing models of engagement do incorporate aspects of experience. For instance, the model proposed by Perski et al. (2017) includes experience as characterized by attention, interest and affect. However, the model provides little guidance on how to support the analysis of engagement with qualitative data of experience. On the other hand, Yardley et al.'s (2016) model of 'effective engagement', identifies integrating the experience of interaction in engagement as a key research challenge. The authors recommend qualitative analysis through both retrospective surveys and Ecological Momentary Assessment[1]. However, their focus is primarily on linking engagement to health outcomes, rather than understanding individual care experiences or informing future DHI designs.

I argue that understanding engagement should go beyond measuring use and compliance to a therapeutic regimen. Qualitative inquiry into engagement can be undertaken using methods such as interviews with DHI participants, collecting open-ended survey data from clinical trials, think-aloud evaluations, and role-play, among others. The analysis of these data can be conducted inductively using thematic analysis (Braun and

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[1] The collection of people's thoughts and behaviors during use, thereby offering ecological validity.

Clarke, 2019), interpretative phenomenological analysis (Smith, 2011) and other reflexive frameworks for qualitative analysis to unpack the meaningful engagement that unfolds from interacting with DHIs.

In regards to the literature on experience in HCI, these are conceptualized to unpack the sense-making and meaning of experience from a dialogical, pragmatic perspective (Hassenzahl, 2008; McCarthy and Wright, 2007; Boehner et al., 2005), and phenomenological perspective (Buchenau and Suri, 2000). ‘Meaningful engagement’ builds from McCarthy and Wright (2007) and Mekler and Hornbæk (2019) frameworks for technology as experience and experience of meaning in interaction.

Disengagement is the absence of use or non-use in a purely behaviorist model. However, in regards to the lens of meaningful engagement, disengagement can be viewed as interaction without purpose – a mode of interaction characterized by apathy, aimlessness or indifference. For example, the phenomenon of “doomscrolling,” or endless, potentially dissociative, scrolling through online news or social media feeds, is a form of disengagement that lacks purpose or meaning (Baughan et al., 2022). In contrast to purposeful interaction in meaningful engagement, this mode of interaction could go undetected in quantitative analyses of engagement that rely on usage data from DHIs. Therefore, a qualitative perspective on engagement can provide an understanding of the experience of interacting with a DHI.

5.4 Chapter summary

This chapter has considered the research question “*What is meaningful engagement with DHIs?*” In conclusion, meaningful engagement is understood by an analytical distinction between purposeful interaction, felt experience, and sense-making. By considering how people experience DHIs as meaningful, research can be done to explore how participants in DHIs experience and construct meaning from their interactions.

Meaningful engagement comes into sharper focus when DHIs are evaluated ’in-the-wild,’ as opposed to solely within the confines of the design process. While Paper I and II presented evaluations conducted as part of the initial design stage, the findings from the third study, carried out within an RCT, offered particularly nuanced insights. The setting of the clinical trial, where the DHI was used as it would be in everyday life, provided a more detailed exploration of meaningful engagement. Researching meaningful engagement with DHIs in clinical trials and other uncontrolled settings adds a layer of complexity and authenticity that is challenging to recreate in more controlled settings.

The main implication of meaningful engagement as a conceptual lens for understanding DHI use is the analytical distinctions it provides for exploring purposeful interaction, felt experience, and sense-making. This opens up for new ways of understanding the experiential qualities of engaging with DHIs, that can be overlooked when evaluating DHIs in regard to efficacy. It can be argued that people are less likely to consistently use a DHI or achieve the desired outcomes if they fail to establish a meaningful connection with it. Thus, an understanding of meaningful engagement can inform the design of DHIs that are more likely to be embraced and used effectively by their intended users. The next chapter considers designing for meaningful engagement.

Chapter 6.
Designing for meaningful engagement

This chapter explores the second research question: *How can we design for meaningful engagement with DHIs?* by discussing approaches used in the studies based on experience-centered design (Wright and McCarthy, 2010) and narrative elements.

Social media platforms such as TikTok and Instagram have become popular, engaging channels for sharing firsthand accounts of the experience of illness (Feuston and Piper, 2019; Avella, 2023). In the design of DHIs, on the other hand, a more "clinically grounded," prescriptive style of language is used to convey health information, which may seem a bit dry compared to what is offered on TikTok. However, just because a DHI is designed to follow an evidence-based therapy (e.g., CBT), does not necessarily mean the DHI has to be dull and colorless.

In this thesis, the emphasis is on the lived experience of mental health and well-being. In line with Svenaeus (2000), the lived experience of *illness* contrasts the biomedical understanding of *sickness* where these are conditions that can be cured or restored back to a former status of health. In this way, illness is here addressed from an experiential perspective – how it is experienced firsthand by people – which stands in contrast to a prescriptive, diagnostic view of health. Through considering the lived experience of illness, this thesis aims to use that experiential knowledge as a resource for designing DHIs that can facilitate meaningful engagement.

6.1 DHI content as a mediator for meaningful engagement

The design of content for DHIs is an underexplored area of DHI research. Content in DHIs is designed to communicate the therapeutic principles of the intervention. This HCI thesis concerns the design of DHIs, with an emphasis on the design of content to facilitate meaningful engagement.

Broadly, we can think of DHIs as formed by three main components: technology, therapy, and content. The technology in a DHI is the mode of delivery for therapy. It can be a web-based intervention, a smartphone app, or a VR application among other technologies used for delivering DHIs. The design of technology is a central aspect of HCI research (Zimmerman et al., 2007; Wobbrock and Kientz, 2016). Therapy in DHIs is chosen and defined by clinicians and health researchers. It can be CBT, dialectical behavior therapy, or some other form of evidence-based psychological treatment. The content of a DHI is the "backbone" (Barak et al., 2009). Content in DHIs can be educative, narrative, and communicate behavior change techniques (Barak et al., 2009).

The content of a DHI can help contextualize the therapeutic principles and techniques in a way that is relatable and understandable to people interacting with a DHI in pursuit of improving their health and well-being. Online clinical health communication is often communicated as prescriptive and fact-based information (Hartzler and Pratt, 2011). When providing self-guided therapy in the use of DHIs, the therapeutic alliance between a client and a therapist may be less apparent than in offline modes of treatment, or even non-existent (Henson et al., 2019). The absence of a strong therapeutic alliance necessitates the facilitation of familiarity and relevance of the therapy, and the participants' sense of purpose in following the DHI (Borghouts et al., 2021). One way of facilitating a relationship between the person using a DHI and the therapy, can be from the use of lived experience as a resource and pivotal point for designing DHI content, as proposed by this thesis. The delivery modes of content (e.g., video, text, and auditory exercises) and the content in itself can influence engagement with the DHI. In all of the studies, narrative content was explored in different ways for mediating experiential perspectives on illness.

6.2 Narrative as a vehicle for mediating experience

Designing narrative content provides an opportunity to leverage experiential knowledge in the DHI, which can motivate people with similar backgrounds. Frank (2013) suggested that narratives enable an understanding of illness that includes emotional, physical, and social dimensions through storytelling. The notion of illness as a narrative aligns with calls for more person-centered care in which the ill person's account of illness is valued (Ekman et al., 2011). For the design of DHIs, storytelling can be leveraged to contextualize psychoeducative material, exercises, and coping techniques with an experience-centered account. The use of narratives to communicate the material of DHIs with an "everyday lens" (Feuston and Piper, 2019) can desensationalize the view of illness and make the material easier to grasp. With this lens, illness can be contextualized in the seemingly mundane humdrum of everyday life, in a way that can be experienced as relatable and authentic.

Experience-centered narrative accounts of illness stand in contrast to the prescriptive, normative language used by medical clinicians to communicate concrete, actionable advice (Hartzler and Pratt, 2011). In social media, there are examples of people who communicate their experience of mental illness in an everyday context (Feuston and Piper, 2019). In the studies presented in this thesis, a similar approach has been used to illustrate and clarify educative material and core training principles in DHIs for supporting women after gynecological cancer and adults with ADHD in everyday challenges.

In the second study, narrative as a component in DHIs was explored as a vehicle to capture and represent the experience of illness. The audiovisual narratives in that study were designed to provide contextualized and personified accounts of life during and after a serious illness. The rationale behind the narratives was to support reflection on life after cancer for those with related experiences. The concept of using narrative as a core component of the DHI was further pursued in the third study. The narratives were designed in cooperation with adults with an ADHD diagnosis. Co-designing the narratives as video vignettes with people that have the lived experience of ADHD provided a unique perspective on how everyday problems can be experienced firsthand.

6.3 Experience as a resource for design

In experience-centered design, lived experience is the pivotal point of design activities. According to Bruner (2004), lived experiences are constructed and reflected in the autobiographical stories we tell of our lives. Qualitative inquiry is in that respect a way to explore and describe lived experience (Wright and McCarthy, 2010).

As discussed, there are many ways in which lived experience can be recorded and explored as a resource for design. As discussed in the background chapter, interviews informed Honary et al.'s (2018) designs for communicating the experience of severe mental illness. In an alternative approach that circumvents some of the emotional work involved in interviews, Balaam et al. (2019) suggested the use of existing narratives accounts of experience in design projects that involve considerable emotional strain for participants or designers. Where the former examples are centered around inquiring into the experiences of *others*, Höök (2013) suggested that designers engage personally through their lived, corporal bodies to attune to the design setting.

In the studies presented in this thesis, experience as a resource for designing was approached in three different ways: (1) from the experience of peers, (2) from qualitative research on the experience of illness, and (3) from the lived experience of participants. In the following, a description of each approach is described, organized by the papers.

Adolescent high school students in a participatory design (PD) workshop presented in Paper I used their knowledge of what it is like to be secondary high school students to design VR scenarios relevant to a fear of public speaking exposure therapy. In being students, the participants enacted their knowledge of what it means to be students in school and have regular public speaking experiences as part of their education. The design workshop was structured around designing scenarios and prototyping VR environments with a 360° camera in an iterative way to let the participants experiment with their designs and discuss their experiences. The participants used examples from their own experiences of feeling uncomfortable while speaking in front of their class, and observations of peer students who found it uncomfortable to speak in front of the class. These examples were discussed and incorporated into the scenarios.

In the second study, former qualitative research on women's experiences of surviving gynecological cancer formed the basis for the design of narratives. The narratives were originally written by a nursing researcher with former knowledge on the subject and discussed and adjusted in accordance with a panel of experts by experience. Using preexisting accounts of experience relevant to the purpose of the DHI saved us both the work of doing qualitative inquiry or PD workshops and the strain of engaging people in the emotional work of addressing the lived experience of illness.

Adults with ADHD participated in the design process of creating video vignettes in a participatory approach in the third study. They served as co-designers and shared their stories, helped choose the format, and contributed to creating scenarios and scripts that were later brought to life as video vignettes. This approach leveraged the participants lived experience into the design situation and gave way to authentic vignettes of ADHD in an everyday context.

Exploring the lived experience of mental health offers an opportunity for experience-centered design of DHIs. In this thesis, such an approach has been used to design interactions with DHIs that embed an experiential knowledge of illness and related phenomena. In the context of mental health, using experience as a resource for design can also help to de-stigmatize illness and make educational material more relatable for users.

6.4 Limitations in experience as a resource for design

A few limitations and trade-offs should be considered when using experience as a resource for design in the context of DHIs for mental health and well-being.

First, if a designer is using their own experiences as a resource, the design would then obviously reflect the designer's perspective. Similarly, if a designer is using the experiences of a particular group of people (e.g., a focus group), the design reflects that group. Clearly, these designs would not represent others' experiences and values. However, involving the perspectives and experiences of several people and groups in a way in which they complement each other can build toward a diversity of perspectives. A reflexive and open-minded approach to understanding and incorporating the experiences of others is thus warranted. Aiming for diversity can involve actively seeking diverse perspectives and continuously questioning and reflecting on one's assumptions and interpretations as a designer or facilitator of PD activities.

Second, using experience as a resource for design can be time-consuming and resource-intensive involving emotion work (Balaam et al., 2019). It may require conducting qualitative research (e.g. interviews, focus groups) or PD workshops, which can be time-consuming and not feasible for all projects.

Finally, using experience as a resource for design may not always be practical or appropriate, particularly in cases where the experience is too sensitive or difficult to discuss with designers. In these cases, other resources (e.g., expert knowledge and existing research) may be more suitable for informing the design process.

6.5 Chapter summary

How can we design for meaningful engagement with DHIs? This section of the discussion has argued that meaningful engagement with DHI can be facilitated through the design of DHI content that leverages lived experiences of mental health and illness. DHIs have the potential to integrate personal, lived experiences into their content. This integration not only allows the interventions to resonate with users but also facilitate a more nuanced understanding of the experiences of illness and mental health. By doing so, DHIs can depart from a strictly prescriptive and clinical language, thus enhancing their relatability and facilitation for meaningful engagement.

This section also discussed the significant role narratives can play in conveying lived experiences. Narratives enable the integration of emotional, physical, and social dimensions into DHIs, thereby providing a more holistic view of mental health and illness. Through their everyday lens, narratives have the potential to lessen the self-stigmatization of illness and to present educative material in a way that users find relatable and authentic.

Despite the potential advantages, using experience as a resource for design is not without its limitations. For instance, designs reflecting a single perspective or a specific group might not cater to the diverse needs of a wider audience. Furthermore, involving lived experiences in design is a process that requires time and resources. And, it may not always be appropriate or feasible, especially when dealing with sensitive experiences.

Addressing the multifaceted challenge of designing for meaningful engagement with DHIs calls for a careful consideration of diverse perspectives, experiences, and resources. Balancing experiential knowledge with clinical expertise, while striving for authenticity and relevance in design, is crucial for facilitating engagement with DHIs in mental health and well-being. Future research should continue exploring innovative methods to integrate lived experiences and narratives in DHI design, to enhance user engagement and, ultimately, intervention efficacy.

Designing for meaningful engagement presupposes meaningful engagement in the design process. By this, I suggest that in order to create an artifact that facilitates genuine and significant interaction or involvement, there needs to be a similarly genuine and significant level of interaction or involvement during its design phase. When designing for engagement with DHIs that connects with a sense of meaning with the DHI participant, those people — or at least their needs, perspectives, and insights as represented by others — should be involved in how that artifact is created. Participatory design and experience-centered design, where future users or relevant stakeholders are actively involved in the design process, offer approaches to involving people directly in design that concerns their practice, knowledge, or experiences. The next chapter discusses user involvement in designing DHIs for leveraging the experiential perspective of illness in design.

Chapter 7.

User involvement in the design of DHIs

This chapter discusses the third research question: *How can we configure user involvement in participatory design of DHIs?* by discussing the PD processes and presenting strategies to involving participants in the design of DHIs.

The design approach used in this thesis has built upon the approaches of participatory design (PD) and experience-centered design. The use of PD as an approach has been motivated by the mutual learning between different roles (Ehn, 2008) participating in the design projects. In this chapter, I discuss the design approaches of the studies presented in Paper I-III in relation to criteria of evaluating PD processes and results, lessons learned from doing PD in a large and complex research and innovation project in the health sector, and consider how user involvement can be implemented in the design process for shaping DHIs.

7.1 Configuring user involvement in the design cases

Doing PD involves a creative process of conceptualizing and forming design alternatives, a decision-making process of making design choices, and constructing knowledge of practices and experiences by involving relevant stakeholders. The overall goal of the design workshops was to facilitate mutual learning between the stakeholders, that being the workshop participants and researchers. By this, we aimed to construct artifacts for the DHIs from an experience-centered approach that would address the first-person experience of living and coping with illness.

In this thesis, I have described three approaches to configuring user involvement in the design of DHIs building on PD techniques: (1) by involving adolescents in making and enacting scenarios of fear of public speaking (Paper I), (2) by sourcing content from qualitative studies of the lived experience of gynecological cancer survival, guided by a panel of experts by experience (Paper II), and (3) by involving adults with ADHD in designing video content for an intervention for adults with ADHD (Paper III). Here, I consider how participants contributed to designs with their expertise and how the design processes were facilitated.

7.1.1 Participatory design of VR scenarios for exposure therapy

In the first study, adolescent participants designed VR scenarios for exposure therapy targeting the fear of public speaking. Tasked with creating situations that trigger such fears, the workshop involved iterative design processes. Participants generated ideas, drew on paper, rehearsed live plays, and recorded these with a 360° camera for VR playback. While the adolescents were not experts in therapy design, their firsthand experience of public speaking fears in a school setting provided valuable context.

In the first study, adolescent participants designed VR scenarios for exposure therapy targeting the fear of public speaking. The workshop was organized around participant groups' iterative design of VR scenarios. We presented the participants with the task of "creating a situation where a person may experience fear of speaking publicly" and introduced the workshop method, the subject of adolescent fear of public speaking and therapeutic principles of exposure therapy. The participants generated ideas, drew scenarios on paper, rehearsed live-action plays of their scenarios, and recorded their enacted performances in front of a 360° camera. The recordings of each live-action play could then be experienced through a head-mounted display (HMD) in VR. The adolescents designed the scenarios by considering the specific situations and contexts in which they had experienced or observed fear of public speaking.

The workshop was framed with a goal of informing future VR technology for exposure therapy. However, the adolescents were of course not experts in designing therapy. At one point in the first design iteration, we, the facilitators, noticed how the groups were designing intense scenarios to maximize the fear and anxiety of the VR user. This prompted a spontaneous intervention from the facilitators, in which a research psychologist held an improvised lecture about models for exposure therapy, repeating key elements of the workshop introduction. Participants learned about how exposure therapy builds on disproving catastrophic thoughts the client may have about being exposed to a certain situation, and how the fear manifests in the client's experience of the situation. This intervention facilitated the mutual learning between the workshop organizers and the participants. On the one hand, the participants focused their efforts on depicting their experience of common public speaking scenarios from their everyday in the schools they attended. And on the other hand, the organizers learned how to better facilitate adolescents' design process for providing scenarios for therapeutic tools.

The participants in this study were selected for being students in lower and upper secondary schools and their interest in participating in a design workshop using new technology. The aim of involving adolescents in the design workshop was to get their view of what the everyday scenarios for fear of public speaking may look like, and how these scenarios unfold. As such, their expertise can be characterized by their firsthand knowledge of the social context in which adolescent fear of public speaking typically take place.

The overall goal of the workshop was, from the overall project's perspective, to gather requirements for further development of a VR app for adolescents exercising public speaking skills. The aim of the DHI this app was designed for was to offer an early intervention for adolescents, modeled after CBT exposure therapy, before social anxiety disorders were developed. As the participants in the design workshop were not screened for a social anxiety disorder or any other illness associated with fear of public speaking, it could be questioned whether the participants were equipped to bring relevant experiences into the design process. However, fear of public speaking is one of the most cited fear in people, reportedly in 50% of 13-year-olds. The workshop focused on the contexts and situations where a fear of public speaking may occur, while integrating the goal of designing scenarios that evoke the common experience of fear of public speaking in adolescents. In this regard, the participants provided valuable insight into the contexts that contribute to a fear of public speaking in a school setting. Furthermore, including participants who have a medicalized fear public speaking could prove very difficult in a workshop setting as they would have to engage in activities closely connected to their phobias.

7.1.2 Designing audiovisual narratives to support reflection on cancer journeys

In the design of a DHI related to gynecological cancer (Paper II), two approaches were used to involve users: incorporating findings of existing qualitative studies in DHI content and consulting with a panel of experts by experience in the design of content. For a sensitive topic such as gynecological cancer, using former studies combined with clinicians' expertise and guidance from user representatives can help establish content relatable to the target population.

The participants were recruited from a local patient organization. All had undergone successful treatment of gynecological cancer. The participants provided their feedback to our designs of audiovisual narratives in a series of meetings, contextualizing their critique by sharing their own experiences of undergoing treatment and life after treatment in regard to their own felt experience, family life, and existential dilemmas. Concretely, the participants critiqued the script of the audiovisual narratives, the visual style of the narratives, and provided alternatives for the design of the narratives. A relevant question of the study design is the representativity of these participants. The diversity of illness experiences cannot be fully represented by a number of participants. As such, we treated the participants as experts by their own experience, not others (i.e., gynecological cancer survivors as a 'population'). That being said, the participants did draw on their view of how their peers coped with illness to support their arguments.

7.1.3 Designing video vignettes with and for adults with ADHD

Adults with ADHD participated in the design of video content for a DHI aimed at improving the management of everyday life challenges in a study detailed in Paper III. The participants in the workshops had personal experience with ADHD and thus first-hand knowledge of everyday life with the condition. First, one participant wrote the script of a 'pilot' video in collaboration with a research psychologist. Then, the participant and researcher made the video in collaboration with a film team. In the subsequent workshops, 12 participants generated ideas for video content centered around the topics of six modules of a DHI for supporting adults with ADHD manage everyday challenges. Following the workshops, research psychologists created outlines for 14 video vignettes to be produced as content for the DHI by the film team.

A challenge in this PD process was finding a balance between the therapeutic goals of the DHI and the experiential perspective of the workshop participants. An experiential perspective on illness can contribute to the authenticity and relatability of the content and challenge the negative stigma often associated with illness. However, DHIs are meant to facilitate therapy and should therefore be designed to support therapeutic outcomes. A purely clinical view of illness and psychological treatment may be difficult for DHI users to understand and need to be contextualized to be more relatable. In this respect, the participants contributed to setting the agenda and the content of the videos, and the clinicians in the project worked to strike a balance between the experiential and clinical perspective of ADHD.

The participants in the design processes of Paper I-III did not have power over the design of technology used for the DHIs. The design of technology is a common goal for HCI and PD research. And for PD in particular, the facilitation and implementation of power-relations between participants and facilitators (Bratteteig and Wagner, 2012). The participatory processes in these cases, however, were oriented towards the design of content of DHIs, rather than the technologies. In the next section, I discuss the PD processes in regard to how they led to participatory results.

7.2 Evaluation of the participatory results

Evaluating whether a PD process led to a participatory result, and what factors contributed to or limited its success, can identify the implications for further research on PD methods in similar contexts. A participatory result is a design of some form that is fundamentally linked to the voices of those who participated (Robertson and Wagner, 2013) and that would not have been possible without the participation from users in forming design choices (Bratteteig and Wagner, 2012). Bratteteig and Wagner (2016b) discussed PD projects by asking whether the projects had participatory outcomes and how, whether the participants can recognize their contribution, and if taking sides was a requisite for the result. In this section, I discuss the empirical cases based in these questions. In regards to taking sides, I here view the 'sides' as the clinical and experiential perspectives on illness.

In the first study, the result of the PD process was a set of VR scenarios made by adolescent participants. The design results were not directly usable for exposure therapy without the guidance and facilitation of a clinician. PD can be defined as a process where "future users [...] participate in all phases of the design process" (Bratteteig and Wagner, 2016a, p. 425), providing participants with direct power over the design result of the end product. In our case, however, the participants did not contribute directly in the subsequent phases of design. Regardless, I view the VR scenarios designed by the participants as participatory results in their final form as 360° VR prototypes as they were the results of the adolescents design processes which they to a large extent had power over. The scenarios provided an authentic view that we could not have conceived on our own. Through the facilitation of the workshop, we balanced the adolescents' first designs of intense and frightening scenarios with the therapeutic perspective that the client experiencing the scenarios is the one producing the fear. The scenarios were used as input in subsequent phases of the VR project, providing the adolescent participants with a certain influence to the design of the DHI that was made in the years after this workshop (Kahlon, 2022).

The user involvement in designing audiovisual narratives in the second study provided participants with a say in the design process by helping us prioritize aspects of the stories, telling their own experience of themes address in the stories, and guiding us in how to approach and describe sensitive issues of gynecological cancer survival. The involvement of experts by experience in the design work was fundamentally motivated by an ambition to empower the firsthand perspective of what it means to live through gynecological cancer in the DHI. The decision to make the audiovisual narratives in the first place was influenced by the participants, as they found textual content difficult to work through after treatment (Sekse et al., 2021). Moreover, in the larger project of creating the DHI in which the narratives were presented, the participants suggested which themes the modules should cover, weekly support from health personnel throughout the program, and mindfulness exercises for support, all of which were included in the intervention design (*ibid*). The involvement of experts by experience provided an opportunity for survivors to have their voice heard in a design that concerned their experiences, values, and needs. Survivors report a lack of follow-up in routine care after successful treatment (Vistad et al., 2011), as did the participants in our project. Therefore, the involvement of the experts by experience meant taking sides with the perspective of those with the experience of cancer illness in development of the DHI, somewhat in opposition to a bio-medical understanding of life after cancer. The participants' contributions to design was reflected in how the audiovisual narratives used a plain language, both in the use of medical language (e.g., 'neuropathy' explained in plain language) and esoteric language (e.g., 'suffering' changed for 'hurting'). Moreover, they guided the visual language of the narratives, helping in striking a balance between the different 'moods' of illustrations.

In the third study, the participatory outcome was the design of video vignettes for a DHI concerning adults with ADHD mastery of everyday challenges. At the beginning of the project, three experts by experience presented their preferred ways of learning about ADHD on their own, and emphasized the style of YouTube vloggers who spoke of ADHD from their own experiences, mixed with 'clinically sound' information. This prompted the research team to initiate the participatory initiative of designing video vignettes for a DHI. The motivation behind this initiative was to enhance the engagement with the future DHI of providing content told from an experiential perspective and clarify core training principles of the intervention. The participants who contributed to the design of the vignettes found the final videos generally positive, albeit a bit simplistic, which they understood was for pedagogical reasons. They appreciated the relatability, educational value, and humor in the videos, recognizing their own contribution to the videos. They suggested more examples of challenging social situations and contextual information, leading clinicians to add introductions to each video for the DHI. The participants endorsed the final versions of the videos. The outcomes of this initiative was the video vignettes, which I see as a participatory result, because the involvement of adults with ADHD in design was crucial in creating content based on the real-life experiences of people with ADHD. The video vignettes nicely framed the overall DHI, providing engaging content for the DHI participants to use in making sense of the skill-building exercises and coping techniques provided with the intervention. However, the overall intervention was defined and designed by research psychologists. Because the clinicians anchored and adopted the workshop outcomes in their pre-defined therapeutic program, taking sides in the PD process was not a requisite of this process. For the video vignettes, however, taking sides here meant the balancing act of integrating the participants' experiential view of living with ADHD with the therapy.

I have here discussed the participatory processes and how they led to participatory results. Each process was different from the other, in particular the extent to which the participants had power over the design process. In the first example, the adolescents participants made the design choices in collaboration under careful facilitation of the facilitators. In the second example, experts by experience did not directly control the design of the artifacts, but had a strong influence on design decisions. In this project, the participants were involved in the design of all aspects of the DHI program, as opposed to the other two cases. In the third example, adults with ADHD participated in designing video vignettes for a DHI by writing scripts and generating ideas for the plots. In summary, the participants of the studies contributed to the design of content for DHIs, using their lived experience as their expertise in the design situations. In the next section, I reflect upon and discuss the context in which these projects were done, a multidisciplinary research and innovation project within the Norwegian healthcare system.

7.3 User involvement in a multidisciplinary health project

The studies of this thesis project was part of a large multidisciplinary health project (introduced in Scientific environment, page i) made up by clinical researchers, ICT researchers, and industry partners. The goal of this research and innovation project was to develop and implement personalized treatment of mental health problems using adaptive technology in the Norwegian healthcare system. By ‘adaptive’, machine learning techniques under the larger umbrella of artificial intelligence was emphasized. Of the five clinical cases involved in this project, four were aimed at producing web-based interventions. In doing collaborative research with my colleagues in this project, I chose to focus my research on the PD of DHIs and, particularly, the design of content for these interventions. Working in the overall project provided good opportunities to do HCI research on the development of digital health services. Collaborating with a wide range of health and computer science researchers, as well as industry partners, along with access to participants, led to research questions and studies that would not have been possible otherwise. In this section, I use my experiences of working in this project to discuss the conditions for implementing user involvement in this multidisciplinary health project.

In the overall project, user involvement was one of the primary strategies for developing useful DHIs. User involvement in health services is incentivized at various levels across European health care systems. In Norway, user involvement in the planning and implementation of health services is regulated by law: “make sure to use patients’, users’ and relatives’ experiences in the improvement of services” (Norwegian Institute of Public Health, 2019, *my translation*). As such, there are strong incentives also in the Norwegian healthcare system to involve people with the experience of illness when designing interventions that concern them.

The project gave preference to the person-based approach (PBA) (Yardley et al., 2015), with the aim that this approach would produce interventions that were acceptable to users, yet anchored in evidence-based research on psychological treatments. The PBA consults future users or representatives of the target population through methods like interviews, informing DHI design decisions through an expert-led exploration of their values and experiences. The PBA’s position on participants’ expertise, however, is different compared to PD of which this thesis is founded on: “We find that users are naturally expert at telling us what they like or dislike about our invention, but most users are understandably less able to generate effective behavior change techniques or good design solutions” (Yardley et al., 2015, p. 7). In PD (Ehn, 2008) and experience-centered design (Wright and McCarthy, 2010), users are central to the design process, their knowledge and firsthand experiences guiding design decisions. For me, coming from an HCI background where ‘users’ are the primary experts (Blandford et al., 2018), and people’s first hand experience is emphasized in design (Wright and McCarthy, 2010), the disregard of users ability to contribute to design came as something of a shock.

The position of Yardley et al. (2015) underestimates the potential contributions of people with illness experiences to the design process. With this thesis, I argue that participants with relevant lived experiences indeed can contribute to the design of DHIs. The development phase of the DHI presented in the third paper combined the use of PBA with PD. The PBA was used to establish a 'logic model' of the intervention and guiding principles for the design, whereas PD was used as an approach to designing key content element for the intervention. Therefore, I see no contradiction in directly involving participants in forming design decisions when working with the PBA with the proper facilitation and weighing of the processes. By 'weighing of the processes,' I refer to the deliberate balancing act that involves valuing the contributions from participants against the theoretical and evidence-based grounding offered by PBA. This is not to undermine the importance of theory-based designs but to emphasize that the balancing of these approaches can lead to DHIs that are enriched by engaging content made from an experiential perspective.

Contrary to Yardley et al.'s (2015) claims that participants are less capable of generating behavior change techniques, the findings of Paper III counter this claim. Although it is recommended that these techniques are grounded in theory and evidence, we found that participants can contribute significantly to shaping their presentation. Furthermore, participants provided valuable coping strategies in the ideation workshop, indicating that they could be enabled to contribute to the design of behavior change techniques with the right facilitation. Through facilitating mutual learning in the design processes, the participants provided their input building from their expertise from an experiential perspective. The resulting DHIs involve design components that we would not be able to construct without their active involvement in the design processes.

In response to calls and developments in involving citizens' perspectives in the design of health services, the PBA has been extended with the addition of Patient and Public Involvement (PPI) (Muller et al., 2019). In this modified approach, representatives of the intended target population of a DHI is invited to take part in not only designing, but also being part of the research team that develops and evaluates DHIs that concern them. The motivation driving this involvement is similar to that of doing qualitative research to inform the design of DHIs in the PBA: to enhance quality and improve the acceptability of the intervention to the target population.

The authors warn, however, of the representativity of participants and how using PPI in designing DHIs may be preferred over the qualitative research phase recommended by the PBA: “PPI is often provided by a small number of dedicated and articulate individuals who may not be typical of the whole target population” (p. 7, *ibid*). This concern about representativeness is a valid critique, but the same critique applies for any number of persons and their supposed group in qualitative research.

In analyzing the PD processes of this thesis, I have thought of the participants as representative of themselves and their own perspective, together bringing a richness of perspective to the design processes. In turn, their produced designs may be relatable by people who share some of their characteristics (e.g., illness, values or identity). In contrast to qualitative research, a participatory approach provides the participants with a say in how their expertise is reflected in the design result. With proper user involvement in PPI or PD, the participants are able to go beyond expressing their views orally, to embedding them practically in the design of the DHI.

In regards to the user involvement in the overall project this thesis project was part of, we could have more clearly defined what we wanted to achieve with user involvement, in addition to setting guidelines for how we would practically implement user involvement. A clear anchoring of user involvement in multidisciplinary research projects can provide structure and a shared sense of purpose among project members.

7.4 Strategies for user involvement in the design of DHIs

User involvement in designing DHIs should be configured to fit each development process’s unique context. In this section, I consider four approaches to user involvement: involving representatives of the target population as co-designers; involving proxies as co-designers; involving representatives as members of a panel; and drawing on existing qualitative research with user panels. These approaches are not mutually exclusive, rather, they can be used in combination with each other or other strategies for user involvement in a way that best fits the purpose of the intended DHI design process.

7.4.1 Involving representatives of the target population as co-designers

The design of DHIs can include representatives of the target population directly in the design process as co-designers. These representatives can be people diagnosed with a particular illness or self-identify with the diagnosis. Recruitment of user representatives can be done through patient organizations that can arrange contact with relevant representatives. Engaging user representatives in the design process gives people with a lived experience of illness a direct influence on the design results. In this way, the DHI can incorporate the practical and experiential knowledge of illness relevant to the target population.

A challenge in using this strategy is to strike the balance between the participants' experiential knowledge and clinicians' theory-based knowledge of the illness. DHIs are developed to help people with health behavior change, and as such, the design process should be directed toward this goal. Therefore, careful facilitation is necessary to ensure that the designs support the larger intervention goals and that the co-design activities provide rich contextualization of clinical knowledge. When recruiting user representatives, care should be taken to ensure that the included participants adequately reflect the values and experiences of people in the target group.

7.4.2 Involving proxies as co-designers

Similar to the former strategy, including proxies for user representatives is possible. These can be clinicians with experience in treating people with an illness (Doherty et al., 2010), the family of people with an illness (Honary et al., 2018), or someone knowledgeable about the context in which the illness is lived. This strategy can be used when access to people with relevant firsthand experience is limited, or the direct participation is too demanding regarding safety for participants' well-being.

7.4.3 Involving representatives as members of a panel

The third strategy is the involvement of user representatives as panel members. This strategy likens to UCD approaches where users are consulted about their preferences in systems design. When designing DHIs, user panels can be consulted to better understand the needs and values of target populations. User panels can be consulted periodically to provide feedback on design,

The main challenge in using user panels as a strategy for user involvement is to ensure that the representatives have a real influence on the design process. Otherwise, user involvement may appear tokenistic in an attempt to legitimize expert-driven proposals and decisions about DHI design (Dahl and Svanæs, 2020). To achieve user involvement, facilitators of DHI development processes should reflect on their process as they go along and make adjustments to ensure participation in design.

7.4.4 Drawing on existing qualitative research

In some cases, access to participants who have relevant experience for a DHI design process may be difficult to reach, or the cost of participating may be too high in relation to the benefit to the participant. This can, for example, be the case in illnesses where active participation entails a self-disclosure that may be demanding for the participant.

Existing qualitative research, when available, can be used to understand the perspective of the people one is designing DHIs for. Intervention designers should carefully assess the qualitative research for its relevance to the DHI, and the kind of content it could aid in generating. These research reports can contribute to an understanding of the lived experience of illness, and thus be used as a basis for designing content for DHIs. When this strategy is used, user representatives could be recruited to consult on the design to ensure that the process is aligned with the values and experiences of the people who will use the DHI.

7.5 Chapter summary

In this section I have discussed the research question *How can we configure user involvement in participatory design of DHIs?* The answer to this research question is complex, as it is fundamentally dependent on the context and specific goals of the PD project. Firstly, configuring user involvement necessitates a clear understanding of what their expertise and roles are in the design process. In the cases presented, people's lived experiences served as the primary basis for their involvement, enabling them to contribute authentically and meaningfully to the design process. In the first study, the adolescents' first hand knowledge of social contexts, where fear of public speaking could arise, proved valuable in generating VR scenarios. In the second study, the experts by experience guided us, the researchers, in making the design decisions, while in third study, the adults with ADHD played a role in designing the video vignettes featured in a DHI. When configuring user involvement for the design of DHIs, PD facilitators should consider their motivation for involving participants in design, and conceptualize what kind of expertise they want to elicit from participants.

Secondly, participants in health projects may not always have direct power over the final design result but can substantially influence the design decisions and process. In all three cases, while the participants did not have complete control over the final design of the DHIs, their contributions fundamentally shaped aspects of the design outcomes. The notion of taking sides is not always a requisite for the PD process. Although in some instances, such as the second study, where it did help in aligning the design with the lived experiences of gynecological cancer survivors, it was not a determining factor for the success of the PD process in other cases. Taking sides when doing PD for DHIs is more about balancing the sides to integrate the experiential perspective in the therapy. Thirdly, the projects presented demonstrate that PD need not always strictly involve future users in all phases of the design process of DHIs. Instead, participants can contribute to the design of certain aspects or stages based on their unique expertise. The second and third point of this discussion can be seen in relation to the context of which the PD projects operated within. When doing PD within a healthcare context, it is necessary to consider and negotiate the expectations that stakeholders hold towards user involvement in the research project.

In summary, configuring user involvement in the PD of DHIs requires a delicate balancing act. It involves understanding the participants' unique roles and contributions, deciding their potential influence on the design process and decisions, and recognizing that user involvement can take different forms in different stages of the design process. On the other hand, the balancing act involves weighing participants contributions against the therapeutic framework of the DHI to make sure that the designs adhere to the sound theory of psychological treatments. The studies presented in this thesis provide valuable insights for future PD projects in similar contexts and contributes to the ongoing discourse on participatory methods in the design of DHIs.

Chapter 8.
Conclusion

How can participatory design be used to shape Digital Health Interventions (DHIs) that facilitate meaningful engagement in the mental health domain? This is a timely question for both Human-Computer Interaction (HCI) and DHI research. As mental health care is increasingly being addressed through new digital intervention modalities, there is concurrently a growing call for person-centered care, which emphasizes the need to involve the experiential perspective of illness in treatment to value the felt experience. Through a comprehensive exploration of the research questions, this thesis argues that participatory methods, when employed thoughtfully, can contribute to shaping DHIs that follow established therapeutic programs while also being engaging on an experiential level.

This thesis has explored how we can use participatory methods to design DHIs for the mental health domain that engage people in using the interventions. With this thesis, I have addressed engagement from an experiential perspective, exploring how people find meaning from interacting with DHIs. Meaningful engagement considers how participants' purposeful interactions with a DHI lead to a felt experience, and the sense-making of that experience.

Three research papers form the backbone of this thesis. In the first paper, a PD workshop method was presented for designing VR exposure therapy scenarios with adolescent participants without experience in designing VR or therapy. The second paper outlined a method for constructing narrative content based on existing qualitative research and user representatives' guidance. The third paper details a PD process of designing video vignettes for a DHI for supporting adults in everyday life. Furthermore, an empirical study of people with ADHD's experience of the video vignettes was presented in the third paper.

This thesis contributes to HCI by demonstrating the value of PD methods for designing DHIs for mental health and well-being. Through the analysis of three studies, we have seen how PD techniques provided insights into the design process from an experiential perspective of mental illness that can be difficult to attain for clinical experts. The empirical material of the thesis papers highlights how the participants experienced the designs made for these interventions as a meaningful and engaging experience. A further contribution to the field of HCI is the implications for how we understand engagement with technology. By applying the concept of meaningful engagement, this thesis expands upon traditional conceptions of engagement and offers suggestions on how DHIs can be designed to be relevant and resonant for individuals with lived experience of mental health issues.

Recognizing that DHIs can facilitate meaningful engagement may help designers to shape future DHIs that are designed to be relevant, realistic, and authentic to people with lived experience of mental health issues. My hope is that this understanding can inform future design processes and ultimately lead to the creation of DHIs that are better suited to support and empower people in their journey towards better mental health and well-being.

8.1 Limitations

The main limitation of this thesis is in the scope of *mental health* in the included thesis papers. The papers focus on common mental health issues, such as anxiety, psychological well-being, and stress. Specifically, fear of public speaking in adolescents, mastery of life after gynecological cancer, and everyday difficulties with ADHD have been addressed. How to configure user involvement in designing DHIs may differ for serious mental health interventions (e.g., interventions for psychosis or self-harm).

A further limitation of the scope is the generalizability of the approaches for designing for meaningful engagement. A more nuanced approach may be warranted in designing DHIs for serious mental health issues. For example, doing PD with people who engage in self-harm activities would require careful ethical considerations and sensitivity to avoid triggering or exacerbating the behavior.

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Part II

The papers

Paper I

Participatory Design of VR Scenarios for Exposure Therapy

Abstract

Virtual reality (VR) applications for exposure therapy predominantly use computer-generated imagery to create controlled environments in which users can be exposed to their fears. Creating 3D animations, however, is demanding and time-consuming. This paper presents a participatory approach for prototyping VR scenarios that are enabled by 360° video and grounded in lived experiences. We organized a participatory workshop with adolescents to prototype such scenarios, consisting of iterative phases of ideation, storyboarding, live-action plays recorded by a 360° camera, and group evaluation. Through an analysis of the participants' interactions, we outline how they worked to design prototypes that depict situations relevant to those with a fear of public speaking. Our analysis also explores how participants used their experiences and reflections as resources for design. Six clinical psychologists evaluated the prototypes from the workshop and concluded they were viable therapeutic tools, emphasizing the immersive, realistic experience they presented. We argue that our approach makes the design of VR scenarios more accessible.

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1 Introduction

Sweaty palms, a shaky voice, and trembling hands — most of us have experienced these sensations while giving a public speech. Fear of public speaking is prevalent in one-fourth to one-third of the general population (Stein et al., 1996; Furmark et al., 1999) and usually begins in adolescence (Wittchen and Fehm, 2003). When the symptoms of this fear persevere and become habitual, they may lead to unfortunate consequences such as social anxiety, depression, academic failure, and more limited employment opportunities (American Psychiatric Association, 2013).

Virtual reality (VR) is used as a tool in therapy for exposing patients with performance-type anxiety disorder to their fear of public speaking (Lindner et al., 2017, 2019). Exposure therapy scenarios in VR are ordinarily designed using computer-generated imagery (CGI), which requires careful 3D modeling and animation that can be time-consuming and costly to create. Furthermore, such designs commonly feature generic environments and scenarios that take a “one-size-fits-all” approach to targeting speaking anxiety.

The emergence of affordable and readily available 360° stereoscopic video cameras has opened up a new design space. This technology allows realistic VR scenarios to be created based on recordings of real people (Meinel et al., 2017; Gelsomini et al., 2017). These 360° cameras have recently been used in VR exposure therapy (Stupar-Rutenfrans et al., 2017), and according to Seol et al. (2017), they provide a tool with “easier means for creating many different scenes/situations and customizing for the particular needs of the patient” (p. 2).

Given that fear of public speaking usually begins in adolescence (Wittchen and Fehm, 2003), we argue that there is a need to tailor exposure therapy designs to this age group. Since we are targeting the exercise tool at adolescents, we have used a participatory approach (Ehn, 2008) to create designs that are based on the lived experiences of adolescents aged 15-17 years.

To address the need for incorporating adolescents’ lived experiences in design, we devised a workshop inspired by experience prototyping techniques (Vines et al., 2014; Buchenau and Suri, 2000) in the design of VR scenarios. Over two days, fifteen adolescents – with the help of five facilitators – produced four scenarios that depict situations in which one might experience fear of public speaking. The participants played out their scenarios as live-action performances, which were captured by a 360° stereoscopic video camera. After some stitching and editing, these videos became VR prototypes aimed at exposing the user to public speaking.

We reviewed and transcribed video recordings of the participants' work process to analyze their approach and identify analytical themes (Braun and Clarke, 2006, 2014). In this analysis, we identified themes relating to how the adolescents used their lived experiences to design VR scenarios, envisioned and composed virtual environments, and made sense of the subject matter. After the VR prototypes were completed, six clinical psychologists evaluated the VR scenarios by viewing them with a head-mounted display (HMD) and assessed each scenario's feasibility for use in therapeutic contexts. The evaluators emphasized the scenarios' authenticity and realism, stating that they considered the prototypes viable for use in exposure therapy.

Our results show that 360° video is a viable tool for designing VR scenarios and is well-suited for constructing realistic and detailed virtual environments. The primary contribution of this paper is the composition of tools and methods we present for designing such scenarios and including participants in the design process.

2 Related work

This section introduces previous research on fear of public speaking, exposure therapy, and virtual reality.

2.1 Fear of public speaking

Fear of public speaking, a subtype of social anxiety disorder, is characterized by an intense fear of humiliation and embarrassment before and during public and social speaking performances. The fear experienced is typically disproportionate to the actual threat posed by the social situation. Furthermore, avoidance-type behavior is often displayed by the individual in these public and social performance situations (American Psychiatric Association, 2013).

This phenomenon is prevalent, with one-third of the US population reporting excessive fear of public speaking (Stein et al., 1996; Wittchen and Fehm, 2003). Social anxiety disorders, such as this fear, may lead to other anxiety disorders, major depressive disorder, and substance use disorders. Further, it is associated with reduced opportunities in academic studies and professional careers, as well as a lower quality of life due to social isolation and withdrawal (American Psychiatric Association, 2013). Social anxiety, in general, is a serious public health concern that often goes untreated (Olfson et al., 2000). Given that fear of public speaking usually has its onset in adolescence, it is important to intervene early to prevent the condition from worsening.

2.2 Exposure therapy

Exposure therapy, a treatment technique within cognitive behavioral therapy, aims to combat patients' fear of catastrophic outcomes by placing them in situations that elicit their fear responses. With repeated exposure to the feared situations, patients' established fears are challenged and eventually inhibited and overridden by their new experiences, a process referred to as inhibitory learning (Craske et al., 2012). *In vivo* exposure therapy (treatment in naturalistic settings) is effective (Taylor, 1996; Acarturk et al., 2009), but logistically complicated to implement, for patients with a fear of public speaking. In public speaking performance scenarios in particular, it is difficult for a therapist to control the stimuli and exposure while in session (Lindner et al., 2017).

2.3 Virtual reality for exposure therapy

The use of immersive virtual reality (VR) in exposure therapy to treat anxiety disorders such as fear of public speaking dates back to the 1990s (North et al., 1997; Lindner et al., 2017). With this technique, an HMD that shows two slightly different segments of an image is employed to present the user with a stereoscopic virtual environment. The HMD is equipped with motion sensors, which allow for constant computation of new images to sustain the presented environment and help create an immersive experience for the viewer (Slater and Sanchez-Vives, 2016).

Levac and Galvin view such applications as a tool in VR-based therapy, in that they require a therapist to "identify specific goals, determine therapy tasks, grade and progress the activity to provide appropriate challenge, monitor performance, evaluate outcomes, and enable patients to link the tasks or activities being practiced in therapy to their real-world context" (Levac and Galvin, 2013, p. 795). Use of VR alone does not constitute therapy. However, when viewed as a tool, VR can be understood as a therapeutic element that can enhance therapy and amplify its positive outcomes.

Using VR as a tool for exposure therapy may, depending on implementation, allow therapists to take control of the exposure level, stimuli, setting, and design of features presented to the patient. Systematic reviews of VR for exposure therapy show that the efficacy of these interventions is similar to that of *in vivo* interventions (Opriş et al., 2012; Powers and Emmelkamp, 2008; Maples-Keller et al., 2017).

HMDs for experiencing VR content have recently become available on the consumer market. Due to improvements in graphical resolution, field of view, and refresh rates, these HMDs can now provide immersive experiences at lower costs. Therefore, consumer-grade HMDs are expected to change the design and use of VR for psychological treatment (Lindner et al., 2017; Rizzo and Koenig, 2017).

An audience is a necessary ingredient in a virtual environment that presents exposure to public speaking. Designing animated avatars that depict human audiences, however, comes with the pitfalls of the uncanny valley effect (Mori et al., 2012; Schwind et al., 2018) and subsequent trade-offs in design between realistic and cartoonish human-like avatars (Seyama and Nagayama, 2007). Hence, designers of these treatments often opt for semi-realistic avatars to represent humans, along with simplified animation of social interactions (Lindner et al., 2017).

While some efforts have been made to include 360° video in exposure therapy (Stupar-Rutenfrans et al., 2017), these feature generic settings – such as an auditorium – that are also commonly seen in computer-animated VR environments for exposure therapy. We argue, in line with Hodge et al. (2018) and Seol et al. (2017), that there is a need to explore tailoring of treatments and ways to rapidly create new VR scenarios. The debates on realism in VR (Slater and Wilbur, 1997; Slater and Sanchez-Vives, 2016) are often focused on pixels and sensory fidelity, but we argue that there is also a need to go beyond this and focus on what is real and authentic in terms of social scenarios, especially when conducting exposure therapy for fear of public speaking.

3 Methods

To address how to create VR scenarios based on the lived experiences of the target audience, we organized our research into three phases. First, we planned a participatory workshop with adolescents, evaluating how 360° cameras can be used to prototype VR scenarios. Second, following the implementation of the workshop, we conducted a detailed analysis of how the participants interpreted and organized their work in making the VR scenarios. Finally, we had six clinical psychologists evaluate the four scenarios that resulted from the workshop, assess their realism, and discuss how the workshop approach could be used to make tailored VR scenarios for exposure therapy.

3.1 Participatory workshop

We engaged adolescents aged fifteen to seventeen in a process of participatory design (Bratteteig and Wagner, 2016; Ehn, 2008; Svanæs and Seland, 2004; Dreessen and Schepers, 2018; Vines et al., 2013), going beyond traditional user consultation and testing by seeking active contributions in the form of design proposals and alternatives. The primary motivation for involving adolescents was to have them not only engage creatively in the design process, but also produce scenarios that are grounded in their lived experiences and life-world. In line with Dourish (2001), we understand life-world as "the intersubjective, mundane world of background understandings and experiences of the world. It is the world of natural attitude and of everyday experience" (p. 106).

Thus, we were mainly interested in adolescents' knowledge of and experience with situations that require them to speak publicly. By involving them directly in the design process, we aimed to build on lived experiences that we would not ordinarily have access to and thus achieve relevant and socially realistic prototypes. The specific way the adolescents participated in the design process was to collaborate in groups on iterative design phases for making a 360° video potentially treating fear of public speaking. They also gave feedback on other groups' work throughout the process. The researchers and facilitators, on the other hand, defined the goals and steps in the work process, provided guidance and background knowledge on central topics (*i.e.* VR, creative work processes, and fear of public speaking), occasionally offered encouragement and advice on the collaboration process, and assisted in the use of technical hardware and software.

We recruited participants from two public schools by distributing an informational flyer. We asked for participants that were between 15-17 years old and had either an interest in designing technology or first- or second-hand experience of fear of public speaking. Participants were recruited from secondary schools, as these educational institutions are settings in which social phobias commonly begin (Wittchen and Fehm, 2003).

Fifteen participants signed up for the workshop, four of whom were female. The board of ethics – The Data Protection Official for research, assessed and approved the study. Participants aged sixteen and older were allowed to personally sign the informed consent form. Three fifteen-year-old participants had their consent forms signed by parents, as required by Norwegian privacy law.

Participants received certificates of participation and compensation in the form of $120 in gift certificates.

The workshop was organized as a two-day event over a weekend. The participants formed groups on their own based on their prior acquaintance as classmates. In total, there were four groups: three groups with four participants, and one group with participants. The goal of the workshop was to produce four distinct prototypes.

3.2 Data collection and analysis

We filmed the participants and facilitators throughout the workshop. Using four cameras, we were able to capture all participants' collaboration on their scenarios. The video recordings provide a detailed view of the adolescents' work process, including how they made sense of their given task and how they understood 360° video and VR environments.

Ten hours of video recordings were transcribed verbatim. All transcribed data was entered into NVivo for qualitative analysis. We used thematic analysis (Braun and Clarke, 2006, 2014) to search for thematic patterns throughout the data corpus. The following question guided the analysis: "How do the participants make sense of their design task and how do they work when designing VR scenarios?" The analysis was performed using a bottom-up, inductive approach, meaning that interesting data excerpts were coded for what they represented in the situational context, not how they fit into our preconceptions of fear of public speaking, design, and participation.

The first author conducted initial coding of the data, using codes such as "realism," "task understanding," "storytelling," and "sharing an experience." Then, the codes were read through and organized into possible themes. Each theme was then mapped out in a conceptual model of the data corpus, with the author ensuring the extracted codes made sense within their themes. Lastly, the themes were refined to avoid overlap and reflect the research question.

3.3 Evaluation

Viewing the prototypes in light of Levac and Galvin's (2013) perspective on VR as a tool for therapy, we performed an expert evaluation with six clinical psychologists. Evaluators were recruited among acquaintances and colleagues. Three of the experts had prior knowledge of and experience with VR for exposure therapy. One had practical and clinical experience using VR in therapeutic practice to address fear of public speaking.

The psychologists viewed the four prototypes using an HTC Vive Pro HMD and were interviewed before and after the viewing based on the following structure: (1) their previous experience with VR and knowledge and practice of exposure therapy; (2) their general impression of the prototypes, assessing perceived realism and how improvements may be made; and (3) the feasibility of using the prototypes as a therapeutic tool.

The goals of this evaluation were to explore both how the VR scenarios may be perceived and experienced by patients (Klasnja et al., 2011) and how they could be used as a tool in therapy (Levac and Galvin, 2013). While we have not done an evaluation with patients, we follow Doherty et al. (2010), who propose that therapists can be used as proxies for patients in evaluation by providing an understanding of how a tool may be perceived and experienced by them.

4 Participatory design of VR scenarios

In this part of the paper, we provide an account of our method for designing VR scenarios and how we applied it in a participatory two-day workshop with fifteen adolescents.

4.1 Process for creating VR scenarios

"A scenario is a construction with the clear purpose of presenting and situating solutions to a problem" (Bødker, 2000). When building a VR scenario, we understand the process to align with Bødker's view of creating a scenario for design (2000), but also understand it to include a dramatic composition that can be acted out, captured by a stereoscopic 360° camera, and rendered into a video that can be experienced in VR.

To prototype VR scenarios with participants, we devised the following iterative process for design: (1) ideation, (2) storyboarding, (3) live-action plays recorded by a 360° camera, and (4) experience-based evaluation.

Ideation

When designing a VR scenario, it is necessary to construct an environment wherein the events take place. A phase of idea-generation (Zimmerman et al., 2007) is necessary to select the elements that make up the scenario's plot and environment. This ideation is performed by discussion and building on co-participants' ideas. The outcome of this phase is a conceptualization of the selected ideas for the next phase of storyboarding.

Storyboarding

Storyboarding is a technique for integrating the conceptualized components of a scenario as a cohesive script (Truong et al., 2006). To compose the script, one can draw comic strips on a sheet of paper. A further method to support storyboarding is the use of a circular piece of paper that illustrates the 360° environment of VR. An overlaying circular sheet with 100° of the circle cut out can be attached to this 360° storyboard to illustrate the user's field of view. This circular overlay can then be rotated to show every potential viewpoint of the planned scene.

Live-action plays

There is a tradition for using role-play as a technique to support the design of interactive experiences in HCI (Vines et al., 2014; Kuutti et al., 2002; Spence, 2016; Svanæs and Seland, 2004; Brandt and Grunnet, 2000; Buchenau and Suri, 2000). To create a VR scenario, one can use actors and props to enact the storyboard as a live-action play, which can be captured via a 360° video camera. The recording can then be stitched and rendered as a 360° video that affords an immersive experience when viewed through an HMD. The configuration of the role-play that is captured, stitched, and rendered to a 360° video constitutes a prototype, which can be experienced, assessed, and reviewed by the designers and other interested parties.

Experience-based evaluation

The VR scenario may be viewed through an HMD for an immersive VR experience. This viewing can be organized as an experience-based evaluation (Buchenau and Suri, 2000) in which one critiques the design and highlights how the scenario may be improved. By experiencing their VR scenarios first-hand, participants can gain insight into how others may perceive the prototype.

4.2 Technical equipment for VR prototyping

A stereoscopic 360° video camera, Vuze+, was used for capturing the participants' scenarios. The camera records stereoscopical video in 4K resolution at 30 frames per second. We used the accompanying Humaneyes VR Studio software for stitching video, minor video editing, and rendering to H264-encoded 360° video files. For viewing the scenarios as VR experiences, we employed Samsung Gear VR HMD devices with Samsung Galaxy S8 smartphones and headphones for achieving spatial audio.

4.3 Workshop implementation

The workshop started with a few presentations aimed at encouraging collaboration, inspiring creative thought, and familiarizing participants with the topic of fear of public speaking. The participants were then led through a series of icebreaker games and received a hands-on presentation on fear of public speaking by a clinical psychologist, demonstrations of how VR works, and an overview of how to iteratively prototype VR experiences with a stereoscopic 360° video camera. We concluded this session by setting the goal of the workshop: "Create a situation where a person may experience fear of speaking publicly."

Participants worked together in groups for 45 minutes to ideate, discuss possible directions for their scenarios, and compose storyboards. Halfway through this ideation phase, a facilitator visited each group to check on progress. The members of one group, for example, stated they had planned their scenarios around the intent to "create an intense experience that would be almost intolerable." Here, the facilitator intervened to reiterate a key point from the presentation on fear of public speaking: usually, for a person who has trouble speaking in front of others, the task of performing is difficult enough.

Following the first ideation and storyboarding phase, the groups of participants presented two ideas for VR scenarios to co-participants and facilitators, who offered feedback in an informal evaluation. In this session, each group chose one scenario to continue developing. The first day ended with taking 360° video recordings of the chosen scenarios, in which the participants helped each other by serving as actors. Four VR prototypes resulted after stitching and rendering. The post-processing of 360° video was done by the facilitators to save time and to prioritize the participants' creative process.

The second and last day of the participatory design workshop began with one of the facilitators, a clinical psychology student, reiterating the critical points of the previous day's presentation on fear of public speaking. The participant groups then continued their work by experiencing and evaluating two scenarios each (their own and one created by another group) with an HMD device for a fully immersive VR experience. One facilitator joined each group to assist the participants with navigating the interface of the VR headset and elicit constructive, critical reflections on their experiences viewing the scenarios.

After this forty-five-minute evaluation period, a joint viewing session of all VR scenarios was conducted, with each group summarizing its evaluations as feedback. Participants gave each other frank and constructive commentary. For example, one individual said, "[The scenario] was realistic, and that is good, but you could work on the actors messing around. It is easier to be drawn in if it feels truer." Following the feedback session, each group reconvened to revise its scenario based on the review. Participants drew modified storyboards, drafted new speaking lines, and rehearsed their scenarios where necessary. The majority of this day was spent capturing the revised scenarios with the 360° camera. Each group did three to four takes of its scenarios, evaluating the performances between takes, and used co-participants and facilitators as actors.

The "best take" of each group were stitched and rendered into 360° videos, shown in a final joint viewing session with all participants. Before we detail the resulting VR scenarios, we turn to an analysis of the collaboration between participants in this workshop.

5 Analysis

This section presents a thematic analysis of the adolescents' design process, focusing on how they used their experiences as input for design, how they envisioned their scenarios, and how they made sense of the task at hand.

5.1 Designing from lived experiences

The participants verbally shared lived experiences to form common ground through which to explore the design challenge and generate reflections on how their scenarios may play out for a viewer. We identify two ways in which the participants shared experiences and stories that shaped the design: (1) sharing a memory of a situation in which one experienced fear of public speaking to spur discussion in the design process and (2) sharing an experience of witnessing someone's fear of public speaking to guide specific elements of the design.

First, we look at how participants used their lived experiences to open discussion in the design space:

> Lars: Every time I am presenting for my class I end up acting like a fool. Everyone thinks it is hysterical [in a good way], and then I am like, "Fuck me, every time I try to act seriously..." And then it is like, "Damn, what was I saying again?" I just crack up.

Early on in the design process, Lars shared this experience with his group and thus made the problem at hand available to discussion. Another participant, Anna, shared an experience of how an audience can make her anxious when she is giving a presentation:

> Anna: When I present in class, I do not care for chatter among the participants. It makes me feel uninteresting and makes me anxious.

While Lars shared an experience of how he can disappoint himself in public speaking situations, Anna described an experience of how audience behavior affects her during a presentation. The former establishes speaking in front of others as a theme, while the latter has the extended utility of contributing a particular variable to the design of the scenarios.

Participants also shared stories of observing other people's fears and used them as a design element.

In the example below, Ivar tells a story of how someone he worked with in class was overcome with pressure from performing a mundane task:

> Ivar: So, like, the first time we got any insight to who she was, well, it was one other person and me, right, and she was merely translating "smart" to Norwegian [from English; the word is the same in Norwegian]. She could not do it. So she, like, broke down because it was too much pressure. From two other people.

This storytelling was used by participants to socially explore the phenomenon of fear of public speaking as a step in their design process, which in the above example led to an early idea that was later abandoned. Here, they observed that it is possible to experience fear of public speaking without being explicitly asked to speak in front of the class. The way stressful situations may occur from mundane conversations.

5.2 Envisioning and composing the virtual experience

To design a scenario, the participants had to compose a virtual environment in which it could take place. Creating this virtual environment entailed the use of design tools, as well as the proposal of a dramatic composition. In the conversation example below, the participants are using the circular storyboards described in section 4 to negotiate decisions about their design. The circular storyboards drawn up for their scenario function as a reference point to discuss the placement of actors and sequencing of dialogue. Employing the storyboards, the participants are negotiating how to incorporate elements such as audience attention to the user into their virtual environment.

> Ivar: You are in the middle of the classroom, and then you get up to explain stuff?
>
> Karsten: Yes, or your teacher is here [pointing at storyboard], and then she asks, like, a random student, like, “Yes, and you? Please tell.” And then that student, maybe one of us, right, as an actor, “Yes, I am this and that, born in China,” or whatever. And then, “Yes, how about you?” and she is then pointing at the student sitting there.

Here, Karsten is using the storyboard and his surroundings to explain how he envisions the scenario. The storyboard is used to situate the user, whom he refers to as the “student sitting there,” within the virtual space.

The following example illustrates how the participants envision the roleplay based on their conception of what will trigger fear of public speaking. In this group’s case, it is the action of someone turning around to look directly at the user. Furthermore, the specific choice they make here incorporates an element of surprise in that the teacher is seemingly randomly asking people to respond.

> Ivar: And then everyone turns around.
>
> Karsten: So he can see that everyone is staring at him, or not everyone, but some, so he must tell them something.
>
> Lars: So it is going to be very on the spot. You are not given anything before that.

This demonstrates how the participants use the design tools to compose the virtual space and its components of actors and dialogue. It also exemplifies how choices related to the construction of dialogue and dramatic composition are based on the adolescents’ conceptions of what it means to experience fear of public speaking.

5.3 Making sense of exposure therapy

Part of the participants’ design process involved building an understanding of the subject matter, namely fear of public speaking and exposure therapy.

Figure I.1: An equirectangular snapshot from *The introduction round*. This snapshot is cropped vertically for appearances.

Initially, participants were unsure of what the goal of their scenarios should be, asking questions like, "What level of social anxiety are we dealing with?" By refining their scenarios, they were able to improve their understanding of the subject matter. The below transcript, taken from an evaluation of a group's first prototype, reflects how participants' understanding had developed since the workshop began.

> Anna: I just realized something regarding our video. The fact that our reaction is so negative will only make the patient or person watching that has these anxieties feel even worse.
>
> Daniel: Yes, I thought the same.
>
> Anna: While all the others are saying something about themselves we are laughing.
>
> Cedric: But the goal here is to make a bad ending? Because that was everyone's focus yesterday. That it should be ...
>
> Bendik: And that is good, right? That people get to practice?
>
> Anna: No, it is supposed to be therapy. You are supposed to get used to talking in front of people. The point is not to make anyone feel worse.

The transcripts illustrate the joint construction of ideas about the condition of having a fear of public speaking and what experience the scenario should offer the viewer, based on a review of the first prototype. Anna makes sense of what the group's prototype is by placing it within her conception of "therapy." She identifies the negative consequences the scenario they have created may have for someone with public speaking anxiety. This sparks a discussion within the group, in which the participants collectively come to understand the purpose they are designing the scenarios for: to create a virtual environment that can help improve users' public speaking abilities. It is then understood by the group members that they should rework the tone and feel of their scenario.

6 VR Scenarios for fear of public speaking

Following the analysis of the participants' collaboration to create VR scenarios, we present descriptions of each group's final prototype from the participatory workshop. A person viewing the scenarios in VR may experience fear of public speaking and practice his or her public speaking skills.

6.1 The introduction round

With the viewer placed among a circle of high school students, this scenario starts with a person introducing himself as the teacher of the class, welcoming everyone to the first day of secondary school (Figure I.1). The teacher shares his name and a hobby he enjoys. Each student then follows in turn, performing the same introduction. One of the students starts talking about something unrelated on his turn, leading the teacher to interrupt the student and cue the circle to continue. The last student before the viewer tells a joke about his skills in performing push-ups, which prompts all students in the circle to burst into laughter. As the collective laugh eases, the teacher asks the viewer to introduce him or herself. Twenty seconds of silence follow, with the students in different modes of attention and suggestive postures. The teacher proceeds by thanking the viewer and the round continues until everyone has introduced him or herself. The teacher concludes by thanking everyone for their participation.

6.2 Interruptions in the classroom

The viewer is placed at a desk in the middle of a classroom with students sitting at their desks. To the left, a fellow student is introducing himself to the class. In front of all the desks, a person easily identified as the teacher thanks the student and instructs the viewer to present a self-introduction. Silence follows for ten seconds, with the students in front of the viewer turning toward him or her in their chairs. Suddenly, the door opens, and a person walks halfway into the room. “Does anyone know where the big auditorium is?” the person asks. “Yes, down the hall and the last door on your left,” a student on the viewer's right responds. The person leaves and closes the door. Mild laughter follows, with the teacher breaking through the laughter to say, “Please continue.” After five seconds of silence, students on the viewer's right become inattentive. The teacher quickly disciplines them, saying, “Please pay attention.” Thirty seconds of silence follow, giving the viewer an opportunity to speak to the class.

6.3 Reminiscing about the weekend during recess

The viewer is placed within a group of friends sitting on couches, casually discussing their weekend during recess. Several conversations are occurring at the same time while music is heard from a phone, making it difficult to follow any one discussion. The subject among the friends is a party they attended the previous weekend. “Everyone was at the party, right?” one person distinctly asks the others in the group. A person to the left of the viewer confirms this. The music goes silent. “Yes, everyone was at the party,” declares a girl in front of the viewer. Immediate silence follows. The boy next to her asks the viewer, “Were you there? I cannot remember seeing you at the party.” Silence follows for ten seconds, while the group of friends pays some attention to the viewer. The focus then diverts from him or her and the conversation picks up again.

6.4 Presenting a field trip in class

The viewer is situated behind six students sitting at their desks, with three students behind desks to the right. At the front of the room, there are large sheets of paper, on which are written key words about a field trip. A seemingly disgruntled teacher mentions something about the field trip and asks the viewer to come forward to summarize it for the class. A fade-to-black sequence follows and the viewer finds him or herself in front of the class with the task of presenting a summary of the trip. The teacher prompts the viewer by saying, “Yes, please begin.” Facing the students, the viewer must improvise a summary of the field trip based on the key words, which are no longer visible. The students look inattentive. After fifteen seconds of silence, one student exclaims, “Please speak louder!” Some students start giggling and the teacher quickly reprimands them. Twenty seconds of silence pass. Suddenly, the sound of a school bell is heard, prompting the students to get up and leave the room for recess.

Having presented each group’s final prototypes, we now turn to the expert evaluation by six clinical psychologists that was carried out after the participatory workshop.

7 Expert evaluation

The psychologists’ feedback is categorized according to the following themes: (1) presence and realism and (2) their feasibility as a tool in therapy.

7.1 Presence and realism

In VR, presence refers to the subjective sense of being present in the virtual environment (Slater and Wilbur, 1997). Describing the experience of the ’introduction round’ scenario (Figure I.1), one evaluator said, *“It felt like I was there, physically, in the group. It felt like it usually does in real life. It’s not like I’ve just had VR glasses on. It was quite convincing.”*

Another evaluator appreciated the anticipatory effect of waiting for one’s turn in the same scenario, saying, *“You can feel it coming. One step closer, one step closer. I could feel it in my body that there was an activation.”*

The evaluator with previous experience using VR for therapy highlighted the more nuanced content that 360° video is capable of capturing compared to CGI. He said, *“Although this is similar to my prior experiences with VR, where you are presenting, this is so much more . . . realistic, down-to-earth. . . . Because you have the adolescents, with their body language, which I think people with fear of public speaking will find quite disconcerting.”*

The evaluators reported being impressed by the realism of the prototypes, noting the actors’ naturalistic performances. One evaluator said, *“If these people [in the scenarios] were actors, then they did a really good job.”* After seeing “The introduction round,” another evaluator asked, *“Is this real? Or are they actors?”* The evaluators responded to the situations depicted in the scenarios as experiences that they were familiar with from their own memories of school.

One evaluator suggested that each scenario could first be introduced from a bird’s-eye view perspective or that the role of the viewer could first be as an invisible bystander, saying, *“I was thinking about how to introduce this more mildly. I would have one [scenario] where I was outside the situation and just observed the group. Then you would know what’s about to happen.”* This psychologist had prior experience in doing *in vivo* exposure therapy and was familiar with the method’s progressive, hierarchical framework (Ollendick and Davis, 2013).

Although stereoscopic 360° videos provide depth of field when viewed via HMD, finer details of features (such as facial expressions) may be blurred in the case of actors who are situated far from the camera. Noting this lack of fine details in distant actors, one evaluator remarked, *“There was a certain ’filter’ that made their faces harder to see. It is important that facial expressions are visible to make the experience as realistic as possible.”* Other evaluators also noted the same visibility issue. However, the resolution was still high enough to sustain the perceived realism of the scenarios.

7.2 Feasibility as a therapeutic tool

Overall, the evaluators were positive about the potential of using VR scenarios like those prototyped through this study in exposure therapy. Most argued that they would not be useful as stand-alone tools, but had the potential to enhance therapy if combined with psychoeducation and specific practice tasks.

One of the potential advantages of 360° videos lies in the readily available, realistic recreation of challenging situations. In the words of one evaluator, *"In a therapy situation, we often play [roleplaying] games where, as a therapist, I play out situations and practice a little with the patient. But this [prototype] is much more varied. It could somehow cause anxiety [more easily]. It is closer to the situation. It is more real than what a therapist can do with exercises and plays. I think the anxiety will go up. And that's good; that's what we want. [It's good] [t]hat we get the patient activated in the therapeutic room, that they get the anxiety activated, that they can get into that situation."*

Another evaluator said that the prototypes in their current form could be very challenging for patients, but still useful as a therapeutic tool, explaining, "If you have been bullied in school, I think this can be really uncomfortable and evoke unpleasant memories." There is an upside to this effect, however, as painful memories and feelings may be difficult to evoke and examine in conversation alone. Patients often have difficulty remembering and articulating exactly what causes the experience of fear in a particular situation and the prototypes can make fear-producing situations immediately available. The use of 360° video in VR was regarded as a hands-on, direct approach that could be useful in therapy.

The absence of control within the virtual environment raised a concern with one of the psychologists. If the scenario becomes too uncomfortable for the person using the HMD, there is no option within the interface to regain control by adjusting the stimuli.

8 Discussion

Our method for participatory design of VR scenarios presents both opportunities and challenges for designing VR exposure therapy with adolescents. In this section, we discuss each phase of the iterative design process and present reflections on using 360° video in exposure therapy for this age group.

8.1 Participatory design of VR scenarios

As explained in section 4, a scenario is a construction that presents and situates a solution to a problem (Bødker, 2000). To realistically construct and situate a solution in a VR scenario, there is a need for a clear description of the environment (including potential actors and props), a storyline, and an understanding of how the environment and storyline can be integrated as a live-action play. The scenario can then be developed into an experience prototype (Buchenau and Suri, 2000) when captured with 360° camera and subsequently viewed through an HMD.

Ideation

The goal of the first phase, ideation, was to generate ideas of situations in which one could experience fear of public speaking. Using their lived experiences as a resource for developing ideas, the participants created potential scenarios that included surprising elements.

In this phase, it is essential to ensure that the participants stay focused on the task at hand. In participatory design, there is a trade-off in facilitator intervention: steering the process towards the desired goal of the workshop versus letting the participants creativity roam freely. Svanæs and Seland (2004) discuss this trade-off and ask, “To what extent do the scenarios and ideas originate from the users, and not from the facilitators or developers?” (p. 485). The appropriate balance can be achieved by: (1) clearly stating the intended goal of the workshop, (2) providing the participants with the necessary information to carry out their work, and (3) directly intervening in the creative process if participants lose track of the workshop goals. While this may be relevant for all phases, it is particularly important to keep participants focused on the overall goal in the ideation phase. Facilitators should ensure they guide participants in conceptualizing and choosing between ideas for further development.

Storyboarding

In their collaborative process, the participants used storyboards, as detailed in section 4, to negotiate the composition and storyline of their scenarios. Our thematic analysis addresses how the storyboard can function as a shared reference participants can employ to situate their ideas and envision their scenarios in a virtual environment. The circular storyboards have a certain pedagogical value in that they aid participants in understanding how scenes need to be arranged to be filmed in 360° video. The camera is situated at the center of the circle and the overlays only allow visibility of 100° at a time, helping illustrate how a viewer might navigate the virtual environment. Some groups in our study, however, had a more dialogue-based storyboard focused on generating the speaking lines for the actors. The main outcome of this phase is a detailed script of how the storyline will be acted out, which can be represented in different ways through the use of comic strips, circular cards, or written lines (Truong et al., 2006).

Live-action plays

Live-action plays, role-playing, and design theater have been used to explore design concepts (Buchenau and Suri, 2000), generate concepts for design (Kuutti et al., 2002), and embody and act out design ideas (Svanæs and Seland, 2004). In our process, however, the plays also served a more concrete purpose in producing a virtual environment. The iterative process helped refine these plays and the participants needed several rounds of rehearsal and up to four takes to get the results they wanted.

Having the adolescent participants perform as actors in their scenarios added to the authenticity and realistic qualities of the prototypes. Although the participants were not professional actors, they played roles that were familiar to them.

Experience-based evaluation

The experience-based evaluation session, in which the participants experienced their scenarios first-hand with an HMD, provided an opportunity for the adolescents to see how their ideas and acting played out in VR. As shown in section 5, this prompted Anna to consider how the scenario should be designed to help the viewer “get used to talking in front of people.” This demonstrates the value of these evaluation sessions in improving empathy for viewers and assessing to what extent the prototype conforms with the ultimate goal.

In assessing the quality of outcomes of a workshop for developing scenarios, Svanæs and Seland (2004) ask a pertinent question: “Are the scenarios accurate in their description of the situations being studied?” (p. 485). This question refers to the produced scenario’s truthful relation to the real world (Svanæs and Seland, 2004). Experience-based evaluation as incorporated in our method is one way of assessing this quality, as it allows the participants to evaluate the realism of what they have designed.

8.2 Beyond pixels and sensory fidelity in VR scenarios

The participatory process was crucial to creating scenarios that appeared to be authentic social situations. In the analysis of the participants’ work process, we can see how they concretely discussed their own lived experiences and gave accounts of others' experiences from their daily life, and how they used this as a resource in the design of their respective scenarios.

When making VR scenarios using CGI, a major challenge is virtual character design (Schwind et al., 2018) and avoiding the uncanny valley effect. In the case of VR scenarios generated using 360° video, however, the main challenges are tied to whether the situation that is portrayed in each scenario seems believable and socially realistic, along with how well the script and storyline are acted out.

While the scenarios feature real people displaying realistic body language as characters, they are still limited by the fact that the interaction is scripted. This highlights an additional challenge with scenarios that have a somewhat complicated storyline and composition of actions. In particular, the difficulty relates to how the participants in the scenario can address the viewer and how the script can be timed to fit what the viewer says and when he or she speaks.

The way turn-taking is accomplished in social interaction (Sacks et al., 1974) depends on micro-pauses and the timing of details such as gazes and gestures. This is challenging to accomplish in a VR scenario, since the actions of the viewer are unknown. While an actor in the scenario can address the camera as a proxy for the viewer, it is difficult to, in a realistic way, signal when the viewer is supposed to stop talking. The technique of addressing the camera was used in all our scenarios. Further research into how to overcome the challenge of having a realistic interactive experience in VR scenarios based on 360° video is needed. In the context of exposure therapy related to public speaking, several possible techniques could be explored. For example, one might include a graphical overlay with a progress bar indicating the speaking time the viewer has available or, alternatively, display a script of speaking lines for the viewer in the form of subtitles in the virtual environment (Brown et al., 2017; Rothe et al., 2018). A key point when designing VR scenarios is to make the storyline clear in terms of when the user is supposed to say something or when a particular action is expected.

8.3 Tailoring VR scenarios for exposure therapy

One of the themes identified in the analysis was that the participants had to make sense of the concept of exposure therapy. There are challenges tied to including adolescents in the process of creating content for therapeutic tools. It was not straightforward for the participants to create scenarios that aligned with the therapeutic makeup of exposure therapy – neither were they expected to or tasked with designing *therapy*. The facilitators intervened to guide some of the groups' processes away from creating situations that elicit as much fear as possible to instead design scenarios in which the viewer could experience conditioned fear responses in a realistic situation.

The expert evaluators found the scenarios convincing in portraying situations that are well-suited to reproduce relevant feared stimuli for adolescents with a fear of public speaking. The evaluators highlighted the social nuances and body language of the actors as key features for making the scenarios realistic and authentic. They further saw the value in using the scenarios as a component of exposure therapy. Still, having realistic scenarios, with familiar scenes, is not necessarily enough to make exposure therapy successful. The idea of using VR as a *tool* in exposure therapy (Levac and Galvin, 2013) means thinking of the VR scenario as only one of the necessary elements of treatment. To use VR scenarios in therapy would, for example, require a therapist to compose accompanying tasks for the patient. Then, the therapist can monitor performance and evaluate outcomes of the therapy.

Furthermore, therapists could, following our method, even tailor 360° video content for specific social phobias that match the patient's condition. This tailoring would enable the therapist to provide appropriate challenges and specific goals based on the needs of the specific patient, but would require access to equipment and someone to act out the plays.

In this study, we have seen that adolescents are capable of participating in a design process and that the produced scenarios have the qualities of being realistic and portraying scenes from a familiar social and cultural context. Thus, they are recognizable for the target group. The main strength of the method is that it can help capture those qualities. The goal of the outlined process is not necessarily to make ready scenarios for use in therapy, but to prototype and materialize ideas and suggestions that are grounded in the lived experiences of the target group—in this case, adolescents. In this sense, the scenarios can function as prototypes that capture ideas and experiences that can be used in a continuing design process. Moreover, the participatory design process can be used to tailor treatments for different target groups and to provide scenarios portraying relevant experiences. This can help frame design solutions specific to particular cultural contexts, social situations, and therapeutic needs.

9 Conclusion

This paper has presented a participatory approach to prototyping virtual reality scenarios for exposure therapy to address fear of public speaking. In our study, we demonstrate how adolescents can be involved in the design of VR scenarios enabled by 360° video recording. We also show how the participants draw on their lived experiences when creating these scenarios. The paper illustrates that 360° video is a viable tool for making the design of immersive VR experiences more accessible, as it requires far less advanced technical skills than creation of CGI-based environments and is less time-consuming. Further, the expert evaluation phase in our study highlighted the authenticity and realism of the scenarios, which were seen as being potentially useful in a therapeutic context. This approach to designing VR scenarios with 360° video offers the potential to tailor VR experiences to many different situations and to specific fears. Our participatory method demonstrates how it is possible to design VR scenarios relatively rapidly and we expect that therapists could build on our approach to design such scenarios and potentially include patients in the process of tailoring VR environments to help address their specific fears.

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Paper II

"This is the story of me": Designing audiovisual narratives to support reflection on cancer journeys

Abstract

Recovering from serious illness involves a bodily and psychosocial reorientation in everyday life. Survivors of gynecological cancer often experience bodily changes, fear of cancer recurrence, and changes in sexual health. This paper explores how we can use audiovisual narratives based on experiences of gynecological cancer survival in the design of an online intervention. From a typology of cancer survival, we designed three audiovisual narratives in an experience-centered design process involving gynecological cancer survivors. The narratives were evaluated by 10 participants formerly treated for gynecological cancer. In a thematic analysis, we explore how these narratives set the stage for identification and reflection by being experienced as relatable, provoking, and realistic. Finally, we discuss how the survivors' experience of the narratives can be construed as meaningful, and how accounts of experiences can be included in a design process to create narrative content for online interventions.

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1 Introduction

Recovering from gynecological cancer may involve dealing with late effects, such as changes to the body, cancer-related fatigue (Sekse et al., 2015), fear of cancer recurrence, and sexual health (Sekse et al., 2019, 2017; Harrington et al., 2010). However, cancer survivors remain largely uninformed of these late effects, which may occur after treatment (Dahl et al., 2013); indeed, most do not regain their previous levels of health and psychosocial wellbeing (Burkett and Cleeland, 2007; Harrington et al., 2010).

Survivors of gynecological cancer need interventions that can support them with educational resources and self-management tools after treatment (Cerna et al., 2019). Online interventions hold the promise of improving access to health services and have lower operating costs than traditional means of healthcare delivery (Rogers et al., 2017; Doherty et al., 2008). As such, online interventions are a promising platform for reaching groups who have been neglected in the healthcare services or who are difficult to reach through traditional treatment channels. Online interventions that aim to improve the psychosocial health of cancer survivors are often delivered through websites (Ross et al., 2020), and they have been found to be effective in improving overall quality of life (Kim and Park, 2015).

A body of work within HCI research has studied how to support cancer journeys with technology (Suh et al., 2020; Hayes et al., 2008; Jacobs et al., 2016). Hayes et al. (2008) introduced the "personal cancer journey" as a concept to describe the period from screening and diagnosis through treatment until the absence of cancer. However, it is recognized that cancer survivors still struggle with late effects after cancer treatment. We therefore argue that there is a need to consider the time after successful treatment when designing technology to support cancer journeys.

For instance, in recovery, survivors of gynecological cancer often must reorient themselves to their new bodily reality and health:

> Confronted with gynaecological cancer, its treatment, and consequences, the women had experienced that their bodies had changed in profound ways. They could no longer take their bodies for granted, and they had to get to know and understand them in new ways. In this respect, surviving gynecological cancer could be seen as entailing a loss of homelikeness in the body and the familiar world. (Sekse et al., 2013, p. 25)

In Frank (2013)'s words, this is "when bodies need voices" (p. 1). To tell one's story of illness is to articulate and understand one's need for improved self-competence and self-care after treatment. Hearing the stories of others and reflecting on and retelling one's own survival story can be steps in the healing process (Frank, 2013). In designing psychosocial support for these challenges, stories and narratives of cancer survival can help mediate survivors' understanding of their illness and, in particular, the changes that women undergo.

In this study, we subscribe to the phenomenological tradition of studying the lived experience of illness (Svenaeus, 2000). From this perspective, *illness* contrasts with the biomedical understanding of *sickness* as a condition that can be cured (Svenaeus, 2000). "Illness" refers to health as it is experienced first-hand, thus including the psychosocial realities that are imposed by living with sickness.

This paper concerns the design of audiovisual narratives for an online intervention supporting women's recovery from gynecological cancer. The intervention was developed as a psychoeducational program addressing women's self-competence and self-care after treatment. Central to the intervention were three audiovisual narratives with three different characters telling stories of cancer survival. The audiovisual narratives were part of an exercise to support women in recognizing and reflecting on their experiences of living through gynecological cancer. This paper focuses on the design of these audiovisual narratives and how survivors experienced them.

The three narratives were based on a specific typology of living through gynecological cancer (Sekse et al., 2012) and embedded contextualized, personified accounts of how survivors may cope with everyday life during and after serious illness. In addition to this typology, prior research on the experiences of survivors underlaid the design of the audiovisual narratives, which took place in collaboration with clinicians and gynecological cancer survivors through a series of focus-group meetings.

In a thematic analysis of 10 in-depth interviews with participants who survived gynecological cancer and evaluated the audiovisual narratives, we show how these narratives can set the stage for identification and reflection. We discuss how survivors engaged with the narratives and how they experienced the narratives as meaningful.

This paper contributes to current discussions on experience-centered design in HCI by exploring how narrative can be used as a vehicle to capture and represent experiences of illness in an online intervention. A key contribution of this work to HCI research is the consideration that life after successful cancer treatment should be addressed in technologies designed for supporting people undergoing a cancer journey. Thus, we here challenge the prevailing cancer-centric views on providing technology to people with cancer sickness by giving special attention to the cancer illness experience as it is lived.

The paper has the following structure. First, we give the background of our research and describe related work. Then, we explain the methods we used for our design-led inquiry, followed by a description of the design process and the resulting audiovisual narratives. We then thematically analyze the evaluation to explore how the participants experienced the audiovisual narratives. Finally, we discuss how the narratives contributed to shaping a meaningful experience for survivors of gynecological cancer, and the implications our findings have for experience-centered design of cancer support technologies.

2 Background and related work

This section of the paper discusses previous research on the bodily and psychosocial experiences of gynecological cancer survivors. We also provide an overview of past research in HCI that has addressed cancer journeys. Then, we present narratives as a form of communicating the experience of illness, and how narratives have been addressed in HCI research. Lastly, we discuss briefly how meaningful engagement with technology can be qualitatively understood.

2.1 Living through and after gynecological cancer

Gynecological cancer is any cancer that starts in the female reproductive organs. As treatment and early cancer-detection methods have improved (Hellbom et al., 2011), the number of gynecologic cancer survivors has increased. However, being *cured* of any type of cancer can produce new problems of which cancer survivors often remain uninformed (Dahl et al., 2013). Surviving gynecological cancer is associated with changes to the body including late effects such as fatigue (Sekse et al., 2015), fear of cancer recurrence, and sexual health (Sekse et al., 2019, 2017; Harrington et al., 2010). Furthermore, certain gynecological cancers, such as cervical cancer, are associated with social stigma (Westbrook and Fourie, 2015): survivors have reported stigma, shyness, and emotional avoidance as barriers in seeking and accessing services regarding their sexual health (McCallum et al., 2012). The immediate period after completed cancer treatment holds an important opportunity for intervening in a patient's need for improving quality of life (Burkett and Cleeland, 2007). However, in Nordic countries, interventions for improving psychosocial wellbeing are not an integral part of rehabilitation plans (Hellbom et al., 2011), and as such these follow-up routines are in need of improvement to better meet the needs of survivors (Vistad et al., 2011). Currently, most cancer survivors do not regain their previous levels of health or psychosocial wellbeing (Burkett and Cleeland, 2007; Harrington et al., 2010). This situation has prompted calls for a person-centric care model, as an extension to the cancer-centric care that is often emphasized in oncological healthcare (Suh et al., 2020).

A typology of how women live through gynecological cancer by Sekse et al. (2012) identified three common types of survival journeys: the emotional- and relationship-oriented, the activity-oriented, and the self-controlled. In Sekse et al.'s (2012) study, the survivors described as *emotional- and relationship-oriented* through their survival journeys were open and expressive about their diseases, and received support from others that enhanced their capabilities to cope with their experiences (Sekse et al., 2012). The *activity-oriented* survivors, in contrast, focused on thinking positively about the future and "powered their way through" toward restitution from serious illness by being rational and focusing on everyday activities, such as those with their families. These two types experienced reorientations in life and a revitalization of values. However, the *self-controlled* type kept the disease at a distance and did not actively work their way through it. These survivors experienced cancer as something entirely catastrophic to their lives and to which they wished to pay no attention. Sekse et al. (2012) argued that survivors are in need of supportive care to enhance their capabilities to articulate and cope with the new challenges they face.

As mentioned above, cancer treatment follow-up often fails to support survivors in handling late effects and specialized needs (National Research Council and Institute of Medicine, 2006; Dahl et al., 2013; Papadakos et al., 2012). However, research on interventions to meet the needs of gynecological cancer survivors has shown promising results for person-based interventions targeting psychosocial needs (Linnet Olesen et al., 2015).

2.2 Designing technology to support cancer journeys

Gynecological cancer survivors need interventions that can support them with educational resources and self-management tools (Cerna et al., 2019). The format, mode of delivery, and session composition must be better understood (Kim et al., 2017) to provide interventions that improve the self-competency of cancer survivors. Self-management interventions are recommended for cancer survivors after treatment because they stimulate improvement in fatigue, physical functioning, distress, and self-efficacy (Boland et al., 2017). Online interventions addressing the psychosocial needs of cancer survivors are feasible and acceptable, with websites being the most common delivery platform (Ross et al., 2020). Regarding the efficacy of such web-based online interventions, a meta-analysis found them to be effective in improving fatigue, depression, anxiety, and overall quality of life (Kim and Park, 2015).

Self-management and social-support interventions for cancer patients and survivors have been explored in HCI research. Social support comprises informational, instrumental, and emotional support and protects people from the adverse effects of stress (Cohen, 2004). Hartzler and Pratt (2011) found that patients on online message boards used a personal, narrative style when giving advice to peers. Their advice was based on lived experiences of trial and error navigating their cancer journey, and they were told as personal stories of how they experienced situations concerning their cancer. The narrative style of patient expertise contrasts strongly with that of the medical clinician, which is characterized by a prescriptive, normative language that gives concrete, actionable advice (Hartzler and Pratt, 2011). Personal health video blogs (vlogs) are examples of narrative communication about the lived experience of illness that provide people with social support through video-sharing sites, such as YouTube (Huh et al., 2014). Huh et al. (2014) found that the video medium allowed intense, personal disclosure of personal experiences that were reflected by peers in the comments sections of these vlogs. Furthermore, health vloggers use specific genres, such as self-documentaries, to provide situated narratives of their experiences (Liu et al., 2013).

Prior work in HCI has explored how to design technology to support the cancer journey. Hayes et al. (2008), for instance, introduced the concept of the personal cancer journey to the field of pervasive computing. Through fieldwork, they found that former patients perceived every survival journey as unique but that journeys also shared commonalities (Hayes et al., 2008). Jacobs et al. (2016) built upon the concept of cancer as a journey and developed a framework for designing holistic health technology to support such journeys. These attempts to understand the cancer experience have conceptualized the journey as the period from screening and diagnosis through treatment until someone is cancer-free and "[r]eturn to normal" (Jacobs et al., 2016, p. 117). Suh et al. (2020) made a valuable addition to this framework by introducing a parallel-journeys framework addressing both the cancer journey and the psychosocial-care journey to care for *the whole patient*, a patient-centered approach that targets patients' quality of life (Jacobsen et al., 2012). However, for many survivors, the journey continues after successfully completing cancer treatment. In a study of young cancer survivors' challenges and information needs after treatment, young adults faced challenges after survival in feelings of isolation, confrontation with a new sense of mortality, and struggles with adapting to a changing body image and identity (Eschler and Pratt, 2017). Recovering from serious illness, such as cancer, can involve a bodily, psychosocial reorientation in everyday life.

2.3 Narratives of illness

Cancer journeys can be conceptualized, formulated, and told as personal illness narratives (Hartzler and Pratt, 2011), which can be used and presented as content in online interventions to convey the experience of illness (Honary et al., 2018). In HCI, the use of narratives has been explored in online communities (Feuston and Piper, 2019; Michie et al., 2018; Smith et al., 2017), videos (Davis et al., 2015; Honary et al., 2018), virtual reality (Flobak et al., 2019; Teng et al., 2019), and technology probes (Clarke et al., 2012). HCI studies have explored diverse subject matters pertaining to narratives: women's reentry to society from incarceration (Teng et al., 2019), abortion rights advocacy (Michie et al., 2018), adolescents' fear of public speaking (Flobak et al., 2019), smoking cessation (Smith et al., 2017), caregivers of people with severe mental illness (Honary et al., 2018), and cancer survival (Eschler and Pratt, 2017).

Honary et al. (2018) designed video stories around the lived experience of severe mental illness. The video stories were designed as content for an online intervention for caregivers of people with severe illnesses, such as bipolar disorder and schizophrenia. The videos featured actors who tell stories sourced from participants with severe mental illness and their caretakers. Honary et al. (2018) stressed the importance of ensuring that the voices of participants are apparent in the videos, and they found personas (see Bødker et al., 2012) to be an efficient technique to preserve the characteristics of experiences across a team of researchers and actors (Honary et al., 2018).

Anchored in a debate on illness and the "sick role" in medical sociology, Frank (2013) provided an understanding of illness through narratives told in the first person by the bearers of illness. Storytellers are, in Frank's account, conceptualized as "wounded storytellers" rather than bearers of disease. As such, the focus is shifted from a purely medical conceptualization of disease to emphasizing the experience of having an illness. In this regard, a storyteller is someone who employs an illness narrative to speak about their experiences. The crafting of a personal illness narrative may widen the possibility of a reorientation in everyday life toward newfound goals and values in light of chronic illness (Frank, 2013; Hinyard and Kreuter, 2007; Pennebaker and Seagal, 1999).

2.4 Engagement and meaning in online interventions

The delivery modes of online intervention content (e.g., video, text, and auditory exercises) and content itself can strongly influence personal engagement with the intervention. Doherty and Doherty (2019) discussed engagement as a concept in HCI and demonstrated how its use in HCI literature varies in scope, from the technical qualities of an interface to the experiential qualities of a user experience. In research on online interventions in the health sciences, engagement is commonly understood as a behavioral component of intervention use. Behavioral components are operationalized as the level of adherence to an intervention program, duration of use, frequency, and other usage statistics. Yardley et al. (2016) discussed how the current emphasis on achieving user engagement with online intervention should be shifted toward "effective engagement," wherein the engagement is measured by the intended outcome of the intervention. In this paper, however, we are primarily interested in meaningful engagement as it pertains to certain qualities of user experience.

Engagement with online interventions is initiated when the content is perceived to be relevant, novel, and aesthetically appealing to the user (Short et al., 2015). According to Short et al. (2015), engagement with such interventions is contingent on a match between intervention content and a user's demographic, psychosocial, and behavioral characteristics. When this match is achieved, the user may be motivated to engage further with the intervention as it may be experienced as personally relevant (Short et al., 2015). Disengagement, however, can be the result of a user's expectation and an intervention design's inability to meet those expectations (Crutzen et al., 2014). Low usability, irrelevant content, and disbelief in the intervention's ability to help the user reach personal goals can further hamper engagement with online interventions (O'Brien and Toms, 2008).

Meaningful engagement with technology has most fundamentally been construed as an existential matter (Kaptelinin, 2018). Rooted in existential philosophy and positive psychology, Mekler and Hornbæk (2019) discussed *meaning* pragmatically as a quality of experience. They conceptualized meaning as consisting of five components: connectedness, purpose, coherence, resonance, and significance. This perspective on what constitutes meaningful engagement with technology stands in contrast to the notion of "effective engagement" and a primarily quantitative operationalization of engagement as tightly linked to the more clinical concept of adherence.

In this study, we view meaningful engagement with online intervention content as a quality of the experience of technology use. We follow Mekler and Hornbæk (2019) in understanding this phenomenon as a construct of how people experience the use of technology as purposeful, coherent with their lives, its significance, its resonance, and how the use of technology connects to their understanding of the self.

3 Methods

In this section, we describe how we designed audiovisual narratives for an online intervention targeting survivors of gynecological cancer. The narratives were designed to give cancer survivors the resources to recognize and reflect on their own experiences after treatment. We also describe an evaluation held with survivors of gynecological cancer to determine whether the narratives could be feasible as content in an online intervention for other survivors.

3.1 Participants

We recruited participants for this study from a local gynecological cancer patient organization using a combination of convenience and snowball sampling techniques. The inclusion criteria were as follows: adult, Norwegian-speaking women who had completed primary treatment for gynecological cancer. The study's handling of participants and collection of sensitive interview data were approved by the data-protection officer of Haukeland University Hospital. Five participants contributed to the design process and participated in the evaluation of audiovisual narratives. These participants are referred to in this paper as *user representatives* for their personal experiences of cancer survival and affiliation with the patient organization. They periodically contributed to the design process over a two-year period in focus groups to both the audiovisual narratives and the online intervention as a whole. Another five participants were recruited for the evaluation. In total, we recruited 10 participants for this research project.

The 10 participants were between 33 and 75 years of age at the time of participation, with a mean age of 50 years. Their primary treatment for gynecological cancer had been completed 18 months to 11 years prior. Treatment varied between surgery, chemotherapy, radiation, and combinations of these treatment modalities. Three participants held full-time jobs, five worked part-time with partial disability benefits, one received full disability benefits, and one was retired. Five participants held university degrees, and five had finished primary or secondary education. Two were single, one was widowed, and seven lived with partners.

The user representatives were given a 500 NOK gift card (equivalent to approximately $60 USD) for their participation in the design of the psychosocial intervention, including the audiovisual narratives. Participants who participated in the evaluation study received a gift card of the same value. Thus, those that participated in both the design process and the evaluation were given a total of 1000 NOK in gift cards (equivalent to approximately $120 USD).

3.2 Study context: Psychoeducative online intervention for women after gynecological cancer

Designing the audiovisual narratives was part of a research project in Norway that included developing an online intervention for addressing the psychosocial needs of gynecological cancer survivors. The intervention was designed to target quality of life by providing women who had survived gynecological cancer the resources to cope with life after cancer treatment better.

The program consisted of six modules designed to be completed by the intervention participants over a six-week period: “everyday life after cancer treatment,” “the changed female body,” “sexual health,” “fatigue,” “fear of recurrence,” and a sixth module for summarizing the program. These modules were defined building on previous research of gynecological cancer survivors’ needs and in accordance with the user representatives that contributed to this study. The program aimed to improve survivors’ self-competence and self-care after completing treatment. While participating in the intervention, each participant had pre-scheduled weekly phone calls with a specially trained nurse or counselor to discuss their progress in the program. Each module consisted of information pertaining to the module’s theme, exercises (e.g., writing reflections), and guided auditory exercises in controlled breathing to master stress and various self-compassion exercises.

The first module “everyday life after cancer treatment” presents the narrative of three female characters who have survived cancer and tell their unique stories in audiovisual narratives. After watching the narratives, the intervention participant is asked to reflect upon and write their own story of survival in a text input field. This text is stored in the intervention program’s database, and the participant has the option to discuss this text with their counselor.

Further details on the online intervention and results of its efficacy in improving survivors’ quality of life will be addressed in another paper.

3.3 Design process for creating audiovisual narratives

Three audiovisual narratives of gynecological cancer survival were designed for the online intervention in an experience-centered design process (Wright and McCarthy, 2010), an approach that seeks to design interactions that attune to users' emotions and experiences. The decision to make the narratives audiovisual was made upon a request from the user representatives to limit the use of text in the intervention program. Each narrative told the story of living through cancer, including the time after completing treatment, from the perspectives of three characters.

The main goal of the design process was to produce narratives that could be experienced thematically and were literally close to survivors' own experiences of living through gynecological cancer. Another aim, in conjunction with the reflection exercise, was to offer those survivors the resources to recognize and reflect on their own experiences.

The design process included a panel of user representatives, a nurse, a doctor, a psychologist, an HCI researcher, and an artist.

Five user representatives contributed to the process. The representatives' first-hand knowledge of the gynecological cancer journey was important to adjust and verify the quality of the narratives so that they were close to the survivors' own experiences. Throughout the process of designing the online intervention, we periodically arranged meetings with our participants to receive feedback and suggestions on our designs. The meetings were arranged like focus groups, where we discussed various subjects pertaining to gynecological cancer survival and showed them our designs for feedback. The representatives told us how they experienced a taboo surrounding their type of cancer, how they received little or no information about late effects, and their frustration about not receiving any follow-up concerning the risk of infertility.

Knowledge base for narratives

The stories and characters presented in the audiovisual narratives were based on former qualitative research on women's experiences of surviving gynecological cancer by Sekse et al. (2012), who created a typology of three types: the *emotion- and relationship-oriented* woman, the *activity-oriented* woman, and the *self-controlled* woman (Sekse et al., 2012). The specifics of these types are further detailed in section 2.

The typology in Sekse et al.'s (2012) work was based on in-depth interviews with 16 survivors of gynecological cancer, all of whom were interviewed twice: (1) approxi-

Table II.1: Three characters for audiovisual narratives of gynecological cancer survival

Name	Type (Sekse et al., 2012)	Cancer type	Treatment mode	Age	Marital status
Ragna	Emotional- and relationship-oriented	Ovarian cancer	Surgery and chemotherapy	54	Single with adult children
Lillian	Activity-oriented	Uterine cancer	Surgery	72	Married, grandchildren
Guri	Self-controlled	Cervical cancer	Radiation and chemotherapy	32	Unmarried, in relationship, childless

mately five years after completing treatment and (2) one year after the first interview. The authors used Giorgi's (1997) phenomenological-hermeneutical approach of meaning condensation to find the essential meanings of the phenomena of surviving gynecological cancer.

The typology offers a structure of gynecological cancer survival. As such, the typology does not represent lived experience *per se* but rather provides structures of experience. Consequently, the knowledge base for the narratives laid a solid foundation for designing the narratives close to survivors' own experiences. Additionally, our team had the expertise of a nurse and doctor with extensive experience working clinically with cancer patients, as well as the panel of five user representatives.

Crafting narratives of gynecological cancer survival

The narratives and characters were initially written and composed by a nurse with a long experience of working clinically and academically with gynecological cancer survivors. Other parties on the design team provided feedback, and the narratives were iteratively improved. The user representatives also gave feedback in our focus group meetings.

We shaped the characters so that each had a certain set of late effects. Together, they created a varied picture of the late effects that typically occur after treatment. For example, Guri struggled with fear of recurrence, infertility, labial adhesion, and an impaired sexual life with her partner, whereas Ragna suffered from afflictions related to menopause, sleep hygiene, cancer-related fatigue, and neuropathy. See Table II.1 for an overview of the three characters, including their health and personal attributes.

Each narrative alternated between a character's first-person perspective and a narrator. Quotations from each character were lifted directly (with permission) or paraphrased from previous qualitative research (Sekse et al., 2012, 2013, 2009, 2010). The narrator progressed the plot by providing the background of the character's statements and changing the scenes (e.g., "Every three weeks for about four months, Ragna received chemotherapy at an outpatient clinic. Although she found it surprisingly easy to get the cures, it was a difficult time for her.").

We sought to avoid coloring the narratives with normative, prescriptive phrasings and assessments of how the characters were coping with their recoveries to avoid alienating those who shared experiences or characteristics with the characters or their stories.

The user representatives provided feedback on the wording of the narratives. For them, it was important that we used a language that was non-technical and easily accessible. Therefore, we avoided medical or advanced language that would be hard to grasp for those uncomfortable with such technical language, changing the wording in parts of the stories (e.g., from "suffering" to "hurting") and adding plain descriptions next to medical terms, such as "neuropathy" and "fatigue."

Giving voice to narrative characters

To give voice to the characters, we recruited nursing teachers as voice actors from a local nursing school by convenience. We chose actors who we thought would fit the characters in voice, dialect, and tone. Each character was discussed with the actors regarding their personal background, cancer type, and storyline. We also discussed the tone that would fit the story and how we imagined that they would sound if they were real people.

Giving visual form to narratives

The artist on the design team produced illustrations to support the narration and highlight different aspects of the story. After experimentation with digital drawing, we chose to use ink and watercolor, as the artist had previous experience with these techniques and the technique provided a form that we thought fit the narratives well.

For each character, we discussed how we imagined the character lived. However, once the audio recordings of the actor's takes on the characters were ready, we had to adjust our visual understanding of the characters so that they would fit the actor's voices.

Figure II.1: Snapshots from the audiovisual narratives showing Ragna (top left position), Guri (top right position), Lillian (bottom left position), and Ragna again (bottom left position). The captions read (translated): (Top left position) Of course, I was happy to finish [treatment], but there was no “hurray!” Rather a “what now?” (Top right position) in the days before the check-up, I go and think about what they will find when they examine me; (Bottom left position) the doctors said it looked like the disease was at an early stage; (Bottom right corner) Today, six months after treatment, Ragna struggles with menopause, sleep at night, and cancer-related fatigue. ©Jorunn Moberg Ohnstad

Illustrations were shown to our panel of user representatives to iterate the illustrations in subject, form, and tone. The representatives gave frank, and critical feedback on the drawings in our meetings at which the artist was not present. For example, representatives were sensitive to how we depicted the female body. In one example, there was a depiction of a woman without a head, a sketch that was quickly dismissed by the representatives. Some illustrations were dismissed for being too “rosy” or naïve in style. We used the feedback to adjust the style of the depictions.

The illustrations were composed into audiovisual narratives with the audio (Figure II.1). Pan and zoom effects were added to the illustrations to accentuate parts of the images that supported the story. Lastly, subtitles were added to support accessibility.

3.4 Three narratives of gynecological cancer survival

Below, we briefly describe the characters and their stories, focusing on some defining characteristics of their cancer survival.

Ragna, the emotional- and relationship-oriented type

Ragna was open and expressive toward colleagues, family, and friends about her ovarian cancer diagnosis, and she received support in return that she claims was invaluable to her, both then and now, as cancer-free. She expected the day of completing treatment would be a day to celebrate. Instead, Ragna was left with new questions about how to cope with life after cancer. Today, she feels uncertain about her future because she fears that she may suffer a recurrence of cancer. However, she points out that her openness with those close to her has helped her, and them, through the process of cancer, like those of the emotional- and relationship-oriented type of cancer survivors (Sekse et al., 2012).

Lillian, the activity-oriented type

Lillian felt anxious after receiving the cancer diagnosis from the gynecological clinic. However, she is, like survivors of the activity-oriented type (Sekse et al., 2012), a practical person, so she kept herself occupied by resuming everyday life. Lillian says she was initially *glad* that they would remove an organ she no longer had any use for. However, she wonders why the doctors and nurses at the hospital said she would not notice that the ovaries and uterus were removed. Since surgery, she has had a distinct bodily experience of the absence of these organs. Although she tries to maintain a positive mindset, she sometimes feels lonely. She also says that she and her husband form a good “team” but that she would like the opportunity to talk to someone about the things she and her husband underwent in relation to her cancer survival.

Guri, the self-controlled type

For Guri, receiving the cancer diagnosis was a major shock. She says, “My life was turned upside down! Ole and I had a dream of a life in the countryside on a farm with many children. The disease has put an end to many of our dreams.” While undergoing treatment, Guri was solely focused on ridding herself of cancer. Since her treatment, she has felt that her stomach is tied up in knots, but she is afraid of addressing her uneasiness. Guri has kept her relationship with Ole, but they have had little intimate contact, and Guri does not know what either he or she wants from their relationship in terms of intimacy. Furthermore, Guri has a fear of cancer recurrence. In her own words, she feels “the anxiety” build up one to two weeks before control appointments. When a control appointment is over and her negative test results arrive by mail, Guri can breathe and relax—for a while. She wishes that she and her partner Ole would receive a more comprehensive follow-up after cancer therapy. The way she does not openly communicate to those close to her, such as Ole, resembles that of the self-controlled type of cancer survivors (Sekse et al., 2012).

3.5 Evaluation with cancer survivors

We evaluated a pilot version of the online intervention with the 10 participants recruited for this study, five of whom also contributed as user representatives in the focus groups. For this paper, the participants' experiences and assessments of the audiovisual narratives are emphasized. One week before the evaluation sessions, the participants were mailed printed copies of the intervention module of which the audiovisual narratives were a part so that they could read them on their own to prepare for the evaluation.

The evaluation sessions were undertaken in a room with two interviewers and one participant. The participants were given a personal computer (PC) to enter the online intervention website and go through the first module of the intervention program and one other module chosen by the facilitators. Each participant was interviewed by the first and last author in an evaluation session, which lasted a maximum of 120 minutes. In the evaluation session, the participant viewed two of the three audiovisual narratives of their choosing to limit the time spent on this part of the evaluation. After each viewing, the two authors interviewed each participant about their experience of the audiovisual narrative guided by a semi-structured interview protocol. We asked participants to (1) describe how they experienced the audiovisual narratives; (2) comment on whether they found the illustrations to depict sensitive issues appropriately; (3) comment on the voice actors' qualities; (4) assess whether other people in a similar situation would identify with the character and her story; and (5) consider the extent to which such an audiovisual narrative may be useful if one has recently been treated for gynecological cancer.

Ethical considerations

In the interviews, we aimed to set an informal yet safe tone between us and each participant to create an informal environment where they could feel safe with us despite the sensitive topic. Interviews with participants who have had painful experiences related to the subject matter can be emotionally demanding for both the interview subject and the researcher (Honary et al., 2018; Moncur, 2013). In our experience, the participants often had stories of their own survivals they wanted to tell us in the evaluation session. As interviewers, we made a conscious choice not to steer interviewees when this happened. When participants chose to share experiences from their own cancer battle and survival journey after viewing the audiovisuals, we let them tell their story however they preferred. The interviews were done by a nurse and an HCI researcher, and they had the chance to debrief their experiences together after each evaluation.

The evaluation sessions were audio-recorded, and all the recordings were transcribed verbatim by this paper's second author. The recordings and transcripts were stored at Haukeland University Hospital's research server. To anonymize the participants, each was given a pseudonym in the transcripts, and personal details that could identify them were removed from the transcripts. However, scrambling keys that connect our participants to their given pseudonyms were made and stored separately. The participants could terminate their participation at any time if they desired, including the removal of all stored data about them.

3.6 Thematic analysis

The transcripts of the evaluation sessions were qualitatively analyzed for themes (Braun and Clarke, 2006, 2014, 2020). The analysis followed Braun and Clarke's (2006) process for thematic analysis. The following research question guided the analysis: "How do survivors of gynecological cancer engage with audiovisual narratives designed for an online intervention?" This question opened up for exploring the experiential qualities of the participants' engagement with the narratives. The first author read the transcripts made by the second author to reacquaint themselves with the material. Then, the transcripts were coded in an inductive, bottom-up process by the first author. Extracts were coded for their semantic meaning as they were interpreted by the coder. Codes with extracts were then collated into possible themes. Suggested themes were then mapped out with their codes to visualize the data set. The first, second, and third authors discussed the codes and their relation to themes. The shared understanding of what the codes were examples of, and how they fit together as whole themes, were achieved pragmatically between the authors through discussion. Following this discussion, four main themes were identified that capture the topics found in the empirical data. Although we present our findings as distinct themes, we want to emphasize that these themes are analytical constructs that each bring out different aspects of how the participants engaged with the audiovisual narratives. They should not be seen as mutually exclusive categories with sharp boundaries, but rather as themes that together express our understanding of the empirical data from the research question. When writing the findings, the quotations used to illustrate the themes were carefully translated from

Norwegian to English.

4 Findings

This section presents our thematic analysis of the evaluation interviews, which revolves around four main themes. First, we describe how the participants could identify with the narratives. Following that, we show how the wording of narratives provoked the participants to reflect on their experiences and unpack how they experienced the narratives' realism. Finally, we address how the aesthetic choices made in the design process were perceived and experienced by the participants.

4.1 "This is the story of me": Identifying with narrative characters

The participants identified with various elements of the audiovisual narratives, such as character, cancer type, treatment mode, life situation, late effects, emotional response, and coping strategies. They all also experienced the stories as similar to their own experiences as cancer survivors. Anna described how the story of Guri was like hearing herself speak of her cancer survival:

> *Anna: Yes, oh my God. It's just like hearing myself, really. That whole story [...] it was very ... Very comprehensive. It was. I think many will recognize themselves in that [exact story].*
>
> *Interviewer: How so?*
>
> *Anna: Um, well, during the video, [. . .] ehm, how do you say . . . when you're done ... when you start treatment, you're up and running. Right? Then you know that you are about to get rid of it and get well, right? So [the time] before treatment is the worst, because then you go and think "how is this going to be?" "What about chemotherapy?" "How about radiation?" "What is it like being in a hospital?" "How . . ."—all of that. And then afterward, where one is quote-unquote healthy, right. Ehm . . . so, that's all right here [in the video].*

In addition to identifying with Guri's story, the story set in motion a chain of associations that reminded Anna of her own experience of treatment and rehabilitation for cancer illness. Anna started reeling off medical procedures, ending with her restoration of health. However, the emphasis on expressing “healthy” in quotation marks can be understood as a tension between narratives of sickness: that of the medical understanding of recovery from disease and that of Anna’s experience of illness that transcends a “cure.” The narratives also expressed this tension, such as Ragna saying, “The doctors said I would be fine after the procedures and that I could continue life as before. But my life was never the same as before my sickness.” Participants used this part of the story in the interview as a point of departure to discuss their own struggles with resuming work and social life under the expectation of having restored health. The participants chose to share their own experiences with the interviewers to demonstrate how they identified with the characters.

In the previous excerpt, Anna explained how she identified with Guri’s story of receiving treatment and the uncertainty associated with medical procedures. Erle, who was 40 years younger than the fictitious Lillian, related to the emotional response that Lillian experienced:

> *Erle: I think, in a way, that even if it is not the same diagnosis or the same treatment, there are things here that you can relate to. Even though it is a completely different life situation, there is something about the thoughts one has, as she [Lillian] explained when she came home from the hospital, um, and a little bit there with the fear of relapse and those things. So, even though I initially saw this one as . . .*
>
> *Interviewer: It is not you?*
>
> *Erle: [pauses] It is not me, but still there are many things that you can relate to. Absolutely.*

In this excerpt, Erle is reflecting on how the story told by Lillian is different from her own. It is also interesting to note how Erle addressed the fictitious character: “There is something about the thoughts one has, as she explained when she came home from the hospital.” Erle uses the personal pronoun “she” when addressing the character Lillian. A different, impersonal way to address Lillian would have been something like, “as was explained by the character in the video.” However, the use of “she” shows that Erle related to more than just the events in the story as told by the character of Lillian but personified and empathized with her, a fictitious character. This interpretation is further supported by the participants' accounts in which they, in some cases, speculated on how the characters were coping with life today and shared their opinions and normative judgments about the character's choices.

Some participants in the evaluation study were in their twenties and thirties at the time of cancer treatment, so some were dealing with infertility, including involuntarily childlessness. Guri was the youngest character, so infertility was a theme in her story, something that resonated with Jenny, one of the participants:

> *Jenny: This is the story of me [chuckles]. No, it is almost a little funny. Ehm, Guri is Jenny. The only thing that does not fit there is this with kids.*

Jenny proceeded to explain how Guri's story specifically differed from hers regarding kids. By comparing the narrative elements of Guri's story with her own experiences, Jenny started to craft a narrative of her own. Participants compared themselves to the fictitious characters Ragna, Lillian, and Guri by looking at differences and similarities with their own experiences.

Similarly, the participant Beate noticed the theme of infertility in Guri's story:

> *Beate: You lose the dream, just like her, right. I, [or] we, did not have children. It was not talked about, and you are just left like a . . . the dream is kind of just crossed out with two strokes of a pen, right.*

Here, Beate responded to the narrative element where Guri says, "The disease has put an end to many of our dreams." This line presented an opening for Beate to elaborate on how she experienced not only her own infertility but also the silence surrounding the topic.

In this theme, we have seen how the participants' identification with the narrative character opened up their recollections of their own experiences and their willingness to share their own stories of living through cancer. In many cases, the participants shared detailed, intimate descriptions of their own stories with us after watching and discussing the audiovisual narratives. Based on this analysis, we establish that the participants experienced the audiovisual narratives as relatable.

4.2 "She 'only' needed surgery": When narratives provoke reflection

The choice of words and phrasing was naturally an important feature of the narratives. The participants experienced some words as provocative and sometimes alienating.

However, as we see in the following excerpts, words can sometimes offer resistance that provokes a reflection on one's own story of illness.

> *Jenny: Eh, so, I've never experienced that anxiety. For [cancer] recurrence and things like that. I have it one to two weeks before control. I am irritable and can bite your head off if you look at me crookedly [Jenny laughs], but I think many have it like that.*

This quote shows that Jenny preferred to use words other than the narrative character Guri, who used the word "anxiety" to describe her experience of the weeks before a control appointment. However, the wording triggered a reflection on Jenny's own experience of the period before control appointments, and that this is something that is normal. Similarly, Beate is concerned with how the word 'only' is prefixed to the treatment mode 'surgery:'

> *Beate: And, yes, that Lillian who got sick, it says: [. . .] "The doctor said it looked like she 'only' needed surgery and would be spared from supplementary treatment."*
>
> *Interviewer: Yes, "only."*
>
> *Beate: Yes, I was treated with "only" surgery, like her, right. So, I identified with that [story]. When I tell people at the hospital and the like, it's not "only" [surgery]. You have a scar going to all the way from up here [points at stomach] all the way down to . . . right.*

In this excerpt, Beate addresses the description of the character's treatment and reflects on how she identifies with the story but that she does not like the characterization in the narrative of prefixing "surgery" with "only." For her, surgery was the most serious form of cancer treatment she had known. The excerpt suggests that Beate felt as though surgery was played down as a not-so-serious treatment option, perhaps with a tension between Lillian's recovery narrative and Beate's. This excerpt shows how the specific wording of a narrative may alienate a person who has a similar history of treatment, albeit a different experience of it.

In this way, we can see that some provocation or resistance that arises from watching audiovisual narratives may at first seem alienating. However, a certain level of provocation may play a role in activating a viewer to reflect on and identify with their own history. Nevertheless, narratives will assume different meanings and be interpreted differently by different people; a narrative element that provocatively mobilizes reflection in some can be so provocative that it alienates others and be so unnoticeable to others that they hardly perceive it.

In the end, reflection on one's own life presupposes a certain provocation. In this theme, we observed that provocations can help elicit the emotional experience of one's survival, thus helping a participant to recognize and reflect on experiences as part of a story.

4.3 "It sounds like a real person": Realism in narratives

In the former theme, we demonstrated how participants identified with the characters and their stories and how they addressed the characters in a personal manner. Such a personification of narrative characters is only possible if the participants find the characters and their stories to be believable and realistic. Erle put it simply after viewing Ragna's story:

> *Erle: It sounds very . . . it sounds like a real person who has somehow experienced cancer.*

The characters were found to be believable and had a form and voice in the audiovisual narratives that made them seem realistic to our participants. In the following, we unpack how participants perceived the audiovisual narratives as realistic. The participants' experiences of realism in the narratives can be understood along three dimensions: realistic, credible, and descriptive.

> *Ingrid: Whether the stories are real is not important but rather that it is a story that could have been real. To hear that someone else also has the thoughts that you think you are alone in having. Because that's what you think. That "I must be completely coocoo to think that way."*

For Ingrid, the stories did not need to be actual stories of real events; it was enough for her that the stories and characters were true to life. Moreover, she found a social quality in the stories in that they mirrored her own experiences and thoughts.

To be credible, the stories needed to handle issues that can be sensitive and hard to cope with in an honest, unvarnished way. The audiovisual narratives offered a "peek behind the scenes" of what it may be like to survive gynecological cancer. Ingrid elaborated that the content was perceived as realistic:

> *Ingrid: It's not the sunshine stories you need, it's the reality you need. And it may be a little hard [when you are recently done with treatment], but it is what it is.*

How the characters overcame cancer in the narratives was, as Ingrid pointed out, a realistic account of how it can be experienced and what kind of thoughts can occur. Ingrid explained that although this depiction of reality may have been painful, "it is what it is." As such, the audiovisual narratives appeared credible to the participants by depicting characters and stories akin to the participants' own experiences.

Another dimension of perceived realism is how well the narratives described survivors and their stories. Dina, a senior survivor, found that Guri's story described the age group that she represented:

> *Dina: I think this story is very good. I think it describes very well the way I have met these girls in the years that I have been active [in the patient organization].*

In this excerpt, Dina takes a third-person perspective of the content. She assumed the role of an expert representative from the patient organization and assessed whether the story was realistic relative to what she had heard in her encounters with young cancer survivors like the character Guri. The richness of detail in the narratives of cancer survival was important for the narrative to be perceived as descriptive by the participants who shared the lived experience of such survival journeys.

In this theme, we observed how the participants perceived the narratives in terms of realism and explored how the narrative experience can be realistic, credible, and descriptive. It is important that the narratives can be perceived as realistic because this provides a true-to-life experience. To our participants, the narratives managed the subject matter in a way that was welcoming to them, as they resonated with their own experiences of living through cancer.

4.4 "It's like entering the forest of sadness": Aesthetic experience of cancer narratives

The way the audiovisual narratives were designed laid the foundation for the participants' experiences of the content. Regarding the style and mood of the illustrations that are used in the audiovisual narratives, Frida found them somewhat gloomy:

> *Frida: It's like entering, ehm, how do you say . . . the forest of sadness. [. . .] There's not much positivity.*

After discussing her experience of the illustrations and how they may have been perceived by someone who had recently ended treatment, Frida concluded,

> *Frida: It's not good if it's too positive either; you have to dare to enter [those subjects and themes] that are painful and difficult. [. . .] I think it could be a support [for someone recently done with treatment.]*

Frida experienced a certain melancholy in viewing the audiovisual narratives. She discussed how the illustrations set a sad mood. However, after reflection on how the illustrations would be perceived by someone recently done with treatment, which we omitted from the excerpt because they were quite lengthy, Frida concluded that it was necessary to create a visually melancholic tone for the audiovisual narrative to have the right emotional weight to support other women experiencing their own survival journeys.

Designing audiovisual narratives of cancer survival, one must make a series of design choices. Narrative elements influence the aesthetic experience and appreciation of the audiovisual narrative. The types of narrative elements in our three audiovisual narratives included, but were not limited to, the storyline, plot points, tone of voice, delivery and pacing of speaking lines, accent, sociolect, style and mood of illustration, and use of colors. The narrative elements set the mood of the perception and, thus, the experience of the audiovisual narratives.

As we discussed earlier in this analysis, people experience narrative elements differently; it is difficult to strike a balance in the design of narrative elements so that they are experienced as neither too gloomy nor too sanguine.

In the following, we focus on the tension between Lillian's narrative of cancer recovery and Beate's experience of recovery in subsection 4.2, expanding and disentangling the formerly addressed tensions in Beate's appraisal of the audiovisual narrative of Lillian in light of the aesthetic experience Beate had of the auditory narration of the story.

> *Beate: Ehm, at times she seems a little too . . . when you read [the story] it seems like she had it pretty rough, but when you hear [the story], it sounds too light compared to how it reads. It sounds like "Yee-haw, yoohoo, hee-hee."*

Whereas we focused on the wording of Lillian's story in the former theme, we see here how Beate's perception of Lillian's tone of voice colored her experience of the narrative. To Beate, Lillian's voice was not believable. According to Beate, if Lillian had experienced the story she told, she would have been unable to tell it in such an eager, upbeat way. Indeed, other participants and members of the design team had noted how the voice of Lillian sounded a little *staccato*. However, some participants who strongly identified with Lillian's persona, such as Erle, did not comment on the tone of voice or delivery.

Defining the aesthetics of audiovisual narratives is an important step in the design process, as aesthetics are essential to forming the experience of the viewer. We have seen how participants found certain design elements off-putting but how those same elements were imperceptible to others. It is crucial in the design of an audiovisual narrative's aesthetic to find a form and tone fitting for the story and type of experience one seeks to facilitate.

5 Discussion

This paper has presented the design of audiovisual narratives aimed at supporting survivors of gynecological cancer in recognizing and reflecting on their experiences of illness. The narratives were designed as part of an online intervention to address the psychosocial needs of gynecological cancer survivors and that aimed to enhance their quality of life.

In this section, we discuss how the survivors experienced the audiovisual narratives of cancer survival as meaningful in an evaluation session and how the use of qualitative accounts of experience in prior research can underlie experience-centered design. Lastly, we provide directions for further research in HCI to support cancer journeys and the sharing of personal illness stories.

5.1 Meaningful experiences of audiovisual narratives of cancer survival

In the analysis, we described how the participants experienced and engaged with the audiovisual narratives as relatable, provocative, and realistic and how they oriented to the aesthetic qualities of these narratives. Here, we discuss these experiential qualities and relate them to Mekler and Hornbæk's (2019) conceptualization of the experience of meaning in interaction, focusing on the components of *connectedness*, *significance*, *coherence*, and *resonance*. This discussion highlights *how* these experiential qualities can be understood as contributing to making the experience of the narratives meaningful.

Mekler and Hornbæk (2019) discussed how the component of *connectedness* framed how the "experience of meaning relates to and is constantly shaped by aspects of the self, including our past behaviors and experiences, personal beliefs and values, our goals and defining memories, as well as our relationships and sociocultural context" (Mekler and Hornbæk, 2019, p. 4). This component addresses the connections between the self and the world. In the analysis, we characterized how the participants related the narratives with their own experiences of cancer survival as relatability. Our description of relatability aligns with this component in that the participants related the characters' traits and stories to their own stories and survival journeys, as exemplified by quotations such as "this is the story of me."

Significance partly concerns how one "evaluat[es] events and experiences relative to one's personal values" (Mekler and Hornbæk, 2019, p. 6). Significance is how one values an activity, such as whether it is deemed important or trivial. In the evaluation, the participants were sometimes provoked and adopted normative approaches in how they experienced the narratives that transcended a simple appraisal of the narrative as a "right" or "wrong" depiction of cancer survival (which is related to coherence). For example, they evaluated whether a coping strategy was suitable for one of the characters. To understand the experiences as significant in this sense is to engage with the narratives normatively—to evaluate and place value on what is happening. What matters is that the story elements provoked reflection rather than being dismissed as irrelevant to personal experiences of survival.

Coherence in Mekler and Hornbæk's (2019) framework concerns how an experience makes sense, which results from how the experience is understood "in relation to life as a whole" (p. 5). For the participants to identify with the narratives, it was important that the narratives made sense and were believable and realistic as stories of cancer survival. The experiential quality of realism thus aligns with the component of *coherence* from

Mekler and Hornbæk's (2019) framework. The participants' experience of realism was also a methodological point; because the participants had experiences of cancer survival, they were in a position to determine whether the narratives were coherent and understandable. The variety of narratives and accounts of experiences in the stories told by the characters were, of course, open to interpretation. The participants made sense of the narratives in different ways; the coherence in the experience of the narratives—the experiential quality of realism—did not have to make sense in the same way for all of them.

Lastly, for this discussion, the component of *resonance* refers to the immediate qualities of an experience. It is connected to feelings and intuition. In our analysis, we described how the participants experienced the aesthetic qualities of the narratives, such as their style, mood, and expression. Aesthetic experiences are described in terms of immediate feelings and sensations, and the participants used words and metaphors such as "too light" and "forest of sadness" to express how they experienced these qualities. Mekler and Hornbæk (2019) did not include aesthetics in their discussion of resonance but used the example of how "reading a poem or gazing at a beautiful landscape might resonate strongly with us" (p. 6) to illustrate it. Relating intuitively to aesthetic aspects is thus arguably part of resonance. In our analysis, we described how the aesthetic aspects of the experiences resonated more or less with the participants. The intuitive, immediate impressions of aesthetic qualities can, in this way, serve as an important component in experiencing audiovisual narratives as meaningful.

The central goal of the narratives within the online intervention is to put the participants in a position to reflect on their own story and cancer journey. There is a connection between reflection and meaning. Mekler and Hornbæk (2019) proposed that "reflective efforts are required to give rise to a sense of purpose, coherence and significance" (p. 9). In our analysis, we used solicited accounts of experiences, and the conversations with the participants in themselves created a room for reflection on how the narratives were experienced. Thus, although it is difficult for us to untangle the relationship between reflection and meaning, they go together, and we see both as key to describing experiential qualities. Overall, the narratives set the stage for identification with and reflecting on the participants' own survival journeys, addressing something that felt important and worthwhile to the participants.

An important factor in making the characters in the narratives relatable to survivors was the use of a specific typology of how women live through gynecological cancer (Sekse et al., 2012). We also gave each of the three characters attributes that described their types of cancer, treatments, late effects, age, and life situations. Together, these characteristics formed a whole picture of survival that all the participants in our evaluation identified with and related to in one way or another.

Seeing others, even semi-fictionalized characters, struggle with the same effects of illness can help one understand one's own story and feel less alone in struggling with illness. Identifying with others and thus articulating one's own needs can be an important part of reorienting oneself to a new everyday life. As such, narratives of survival journeys can be a meaningful, important tool in enabling survivors to reflect on their own experiences and express their needs for support (Carlick and Biley, 2004).

Presenting stories of illness as audiovisual narratives in an online intervention can provide contextualized accounts of survival journeys. The plot and storyline of a narrative are well-suited to depict and represent the dynamic and spatio-temporal aspects of cancer journeys, and the use of characters in narratives can help to keep a first-person perspective in the story, thus retaining the inherently subjective nature of cancer survival experiences.

5.2 Designing narratives of illness

For narratives of illness to be perceived as meaningful, it is important that they are relevant to those who share the same course of illness. This paper has described our process of designing audiovisual narratives anchored in past studies of the experience of serious illness. The starting point for designing such narratives is gaining access to people's experiences of illness.

In past studies, personas have been used to represent participants with the experiences of illness in a design process (Honary et al., 2018), and micro-phenomenology interviews are a specialized design technique to capture experiences and unpack the tacit knowledge of participants and designers (Prpa et al., 2020). Participatory design establishes the participants as co-designers (Ehn, 2008; Muller, 2002), and as such they partake in constructively imagining how technology can be adapted and which meanings it can constitute for the groups the participants represent.

The two latter methods for representing participants in design processes are well-suited for experience-centered design of narrative content for online interventions as they put the participants in a central position for articulating their accounts of lived experience. However, access to participants with experiences of serious illness can be difficult for HCI researchers to attain. As an alternative, when such participants are out of the reach of intervention designers, Doherty et al. (2010) suggested asking therapists to be proxies for patient perspectives in a mental healthcare context. Therapists can provide a clinical perspective and help designers and researchers understand the clinical needs of a target group, and they can sometimes provide secondary accounts of experiences of their clients from their practices. However, it should be emphasized that such accounts are indeed secondary, and often told from another perspective and somehow removed from the person who actually has the lived experience. Moreover, they are not a result of a systematic synthesis of accounts as is the case with qualitative studies of patient experience. We suggest that designers should use such secondary accounts with caution and rather strive for retaining the authenticity of the lived experience of illness in their experience-centered design processes.

In our study, we based the narratives on qualitative studies and clinicians' professional experiences of working with gynecological cancer patients. Former studies have provided rich descriptions of the experience of surviving this type of cancer—in our case, through accounts of the experience of survival condensed into a typology. Furthermore, the user representatives who participated in the design process helped guide the design of audiovisual narratives by providing feedback to the wording of the narratives, use of imagery and aesthetic qualities. In our experience, designing from pre-existing accounts of experience in combination with constructive input from a panel of user representatives worked well to retain a certain authenticity in the narratives while taking heed of the values and experiences as expressed by the user representatives. Without the qualitative studies as a starting point for designing audiovisual narratives, we would have had to plan a far more comprehensive design process with a more extensive involvement of user representatives in articulating the narratives. Although such a process could have been feasible, it would have put higher strain on the participants and as such heightened the risk of research fatigue which would have been detrimental to both participants and the study.

Honary et al. (2018) discussed how designing videos around lived experiences of serious illness can also be an emotional process for designers and how, in their own study, they "encountered the need for protecting researcher's wellbeing[,] which we were not prepared for" (Honary et al., 2018, p. 9). In conducting our study, we found that between the two interviewers, a nurse and an HCI researcher, the nurse was far better prepared and equipped to handle the emotional strain of interviewing participants that evaluated the narratives when they chose to share painful experiences related to the subject. This competence is a natural part of emotional work, as nursing can be, and is something that requires training and practice. Maintaining researchers' emotional wellbeing during emotional work requires expertise (Wolters et al., 2017), and perhaps more importantly, the emotional strain imposed on participants has prompted calls for understanding experiences through alternative sources, such as pre-existing narrative accounts of experience (Balaam et al., 2019).

Former qualitative studies of lived experiences are valuable resources in designing narratives of illness, especially when access to participants is difficult to achieve, and they can help circumvent activities in user research that are emotionally demanding for both participants and designers. We recommend that designers make careful considerations in how they involve participants with the lived experience of serious illness in their design processes, and create safe expectations for the participants about what participation in the process means, and what expectations they will meet. It is important not to waste the participant's time, and to facilitate safe spaces for contributions to a sensitive topic.

5.3 A broader perspective on cancer journeys

Women's health has predominantly been researched by the medical sciences. A growing body of HCI research, however, has been laying the groundwork for supporting women's health with technology beyond a strictly medical model of health (Lazar et al., 2019; Felice et al., 2021; Bardzell et al., 2019). By including an experiential, pragmatist perspective on health, researchers are exploring lived experiences of women's health issues and their implications for the design of health technology (Lazar et al., 2019; Almeida et al., 2020; Felice et al., 2021). In this part of the discussion, we consider how HCI research can contribute to the care of female cancer patients, and we briefly discuss the stigma and marginalization of certain types of female cancers and how technology for supporting cancer journeys can be involved in life after cancer.

Breast cancer is a form of female cancer that is recognized throughout the world by the pink ribbon symbol. These ribbons are part of a marketing campaign to challenge stigma and to normalize breast cancer, and they have been successful in raising awareness in many parts of the world (Harvey and Strahilevitz, 2009). For gynecological cancers, however, taboos still exist and have been identified to be closely linked to female sexual behavior (Westbrook and Fourie, 2015). Westbrook and Fourie (2015), for example, argued that the information engagement of women with cervical cancer is restricted by social stigma, gender roles, and medically situated views on sexuality. This analysis resonates with our experiences from talking with survivors in focus groups while designing the narratives and the online intervention. Participants told us that they received little information about intimate health at their clinics and that sexual health was rarely brought up by clinicians, if at all.

HCI researchers should envision new ways that technology can support the psychosocial realities, informational needs, and self-management of people forced to embark on cancer journeys. Technology has the potential to support people with self-management of chronic disease with their informational needs and overcome obstacles to essential information for improved bodily and psychosocial health.

Regarding the cancer journey, important contributions have been made to HCI research in conceptually understanding the life-altering ordeals around healthcare technology (Suh et al., 2020; Hayes et al., 2008; Jacobs et al., 2016). Although these efforts to support cancer patients throughout their journeys are commendable and have inspired the present study, we call for an expanded focus that recognizes and respects that a survival journey can continue after one's immediate health problem—in this case, the cancer disease—is resolved and health is "restored," so to speak, in biomedical terms.

In Sekse et al.'s (2013) study of life five years after gynecological cancer, they found that the illness left a lasting imprint on women's bodies. These findings by Sekse et al. (2013) were mirrored by the participants in our focus group, particularly one who expressed it like this: "They [the surgeons] removed half of my femininity." A common theme among the participants was how they were largely uninformed of the late effects of cancer and treatment and that they felt left to their own devices to readjust to everyday life.

A broader perspective on illness informed by the feminist HCI agenda (Bardzell, 2010; Bardzell and Bardzell, 2011) could position researchers and designers of technology to see beyond the biomedical, cancer-centered care of disease. We follow Lazar et al. (2019), Almeida et al. (2020), and others who challenge and transcend prevailing, dominant medical paradigms for understanding illness and suffering in women's health, and we argue for the adoption of a holistic, experience-centered approach when designing technology to support cancer journeys. Such an approach should involve the understanding that people with any type of cancer may be exposed to various forms of stigma and marginalization.

5.4 Limitations and future directions

We have established that the audiovisual narratives cued the participants to share their own experiences and narratives of survival during the evaluation sessions. This paper follows Frank's (2013) notion that an embodied illness narrative is an essential part of understanding one's own story of illness. However, our work diverges from Frank's in how "the wounded storyteller" finds their voice in illness. To Frank (2013), stories of illness are always social because they are told to *someone*. As such, to Frank, narratives are dialogical because they are situationally adapted to how their accounts of experience are recognized by those listening. The narratives presented in this paper, however, were monological and semi-fictionalized. When experienced in the context of the designated online intervention, the narratives are followed by a reflection exercise that asked participants to tell their stories of survival. One limitation of this study, however, is that we have not yet studied how well this exercise supports survivors in telling their own stories; empirically ascertaining its effects is beyond the scope of the present study.

Future directions for research on supporting cancer survivors in recognizing and reflecting on their experiences of survival may want to explore how to design ways to share stories between peers. Such peer support could be designed to help people with experiences of illness grow from their experiences. However, sharing stories of illness is a delicate matter that requires careful facilitation and ethical design considerations (Andalibi and Flood, 2021).

6 Conclusion

Cancer survivors often face challenges in reorienting their everyday lives after life-threatening diseases, and they sometimes lack the care they need in these dire situations. This paper has addressed how narratives of cancer survival can provide survivors with support for recognizing and reflecting on their own experiences of survival. Through an experience-centered approach to design, we explored how to design audiovisual narratives based on previous accounts of experiences. We found that survivors experienced the audiovisual narratives as meaningful, in that they were experienced as relatable, provocative, and realistic. Based on these findings, we argue that such narratives are particularly well suited to provide rich and contextualized pictures of cancer journeys that could help survivors in a reorientation to a new everyday life. Future research should address how we can include narratives of cancer survival in design with interactive formats and peer support for sharing survival stories as part of online interventions.

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Paper III

Designing Videos With and for Adults With ADHD for an Online Intervention: Participatory Design Study and Thematic Analysis of Evaluation

Abstract

Background: Adults with attention deficit hyperactivity disorder (ADHD) represent a heterogeneous group with both strengths and difficulties associated with the diagnosis. An online intervention attuned to their needs may improve their everyday functioning. When designing online interventions, it is important to adapt the therapeutic content to the values and needs of the target group.

Objective: This paper describes and evaluates a participatory process used to produce content for an online intervention for adults with ADHD by producing video vignettes clarifying core training principles grounded in the participants' everyday experiences.

Methods: We report on the qualitative data from 2 research phases: the design and evaluation of video vignettes for an online intervention. In the first phase, 12 adults with ADHD, 2 clinicians, and 2 research assistants participated in the production of video vignettes for the online intervention. In the second phase, participants (n=109) gave feedback on the videos as part of a clinical trial of the intervention. A subgroup (n=7) was interviewed in-depth regarding their experiences with the videos. The qualitative data were analyzed using thematic analysis.

Results: In the first phase, the participants with ADHD contributed with experiences from challenging everyday situations. In the process, we navigated between therapeutic principles and the participants' experiential perspectives to create content relevant and consistent with the target group's values and experiences. In the second phase, we identified 3 themes related to the participants' experiences and interpretation of the video vignettes: (1) recognition of ADHD-related challenges, (2) connection with the characters and the situations, and (3) video protagonists as companions and role models for change.

Conclusions: A participatory design process for designing online mental health interventions can be used to probe and balance between the therapeutic principles defined by clinicians and the participants' experiences with mental health issues in the production of therapeutic content. In our study, the inclusion of video vignettes in an online intervention enabled a contextualized and relevant presentation of everyday experiences and psychosocial factors in the life of an adult with ADHD.

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1 Introduction

1.1 Background

Interactive technology has the potential to enhance mental health treatments by improving their access, affordability, and effectiveness (Doherty et al., 2010). When designing online psychological interventions, emphasis on engagement and relevance for the users is a key element (Doherty et al., 2012; Yardley et al., 2016, 2015a; Karekla et al., 2019). To achieve this engagement, a match between the intervention's content and the person's psychosocial and behavioral characteristics is essential (Short et al., 2015), as it can lead to higher satisfaction and, thereby, higher engagement and better outcomes (Borghouts et al., 2021). Moreover, considering the perspective of people with mental illnesses has been recognized as a way to ensure that the content is relevant and consistent with their values (Eysenbach, 2005; Honary et al., 2018a; Blandford et al., 2018). Previous studies have, therefore, employed person-centered approaches when designing content for online interventions, such as user-centered (Yardley et al., 2015b; Honary et al., 2018a) and participatory (Wadley et al., 2013) design methods.

In general, online interventions with guidance from a supporter (e.g., a therapist) result in higher engagement and improved treatment outcomes when compared to unguided interventions (Borghouts et al., 2021; Baumeister et al., 2014). This means that the social interaction with a supporter is a primary contributing factor to the success of the intervention (Chikersal et al., 2020). Unguided interventions are still commonly chosen when searching for low-cost therapeutic resources for people with limited access to mental health care services (May et al., 2009). Unguided interventions do, however, place new demands on how therapy should be presented to clients (Borghouts et al., 2021). Without a relationship between client and a therapist, an unguided intervention regimen requires content that is clearly recognizable to the target group (Borghouts et al., 2021). Generally, people expect a user experience (see Hassenzahl, 2008) that caters to their needs and desires related to the technology and the context of use (McCarthy and Wright, 2004). In a similar vein, Borghouts et al. (2021) found that people are more likely to engage with an online intervention if they experience "the program to be useful and a good fit for them" (p. 12).

Adults with attention deficit hyperactivity disorder (ADHD) are expected to benefit from an unguided online intervention, as it is a low-cost, easily accessible, and flexible alternative. This is related to the disorder's frequency, with an estimated prevalence of 2%-7% (Fayyad et al., 2017); heterogeneity; and characteristics. ADHD in adults is defined by core symptoms of inattention, impulsivity, and hyperactivity (American Psychiatric Association, 2013) and persistence of symptoms from childhood (Kessler et al., 2005a; Barkley, 1997). They frequently report problems related to self-regulation (Barkley, 2015; Faraone et al., 2019) and commonly face several everyday challenges (Turgay et al., 2012; Franke et al., 2018). Pharmacological treatment is the first choice of intervention for this disorder, but many adults commonly ask for nonpharmacological alternatives (Solberg et al., 2019). Still, most individuals with ADHD do not have access to psychological treatment in adulthood (Solberg et al., 2019). Technology may, thus, represent an opportunity to support adults with ADHD (Cibrian et al., 2020).

Qualitative studies of everyday experiences of people with ADHD provide insight into the lived experiences of having ADHD and demonstrate how the term "people with ADHD" refers to a heterogeneous group and that there are several positive traits attributed to the disorder. In a study by Holthe and Langvik (2017), a group of women with ADHD reported positive attributes such as "high energy, creativity, determination, ability to get easily interested and excited about new things, adventurousness, and willingness to take risks" (p. 8). In another study, diagnosed adults reported curiosity and hyperfocus as positive attributes of their disorder (Sedgwick et al., 2019). In a study by Wiklund et al. (2017), entrepreneurs with ADHD defined their impulsivity and hyperfocus as the major drivers of their entrepreneurial action. However, the participants in the study by Holthe and Langvik (2017)also described challenges in everyday life, including poor time management of daily plans and procrastination of tasks that lead to a sense of constantly being behind schedule. Adults with ADHD who were diagnosed in adulthood (i.e., growing up with undiagnosed and untreated ADHD) reported that they were ridiculed and received negative comments from their peers and families during childhood, such as being referred to as “stupid, lazy, and disruptive” (Young et al., 2008). The participants in this study also reported that they coped with the negative feedback by either accepting the remarks as accurate representations of their character or by ignoring the remarks altogether to evade feelings of low self-esteem (Young et al., 2008).

Public stigma causes additional challenges to people with ADHD (Kooij et al., 2019; Ponnou and Gonon, 2017; Hinshaw, 2018; Ray and Hinnant, 2009; Lebowitz, 2016; Lebowitz et al., 2016; Mueller et al., 2012; Schmitz et al., 2003). Stigma refers to socially situated characteristics of a person that enable the dehumanizing processes of prejudice, stereotypification, and discrimination (Goffman, 1986). Stigma toward people with mental disorders is common, imposing social misfortunes on them (Lebowitz, 2016; Hinshaw and Stier, 2008). In adults with ADHD, public stigma is commonly converted into self-stigmatization, a tendency to internalize negative public attitudes and beliefs of one’s characteristics (Bathje and Marston, 2014; Corrigan et al., 2010). Consequently, they may experience decreased quality of life, discontinuation of treatment, social isolation, and low self-esteem and self-efficacy (Mueller et al., 2012; Hinshaw and Stier, 2008). Young et al. (2008) showed that adults with ADHD who learned to emotionally accept their diagnosis and themselves, ultimately, had enhanced self-esteem and received improved support from people close to them. Similarly, in a study with adolescents with ADHD reporting retrospectively on self-stigmatization (McKeague et al., 2015), some participants had gained resilience against negative judgments through the confidence in themselves and the acceptance by those close to them.

Disclosures of mental health in social media have challenged public stigma and empowered people with mental health issues (Andalibi et al., 2017, 2016; Davis et al., 2015; Liu et al., 2013; Huh et al., 2014). Visual stories have particularly influenced the connection and empowerment of those with lived experiences similar to those disclosed (Davis et al., 2015; Honary et al., 2018b; Clarke et al., 2013). Feuston and Piper (2019) focused on how people share narratives of their mental illness on social media, through the analytical framework of small stories (Georgakopoulou, 2015), emphasizing their importance in understanding mental illness from an experiential point of view. This type of health communication differs from the prescriptive, fact-based style of clinicians’ expertise since patients’ expertise is characterized by a narrative style of coping with day-to-day challenges by trial and error (Hartzler and Pratt, 2011). Moreover, it is recognized that seeing how others handle everyday situations can contribute to learning of new behavior (e.g., Bandura's social cognitive theory (1977a; 1977b)). Studies on how people disclose their struggles with mental illness on social media and the associated engagement with these media should have implications on the content design of online interventions. Narrative communication has also been used as a tool in health behavior change (Hinyard and Kreuter, 2007), recently by the use of short videos in an intervention for reducing stigma towards people with schizophrenia (Amsalem et al., 2021a,b) and increasing treatment seeking for depression (Amsalem and Martin, 2022). In these videos, schizophrenia is presented "with a human face rather than as a 'brain disease"' (Amsalem et al., 2021a, p. 636) and show people with severe mental illness being capable of working and having meaningful relationships. Addressing the experiences of adults with ADHD through an everyday lens (Feuston and Piper, 2019) was, therefore, our objective when designing therapeutic content that is relatable and relevant to the target group.

1.2 Aims and Objectives

This study goes beyond the focus on the management of core symptoms and considers everyday experiences of adults with ADHD in the design of an online intervention. We explored how a participatory approach can ensure that the participants' perspectives are included in the design of psychoeducative therapeutic content in mental health interventions. With this aim, we directly included adults with ADHD in the design process to empower their perspective through active participation. In this study, their experiences were ultimately represented as video vignettes in an online intervention, which aimed at communicating the therapeutic principles and coping techniques. A further aim of this study was to explore how participants in an online intervention experienced and made sense of the video vignettes.

2 Methods

2.1 Study Design

The qualitative research presented in this paper was conducted in 2 phases: (1) a participatory process for the design of video vignettes as psychoeducative, therapeutic content for an online intervention for adults with ADHD; (2) the collection and analysis of qualitative feedback on the video vignettes during and after a clinical trial of the online intervention.

2.2 Study Context: “MyADHD” Online Intervention

The intervention addressed in this paper, MyADHD, was designed as a modular web-based course. Once a module was opened, the participant could browse freely within all the available modules and revisit content as they saw fit. MyADHD is comprised of 7 modules representing different topics (Introduction, Breathing, Stop, Emotions, Planning, Acceptance, and Conclusion). Each of the first 6 modules included psychoeducative information, skill-building exercises, and coping techniques for everyday challenges for adults with ADHD. Additionally, each module featured 2 video vignettes that explained the use of coping techniques and contextualized their suitability and application.

The process of designing the intervention was established on the *person-based approach* (Yardley et al., 2015b,a). In designing the program’s content, the method was extended by including adults with ADHD as co-designers through a 3-year participatory process. The intervention builds on the therapeutic principles of cognitive behavioral therapy (CBT), Goal Management Training, and dialectical behavioral therapy (DBT). The intervention aims to improve everyday functioning in adults with ADHD by providing psychoeducation, skill-building exercises, and coping techniques.

2.3 Phase 1: Participatory Design Study

Participatory Design

We position our design process as participatory design (Ehn, 2008; Robertson and Wagner, 2012; Bratteteig and Wagner, 2016; Muller, 2002). According to Ehn (2008), this approach to designing technology is strategically motivated from 2 different levels: (1) a democratic commitment to ensure the end users’ representation in the processes of making technology that concerns them (Ehn, 2008; Muller, 2002), and (2) “the importance of making the participants (sic) tacit knowledge come into play in the design process” (Ehn, 2008, p. 94). Our study was essentially concerned with the second level: the engagement of those with an ADHD diagnosis in the design process.

Participants

A total of 12 participants were recruited from a local division of a nationwide, voluntary patient organization for people with ADHD and their relatives. The participants were defined as experts by experience. Originally, 3 participants were recruited by convenience sampling. When the participatory design process reached a stage where we were designing content, the number of participants was increased to 12 to improve the representation of the diversity in the target group. This further recruitment was done by combining convenience and snowball sampling. Participants were given a gift certificate of 200 NOK (US $24) for their contribution to the design process.

The team also included 2 clinical psychologists (clinicians) and 2 clinical psychology students employed as research assistants in this study (assistants). These participants had a facilitating role in the design process.

Workshops

o understand preferences and needs for web-based services, the research team invited a small group of adults diagnosed with ADHD (n=3) to participate in meetings and workshops. In an early meeting, they were asked to discuss and evaluate the benefits of already available information (e.g., social media, webpages, YouTube), and to present their evaluations at the next meeting with the research team. Videos on social media were their preferred format, exemplified by videos presented by a YouTube ADHD health vlogger (e.g., “How to ADHD” on YouTube YouTube, 2021). The participants emphasized the light-hearted, self-deprecating humor displayed on the YouTube videos and described the importance of not being talked down to by someone in a “superior position” (the participants’ quote). From this and other follow-up discussions, the research team decided to design short video vignettes as the core content of the online intervention.

The participatory design process was predominantly performed through workshops where the different parties (i.e., participants, clinicians, and assistants) discussed and committed to shared goals by the methods of ideation and co-design. The workshops were organized by the clinicians and the assistants and were documented by note-taking and archiving workshop materials. In the workshops, the facilitators asked open-ended questions to engage participants in discussions of how ADHD impacted their everyday lives and how they coped with challenging situations.

2.4 Phase 2: Evaluation

Overview

The evaluation presented in this paper was done as part of a clinical trial conducted between May 2020 and October 2020. Participants were expected to complete the MyADHD intervention over 7 weeks, with 1 new module becoming accessible every

Table III.1: Pre-trial Adult ADHD Self-Report Scale (ASRS) scores for 109 participants.

ASRS full scale		Inattention scale		Hyperactivity-impulsivity scale	
mean	sd	mean	sd	mean	sd
49.7	9.2	26.8	4.6	22.8	6.3

week regardless of the participants' progression. The intervention was unguided, with the only supporter interaction being a pretrial telephone screening and an automated SMS text messaging notification each time a new module was released. The criteria for inclusion in the study were (1) age 18 years or above at inclusion and (2) a self-reported diagnosis of ADHD. Exclusion criteria were (1) current self-reported diagnosis of a severe psychiatric disorder and (2) other ongoing psychological treatment. The patient organization distributed a recruitment website on their Facebook Pages in May 2020, 2 months into the global COVID-19 outbreak. The study was approved by The Regional Committee for Medical Research Ethics of Western Norway (2020/90483).

Participants

The clinical trial included 109 participants, 88 of whom (80.7%) identified as women and 21 (19%) as men. Participants' ages ranged from 22 to 62 years (mean 36 years, SD 9 years). More than half of the participants (62/109, 56.9%) reported having completed university- or college-level education. At the time of inclusion, 67.9% (74/109) reported being employed or students, and 32.1% (35/109) were on sick leave or unemployed or received a disability pension. The participants' pretrial scores on the Adult ADHD Self-Report Scale (ASRS) (Kessler et al., 2005b) are shown in Table III.1. More specifically, 1 participant scored below threshold (17 points) on both the inattention and hyperactivity-impulsivity subscale, while 108 (99.1%) participants scored above the screening threshold on one of the subscales (Yeh et al., 2008). Informed consent was signed by the participants upon logging into the online intervention website for the first time. All participants were given a gift certificate of 400 NOK (US $48) upon completion of the study's posttrial questionnaires.

Online Intervention Procedure and Data Collection

For each module, apart from the first Introduction and seventh Conclusion modules, participants watched 2 video vignettes: (1) a version of a situation where the protagonist experiences everyday challenges associated with the topic of the MyADHD module

Table III.2: Breakdown of qualitative feedback gathered from module evaluation within online intervention.

Feedback item	Mean number of words (SD)	Responses
Intro videos	10.5 (10)	51
Breathe videos	9.5 (13.8)	61
Stop videos	12.8 (17.1)	49
Emotions videos	13.2 (20.1)	35
Planning videos	8.3 (14.4)	43
Acceptance videos	6.5 (7.2)	36

and (2) a version of the same situation where the protagonist successfully handles the situation with the use of a technique featured in the MyADHD intervention. Example videos are available in Multimedia Appendices 1-4. Descriptions of all videos are available in Table S1 in Multimedia Appendix 5.

At the end of each module, participants were asked to rate their satisfaction with the module's content and to provide qualitative feedback about their opinion on the module. The following 3 questions were asked, with an open-ended text input field for each question: (1) "What did you like best or what did you find most useful in this module?" (2) "What did you miss or what disappointed you in this module?" and (3) "In the module, you saw some videos. How would you evaluate them?" The seventh and final module was a summary of all the material and asked the participant for the key takeaways of each module. Lastly, participants completed a posttrial questionnaire on the entire intervention. Across 6 modules, 79 participants (79/109, 72.5%) provided feedback on the videos, with a total of 275 responses and 2850 words. See Table III.2 for further descriptive statistics about data referring exclusively to videos (question number 3).

All data recorded for this study, including the interview transcripts, were securely stored on a hospital research server. All participants were free to withdraw their participation and have their data removed at any time.

Data Collection: Interviews

In a posttrial survey, participants were asked to be interviewed in-depth regarding their experience with completing the intervention. The inclusion criterion was to live in the vicinity of the hospital that ran the main study. To this petition, 20 participants responded positively, and 13 did not qualify for inclusion due to their geographic location. Among the 7 interviewees, 6 self-identified as women and 1 as a man, and they were aged between 27 years and 47 years (mean 35 years, SD 8 years). Participants were interviewed for an average of 1.5 hours at 1-5 weeks after completing their participation in the study.

Procedure The interviews followed a semi-structured interview guide (Kvale, 2007). The interview focused on the participants' experience with the videos and included the following open-ended questions: "What do you think of the videos?" "What do you think of the characters?" "What do you think about the situations in the video?" and "How did the videos help you to complete the program?" However, these questions were used more like a checklist for the interviewers rather than a guide, so that the conversation originating from the questions would flow as freely as possible. The interviews were conducted by 1 human-computer interaction researcher (HCI) and 1 research assistant.

Data Analysis

The qualitative feedback and the interviews were analyzed following the procedure by Braun and Clarke for reflexive thematic analysis (Braun and Clarke, 2006, 2020). Interviews were transcribed verbatim. Qualitative data from the online intervention were combined with the interview data. Each interview participant was given a gender-neutral pseudonym in the transcripts. Data excerpts from each participant in the online intervention were given a random numerical ID code, with no inclusion of identifying information in the transcripts.

The first author coded the dataset. The following research question was formulated to guide the analysis: "How do participants in the online intervention experience and make sense of video vignettes designed for the intervention?" A semantic, inductive approach was applied to the coding of excerpts, meaning that the coder aimed to understand the participants' statements as descriptions of their experience. The themes, with their codes and excerpts, were discussed between the first, second, and third authors. Then, codes were rearranged into 3 themes. Upon writing the report of the analysis, quotes that described characteristics and variations of the themes were carefully translated into English.

Figure III.1: Stills from the video vignettes: (1) Nora procrastinates at her office, (2) Nora is at home doing a planning activity to get her work done during overtime, (3) Erik stresses through the morning routines; his wife and the children's toys are visible in the background, (4) Erik takes a moment to perform a breathing exercise in a moment of distress.

3 Results

3.1 Phase 1: Participatory Design Study Design Process

Design process

The clinicians in the research team discussed the therapeutic rationale for designing videos as content for an online intervention, following the practice of defining guiding principles in the person-based approach (Yardley et al., 2015b). They defined 3 core aims: (1) to increase engagement with the intervention using experience-centered content, (2) to clarify and provide examples of core training principles and help participants make connections between the material and their own experiences, (3) to address self-stigmatizing beliefs in adults with ADHD. These aims guided the process of designing videos for the MyADHD intervention.

In response to the participants' request, we made a pilot video intended to display a realistic view of the everyday life experiences of an individual with ADHD. One of the participants expressed an interest in sharing experiences from her everyday life and the impact of ADHD on these activities. Her inclusion in the video production was an effort to resonate with the target group's experiences and values in the video. The participant met with an actress hired for the production. Together, they constructed the character of Nora Figure III.1 as the protagonist of the pilot and wrote the outline based on the participant's experiences and characteristics. Following this activity, a film production company was hired to adapt the outline into a screenplay and make a video. Next, the participant, a clinician, and an assistant read through the screenplay and approved it after minor revisions to the humoristic tone. During the recording of the video, the participant, a clinician, and an assistant acted as consultants to the actor and the crew to help achieve a result close to the original vision.

The pilot video received positive feedback from health care professionals, students, and a local ADHD patient association. Participants advised the research team to address family life. A second character, Erik Figure III.1, was created. This protagonist represented those adults with ADHD meeting challenges when they combine family, work, and personal life, and a series of videos for the online intervention was produced Figure III.1.

Characters

Erik is a family man around the age of 40 years with ADHD. After meeting new demands in his role as a father and husband, he struggles with maintaining his emotional control in stressful situations. Combining work and family life creates situations in which he quickly loses his temper and, thereafter, feels ashamed.

Nora is a woman in her 20s with ADHD. She is a young professional in finance who has a higher education. She struggles with inattentiveness, being easily distracted and forgetful, and often puts off important tasks.

A workshop to generate ideas for MyADHD video vignettes was organized with 12 participants. The participants were asked to share their experiences related to the topics of the modules for MyADHD. The participants were divided into 3 groups, and a facilitator (clinician or assistant) would ask them to describe challenges, daily situations, and coping strategies for each of the topics. In addition, the 2 actors who would play the protagonists attended the workshop, listened to the participants, and asked questions of the participants to better understand their roles.

The participants contributed with experiences from their everyday lives. For example, one participant told a story of being distracted from pressing matters at work by a bird outside her office. Another said that “one time, while at work, I drifted away and searched the web for ‘what is the difference between a magpie and a crow?’” Participants also described difficulties in relation to others, such as not feeling accepted as “a person with ADHD” because their behavior was not within others’ expectations of people with ADHD, or that their challenges were not taken seriously by their acquaintances (e.g., “when people tell me that ‘everyone’s like that’ and that ‘everyone forgets things or are unfocused,’ it becomes difficult to accept that I have ADHD, and I need help coping with my symptoms”). Regarding coping strategies, they found breathing exercises to be helpful, but often difficult to follow and complete because their focus could drift away from the activity. Many participants made “to-do lists” daily and set alarms on their phones to remember appointments. For further examples of the participants’ experiences and suggested coping strategies, please refer to Table S2 in Multimedia Appendix 6.

After the workshop, a clinician and the assistants created outlines for video vignettes to accompany the 6 modules of MyADHD. Notes from each of the 3 focus groups were compared and analyzed to extract topics and experiences appropriate for each module. Based on this analysis, outlines for 14 video vignettes were written. These outlines were rewritten into movie scripts in cooperation with the film production team.

During film production, a clinician acted as the consultant and oversaw the process. The film crew applied cinematic techniques of comic timing in acting, pacing in editing, and the use of music to make the videos engaging.

The final videos were shown to the participants who took part in designing the vignettes. Feedback was overall positive, but some found the videos a little too light, because several of the described challenges tend to be experienced simultaneously. Nonetheless, the participants also expressed an understanding for this reduction due to the pedagogical purposes. Overall, the videos were described as recognizable, pedagogical, and easy to follow. They were considered humorous, which was emphasized as a positive trait. The participants reported recognizing themselves in the video and a feeling of being less alone with their challenges. The participants requested additional examples of challenging social situations and how to improve the handling of such situations and more context to understand the challenges and exercises shown in the videos. Subsequently, the clinicians wrote text to introduce the context of each video for the online intervention. The participants approved the final version of the videos.

3.2 Phase 2 Findings: Evaluation

In this section, we present the analysis of qualitative data collected from participants (n=109) who participated in the clinical trial of MyADHD, phase 2 of our study. Common themes included how the participants viewed the characters and their situations and how the videos reflected their own everyday experiences. Furthermore, the participants responded to the videos by showing empathy with the characters, relived their own past experiences in similar situations, and reported that they felt less alone with their challenges and that they used the characters as role models for coping with their everyday problems.

Some participants reported that the videos were the most positive part of the MyADHD intervention. They described them as the main motivation to register for the study, among other things. They declared that watching others experiencing challenges like theirs was self-affirming. Although the use of video was received positively, some participants did not appreciate them: They found the videos boring and too long or too slow, while others found them too short. One participant reported that:

> *I have not seen them. #impatient [P. #22]*

Theme 1: "You Can See the Experience" – Recognizing ADHD-Related Challenges

The participants described how the videos depicted situations they recognized from their lives. In addition to the concrete situations, the participants also recognized themselves in the fictional characters of Nora and Erik. In this theme, we unpack how the videos were perceived by the participants as renditions of life with ADHD. We give attention to the participants' experiences of whether the depictions are perceived as realistic to what it means to have ADHD in everyday situations.

In one of the videos, Nora is distracted at work by various events (e.g., a bird outside the window of her office) and must work overtime to complete her economic report. Participant #60 recognized this situation and wrote:

> *The movies show just the way I feel in everyday life. The hours fly by, and I do not know what I have done.*

Certain story elements were recognizable for other participants:

> *I have several times lost concentration due to birds when I am at work. So that example was a bit funny. :) [P. #3]*

Seeing that the presence of a bird outside Nora's office could consume so much of Nora's day was easy to relate to in a humorous manner. The response of Participant #63 further shows that it was possible to recognize oneself in the video while finding it funny, as they simply put it: "[It] was like seeing myself [emoji: Face with Tears of Joy]."

As the videos portrayed relatable characters and situations because of their ADHD symptoms, it is interesting to investigate their level of credibility. In the interview, Charlie explained that seeing the way that the characters handled challenging situations resembled similar experiences they had:

> *You can see the experience from [the videos], and it is not made in such a way that seems fake. You know...you can watch a feature film and you can see that it is fake. This is realistic.*

The content of the video appeared credible to Charlie, and they went on to explain how seeing the videos made it possible to see their own actions in a new light:

> *[The videos are] done in a way that allows me to see my negative things without it becoming uncomfortable. I do not feel offended.*

Elliot shared how the situations displayed in the videos reminded them of concrete experiences and similar situations, such as driving off without noticing or remembering the coffee cup on the roof of the car before it is too late. However, regarding the experience with having ADHD, Elliot was not convinced that the videos gave a credible impression of the felt experience. Elliot said that the videos do not capture the turmoil of having a family and explained how ADHD is heritable and, thus, something their children struggle with as well:

> *I think [the videos] fall flat. Because it...it does not say anything about the seriousness, in a way, how fierce those [situations] actually are [...] So, I have been sitting in the mornings [after the family is out for work or school] crying. And it is not something I had been doing much before. And I am not afraid of emotions per se, but I am not used to crying. But I have been left behind with such...deep, deep despair and, uh...crying after being called the most insane things by my teenage daughter and her brother, who is a little younger.*

The way the participants related to the videos depended on their experiences with similar situations. Elliot criticized the video of Erik's morning routine, based on a personal comparison.

The characters in the videos were portrayed by actors that followed an agreed-upon script. As such, the videos communicated a certain understanding of what it means to have ADHD. One participant wrote about the first video with Nora:

> *I do not identify with the character; I get the feeling she was chosen to "look like" she has ADHD. However, some parts of what she said were more relatable. [P. #15]*

The participant distinguished between what is shown and what is said. The use of quotation marks can be interpreted as an ironic remark, and, therefore, such a depiction (i.e., to "look like" having ADHD) is an inconceivable feat to truly accomplish. Looking like something includes imitating the mannerisms supposedly associated with it.

By the third module, the same participant had now changed their mind about whether Nora as a character was relatable: "This time, the video with Nora was 'spot on,' it is definitely like me" [P. #15]. They went on to describe how Nora's postponing chores was relatable. Here, the participant qualified the character of Nora as realistic because what she does is what the participant does. However, the participant did not revisit the previous theme of "looking like ADHD." Elliot, who said the videos did not depict their experiences with ADHD accurately, was much more positively inclined to how Erik represents a "person with ADHD":

> *He is like many, many others with ADHD. He is a dude that lives a family life and tries to handle his shit. He is not a caricature. He is...a normal dude, and that is nice.*

Overall, the participants did not report a feeling of being misrepresented as a caricature of people with ADHD, except for participant #15 who gave a statement that could be interpreted in that direction.

Theme 2: Relating to the Characters and Their Situations

In this theme, we take a closer look at how the participants related socially and emotionally to the characters and their situations.

Alex said that the videos showing how to apply the techniques in corresponding situations were motivating:

> *I see that they can cope or make a change. [...] It inspires and motivates me to use the techniques shown in the videos, and the others [that are not covered in videos]*

Furthermore, Alex said that the videos show how the techniques are meant to be used:

> *Of course, I could have made the connections [between the technique and their intended outcomes] myself, but there is something extra with those videos: You get to see [how it is done]*

Thus, by setting an example of how to use a technique in the videos, the participants further understood the application of the technique in a certain context.

The video in which Nora is distracted during housework by a phone call from a friend who needed help purchasing a new dress (see example 2 in the Phase 1 Results section) received varied interpretations by the participants. Dylan speculated that Nora's decision to go shopping with her friend was an act of procrastination because shopping with a friend is generally a more attractive option than housework:

> *It's a lot more fun to be with your friend, [...] it is really just that simple, that you do what is fun, right? But then things are constantly postponed, and then you come home, like Nora, to a messy apartment.*

On the contrary, another participant related personally to Nora's video, having a bad conscience when putting her needs before an important task:

> *[I] see that personality also plays a role here. [To what extent] do you get a bad conscience for your friend if you postpone or drop her [need for help]? I, myself, have had to do a major cleanup in my head over the past year to make more room for myself and my chores. It feels a little selfish and it is hard. But necessary. [P. #81]*

Similarly, Dylan explained the turmoil that postponing chores can lead to:

> *And then, for me, for example, that's when the negative self-talk begins: "That is what you should have done." And then, you start cleaning, and then, it becomes a very big thing, a very negative thing.*

The participants emphasized different aspects of the videos that made sense in relation to their own experiences in social situations where dilemmas can create feelings of uneasiness. Participant #81 and Dylan agreed that Nora represents how the negative outcomes of the dilemma commonly are turned inwards, either towards the self as feelings of guilt (#81) or as the negative self-talk described by Dylan. The participants showed empathy with the characters and used the situation in the video to contemplate their own experiences with everyday challenges and self-stigma.

We now turn to how the videos aroused negative feelings and recollections of past experiences in some of the participants. Alex found similarities between his or her own life and Erik's morning routine in the videos for Module 2 (Breathe):

> *It is a situation I want to handle better. I should be able to do it, a few minutes for myself without an audio file, where I could breathe and relax the way he did in the video. I have not managed that yet, because I do not remember to do it.*

Alex saw that Erik handled the situations in a better way because he had internalized techniques for controlled breathing to alleviate stress. Alex, on the other hand, said that they "should be able to do it," but has not yet been able to implement the technique in everyday life. Alex needed a reminder for the breathing exercise, which seemed to be disappointing in comparison to the character Erik's apparent mastered application of the technique.

In Module 6 (Acceptance), Erik is in a video conference planning a party with his friends. Erik loses focus and, when asked a question, becomes agitated and slams the laptop computer shut. Participant #62 wrote in the evaluation of this module:

> *[It] is useful to have a reminder to be kind to yourself. [I] realize that I still have a way to go when it comes to self-acceptance.*

However, in the evaluation of the videos, the participant stated that "I thought this video was painful to watch, I cried afterward." In the posttrial evaluation of the entire intervention program, the participant wrote that "[...] I could not complete the module [on acceptance] after the first video." The negative experience with the video impeded the completion of the module, although this participant had identified it as useful. Unfortunately, we lack additional information on the participant's experience of the situation. However, this example of adverse effects shows how videos that depict sensitive issues can be painful for participants that have lived such issues.

In this theme, we have seen how the participants reacted to the videos, sometimes by showing empathy with the characters and other times reflecting on their similar challenges.

Theme 3: Video Protagonists as Companions and Role Models for Change

The videos were motivating for the participants when there was a certain agreement between the depiction of ADHD in the video and the participant's own experiences. In this theme, we explore how some participants related to the protagonists as role models for change.

One participant wrote the following as feedback to the videos that were shown in Module 6 (Acceptance):

> *For me, the videos are the best! At the same time, it hurts. But they show an educated, well-versed lady who struggles with the same things as me, and this is motivating. [P. #50]*

Here, the participant described how they were motivated by the protagonist Nora, despite the videos provoking negative feelings. For participant #50, Nora impressed and motivated them. The protagonist appeared to be a "educated, well-versed lady" at the same time as she struggled with relatable challenges in everyday life.

The protagonists in the video served as role models for the motivation of the participants. Participant #81 found it helpful to see that others had similar thoughts and actions and used Nora as starting point for a reflection on their present situation:

> *Nora says that she will be better at using her time more constructively. [And] she will not be impatient if she does not see results right away. It is the same with me. [...] [I] do not have everyday routines yet. [I have a] new job, a new place to live, and I am looking for a romantic partner. So, making routines can be a bit of a challenge now.*

Even though the participant does not explain how Nora influenced their perspective, their attitude toward their own life is influenced by knowing Nora as a character.

Participant #60 further elaborated on Nora being a role model, in the posttrial evaluation of the intervention program:

> *My biggest challenge in everyday life is postponing boring things, and it was precisely the video with Nora where I recognized myself. I set goals in everyday life. Thus, I have pushed myself to do all these routine chores better than before. I tidy up the apartment more often. The dirty dishes do not stay that long; instead, I clean them daily. I do the laundry, hung it up. This has been better almost throughout the training program.*

It is striking how the participant's reported improvements on everyday chores mirrored the challenges that Nora faces in the videos. The way that the participants addressed the protagonists shows that the videos contributed a social component to the intervention program.

Another social response to watching the videos is reflected in the report of feeling less alone:

> *It is good to watch the videos; it gives a feeling of not being alone when struggling with various things. And it gives me a sense of mastery in knowing I can do a lot of things that others are struggling with. [P. #19]*

Alex found comfort in the videos:

> *I was looking forward to the movie clips because they felt so familiar. I saw myself and it was amazing – what can I say? – good to feel that others are like that too.*

Dylan, who struggled with feelings of low self-esteem and mental turmoil, found comfort in learning that others may feel the same way:

> *It has actually been a huge relief to find out that there are others who have it just like you; you are not as unique as you thought!*

The experience of feeling less alone when struggling with everyday life was a relief for the participants. They learned about what it was like to have ADHD as an adult through participating in the intervention. For example, Dylan had little knowledge about ADHD, other than receiving the diagnosis and medication from their local psychiatric clinic, before participating. The study and the videos taught Dylan that their struggles with self-esteem and negative self-talk were something that others also experience.

Finally, participant #74 wrote in the posttrial evaluation that seeing the characters live ordinary lives was a positive aspect of the intervention program:

> *Seeing other adults with ADHD, who live ordinary lives, in the videos, has been very nice, and [...] the focus on the fact that there is a lot of positive [aspects of] the diagnosis. I live a very good life myself [emoji: Heart]*

4 Discussion

4.1 Principal Findings

Overview

In this study, we addressed the design of therapeutic content, in particular video vignettes, for adults with ADHD founded on the experiences of their peers. It was carried out as a participatory design study, followed by qualitative feedback from participants in a clinical trial of an online intervention.

Our findings show that the video vignettes' depiction of everyday situations resonated with the participants and, as a result, reflected their experiences. The participants recognized the situations and used the characters as role models for change.

4.2 Maintaining Authenticity in Narratives for Online Interventions

Personal narratives on social media have become an increasingly important and popular source of information about physical (Davis et al., 2015; Liu et al., 2013; Huh et al., 2014) and mental health (Andalibi et al., 2017; Feuston and Piper, 2019). Here, we discuss how videos based on personal narratives were used to create engaging content for the MyADHD intervention. We further discuss the trade-offs between maintaining authenticity and stylizing characteristics of mental health and how they affect stigmatization.

The use of video vignettes was an engaging feature of the MyADHD intervention, and by producing our videos, we could ensure that the content would abide by the therapeutic principles. Video as a design material offers diverse ways to contextualize narratives. For example, the choice of actors, location, set decoration, editing, and general style of the video lay the foundations for the viewer's experience with the content. However, in our intervention, the protagonist Nora seemed to be "chosen to 'look like' she has ADHD," as reported in theme 1 in the thematic analysis. This remark is timely because ADHD is associated with public stigma, often perpetuated in media reports (Kooij et al., 2019; Ponnou and Gonon, 2017; Hinshaw, 2018; Ray and Hinnant, 2009). In the video vignettes of MyADHD, the actors who portrayed the protagonists acted as if they had an ADHD diagnosis. The actors' performance can come off as a caricature that, in turn, reinforces self-stigmatizing beliefs in people of the target group or may cause skepticism about the authenticity of the narrative. Perhaps the credibility of the narrative could be better maintained if the video vignettes followed people with ADHD. A documentary style might resemble more the way health vloggers share their experiences with diagnosis and illness (Davis et al., 2015; Liu et al., 2013; Huh et al., 2014), and have been utilized in the studies by Amsalem et al (Amsalem et al., 2021b; Amsalem and Martin, 2022), using people with the lived experience of schizophrenia in videos to reduce public stigma.

Honary et al. (2018b) found that using actors as "talking heads" representing the lived experience of mental illness in videos was important for the protection of the identity and anonymity of the participants in their study. However, in some cases such as interventions for groups that experience public stigma, active participation in the content may be a meaningful and empowering activity for the participants. Designers of interventions for people with mental disorders could explore the possibility of the participants participating in video vignettes narrating their everyday life, provided they are motivated and informed about the implications of such exposure. Representatives of the target group are excellent communicators of authentic experiences of mental health issues in everyday life. Such participation, however, requires careful considerations of the ethical implications. Whereas sharing personal experiences of mental health on social media is a private initiative, to disclose a person's mental health in the context of a research study is essentially a public matter. Research-led disclosure would require a thorough assessment and follow-up of the participants' safety.

Based on our thematic analysis, we found that the participants perceived the protagonists Nora and Erik as characters. The participants related to them as examples of how ADHD symptoms may manifest in everyday life while being aware of the boundaries of the characters and understanding that they do not necessarily generalize the ADHD experience. Looking like someone with ADHD, however, can take many forms since people with ADHD represent a heterogeneous group with diverse characteristics and experiences. For example, the video content designed in this study is limited to a dichotomy between male and female ADHD. However, people's gender identities are known to be fluid, implying that inclusive intervention content is needed. Future research should explore how we represent the diversity of mental health in online interventions. For example, including people with multiple marginalized identities as reported in former studies (e.g., Russell and Fish, 2016) is an exciting possibility in the processes of designing more diverse and inclusive online interventions.

In designing video vignettes that apply narratives of the everyday lives of people with mental health disorders, designers must be aware of the trade-off between preserving the authenticity and reinforcing stigmatizing characteristics of mental health. Using actors protects the identities of people with mental health problems, while, on the other hand, affects the authenticity and may contribute to stigmatizing caricatures of the experience of mental health.

4.3 Grounding Therapeutic Content in Everyday Life Situations

Online clinical health communication has been described as fact-based and prescriptive (Hartzler and Pratt, 2011). In our experience, this conceptualization is transferable to the communication of therapeutic content in psychological online interventions. In this part, we discuss how we have explicitly focused on everyday situations to help adults with ADHD integrate the MyADHD intervention in their daily lives. We emphasize the importance of striking a balance between the experiential, lived perspective of mental health with the more prescriptive, clinical presentation of how to self-manage mental health when designing video vignettes.

In online interventions, exercises and coping techniques from CBT, DBT, and other therapies are presented through text, audio, or video; they guide the participant in successfully applying these techniques and self-managing their mental health. However, in the design of unguided online interventions, it is particularly important to consider how the techniques are presented. In this case, the absence of a therapeutic relationship places greater demands on the design of the therapeutic content. Exercises and techniques can be difficult to understand as they are intended. They presuppose the understanding of both the application and the relevance to one's everyday life. For the intervention to be effective and meaningful, the exercises and coping techniques should be exemplified by everyday relatable situations. By doing so, the techniques can be transferable and implemented into day-to-day challenging situations. Seeing peers cope with challenging situations may enhance one's sense of self-efficacy (Bandura, 1977a,b).

The video vignettes in MyADHD offer contextualization of difficult everyday situations in scenarios recognizable and relatable to adults with ADHD, based on their own experiences. For example, in the first video for Module 2 (Breathe; see Table S1, Multimedia Appendix 5), the protagonist, Erik, was overwhelmed with stress by the morning routine with the family. In the follow-up video, Erik applied a coping technique to prepare himself before getting on with the morning routine and, thus, had a less stressful morning with his family. In this way, the videos contextualized psychological coping techniques by showing their intended use and outcomes in a variety of everyday situations. We established the psychological coping techniques using examples of mundane everyday situations. Thus, we followed Feuston and Piper's (2019) focus on the lived experience of mental health through an everyday lens. By grounding the therapeutic content in the daily struggles, we sought to challenge sensationalized (Ponnou and Gonon, 2017; Ray and Hinnant, 2009) and stigmatizing (Lebowitz, 2016; Mueller et al., 2012) narratives of what it means to live with ADHD.

The video vignettes portrayed people with ADHD through characters that held steady jobs, good relationships, and meaningful everyday lives. In this way, we tried to formulate an alternative to didactic, theory-driven narrations of therapeutic content. By providing a clear context to both the symptoms of and coping techniques for ADHD-related challenges, we sought to offer a nonsensationalized view of the disorder that resonated with our participants. In theme 3 of the phase 2 findings, we analyzed how the participants were inspired by the character Nora's actions. The participants' reports of feeling motivated when seeing the characters coping with ADHD-related challenges could be seen in light of Bandura's (Bandura, 1977a,b) social cognitive theory, where observing role models is essential to facilitate learning. However, the videos might be less relatable and motivating when they show the coping techniques perfectly applied, especially to those that know how difficult those efforts can be. This is exemplified by Elliot's statement in theme 1 of the phase 2 findings: According to the participant, the videos "fell flat" regarding the depiction of everyday life with ADHD. This shortcoming can be explained by the context (i.e., an online intervention with therapeutic aims) or the participatory process of designing the video vignettes.

Blandford et al. (2018) addressed how health and HCI research understand user needs from diametrically opposing positions: from a theoretical and evidence-based viewpoint (top-down) (Michie et al., 2011) and from consulting or involving users directly as participants in design activities (bottom-up) (Bratteteig and Wagner, 2016), respectively. For therapeutic content to be properly grounded in the everyday experiences of the target group, a bottom-up approach is required. Involving participants in design activities permits the creation of realistic and relatable scenarios. However, it is necessary to be conscious of the activity one is designing for, which, in this study, was an online unguided therapy aimed to improve the management of everyday challenges for adults with ADHD. The design of content that is both effective in mediating therapy as well as relevant and consistent with the target group's experiences and values must be guided by both therapeutic aims and an experiential perspective on mental health. This, in the context of online interventions, requires a balance between the sometimes conflicting prescriptive and experiential views on mental health.

4.4 Configuring Participatory Design of Intervention Content

Here, we discuss how participatory design can complement and extend specialized approaches to the design of online interventions to align the content with the values and experiences of the target groups. Furthermore, we discuss how the participatory process applied here could be adapted for the design of online interventions destined for other target groups.

Designing narratives of mental health as content in an online intervention requires understanding mental health from an experiential perspective. Therefore, careful consideration of representing the diversity of experiences and identities of the target group is necessary to be inclusive of a variety of identities. Here, we argue that a participatory design process that includes people with first-hand experiences of relevant mental health issues is an appropriate method. Participatory design can include the voices of people with a breadth of experiences and help strike a balance between the lived experience and the therapeutic expertise of clinicians.

The MyADHD intervention was developed following the person-based approach (Yardley et al., 2015b). Although this approach is partly rooted in user-centered design methods, Yardley et al. (2015b) explicitly differentiated this approach from participatory approaches that include co-design activities:

> A potential problem with [the co-design] approach is that it encourages

> users to try to anticipate the needs of others, which they are unlikely to do well, rather than simply reporting their own experiences and views, which they do very well. We find that users are naturally expert at telling us what they like or dislike about our intervention, but most users are understandably less able to generate effective behavior change techniques or good design solutions. (Yardley et al., 2015b, p. 7)

In the development of MyADHD, however, we used the co-design method of participatory design to specifically engage people with ADHD and make their voices heard in the process of designing therapeutic content. We found that the participants were not just experts on "what they like or dislike," but intimately knowledgeable of ADHD as it is lived by their first-hand experience and tacit knowledge of being diagnosed with ADHD. Building on their knowledge, we designed content that represented the participants of the intervention study. So, we have constructively extended the person-based approach by including participatory design in the process of designing content for the MyADHD intervention.

In this paper, we showed that the core therapeutic aims defined by clinicians are retained while, at the same time, people's experiences with ADHD are directly included in an online intervention through participatory design. According to Yardley et al. (2015b), participants are "less able" to generate behavior change techniques. It has been recommended that the behavior change techniques of online interventions should be based on sound theory and evidence to substantiate their effect (Yardley et al., 2015b; Michie et al., 2011; Craig et al., 2008). In this study, the participants primarily contributed to co-designing the presentation of behavior change techniques. In the ideation workshop, participants did, however, also contribute by suggesting coping strategies that they used to manage their everyday lives (see Table S2, Multimedia Appendix 5 for a diverse selection of suggestions). It is our position from conducting this study that participants can be *enabled* to contribute to the design of behavior change techniques — this is a matter of proper design process facilitation.

According to Bratteteig and Wagner (2016), participatory design "may have to operate in a highly structured environment that imposes particular 'rules' and surely it has to define its own ways of operating" (p. 456). Referring to this, we took a pragmatic position: The clinicians defined the clinical needs and the treatment outcomes according to theoretical models and their expertise. In this study, the use of principles and techniques from psychological interventions coupled with psychoeducation enhanced the perceived mastery of everyday life challenges for adults with ADHD. Experts by experience contributed by narrating their everyday life and were, thus, in a position to share "what the user wants." Here, it was a request to use videos to narrate content that the participants not only suggested but also took part in designing.

The design process led to mutual learning among the parties (i.e., clinicians, participants, and the film production team) involved in the design of the video vignettes. This learning was developed within meetings, workshops, and film production sets. For example, clinicians would learn about specific difficult situations for the adults, whereas the participants learned how their experiences fit within a clinical viewpoint and boundaries for the management of ADHD symptoms. The film production team conceptualized these ideas into a video format. The video scripts would then be reworked under the other parties' perspectives. The presentation of the video vignettes was further enhanced as engaging content by the skillful execution of the film production team. The video vignettes were, in a sense, grounded in the tacit knowledge (Ehn, 2008) of the participatory design participants. The lived experience of having an ADHD diagnosis was not available to the clinicians initially; the participants brought their experiences into the process through the mutual learning facilitated by the participatory design process.

The design process of making video vignettes for the MyADHD was costly and time-intensive: It required resources for a film production team that would realize the vision of the participatory design process. However, we encourage the application of our process in the development of psychological online interventions that aim to create therapeutic content grounded in everyday contexts for their target groups. Similar to how health vloggers produce technically simple productions with consumer products (e.g., smartphones, web cameras), designers of content for psychological interventions can do the same.

We suggest that resonance with the participant's values and experiences is vital for this kind of content to be perceived as meaningful and further suggest that researchers and designers of online interventions should strive to achieve this in their efforts to produce narrative content that supports therapeutic principles.

Person-centered approaches to design have been emphasized as essential to create content that is adapted to the target group's shared values and experiences (Eysenbach, 2005; Honary et al., 2018a). In this regard, we found the co-design activities of the participatory design method complemented the person-based approach in developing online interventions. The participatory design approach comes from a democratic perspective of giving future users a say in the design of information technology solutions (Muller, 2002; Ehn, 2008) and, therefore, can be used to align the intervention with the values, experiences, and needs of potential adopters. However, for the designed content to be successful in supporting therapeutic principles, the participatory design for online interventions needs to be carefully facilitated. We recommend that researchers and designers of online interventions adapt co-design to their target group and specific purpose – there is no one-size-fits-all approach to meaningful co-design.

Regarding the involvement of people with ADHD in our process, we found, contrary to (Yardley et al., 2015b), that the "users" were indeed competent in generating adequate design solutions. In our experience, the participants contributed with interest and determination in designing creative, novel narrative content. Their contributions possessed qualities in ways we could not have anticipated. We found their involvement in this study decisive in designing content that represented the target group's values and experiences.

4.5 Limitations

This qualitative study has limitations. First, in the clinical trial and the follow-up interviews, women were overrepresented compared to men. Thus, our findings may not be representative of men with ADHD. Second, the ADHD diagnosis was self-reported. Last, this is a qualitative study and thus does not ascertain the videos' or the intervention's clinical effects. Further details of the study design and dissemination of the effects and clinical outcomes will be reported in a separate publication.

4.6 Conclusions

In this paper, we presented our process for designing video vignettes portraying challenging situations of living with ADHD, with the participation of and directed to adults with ADHD in a therapeutic context. Based on our findings, the approach of using an everyday lens and describing ostensibly mundane and everyday contexts in the videos was well-received by the participants in a clinical trial of an unguided online intervention. The videos provided rich and contextualized illustrations of life with ADHD, designed beyond the need for self-management in core symptoms. Applying a participatory approach when designing for online interventions, however, requires a balance between the lived experience as reported by the participants and the therapeutic expertise of the clinicians to be relevant to the target group.

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Appendix

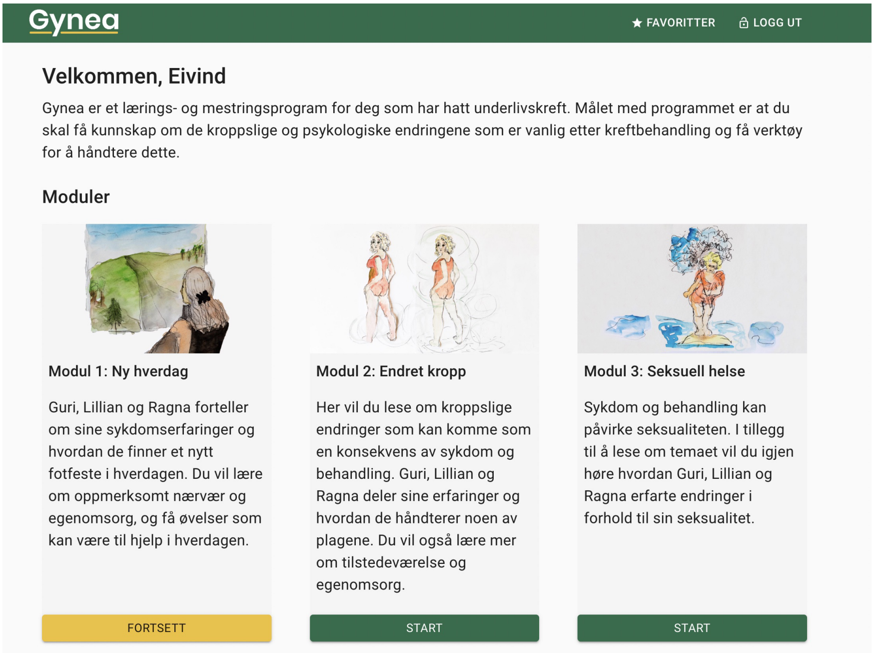
Appendix A

Design of digital health interventions

While working on the INTROMAT research and innovation project, a generic design for a web-based Digital Health Intervention (DHI) (Figure A.1) was designed by me in collaboration with colleagues at the project and industrial partner *Youwell* (both the name of the company and their intervention platform).

It was first designed as a prototype in Adobe XD, then developed in the GatsbyJS framework, built on top of the React JavaScript library as a proof-of-concept web application. Following initial user testing, it was then implemented in Youwell's frontend by engineers of the industrial partner (Figure A.2). Following the implementation, the frontend was further refined in close collaboration with Youwell engineers, making it responsive for all screens and adjusting the designs for new features.

The DHI was used for the studies presented in Paper II and III (Figure A.3), and was also used for other cases in the INTROMAT project.



Velkommen, Eivind

Gynea er et lærings- og mestringsprogram for deg som har hatt underlivskreft. Målet med programmet er at du skal få kunnskap om de kroppslige og psykologiske endringene som er vanlig etter kreftbehandling og få verktøy for å håndtere dette.

Moduler

Modul 1: Ny hverdag

Guri, Lillian og Ragna forteller om sine sykdomserfaringer og hvordan de finner et nytt fotfeste i hverdagen. Du vil lære om oppmerksomt nærvær og egenomsorg, og få øvelser som kan være til hjelp i hverdagen.

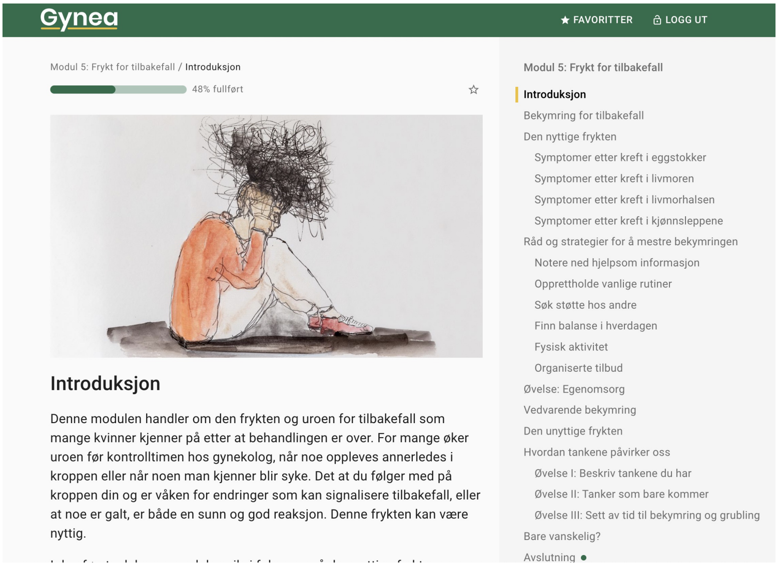
Modul 2: Endret kropp

Her vil du lese om kroppslige endringer som kan komme som en konsekvens av sykdom og behandling. Guri, Lillian og Ragna deler sine erfaringer og hvordan de håndterer noen av plagene. Du vil også lære mer om tilstedeværelse og egenomsorg.

Modul 3: Seksuell helse

Sykdom og behandling kan påvirke seksualiteten. I tillegg til å lese om temaet vil du igjen høre hvordan Guri, Lillian og Ragna erfarte endringer i forhold til sin seksualitet.

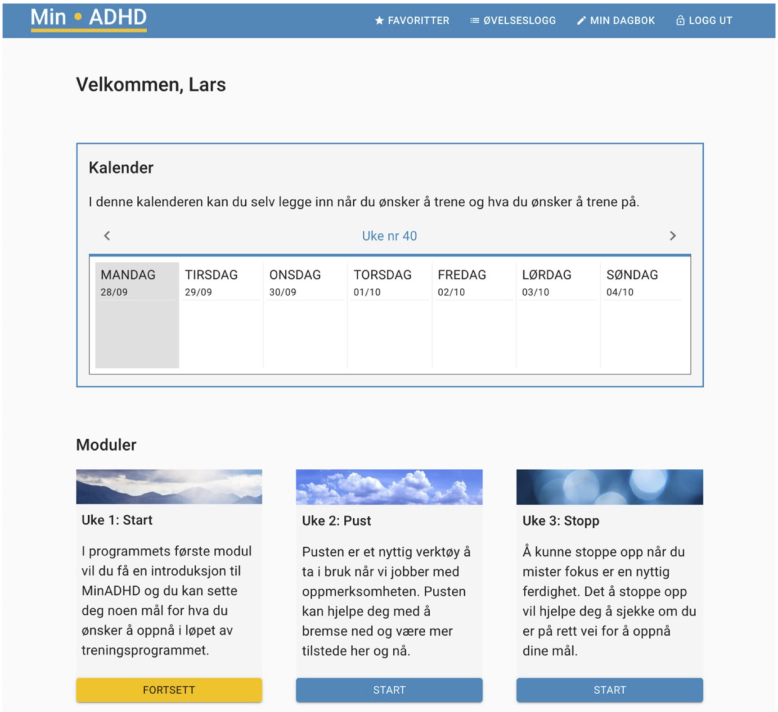
Figure A.1: The front page of the *Gynea* DHI website. Shows a preview of six modules.



Introduksjon

Denne modulen handler om den frykten og uroen for tilbakefall som mange kvinner kjenner på etter at behandlingen er over. For mange øker uroen før kontrolltimen hos gynekolog, når noe oppleves annerledes i kroppen eller når noen man kjenner blir syke. Det at du følger med på kroppen din og er våken for endringer som kan signalisere tilbakefall, eller at noe er galt, er både en sunn og god reaksjon. Denne frykten kan være nyttig.

Figure A.2: The first page in a module in the *Gynea* DHI.



Velkommen, Lars

Kalender

I denne kalenderen kan du selv legge inn når du ønsker å trene og hva du ønsker å trene på.

MANDAG	TIRSDAG	ONSDAG	TORSDAG	FREDAG	LØRDAG	SØNDAG
28/09	29/09	30/09	01/10	02/10	03/10	04/10

Moduler

Uke 1: Start

I programmets første modul vil du få en introduksjon til MinADHD og du kan sette deg noen mål for hva du ønsker å oppnå i løpet av treningsprogrammet.

Uke 2: Pust

Pusten er et nyttig verktøy å ta i bruk når vi jobber med oppmerksomheten. Pusten kan hjelpe deg med å bremse ned og være mer tilstede her og nå.

Uke 3: Stopp

Å kunne stoppe opp når du mister fokus er en nyttig ferdighet. Det å stoppe opp vil hjelpe deg å sjekke om du er på rett vei for å oppnå dine mål.

Figure A.3: Main page of *MinADHD* (translated MyADHD) intervention used in the study for Paper III.

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