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PhD thesis

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Experiences with narrative courses for people who have or have had cancer

An ethnografic study

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List of papers

The dissertation is based on an ethnographic field study divided into three sub-studies. Findings from these are reported in three scientific papers:

Sub-study I:

Gärtner, H. S., Blix, B. H., Raunkiær, M., & Timm, H. (2024). 'There is nothing beautiful or life-affirming in it': experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer. Mortality. Advance online publication. https://doi.org/10.1080/13576275.2024.2360521

Sub-study II:

Gärtner, H. S., Blix, B. H., Raunkiær, M., & Timm, H. (2024). "The most fantastic thing is coming here as an individual and going to bed as part of a group": participants' experiences from a residential course, for people with advanced cancer. Omega - Journal of Death and Dying, e-bub ahead of print. https://doi.org/10.1177/00302228241264876

Sub-study III:

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Roikjær, Stine Gundtoft, **Gärtner, Henriette Søby,** Timm, Helle (2022): Use of narrative methods in rehabilitation and palliative care in Scandinavian countries: A scoping review. Scandinavian journal of caring sciences, 06/2022, Volume 36, Issue 2

Gärtner, Henriette Søby, Timm, Helle, & Raunkiær, Mette (2021). Meningsfulde fællesskaber for mennesker med kronisk, fremadskridende kræft. *Omsorg*, *38*(4), 55-59.

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I dedicate this work in loving memory of my mom and dad.

A part of me will forever feel homeless without you.

Preface

I barely reached adulthood before I lost both of my parents. I have no recollection of my father being well: my memories of him are clouded by the pain of 'all that never was' as I witnessed him fade slowly and painfully away throughout my childhood. The loss of my mother was a somewhat classic cancer story. We had two years from her diagnosis with advanced lung cancer until she left this world, in hospice care.

What I am trying to say is that I am no stranger to suffering.

Living through a childhood of uncertainty and growing into adulthood with loss, grief and my hopes for the future in a bound fellowship has made me who I am, both as a person and as a researcher. These personal experiences have paved my path to writing this dissertation and shaped how it took form. Whenever I doubted my capabilities or motivation to withstand and endure the trials of the PhD journey, I always ended up, side-by-side with the participants in the narrative courses. Taking their experiences seriously has always been personal to me. Their stories always transcended what I thought I knew: about suffering, about death, but most importantly, about life.

On the other hand, this dissertation ended up becoming a story of why we must never take for granted that what we believe to be good and purposeful also is. In 2021, when I was employed to evaluate the narrative courses as part of a larger programme on combined rehabilitation and palliative care approaches for people with cancer, I had no idea how much of the participants' experiences with the courses were influenced by other circumstances than the narrative exercises. My field encounters with the participants in the narrative courses who experienced the courses as harmful turned my thoughts about doing an evaluation around. They reminded me to stay curious and dare to start over, rethink the questions I was expected to ask and take an exploratory approach to their experiences and stories.

I developed a determination to explore the participants' experiences with the narrative courses more openly, and to nuance and challenge my own pre-understanding of the significance of narrative and the influence of context. This dissertation will illustrate my research journey in exploring this complexity.

In many ways, this dissertation has become a story on its own. It has become a story I am proud to tell and now call part of my own life history.

Acknowledgements

The first round of appreciation belongs to the participants in the narrative courses. I thank you for letting me into the most intimate and vulnerable parts of your lives; and for accepting my presence both when you cried and laughed. Naturally, I could not have written this dissertation without you. Yet, most importantly I feel like I learned so unimaginably much about life from you. For that, I am eternally grateful.

I would like to thank my research group at SIF. You have been the best of colleagues. Supportive, inspiring and often very funny. Especially thanks to Marie Broholm-Holst, whom I got to be office buddies with. I deeply appreciate all our talks, bad jokes, and trips down the street to grab a coffee and catch up.

Over the past three years, I have met many other PhD students who had to continuously fight for their voice and their sense of worth throughout this learning experience. I am forever grateful for my continually understanding and supporting supervisory team, who made my journey feel secure: Professor Mette Raunkiær, Professor Bodil H. Blix and Professor Helle Timm. I am grateful for your trust in me, your exemplary academic patience and your professional attention. Thank you for allowing me to lean on you and your knowledge. A special thanks goes to my main supervisor, Helle Timm. You have caught me and guided me through both academic and personal challenges in ways that I could never have imagined. Your guidance has been the safe harbour of my (academic) life, and I feel so privileged to have shared these past years with you. You have a way of being in this world that I find both honest and admirable. I would never have done this if it were not for you.

To the Danish Cancer Society, REHPA and The University of Southern Denmark, I am grateful for the necessary financial support. Thanks to all my former PhD colleagues, especially those of you from REHPA, who I got to grow up with, PhD-wise. It has been such an honour to share this (collective) experience with you and to watch each of you being awarded your PhD degree.

My deepest appreciation goes to my husband and best friend, Daniel, and to our three wonderful daughters: Asta, Ellen and Agnes. You are the meaning of it all. Jeg elsker jer for evigt.

Henriette Søby Gärtner

Contents

Sub-study I-III

1. Introduction

> “You need to react in certain ways [to having cancer], maybe more like I did the first time I was diagnosed, when I cried over everything and felt really terrible. Why do people say things like “you are managing it all so well”? Well, maybe I do, but I’m not doing it to handle it well, I’m doing it to cope. It’s not a role for me; I’ve just decided to get the most out of life. I’ll squeeze this life for everything I can get, right? You may begin to think it’s a waste to buy a new dress because I already got so many – but hell no, they must just throw them away after I’m gone” (Female participant: interview #9, REHPA I).

By opening this dissertation with an empirical excerpt illustrating a snippet of the complex struggles of living with cancer, I hope to foreground the foundation of this study: the participants’ experiences. This study is based on the experiences of 42 participants who had or have had cancer and who participated in one of four narrative courses in Denmark.

Having cancer may be best understood as suffering from a ‘deep illness’ (Frank, 1998) as it is linked to a complex symptom burden that extends beyond the body and also affects existential, social and psychological dimensions of peoples’ lives (Lewandowska et al., 2020). An illness is considered deep when it permeates every aspect of life, influencing everything from daily decisions to thoughts of the future (Frank, 1998). Following Bury’s terminology, cancer may cause a ‘biographical disruption’ (Bury, 1982), a term that likewise captures how serious illness threatens everyday life (Bury, 2001), by damaging the patient’s sense of continuity and identity (Hydén and Brockmeier, 2008). A common characteristic among the participants in the narrative courses was that, regardless of their prognosis, they were ‘deeply ill’ with cancer.

As the incidence of cancer rises worldwide (Sung et al., 2021), we will most likely all face the consequences of cancer. If we have not already lost people we love to cancer, we almost certainly will. Just as we could eventually face the diagnosis ourselves. In Denmark, cancer is the leading cause of death (Sundhedsdatastyrelsen, 2023a), with cancer accounting for almost 30 % of all adult deaths between 2018-2020 (Jarlbæk et al., 2024). Before turning 75 years of age, one out of three Danes will be diagnosed with cancer (Sundhedsdatastyrelsen, 2023a). Cancer thus continues to be both a global, a national and an individual concern. Even if more people are diagnosed with cancer, the incidence of people living with cancer also increases (Sundhedsdatastyrelsen, 2023b). People with incurable cancer now may live extended lives, receiving more life-prolonging treatments and the possibility of living years without active disease – however, they still face a complexity of symptoms and how to support their needs remains under researched (Mollica et al., 2022; Stegmann et al., 2021; Kaasa et al., 2018). Cancer brings severe life-altering consequences to life and thus seems inevitably connected to suffering (García-Rueda et al., 2016; Hubbard and Forbat, 2012). The desire to help alleviate the various forms of suffering caused by severe illness drives the efforts of many researchers and healthcare practitioners and serves as the motivation behind this dissertation.

One way to help ease the suffering caused by cancer is through the use of narrative, a research area that has gained traction within the past 50 years (Wind and Vedsted, 2008). The underlying premise is that narratives may help re-establish a sense of coherence and meaning in life when illness has introduced chaos and disruption (Kleinman, 1998; Frank, 2013; Mattingly, 2012; Wind and Vedsted, 2008). Based on these assumptions, Danish professionals developed what I broadly refer to as ‘narrative courses’. These narrative courses were implemented in two different settings, each with different participant groups.

Exploring the participants’ experiences

I have chosen to ethnographically explore the participants’ experiences with the narrative courses. Experience thus becomes a central concept. Broadly, experience is both an intrapersonal phenomenon, referring to how it manifests in the individual’s body and mind, and an interpersonal phenomenon, meaning how it occurs through social interaction (Paulsen, 2020). Experience can be studied from various research traditions, including the phenomenological/hermeneutic tradition and the constructivist/interactionist tradition. Although phenomenology and constructivism exist on a scientific continuum, the perception of the object of analysis differs between these traditions (Järvinen and Mik-Meyer, 2005). In phenomenology, the focus is on exploring the essence of the studied phenomenon from the viewpoint of those who experiences it (subjectively), determining the meaning of the ‘lived experience’ (Neubauer et al., 2019; Berg-Sørensen, 2013). Essentially this means that the object of analysis is studied as a ‘fixed’ and stabile phenomenon, something that may be uncovered by the researcher, whereas a constructivist approach will understand and explore the phenomenon as dynamic, unstable and multifaceted. It is in this latter understanding that the term ‘experience’ is used throughout this dissertation. This acknowledges the complex and dynamic nature of experience and emphasizes the importance of understanding the circumstances and environment in which experience is expressed and negotiated. Incorporating this concept into ethnographic inquiry, I found inspiration in the approach by Kleinman and Kleinman (1991), which emphasises focusing on ‘what is at stake’ for people in the studied field. They emphasise the social situatedness of experiences, noting that interpersonal experiences are shaped by specific times and places, what they identify ‘a local moral world’:

> ” We define experience not as a subjective phenomenon - something that a single person "has" - but as an interpersonal medium shared by, engaged in and also mediating between persons in a local world” (Kleinman and Kleinman, 1991: 295).

This terminology of local moral worlds translates to “local contexts of experience” (Kleinman and Kleinman, 1991: 296). It also implies that ‘experience’, such as illness, is always shaped by a local context along with a social and cultural context (Kleinman, 1998). Furthermore, narrative and experience are concepts that are closely linked, although both concepts are not easily contained in narrow definitions (Levy, 2005). Narrative may be a medium for expressing intrapersonal experiences (Høybye et al., 2005; Mattingly and Garro, 2000), however, I do not view narrative as merely a reflection of experience. Just as much as narrative shapes and gives meaning to experience, it also *creates* experience (Levy, 2005; Hydén, 1997). Central to my understanding of experience is therefore, in line with this dissertation’s position in social constructivism, the idea that narrative and experience are inseparable concepts: experience is narrative, and narrative is experience. Furthermore, as a researcher, I am also embedded in the participants’ ‘local context of experience’, making me part of the context and intertwined with their experiences and stories.

The majority of the participants in the narrative courses lived with incurable cancer, a group of patients that could be described as suffering from ‘prolonged incurable cancer’ (Stegmann et al., 2021). In this dissertation, I refer to this group of participants as having advanced cancer. Most had metastatic cancer and were either undergoing or taking a break from life-prolonging treatments. The other group of participants either had cancer or were in remission, with the prognosis of becoming cancer free. Although the participants are cancer patients in a biomedical understanding, I view them as participants in both the narrative courses *and* this research study. Furthermore, I rely on the distinction made by Kleinman (1998), in which the word ‘disease’ captures the biomedical identification of a bodily pathology, whereas ‘illness’ captures the patient’s illness experience, such as that of suffering. Although the patient’s illness experience is individual, illness experiences are (like narrative) culturally shaped, impacting how being ill is experienced (Kleinman, 1998).

I believe that it is essential to clarify that none of the participants in the courses were considered to be in the terminal phase of their illness at that time, defined as an expected survival of months or less (Hui et al., 2014), despite their prognosis. It is often characteristic of people living longer with incurable, metastatic cancer that they maintain a relatively high level of functioning throughout much of their illness trajectory (Knaul et al., 2018). With few exceptions, the severity of the participants' illness, prognosis and potential sequelae were not immediately apparent to the naked eye.

Study aim

The overall aim in this dissertation was to explore the participants' experiences during and after participating in a narrative course for people who have or have had cancer.

Before I present this study's research questions, it is essential to acknowledge that research questions (and the overall aim) often change in ethnographic research (Hammersley and Atkinson, 2019). As I engaged with the participants during fieldwork, I gained a deeper understanding of the complexity of their experiences. New insights emerged, necessitating the refinement of the overall aim and the adjustment of the research questions multiple times.

Based on this refinement and in dialogue with the field, I ended up exploring the participants' experiences from three angels, presented in Sub-studies I-III. Each sub-study was guided by the following research questions:

- How and in what ways did the participants in the narrative courses report experiences of harm? (Sub-study I)

- Were the narrative courses perceived as significant by the participants and, if so, in what ways? (Sub-study II)

- What were the experiences with the collective story exercise for participants with advanced cancer participating in the narrative courses? (Sub-study III)

Background

To support the complex needs of people with advanced cancer, the narrative courses were designed to combine rehabilitative and palliative care approaches. The narrative courses were implemented in two distinct settings with different participant groups: a residential research clinic and a municipal rehabilitation centre. These settings form the empirical foundation for this study and also represent two different rehabilitation offers available to people with cancer in Denmark.

In the following section, I wish to provide background to the overall concepts of rehabilitation and palliative care and present important key literature, relevant concepts, dominant theories and empirical studies that situate this study within the current knowledge. Next, I turn to the concept of narrative as I will provide details on the use and relevance of the concept of narrative for people with severe illness, along with how narrative methods are currently applied to support the needs of patients and their next of kin. Lastly, I will introduce the narrative courses, including the settings, the underlying theoretical assumptions, background, organisation and contents.

Rehabilitation and palliative care for people with cancer

Both rehabilitation and palliative care are notions of the World Health Organization's (WHO) universal health coverage, which implies that all people should have access to the necessary health services, and both approaches aim to improve or maintain quality of life for people with life-threatening illness (Timm et al., 2021a; WHO, 2023). Rehabilitation and palliative care approaches have many similarities as the contents of the offers may overlap; however, the intention behind these efforts often differ (Sundhedsstyrelsen, 2018). Differences and similarities in the two approaches are of relevance to this study as the narrative courses included and coordinated the principles and rationales of both rehabilitation and palliative care.

Rehabilitation

Functioning stands central within rehabilitation definitions (Meyer et al., 2020). The term applies to the process of aiding the patient to recover from illness, including its physical, social and psychological dimensions (Meyer et al., 2020; Sundhedsstyrelsen, 2018). The Danish Health Authority adheres to the WHO definition of functioning, resting on the International Classification of Functioning, Disability and Health model (ICF) (Sundhedsstyrelsen, 2018). The ICF is a holistic biopsychosocial model used to describe how functioning has three interdependent dimensions: body functions, body structures, and activity and participation (WHO, 2001; Timm et al., 2021b; Gärtner et al., 2023).

While multiple definitions of rehabilitation exist (Gärtner et al., 2023), with the Danish Health Authority adhering to the WHO's definition (Sundhedsstyrelsen, 2018), another definition seems especially relevant in a Danish context. In 2022, the Danish White Paper on rehabilitation offered an updated perspective on the rehabilitation approach, presenting a definition that has gained consensus among various stakeholders and practicians in Denmark (Maribo et al., 2022):

> ”Rehabilitation is offered to people who experience or are at risk of experiencing limitations in their physical, mental, cognitive and/or social functioning in their day-to-day life. The purpose of rehabilitation is to enable a meaningful life with the highest possible level of activity, participation, mastery of daily tasks, and quality of life. Rehabilitation is a collaborative process between a person, their family, professionals and other relevant parties. Rehabilitation programmes are targeted, systematic and based on the person's perspectives and overall life circumstances." (VeluxFonden, 2022).

I apply this definition of rehabilitation to this study as it is holistically founded on the patient's needs and perspectives. Rehabilitative services can support people suffering from cancer by addressing a potential decline in functioning, such as independence and activity, while also helping them maintain their sense of dignity and meaning in life (WHO, 2023; Sundhedsstyrelsen, 2018). In Denmark, rehabilitation is structured within the Danish healthcare system and cancer rehabilitation is tax-paid and offered to people who have or have had cancer. In Denmark, cancer rehabilitation is primarily organised in the municipalities, including individual and group efforts with variations. Rehabilitation efforts include initiatives such as physical training, dietary consults and counselling by psychologists and/or social workers (Hoybye and Tjornhoj-Thomsen, 2014; Thuesen et al., 2017). While rehabilitation for cancer patients has gained substantially more attention within the past decades (Tjørnhøj-Thomsen and Hansen, 2013), cancer has always been strongly associated with palliative care (Thuesen and Timm, 2014).

Palliative care

The Danish definition of palliative care extends from the WHO's definition in which palliative care is understood as an approach that aims to improve quality of life for patients with life-threatening diseases and their families by relieving symptoms of suffering (WHO, 2020; Sundhedsstyrelsen, 2017). Although traditionally palliative care was primarily available to people suffering from cancer, in 2017 the Danish Health Authority recommended irrespective of age or diagnosis, all people suffering from life-threatening diseases should be offered palliative care (Sundhedsstyrelsen, 2017).

Historically, palliative care stems from the hospice philosophy movement founded by Cicely Saunders in England in the 1950´s (Timm et al., 2021a). Central to understanding the relief of suffering in the palliative care approach is Saunders's concept of 'total pain'. This concept has gained significant traction in the development of palliative care and the establishment of hospices (Timm et al., 2021a). Saunders's concept of total pain reflects how pain must be understood as a multidimensional phenomenon (Strang et al., 2004), capturing the complexity of suffering including physical, social, psychological and/or existential dimensions (Wood, 2022). Formerly, palliative care was thought of as applicable only to the patient's terminal phase, delivered as end-of-life care when progressive illness had a prognosis of months or less (Kaasa et al., 2018; Radbruch et al., 2020; Hui et al., 2014). Internationally, the understanding of palliative care has evolved to encompass the entire illness trajectory of individuals living with life-threatening diseases (Knaul et al., 2018). In this new understanding, the palliative care continuum covers the time from diagnosis to death (and bereavement) and recognises how a patient's palliative needs may be dynamic and changing. People with metastatic cancer, in particular, may experience needs for both palliative care and treatment and alternate between the two, while continuing to have a quite high level of functioning despite their prognosis (Knaul et al., 2018). Most participants in this study fall into this latter classification of individuals with palliative care needs.

Palliative care is, by definition, holistic and multidisciplinary and may be integrated alongside other approaches, such as rehabilitation (Sundhedsstyrelsen, 2017; Dieperink et al., 2021). In Denmark, palliative care is organised into specialised and generalised efforts. Specialised palliative care is provided by professionals with palliative care as their main task. Professionals in specialised palliative care have distinct knowledge and training in palliation and practice in palliative care units and teams or at hospices, whereas generalised palliative care is conducted by professionals in hospitals and the primary care sector, such as care staff, nurses, general practitioners (GPs), psychologists or physiotherapists (Radbruch et al., 2020; Sundhedsstyrelsen, 2017).

Although traditionally offered as separate healthcare services, it is now recognised that combining or coordinating rehabilitation and palliative care earlier in the illness trajectory can be beneficial for patients (WHO, 2023; Møller et al., 2023a).

Coordinated rehabilitation and palliative care

Over the years, the concept and practice of offering rehabilitation and palliative care in combination has been described using various terminology, including 'integrating rehabilitation into palliative care' (WHO, 2023), 'rehabilitative palliative care' (Nordentoft et al., 2022), 'palliative rehabilitation' (Dietz, 1969; Neo et al., 2021), ‘coordinated rehabilitation and palliative care’ (Thuesen et al., 2016) and ‘combined rehabilitation and palliative care’ (Gärtner et al., 2023), among others. While there may be significant differences in the aim and practices associated with these definitions, I will primarily use the terminology of ‘combined’ or ‘coordinated rehabilitation and palliative care’ in this dissertation, acknowledging that even this terminology may carry varying implications.

A key argument for the coordination of the two approaches hinges on the assumption that patients in palliative care may experience rehabilitative needs, such as help to maintain or increase their functioning, just as patients in rehabilitation may experience a need for professionals to address end-of-life issues (Timm et al., 2021a; Thuesen et al., 2016). Increasing research is being devoted to studying how the two approaches may be combined to benefit patients (Thuesen et al., 2016; Timm et al., 2021a; Gärtner et al., 2023). However, evidence on the most successful methods for combining them is sparse (Nottelmann et al., 2019). During my study period, I was involved in conducting a scoping review, aimed at mapping and discussing, what happens to the goals of each approach when rehabilitation and palliative care were combined in interventions (Gärtner et al., 2023). Based on our literature review, which included ten international papers of five combined rehabilitative and palliative care interventions, we found that goals related to social dimensions, social participation, the patient’s personal goals and spiritual dimensions were often lacking as a focus in these combined interventions. This suggests that when rehabilitation and palliative care are combined, certain dimensions within the ICF classification receive more attention than others. Similarly, physical, and psychological dimensions, as emphasised in the ‘total pain’ framework, were more prominently featured in intervention evaluations, often at the expense of social and spiritual dimensions (Gärtner et al., 2023).

The coordination of rehabilitation and palliative care has mainly focused on people with advanced, life-limiting illnesses. However, numerous scholars have shown that being cancer free does not necessarily alleviate the ongoing suffering that the illness may still cause (MacDonald et al., 2021; Hansen and Tjørnhøj-Thomsen, 2008; Sontag, 1991). This suggests that palliative care principles may also be beneficial to this group of patients. Six out of 42 participants in the present study had a better prognosis than the 36 participants with advanced cancer at the time of the fieldwork and thus were not the primary target group of generalised palliative care. However, scholars suggest that focusing on the parallels between rehabilitation and palliative care may help advance both approaches individually; by making rehabilitation efforts more responsive to suffering and its alleviation, and by encouraging palliative care efforts to consider functioning as a key factor in relieving suffering (Timm et al., 2021b).

Narrative

Since the 1980s, there has been a significant surge of interest in narratives within the social sciences and the humanities, commonly referred to as ‘the narrative turn’ (Bo et al., 2016; Czarniawska, 2006; Hydén and Brockmeier, 2008; Blix and Sorly, 2017). This growing interest in narratives extended beyond the traditional literary theory understanding of narrative as text, expanding into an exploration of narrative as a dimension of social life (Czarniawska, 2006). The narrative turn influenced various disciplines, reflecting an increased interest in individual and collective narratives to understand human experience and the influence of social context (Sarah, 2013; Bo et al., 2016).

This interest in narrative spread from social sciences and humanities into the medical world as well (Ahlzen, 2019). In his book ‘The illness narratives’, American anthropologist and psychiatrist Arthur Kleinman brought the focus on narrative into clinical practice. Kleinman (1998) argued that for clinicians to provide better diagnoses and treatments, they must be trained in listening to and interpreting the patients’ illness narratives (Hydén and Brockmeier, 2008). On the basis of this connection between medicine and narrative, Rita Charon became a notable forerunner of the now internationally recognised medical discipline of ‘narrative medicine’. Narrative medicine, in its essence, aims to improve the physicians’ narrative competencies so that they may recognise the patients’ narratives and become more emphatic in the clinical encounter. To teach narrative competency, Charon argues for the effect of medical students practising reading literature, training them to recognise, interpret and be moved by illness narratives (Charon et al., 2017; Charon, 2008; Rasmussen and Sodemann, 2020).

During the 1970s and 1980s, along with the boom in narrative theory and research, narrative therapy was founded as an alternative method to former dominating methods in psychotherapy. A founding father was Australian social worker and family therapist Michael White (Brown and Augusta-Scott, 2007; DeKruyf, 2007). Inspired by scholars such as Foucault and Bruner, narrative therapy rests on a post-structuralist foundation, rejecting the idea of essentialism, which otherwise had dominated the therapeutic landscape (Holmgren, 2006; White, 2006). The premise of narrative therapy is that the stories people tell of themselves create meaning to their lives and therefore constitute identity. To create changes in life and deal with distress, one must pay attention to the dominating stories in life and through a re-authoring of these stories choose new ways to narrate one’s life (Brown and Augusta-Scott, 2007; White, 2006). In healthcare, there has been increased interest in the approach of ‘narrative care’. Narrative care emphasises the role of narrative in care practices and as interventions in institutional settings, highlighting how professional care providers may help co-compose and foster evolving narratives, thereby improving the quality of care (Blix et al., 2019; Berendonk et al., 2020).

Summing up, within the last fifty years, narrative has become recognised as a fundamental human practice, constituting the way we as humans create, express and give meaning to our experiences (Hyden, 2017). Research and theory focused on the illness narratives of people living with serious life-threatening illnesses have gained particular attention (Frank, 2013; Kleinman, 1998; Mattingly, 2012). The studies of illness narratives may encompass analysis of how the patient makes sense of living with a serious illness (Frank, 2013) and/or how illness narratives are constructed within the cultural and social settings in which they are told (Bury, 2001). This focus on the illness experiences as expressed in narrative may provide us with valuable knowledge on illness and suffering. The use of terminology within the narrative research field is often hazy: 'storytelling', 'narrative' and 'life-story', sometimes referring to the same or entirely different understandings of the concept (Blix and Sorly, 2017; Mattingly and Garro, 2000). Simply referring to 'narrative' is not without its challenges. In this dissertation, I have attempted, though not always successfully, to adhere to a consistent use of terminology, reflecting the complexities and inconsistencies present in the field itself. In Chapter 2, I will elaborate on my understanding and how I use the 'narrative' and 'story' terminology throughout this dissertation. Mostly, though, I use the terms interchangeably. Furthermore, the concept of narrative ranges from more philosophical beliefs about the nature of human life, constituting a view of our existence (Levy, 2005), to being perceived humbly as a research method or, maybe by most people, as an everyday practice (Czarniawska, 2006; Freeman, 2015).

Narrative is a core concept in this dissertation for three key reasons: 1) The narrative courses rest on a specific understanding of narrative, including narrative exercises. 2) The empirical data exhibit narrative characteristics. 3) Narrative theory was applied in the analysis. Distinguishing between these different applications of narrative throughout this dissertation thus becomes essential. Further, narratives exist and work on different levels in society. My understanding of narratives is that they, no matter how subjective they seem, are always constructed in a particular social and cultural context, shaped by 'communal ordering principles' that guide how people feel, think and act (Bamberg, 2007).

A compound use of terminology seems to exist on this 'ordering principle', including terms such as 'master narratives' (Bamberg, 2007), 'meta narratives' (Atkinson and Rubinelli, 2012), and 'culturally available narratives' (Thomsen et al., 2016). In this dissertation, I have chosen to capture this ordering principle (on a macro level) through the terminology of 'master' and/or 'dominant' narratives. These master narratives are repeated in society, evidently internalised and negotiated on individual, group and institutional levels. For instance, on an organisational level, economic discourses may shape rehabilitation practices (Graff et al., 2023) and on the individual level, master narratives of favourable illness prognoses shape the individual illness experience (Schoenau, 2022).

Cancer narratives

In the narrative courses, all participants had or have had cancer. Therefore, I find it relevant to engage with important literature and research that explores how cancer narratives are shaped by and embedded in the social and cultural context, impacting how living with cancer is experienced.

As already mentioned, cancer no longer always leads to imminent death. More people live extended lives with cancer, which has sparked discussions and shifts in the way we talk about people with cancer (Bell and Ristovski-Slijepcevic, 2013). Despite lack of international and clinical consensus on its definition, the term ‘cancer survivorship’ is increasingly used to refer to all individuals diagnosed with cancer, regardless of their prognosis or survival rate (Skowronski, 2019). The concept of cancer survivorship as a life-long condition was introduced to move beyond the simplistic dichotomy of viewing cancer patients as either cured or not cured (Marzorati et al., 2017; Plage, 2020). However, this cultural shift in rhetoric – from seeing individuals as cancer survivors rather than victims – has crystallised into dominant master narratives. These narratives impact the individual’s experience of illness and influence societal expectations about how one should manage life with cancer (Danesi et al., 2020). Consequently, cancer survivors may feel a strong imperative to live morally good and authentic lives (Frank, 2003; Plage and Kirby, 2022) and to adopt attitudes of hope and willingness to fight their cancer (Saillant, 1990). Others have researched the dominance of metaphors in cancer and how these metaphors shape and limit patients’ experiences, with Susan Sontag’s ‘Illness as metaphor’ book as a celebrated example (Hansen, 2018; Sontag, 1991). Violent or military metaphors, such as ‘battle’ and ‘warrior’, still seem to dominate discussions about cancer (Wackers et al., 2020; Adamsen et al., 2001; Hanahan, 2014; Hansen, 2018). In a qualitative study of women with metastatic breast cancer, Hulse et al. (2024) found that military metaphors were frequently used and, in some cases, experienced as helpful. However, the authors found how these military metaphors could impose an emotional pressure to remain positive and appear strong, thereby suppressing expressions of the distress connected to living with incurable cancer.

These examples show how, like all narratives, individual cancer narratives are shaped by social and cultural master narratives. These master narratives work as models for our understanding of human life, such as behaviour, norms and values (Hansen, 2018). Master narratives may also be thought of as 'dominant' as they prescribe us a range of culturally available narratives. Some scholars have established typologies, useful for understanding which illness narratives are culturally available. Frank's (2013) three illness narrative models – restitution, quest and chaos – are well known and will be further elaborated on in Chapter 2. Furthermore, scholars have focused on the impact of the general public attention towards cancer, including how media coverage broadens the range of illness information to patients, thereby shaping and impacting the available illness narratives (Bury, 2001; Bell, 2012).

In a Danish context, several recent studies have explored how dominant cancer narratives shape illness experiences and expressions. Schoenau (2022) observed how a restitution narrative of 'being lucky' came to dominate in the stories of patients with operable lung cancer (Schoenau, 2022). Similarly, Sidenius (2019a, b) demonstrated how women with endometrial cancer often adopted the notion of their cancer as 'good' and felt compelled to tell stories of 'feeling lucky', based on a biomedical understanding of their illness's favourable prognosis (Sidenius et al., 2019a; Sidenius et al., 2019b). Like others within international research, Bell (2012) examined how breast cancer survivors' dominant narratives create pressure on other cancer patients, leading to expectations that they will 'emerge from the cocoon of cancer diagnoses and treatment as a new and improved person' (Bell, 2012: 586). In this line of research, cancer narratives are not just regarded as impacted by social and cultural master narratives but as highly politicised (Nielsen, 2019). This has led to the emergence of and research within 'counter-narratives' that serve as a counterweight to the dominant master narratives (Nielsen, 2019; Bamberg and Andrews, 2004). In her book 'Disrupting breast cancer narratives: stories of rage and repair' Nielsen (2019) highlights these counter-narratives, focusing on stories of anger, especially towards the politicised 'Pink Ribbon' movement that dominates breast cancer media coverage internationally.

The above-mentioned research illustrates why illness narratives are not just personal stories about illness, and why the participants' experiences in the narrative courses must be viewed in this light.

Applied narrative methods for people with life-threatening illness

In addition to exploring narratives as analytical objects, there is a growing trend to use narrative methods more strategically and systematically for people suffering from life-threatening illnesses. In this dissertation, I refer to this approach as the 'applied narrative method', which also encompasses my understanding of the narrative courses. By this, I refer to specific narrative interventions, courses or methods, that rest theoretically on some notion of narrative theory and logic, incorporating for instance ‘storytelling’, ‘life story’ or ‘narrative’ in a systematic way (Jess et al., 2023; Knox and Svendsen, 2015; Hansen et al., 2018; Martínez et al., 2017).

In 2021, Roikjær et al. (myself included) conducted a scoping review, identifying how applied narrative methods were used systematically among people with life-threatening illnesses and their next of kin in Scandinavia (Roikjær et al., 2021). Examples based on the findings from this scoping review are Socratic dialogue sessions, used in the rehabilitation of cancer patients (Knox and Svendsen, 2015), creative writing courses inspired by narrative medicine (Hansen et al., 2019; Hansen et al., 2018) and the use of patient diaries in intensive care units, aimed to help patients reconstruct their illness trajectory after having been unconscious or sedated (Egerod et al., 2011; Bäckman and Walther, 2001). Overall, we identified 17 different applied narrative methods that varied much in terms of their aims, theoretical assumptions, structure, contents and outcomes (Roikjær et al., 2021).

Narrative interventions have been developed and evaluated on an international scale. Wise et al. (2018) conducted a randomised controlled trail (RCT) to evaluate the effects of a telephone-based narrative intervention for people with advanced cancer. During the intervention, the patients were interviewed based on life-story questions. Their stories were then edited and shaped into a coherent story for them to share. Wise et al. (2018) concluded that the intervention had positive and promising effects on improving the patients’ well-being. Furthermore, based on the approach of narrative medicine, Cepeda et al. (2008) conducted an RCT evaluating the effect of an emotional disclosure narrative intervention for people suffering from cancer pain. For three weeks, the randomised intervention group was instructed to write for a minimum of 20 minutes a day about how their cancer impacted their lives. Through subgroup analysis, the authors demonstrated that patients who engaged in high emotional disclosure in their narratives experienced less pain and had higher well-being than those who disclosed less.

Within palliative care, the use of dignity therapy has been extensively researched and found to be particularly meaningful (Houmann et al., 2014; Houmann et al., 2010; Martínez et al., 2017; Lee and Jeong, 2023). Dignity theory is a therapeutic intervention directed to terminally ill patients based on storytelling. The overall aim is to address distress in those who are dying by inviting them to create a narrative legacy document, based on the most important issues in their lives (Chochinov et al., 2005).

Critical perspectives on the narratives of rehabilitation and palliative care

The participants' experiences with the narrative courses must be understood within the context of the broad range of research and theory mentioned above. However, before I offer a more detailed description of the narrative courses, I believe it is relevant to connect these topics more thoroughly.

As I have introduced above, rehabilitation and palliative care approaches are implemented in both Danish and international healthcare settings. However, the way these approaches are delivered, prioritised and to whom they are provided are outcomes of policies and may not be regarded as neutral or without consequences (Tonnesen et al., 2022). Over the years, some scholars have taken on the task of critically challenging the assumptions and logic of cancer rehabilitation (Hansen and Tjørnhøj-Thomsen, 2007; Hansen and Tjørnhøj-Thomsen, 2008). Hansen and Tjørnhøj-Thomsen (2008) examined how a dominant rehabilitation narrative of 'sick-helped-cured' is problematic in the context of cancer, where patients may never be fully cured. The authors identified the emergence of a new somewhat illusory narrative: 'sick-helped-as-if cured', which is produced and reproduced through technologies of power and the self, through governance. Hansen and Tjørnhøj-Thomsen (2008) show how the rehabilitation narrative represents an individualistic model of rehabilitation that places the patient under a 'moral imperative' to take individual responsibility for their illness and recovery. These findings are mimicked in similar research on different patient groups. For instance, Tonnesen et al. (2022) showed how individual goal setting (a normal rehabilitative practice) for people with Parkinsons' disease was often problematic as it was heavily intertwined with global rehabilitation discourses of individual accountability in rehabilitation. The authors illustrated how different logics and normative assumptions about rehabilitation were at play in the goal-setting encounter. In addition to these findings, Bergquist Røberg et al. (2017) conducted a critical discourse analysis to explore how rehabilitation professionals' language and talk about their work influence their practices in the wake of a Norwegian coordination reform. Bergquist Røberg et al. (2017) concluded that health policies affect how rehabilitation professionals attribute worth to rehabilitation services, often promoting an ideal of the independent and self-managing patient. Graff et al. (2023) further investigated organisational narratives in dementia rehabilitation, identifying four organisational narratives, that shaped a specific organisational client identity. These narratives, in turn, had a profound impact on both the rehabilitation care practices and the patient's life possibilities.

The above-cited examples show how patient behaviour and experience are influenced by master narratives or 'the logic' of rehabilitation, which must be considered when exploring the participants' experiences in this study. Beyond rehabilitation, this critical stance can also be applied in palliative care. Just as in rehabilitation, patients at the end of life are not exempt from the normative expectations of what it means to be a ‘good patient’. At the end of life, patients may feel the societal pressure to be a good patient and to ‘die with dignity’. This expectation of experiencing a ‘good death’ has a major impact, shaping the experiences and decisions made by everyone involved in the end-of-life situation (Proulx and Jacelon, 2004; Coret and Martimianakis, 2023). Both ‘the good death’ and the ‘dignified death’ are therefore normative concepts, underscoring why also dying is a social phenomenon and must be understood in this light (Jacobsen, 2010). Scholars have explored how ‘the good death’ is an ideological construction, monopolised by the hospice movement. This can lead to increased institutionalisation of care, potentially resulting in negative outcomes for patients, such as heightened social control and diminished autonomy (Jacobsen, 2010; McNamara, 2004; Floriani and Schramm, 2012; Hart et al., 1998).

The narrative courses

Having situated this study in the relevant research landscape, theories and key literature – comprising the central areas of rehabilitation, palliative care, and narrative, I will now focus on the narrative courses.

The development of the narrative courses, along with the research presented in this dissertation, is part of a large innovative research programme named ‘CRP – coordinated rehabilitation and palliative care’, supported financially by the Danish Cancer Society (Funding registration no. R280-A16681). The purpose of the programme is to examine ways to meaningfully coordinate rehabilitation approaches (primarily the support of functions) with palliative care approaches (relief of suffering). The overall aim of the CRP programme initiatives, including the narrative courses, was to support quality of life for people with cancer.

The narrative courses were designed on the basis of a previously tested and successfully evaluated the narrative course for long-term human immunodeficiency virus (HIV) survivors, conducted at the REHPA - the Danish Knowledge Centre for Rehabilitation and Palliative Care, research clinic (Jess et al., 2023; Jess and Timm, 2019). These narrative courses overall aimed to contribute to or enhance the participants’ quality of life, identified as a sense of coherence, meaning and hope in life. The HIV course was designed and implemented by two external course designers, a psychologist and a nurse and family therapist, respectively. This initial narrative course included a user involvement phase, involving a user panel at REHPA, which included patients and family members of people with life-threatening illnesses. The user panel helped to qualify and adjust the narrative method and exercises. In collaboration with the professional staff in the research clinic and Helle Timm, a professor at REHPA at that time, the external course designers adapted the course contents to accommodate the needs of people with advanced cancer.

These adaptations were primarily practical and instituted to accommodate the participants' potential physical and mental resource limitations. Furthermore, an objective in designing and implementing the narrative courses was to explore how applied narrative methods could contribute to the coordination of rehabilitation and palliative care.

Prior to the decision to proceed with the narrative courses, two coordinated rehabilitation and palliative care (CRP) pilot courses for people with advanced cancer were tested in the research clinic in 2019-2020. The purpose of these courses was to allow the research clinic professionals to test the feasibility of planning and implementing courses that included both rehabilitative and palliative care elements for people with advanced cancer. Findings indicated that some significant needs of the participants, such as their desire for help in finding more joy and lightness in life (Raunkiaer and Gärtner, 2020; Raunkiaer, 2022; Gärtner et al., 2021), supported the feasibility of continuing both the narrative courses and work with this target group. At this time, I had recently been hired as a research assistant/AC consultant at REHPA and contributed to the evaluation through participant observation during the second CRP stay (Raunkiaer and Gärtner, 2020).

To educate the research clinic professionals in conducting the narrative courses, a training course was held at the research clinic in April 2021. This training course was facilitated by the course designers and spanned over three days with a residential stay and a follow-up day at the clinic. The participants included all relevant clinician staff, including nurses, physiotherapists, a social worker, the clinician leader, myself and my main supervisor, Helle Timm. I perceived our attendance primarily as an opportunity to acquire personal experiences with the narrative exercises as the training course required us, the participants, to personally engage with the narrative exercises. Later, I will reflect on how these personal experiences influenced the data generation and analysis process. It is important to note that the professionals were responsible for the final design and implementation of the narrative courses in both settings. Please see Figure 3 for a timeline of the process and all relevant background activities, including the narrative courses.

The settings of the narrative courses

The research clinic

The narrative courses I-III were conducted as residential courses at the REHPA research clinic. REHPA is a publicly owned and funded knowledge centre in Denmark. Besides aiming to generate, share and collect knowledge to benefit people living with life-threatening illnesses, REHPA also operates a research clinic, located in Nyborg. The objective of the clinic is to develop, test and evaluate different methods used within rehabilitative courses for people with life-threatening illnesses to overall benefit society and the healthcare system (Rasmussen et al., 2020). Coordination of rehabilitation and palliative care is a central focus of REHPA and the narrative courses were an innovative research-anchored program, tested in the research clinic (Rasmussen et al., 2023). It is essential to highlight that the research clinic offers a unique rehabilitation service in Denmark, provided entirely free of charge to the participants, with the only cost being their personal transportation to and from the clinic.

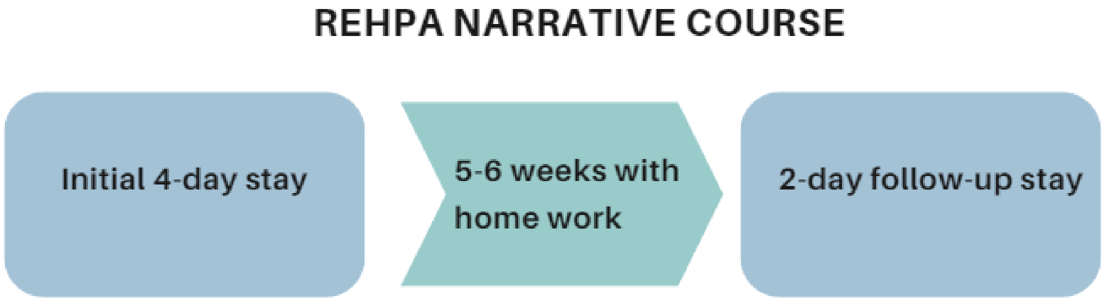
REHPA and the research clinic are organisationally nested in the Region of Southern Denmark, which is a governmental organisation, tasked (among others) with managing the public hospitals in the region. The research clinic is located on the ground and top floor of Nyborg Hospital, which is located in beautiful nature and close to the historic setting of Nyborg Castle. All participants were provided with private rooms, often with a private bathroom. The rooms, like the rest of the clinic, are decorated with modern furniture, artwork and plants. The walls are painted in soothing colours inspired by nature and guided by the design principles of 'architecture and relief', creating a calm and welcoming atmosphere (Falk and Timm, 2018; Rasmussen et al., 2020).

The research clinic shares a history with the former Rehabilitation Centre Dallund (RcDallund). RcDallund offered residential rehabilitation stays that were comparable to those of the REHPA research clinic. RcDallund was run by the Danish Cancer Society (Rix et al., 2011), but in 2012 RcDallund was merged with the Knowledge Centre for Palliative Care (PAVI) and REHPA was founded (Rasmussen et al., 2020). This shared history remains important to this dissertation as much research on the rehabilitation of cancer patients in Denmark was formerly conducted at RcDallund (Hansen et al., 2011; Tjørnhøj-Thomsen and Hansen, 2013; Hansen and Tjørnhøj-Thomsen, 2008; Høybye et al., 2008).

The courses were advertised by REHPA through flyers (see Appendix I) and were limited to participants who had advanced cancer. To participate in the course, all participants furthermore had to speak and understand Danish, be self-reliant in terms of care and medicine and accept to contribute to the research at the clinic. Prior to their enrolment at the clinic, the participants were referred to REHPA by their doctor and, based on an individual assessment, enrolled at the narrative courses. The professionals at the research clinic involved were nurses, physiotherapists and a psychologist, along with other research clinic support staff, including kitchen staff and evening and night hostesses.

The narrative courses were organised as an initial residential stay of four days (three nights) and a follow-up stay of two days (one night), see Figure 1 for course flow.

Figure 1: Course flow, REHPA



The municipal cancer rehabilitation centre

The narrative course IV was conducted once at a municipal rehabilitation centre. It was conducted by the narrative course designer, the psychologist and a social worker from the centre. Conducting the narrative courses in the municipality was not originally part of the CRP program, and it was therefore planned and conducted independently from the courses at the research clinic. I was invited to participate as a researcher. Data generated in this setting are used only in Sub-study I.

For reasons I will elaborate on in Chapters 3-4, I have chosen to keep the municipal rehabilitation centre anonymised. The rehabilitation centre, housed in a modern building in a large Danish municipality, was designed to provide rehabilitation services to people affected by cancer, either during or after their treatment. The centre offered various support, including psychical training, dietary consults, workshops, group activities and individual counselling. The narrative course in this setting was organised as a day course, initially spanning three days in September 2021, running from approx. 9.00 AM to 3.30 PM. It included two follow-up days, one held in October 2021 and the other in early January 2022 (delayed due to illness). Participation was free of change; however, unlike the research clinic, participants were required to bring their own lunch. Coffee, tea and afternoon fruit/cake were provided.

The course was advertised as a five-day 'life-story' rehabilitation course, with participants recruited by the centre professionals from among existing users of the rehabilitation centre. The course was advertised to participants who were either cancer free or currently undergoing treatment with a prognosis of becoming cancer free. To align expectations and ensure appropriate visitation, the course professionals conducted initial conversations with the participants before the course began. Figure 2 illustrates the course flow in this setting.

Figure 2: Course flow, municipal rehabilitation centre

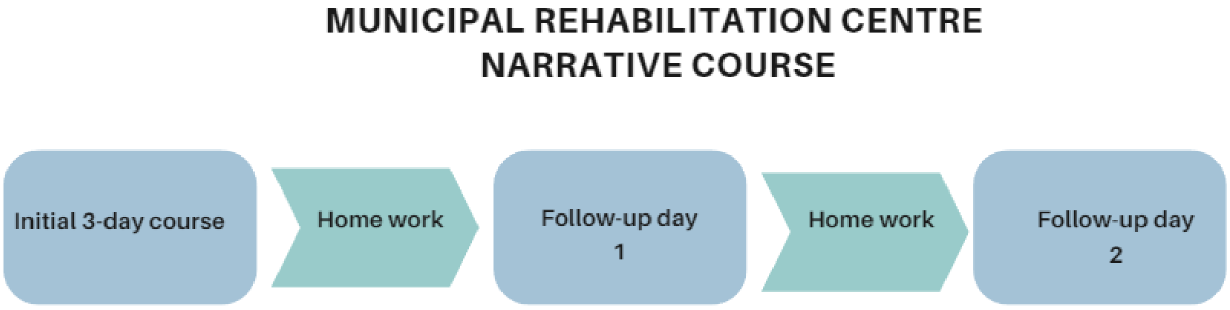
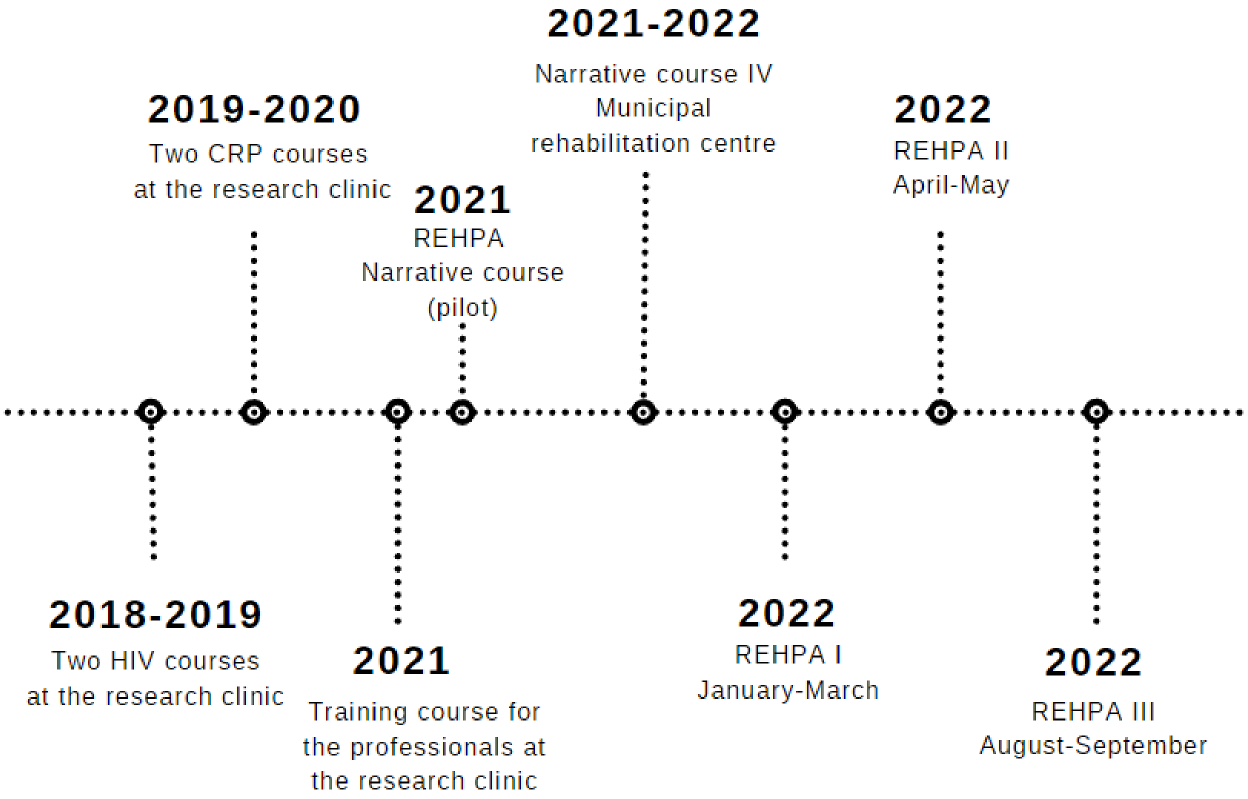


Figure 3: Timeline of relevant activities and the narrative courses



Assumptions underlying the narrative approach

The theoretical assumptions behind the narrative courses and the chosen narrative exercises were derived from different theoretical and methodological perspectives on the possibilities and potential of the narrative approach, as previously discussed. A core assumption was that storytelling is a social practice through which we construct our identities, shaped by the stories we tell and hear (Frank, 2013; Kleinman, 1998).

Inspiration was also drawn from the Canadian psychiatrist Harvey M. Chochinov's dignity therapy (Chochinov et al., 2005). His work on implementing a life story approach for patients in palliative care has inspired the course methodology, which is focused on enhancing participants' sense of meaning in life, even as they approach the end of life (Chochinov et al., 2005; Jess et al., 2023). The construction of a narrative document (the collective stories) during the narrative courses was particularly inspired by the concept of constructing a 'generativity document' in dignity therapy (Chochinov et al., 2005). The narrative courses incorporated this into a narrative exercise that culminated in the construction of a document (see Table 1).

As mentioned, Michael White has had a profound impact on the use of narrative in psychological work, and his work on narrative theory and narrative methods has likewise played a major role in the narrative courses (Rasmussen et al., 2023). Based on White's theory, a key assumption is that by explicitly focusing on the dominant stories participants tell about their lives, they can be guided to adjust or alter these narratives. This process can help them achieve a stronger sense of coherence, meaning and direction in their lives (Rasmussen et al., 2023; White, 2006).

The contents of the narrative courses

The narrative courses included working with elements of the participants' life stories. Upon arrival, the participants received a physical compendium and an empty notebook. The compendium consisted of approx. six narrative exercises and small written introductions. The participants were encouraged to complete the exercises with as much written text as possible, either on the pages in the compendium or in the notebook. Each session in the course programme was paired with an exercise connected to the narrative theme of the course, such as working to identify and reflect on the participants' social network or turning points in their lives. Every exercise session started with individual written work, followed by verbal group work and ended with a plenum talk (Gärtner et al., 2024b). Table 1 displays an example of the narrative exercise overview, depicting an initial stay at the research clinic (Gärtner et al., 2024a), still, the narrative exercises were fundamentally the same at the municipal rehabilitation centre. See Appendix II and III for exercise examples.

Table 1: The narrative exercises (re-used from Gärtner et al. (2024a))

Day/ Duration	**Exercise**	**Purpose**	**Description of session**	**Materials**
Day 1 3 hours, 15 min.	Constructing a collective story about life with advanced cancer: Five questions about life with cancer and the consequences hereof	To create a cohesive, structured collective story about life with advanced cancer To help the participants construct an alternative story to counteract possibly dominating narratives about life with advanced cancer	The exercise consisted of four parts: 1) individual work, answering the questions; 2) group work focusing on finding what was common in their answers; 3) an audio-recorded plenary interview in which all groups were encouraged to share "commonly recognisable" elements of their answers. This interview was thereafter professionally transcribed and edited into a coherent "collective story"; 4) the collective story was read out loud by a professional on the last day of the initial stay	The participants were presented with five questions about their illness and/or their treatment and how it had impacted areas in their lives, such as their social circumstances or psychological well-being The participants received a copy of the collective story to bring home
Day 2 1 hour, 30 min.	Turning points and special events in life	The goal is to help the participants look back at important life events and recognise their importance and meaning To help the participants identify alternative stories about their lives	The participants identified important turning points in life inspired by three questions: 1) What came before the event? 2) What significance did the event have for your life? 3) Which resources were helpful during the event/turning point? The participants plotted turning points chronologically onto the "lifeline"	Three questions about an identified turning point A paper with a line indicating the progression of life

Day 2 1 hour, 30 min.	Important relationships in life (network mapping)	To help the participants recognise important relationships in life	The participants were invited to reflect on important relations in life, such as family, friends, healthcare professionals and colleagues. In the first round of the exercise, the relations were to be plotted on a circular map with the participant in the centre. The proximity to the centre illustrated a feeling of personal connection In the second round of the exercise, the participants were asked to reflect on how satisfied they were with their network. Next, they were asked to plot the relations again and mark them with arrows pointing either towards or away from the centre, indicating how they wished the relations to be. The professionals emphasised that it was legitimate to wish relations to be more distant	Circular network map
Day 3 3 hours	Roles and functions in life	To help the participants reflect on important roles and functions in life	The participants were asked to identify important roles and functions in life and reflect on which of these they were satisfied with, which they wished to strengthen and which they wished "to cut back on"	Three questions about roles/functions in life
Day 4 3 hours	Personal values and value-based actions	To help the participants connect with their personal values and help them decide on some specific goals and actions based on their chosen values	First, the participants were to mark all 55 values as either "not important", "important" or "super important". Next, they were asked to limit their answers to six of the "super important values." Thereafter, they were asked to choose two values they wanted to work with regarding transforming them into goals and actions	A list of 55 examples of what personal values could be Six questions about specific goals and actions to be made Letter exercise: The participants were asked to write a handwritten letter to themselves in which they wrote about their chosen value-based goals and actions. The letter was

				mailed to the participants and delivered between the initial and the follow-up stay

Furthermore, Table 2 provides an example of the course programme from the research clinic, which was largely consistent across both settings. However, certain activities, related to social time and breakfast/dinner, sessions with the chaplain and the optional ‘inspiration session’, were unique to the research clinic courses. Besides the formalised sessions in which the participants worked with the narrative exercises, some sessions incorporated soft physical movement. These sessions focused only on bodily movements, relaxation and practising mindfulness. On the second evening of the courses in the research clinic, a chaplain with experience from other REHPA courses conducted an evening session. Guided by the chaplain, group discussions were initiated, revolving around topics such as dying, existential loneliness and what it means to be human.

A distinctive feature of the research clinic program was the ample time allocated for participants to socialise or retreat to their private rooms during the day, and to engage in social activities during the evening. All meals were served in the dining room, naturally fostering conversations and connection among participants. In the research clinic narrative courses, establishing a sense of community among the participants was an integral part of the formalised programme (Rasmussen et al., 2023) and social interaction was encouraged by the clinic professionals.

Table 2: Day programme, an example from the research clinic

Monday 24/1	Tuesday 25/1		Wednesday 26/1		Thursday 27/1
9.45-10.15 Arrival and accommodation 10.45-12.00 Welcome, introduction and presentations	7.30-8.15 Breakfast		7.30-8.15 Breakfast		7.30-8.15 Breakfast
	8.45-9.00 Morning assembly		8.45-9.00 Morning assembly		8.45-9.00 Morning assembly
	9.00-11.30 Turning points in life		09.00-12.00 Roles in life		09.00-12.00 Value-based actions in the future. Summary
12.00 Lunch	12.00 Lunch		12.00 Lunch		12.00 Lunch
13.15-16.30 The collective story about life with cancer 17.00 Introduction by evening hostess	13.15-14.15 Body and movement 15.00-16.30 Meaningful relationships	13.15-14.45 Meaningful relationships 15.15-16.15 Body and movement	13.15-14.30 Yoga 15.00-16.15 Optional: Inspirations - how can I work with my narrative?	13.15-14.30 Optional: Inspirations - how can I work with my narrative? 15.00-16.15 Yoga	13.00-13.15 Check out from the rooms 13.15-14.15 The collective narrative and its significance 14.15-15.00 Evaluation and closing 15.00 Departure
18.00 Dinner	18.00 Dinner		18.00 Dinner		
Social time	19.30-21.00 To confront death - With a chaplain		Social time		

Changing elements of the narrative courses

The covid-19 pandemic that impacted most of the world during 2020-2022 also had some impact on the narrative courses. First, the research clinic reported on recruitment issues with the courses as some participants were reluctant to subject themselves to the risk of contagion (Rasmussen et al., 2023). Second, due to pandemic restrictions, the first narrative course in the research clinic had a different composition of professionals, with a nurse and research clinic leader, who had participated in the training course, assumed the role of course leader. Consequently, the reading of the collective story on this course was delayed and postponed to the follow-up stay.

A central finding, presented in study II (Gärtner et al., 2024a), was that the participants expressed confusion as to how to understand the term ‘life stories’. Overall, there was often a misalignment between the intention/aim of the courses and the participants’ expectations. To meet the expectations of some participants who anticipated receiving more tools to work on their own life stories, the research clinic professionals introduced an optional inspiration session in REHPA course II and III. During this session, participants were encouraged to share their thoughts, wishes and experiences related to making variations of their life stories, such as written legacy documents.

Some participants experienced harm during the narrative courses (Gärtner et al., 2024b). In response to some participants openly expressing frustration during their stay at the research clinic, the professionals made some minor changes. One key change was to more clearly communicate what participants could expect during the courses and how to manage any adverse consequences that might arise. Additionally, individual debriefing sessions were offered to some participants, and a more comprehensive telephone assessment was conducted before participants were included in subsequent courses.

2. Theory

All research needs considerations to what constitutes ‘knowledge’. Through my quest to put down coherent pieces in this study’s ethnographic puzzle, I held on to an interpretative epistemological position inspired by social constructivism. First, my aim for this section of the dissertation is to account for the epistemological framework on which this study is founded and reflect upon the consequences of this.

Second, I will introduce the key theoretical frameworks that has informed this study. This includes my approach to and analytical use of the concept of narrative as a theoretical concept, along with how other theoretical inspirations shaped this dissertation – from study design and analysis to the presentation of findings.

A social constructivist position

To simply claim a social constructivist position seems to me a bit unspecific. The term ‘constructivism’, ranges from phenomenological theoretical positions to poststructuralism (Frello, 2012). Furthermore, much debate has been concerned with discussing different understandings of *what* is constructed within constructivism and whether the constructivist paradigm only extends to the social world or includes the physical world as well (Andersen, 2007).

Taking a social constructivist approach in this study also implies disregarding an essentialist understanding of the studied field and phenomena under investigation. This perspective influenced my selection of theories, methods and analytical strategies as I did not aim to uncover hidden truths or reconstruct any element of a fixed, essentialist version of reality. Consequently, I did not regard the participants’ experiences simply as stories or projections of ‘what happened’. Instead, I have interpreted their experiences as being shaped by the influences of the social world, including relationships, language and power. My aim was not to explore a notion of the participants’ ‘lived experiences’ in the phenomenological sense, which often seeks to uncover the inner experience of each participant. Rather, I focused on understanding how these experiences are constructed and influenced by the broader social and cultural context.

Social constructivism challenges the taken-for-granted assumptions about identity that may dominate in psychology (Burr, 2019). This approach has inspired me to explore the participants' experiences, including their sense of identity, as social and culturally dependent, viewing them as dynamic rather than stable, subjects of continuous negotiation, often characterised by ambiguity and fluidity. By adopting a constructivist perspective, I have recognised language as a powerful resource that goes beyond merely expressing human experience. While this focus on language could have led to discourse analysis, I chose instead to consider language both in its specific social interactions and within a broader social and cultural context, following the approach of others in this field (Burr, 2019). The social constructivist paradigm also shaped my approach to how knowledge is generated, emphasising that I, as a researcher, cannot be separated from what I study. In this view, nothing or no one exists separated from context (Järvinen and Mik-Meyer, 2005). Yet, this perspective raises the question of how to produce findings that can be recognised as legitimate scientific knowledge. For Haraway (1988), all types of knowledge are embodied, situated and partial and must be viewed as such. Knowledge cannot be produced from 'nowhere', meaning that one way to accomplish objectivity in research is to hold the researcher accountable for the knowledge production (Haraway, 1988). Throughout this dissertation, I have aimed to be transparent in my production of knowledge as discussed in the next chapter. My aim is to highlight that findings in this dissertation represent a snapshot of interpretations and analysis, shaped by a specific time, place and a specific person.

Exploring the concept of context

Adopting a social constructivist position necessitates a keen awareness of context, which has been a key concept in this dissertation. Context served both as a theoretical foundation and an empirical finding, as detailed in Sub-study II. Therefore, attending to context has been essential for my exploration of the participants' experiences. However, when discussing context, I refer to it as two distinct phenomena: firstly, as the local context, the empirical settings where the narrative courses were conducted; and secondly, as a term that captures the much broader social and cultural context in which all our lives are embedded. I will elaborate on this broader understanding later in this chapter, particularly in relation to narrative theory. In this section, however, I will focus on unpacking the theoretical underpinnings of the local context.

Although this distinction between the two forms of context may work well at the analytical level, separating the two dimensions is also a construct. I have chosen to make this distinction anyway because it simplifies the concept of context by reducing its complexity. Furthermore, I find it important to note that context is also a constructed phenomenon, created and negotiated in interactions, wherefore it must be understood as something people *do* rather than as a stable entity (Hansen et al., 2011; Duranti and Goodwin, 1992). Although I work with a simplified version of the concept of context, I do not regard context as something that exists 'out there', separate from human conduct (including my own). To address the potential loss of complexity and the synergy between these distinctions, I have consistently engaged in a reflexive practice, challenging my own 'taken-for-granted' assumptions about context throughout this dissertation.

Context as a frame in and around the setting

Searching for a theoretical approach for analysing the influence of context-specific parameters in empirical settings, I was inspired by Hansen et al. (2011), who devoted specific attention to how contextual parameters shape participants' experiences and therefore influence specific intervention outcomes. Not only do Hansen et al. (2011) offer insight into *how* influential context is, but what was further relevant to me was how they reported on findings from a Danish rehabilitation course largely resembling the narrative courses conducted at the research clinic. Hansen et al. (2011) base their analysis on Duranti and Goodwin's (1992) theoretical approach to context. Although this work is strongly related to linguistics, I find their take on context useful, although complex. I have used it as an overarching lens to explore the influence of context in and around the empirical settings.

According to Duranti and Goodwin (1992), context must be understood in terms of four parameters. First, is the contextual parameter they identify as 'setting'. This encompasses a social and spatial structure surrounding the interaction. Second, they identify the 'behavioural environment', examining how participants use their bodies and actions as a resource to shape the conversation. A third contextual dimension considers how language is embedded within the context and contributes to the surrounding context. Lastly, they speak of context as 'extra-situational', meaning how talk extends beyond the local setting, drawing on extended background knowledge (Duranti and Goodwin, 1992).

In this dissertation, I have selectively engaged with aspects of the theoretical contribution proposed by Duranti and Goodwin (1992), given its strong relevance to the study of language. Their fourth element of context, which I refer to in this dissertation as 'the broader social and cultural context' (Gubrium and Holstein, 2009), was better addressed through the application of narrative theory. In examining the context within narrative, I drew inspiration from Gubrium and Holstein's (2009) notion of 'the narrative environment'. This perspective guided investigation into how the setting influenced which stories were told (and which were not), the implications for the participants and how prevailing understandings of key concepts within the setting, such as rehabilitation, impacted the contents of narratives. Although the perspectives of Duranti and Goodwin (1992) and Gubrium and Holstein (2009) are similar, I find that they have different qualities as analytical lenses. While the perspective of ‘narrative environment’ by Gubrium and Holstein (2009) aligns solely with narratives, I find the perspectives of Duranti and Goodwin (1992) more fruitful for exploring, for instance, how the spatial space in the research clinic impacted the ways the participants interacted.

Narrative

> “Attention to human suffering means attention to stories, for the ill and their healers have many stories to tell. Serious illness takes people from ordinary to extraordinary. Trying to understand those with severe illness may be rather like, as Sacks says, making "house calls at the far borders of human experience" (Sacks 1995: xx). The stories of the very sick and disabled comprise a "literature of extreme situations"” (Mattingly, 2012: 1).

A key theoretical and analytical focus of this study has been the influence and importance of the narrative. I was genuinely surprised to find that ‘narrative’ not only served as the applied method in the courses but also became a concept of substantial theoretical importance. Initially, I tried to distinguish between the applied method of narrative, narrative theory and narrative analysis, thinking that my study focus was solely on the first. During the research process, it dawned on me that, as stated by Mattingly (2012) in the above-mentioned quotation, it is challenging to attend to participants’ suffering without explicitly attending to their stories. Although my initial aim was not to explore the participants’ narratives *per se* (such as through dedicated narrative research and analysis), the consideration of the theoretical influence of narrative evolved into a central element in this dissertation. To make my theoretical position on narrative clear, I will first describe how I understand and define the concept of narrative. Next, under the headline ‘What is narrative?’, I will present key theoretical perspectives that shaped (although in different ways) my thinking on narrative throughout this dissertation. After having introduced these diverse theoretical perspectives, I will adopt a critical position towards narrative before concluding this chapter with a brief introduction to some key theoretical perspectives on social interaction, specifically focusing on the concept of community.

Defining narrative in this dissertation

I have been inspired to organise my understanding and use of the concept of narrative by drawing together insights from a broad theoretical landscape. However, as I have already disclosed in my introduction, my use of language regarding narrative and storytelling has not been consistent throughout this work. Above all, I believe this reflects how writing a dissertation is a *learning-by-doing* experience.

Naturally, my understanding of narrative has evolved and deepened over the course of this project. Secondly, my inconsistency in language aptly mirrors the narrative research field, where the use of terminology varies (Mattingly and Garro, 2000). Some distinguish between narrative and story, like Frank (2013), while others use the words interchangeably (Blix and Sorly, 2017; Gubrium and Holstein, 2009). Throughout this dissertation, I use the terms interchangeably, including other synonyms like 'accounts'. However, not distinguishing between the terms has not always been straightforward. I have often struggled to differentiate between concrete, empirical 'stories' and the more abstract, analytical 'narratives', especially in Sub-study III. In this sub-study, I learned just how challenging it can be to describe the exercise accurately. By using the terminology of 'stories' while referring to the 'collective stories' as an exercise in the courses, I aimed to minimise the possibility that the 'collective stories' (on a micro level) were confused with what is often called 'collective narratives', 'dominant narratives' or 'master narratives' (on a macro level) in narrative research. Furthermore, it seems relevant to define what a narrative is, beyond merely addressing its terminology. Broadly speaking, I consider narratives to be socially constructed. I have further gathered my understanding of narrative as being characterized by their workings as 'actors', by their characteristic of being centred around a meaning making plot and by their 'effect' on people (Frank, 2013; Gubrium and Holstein, 2009). Narratives do not only mirror lived experiences, but all parts of narrative are elements in a constructive process, involving an intertwining of the text, the context and the meaning (Mattingly and Garro, 2000). I therefore understand the concept of narrative from a social constructivist perspective in which narratives gain significance through their use in social interactions (Gergen and Gergen, 2006: 140).

What is narrative?

Narrative is a fundamental human activity. By narrating we not only express ourselves and our experiences, we also make sense of the world and create meaning in our lives (Hydén, 1997). Fundamental in this position to narratives is that no story is a pure re-telling of actual events. Narratives do not reflect any notion of objective reality (if that thing could be thought to exist). They are dynamic, shaped by and negotiated in interactions (Hydén, 1997; Thomsen, 2016). Frank (2012) emphasises the social element of narrative and situates all narratives within the context of culture, which also offers specific scripts from which the narrative takes form:

> "A storyteller tells a story that is his or her own, but no story is ever entirely anyone's own. Stories are composed from fragments of previous stories, artfully rearranged but never original" (Frank, 2012: 35).

Inspired by this and by Gubrium and Holstein's (2012) notion of ‘narrative reality’, I consider storytelling as socially situated within a specific context, impacting my understanding of the participants’ stories and experiences. I have not disregarded the content of their stories, which became an important element in Sub-studies I and III. However, my primary focus on narrative in this dissertation, aligned with Bury (2001) has been to explore individual (and collective) narratives in their relation to the social world and cultural context. Analysing the narratives in relation to the broader context (as presented in Sub-study I and III) has made me attentive to how some narratives are culturally available (and favoured), while others are not.

Some scholars argue that an important aspect of narrative is not only how its organisation adapts to different circumstances, but also how its legitimacy depends on the listener’s ability to recognise and attribute meaning to it (Bo, 2016). Plummer (2020) argues: “Narratives in themselves do nothing: a text without a reader has no meaning” (48). This dual attention on both the teller and the listener, and how each impacts the narrative itself, has been fundamental for my understanding of narrative. This perspective led me to view narrative not just as a story but as an act of telling – an approach I interpret through the lens of performativity. In this, I have been inspired by scholars who view narrative in its embodied nature, understanding narrative as both ‘a making’ and ‘a doing’ (Peterson and Langellier, 2007; Langellier and Peterson, 2004; Hyden, 2008) (which became of particular importance in Sub-study III). Deepening my understanding of narratives as a performance action, linking the teller and listener in a specific context, I found inspiration in Hydén and Brockmeier’s (2008) formulation: “To understand storytelling as performing means imagining the space between the teller and listener being filled in a physical, spatial, and bodily fashion” (Hydén and Brockmeier, 2008: 10).

Originating in the Latin phrase ‘narrativus’, meaning ‘to tell’, narratives are further characterised by their centeredness around a meaningful plot (Thomsen et al., 2016). This ‘plot’ implies forward motion in the narrative and through the plot, meaning is attributed to the narrative, making it into a coherent story. Important, though, is how meaning is attributed to the narrative retrospectively as it is shaped in the present moment of telling. This present is also determined by the specific context. Narratives about the future are inherently connected to both the past and the present as they are shaped by the context in which they are told, building upon and limited by the culturally available narratives (Thomsen et al., 2016). Although Järvinen (2000) speaks specifically of life histories in the following quotation, I find her metaphor striking and illustrative of this interconnectedness between the past, present and future in narrative:

> ”A life history is like a boomerang: it is thrown from the present to the past, and returns with a force bearing it into the future, but the direction and force is determined by the present, and by the form of the life history (the boomerang) itself” (Jarvinen, 2000: 385).

As underscored by this quote, the personal teller is no longer the same person as the ‘I’ the story concerns. Moreover, although narratives tell of events and experiences, they are based on specifically selected, connected and organised events that fit into a coherent and meaningful story, catered to a specific audience (Riessman, 1993). These perspectives stress the dynamic nature of narratives and emphasise how essential narratives are to our construction of identity, per their capacity to establish a sense of meaning in our lives (Thomsen et al., 2016; White, 2006; Hydén, 1997). Although I have not explicitly worked with the concept of narrative identity, it stands out as such an underlying theoretical term within narrative research, which have shaped my understanding of narrative.

> ”To tell the story of life may be one of the cores of culture, those fine webs of meaning that help organize our ways of life. These stories – or personal narratives – connect the inner world to the outer world, speak to the subjective and the objective, and establish the boundaries of identities (of who one is and who one is not)” (Plummer, 2007: 395).

Narrative and identity are often closely linked by scholars in narrative research, and it is often recognised that narrative is a way to negotiate our identity. The concept of ‘narrative identity’ rest on the argument that we become the stories we tell about ourselves (De Fina, 2015; Bruner, 2004). Through narrative, the teller may present specific events and stories that, in negotiation with the listener, help the teller compose a version of herself; a version of her identity (Hyden, 2010). As put forward by Plummer (2007) in the above quotation, identity is established in these narrative connections created between our inner and outer worlds.

Narratives in the context of illness

The emphasis on narrative in our everyday life practices and its connectedness to identity does not lose its significance when one falls ill. In conformity with the much-used terminology I presented earlier, put forward by Bury (1982), illness is a disruption of life as one knows it. Consequently, the organisation of life events into a coherent narrative is disturbed (Hyden, 2010). Narrative may repair the damage caused by this disordering:

> “Narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework” (Hyden 1997: 53).

Investigating illness narratives helps us understand how living in the midst of the disruption of life that illness causes is experienced and managed (Mattingly and Garro, 2000). For the patient, illness narratives enable communication and negotiations with the outside world (Hydén, 1997). Narrative is what gives voice to the patient’s illness experience and suffering, contrasting the biomedical focus on the pathology (Kleinman, 1998).

A major theoretical contribution to medical sociology, dedicated to the study of illness narratives, is Arthur Frank’s (2013) ‘The wounded storyteller’. Especially in Sub-study I, I turned to Frank’s (2013) typology of illness narratives: ‘restitution’, ‘quest’ and ‘chaos’ to establish what the participants’ experiences of harm reflected. Rooted in his own patient experiences, Frank (2013) aimed to describe how both the storyteller and the listener structure and interpret illness narratives within these three shared ways of narrating illness. The first narrative type Frank (2013) presents is the restitution narrative. The basic plot in the restitution narrative revolves around falling ill and becoming well again. An interesting element in the restitution narrative is how it portrays in what ways patients *learn* to speak of their illness: from institutional medicine and popular culture to interest groups. Restitution narratives imply a cure to illness and suffering, a restoration of the body; and as a narrative type, it remains unavailable for those who may never hope for restitution (Frank, 2013). The second narrative type presented by Frank (2013) is the chaos narrative. Following Frank (2013), true chaos narratives are non-stories as a person who is living the chaos would be unable to turn their experiences into a story. In this sense, chaotic narratives are without plots and coherence, and the people living in the chaos are unable to reflect upon or distance themself from their stories. Frank (2013) formulates it like this: “To turn chaos into a verbal story is to have some reflective grasp of it. The chaos that can be told in story is already taking place at a distance and is being reflected on retrospectively” (Frank, 2013: 98). My biggest concern with adapting the theoretical framework offered in ‘The wounded storyteller’ was with Frank’s (2013) typology of ‘the chaos narrative’, which I found too limited. As in Frank’s (2013) typology, I found no structure to aid in the interpretation for those of the participants in the narrative courses who narrated of suffering, as further discussed in Sub-study I. The final illness narrative type in Frank’s (2013) typology is the quest narrative. In quest narratives, the teller uses the illness to embark on a journey – a quest, in which they become the hero. In the quest narrative, the teller passes on valuable experiences and insights that they gained from falling ill, wherefore quest narratives imply individual ethical responsibilities (Frank, 2013).

Taking on a critical position to narrative

The abductive approach, which I will elaborate on in the next chapter, enabled continuous refinement in terms of theory. I initiated the research process with an overall understanding of the significance of narrative, largely derived from the above-mentioned theoretical and empirical concepts. Narrative theory had a place in my mind when I encountered the field, so to speak. Yet, in the field encounters, I quickly learned, in an a-theoretical, embodied way, how my (at that time limited) theoretical understanding did not suffice in my attempt to understand how some of the participants' experiences of harm were also linked to the concept of narrative. Needing another set of theoretical lenses to explore and comprehend the dark sides of narrative, I turned to scholars who have publicly contributed to this area of study.

Galen Stawson's article "Against narrativity" from 2004 is one of the most famous and probably most influential academic critiques of the focus on narrative (Hyvärinen, 2012). Simplistically put, Strawson (2004) contests how scholars in narrative research take for granted that humans are all natural storytellers. His work influenced many other scholars. For example, philosopher Angela Woods has contributed to strengthening this critique of narrative. I find the most compelling critique of narrative, as argued by Woods (2011), to be the idea that a narrow understanding of the 'natural' concept of narrative and narrativity in human life may isolate and cause suffering for those who do not consider themselves storytellers and, thereby potentially limiting diversity.

Other scholars have inspired me to take on a more cautious position to narrative, such as those who challenge the narrative coherence paradigm (Hyvärinen et al., 2010a). These scholars contest the 'taking for granted' idea within narrative research, that 'good narratives' are those that are linear and chronological and function to create coherence in the narrator's experiences. Furthermore, they contest a dominant idea in narrative theory, namely that such 'coherent narratives' make people live better and more ethical lives. Even further, they ask if this 'coherence paradigm' may become harmful for those who neither can nor will adhere to the norms within narrative theory (Hyvärinen et al., 2010b). Additionally, as highlighted by Atkinson and Rubinelli (2012), a central limitation of the study of illness narratives is that the influential term of 'disruption' caused by illness is presumed rather than challenged. Yet for some, an illness like cancer may not be perceived as a major disruption in life but rather as just one of many challenges. In such cases, understanding their suffering through the lens of narratives may be less relevant. In Sub-study I, these perspectives led me to build on and challenge Frank's (2013) three illness narrative types. Yet, most importantly, they provided me with an overall more nuanced frame of interpretation regarding the significance, use and limitations of narrative.

Exploring the influence of social interactions

Given my sociological background, I have been particularly focused on exploring the influence of social dimensions of the narrative courses, in relation to the aforementioned theoretical frameworks. Through my fieldwork, detailed in Sub-study II, I realised the need for a comprehensive theoretical framework to explore the concept of 'fællesskab', a Danish term that inadequately translates into the English word 'community'.

I turned to a theory and definition offered by Mcmillan and Chavis (1986) called 'sense of community'. I found this theory quite useful for understanding not just why the narrative courses were experienced as a community, but also why these community feelings were promoted, and how the community became important to the participants' experiences of the courses. Essential in the theory are the four elements of membership, influence, reinforcement and shared emotional connection (Mcmillan and Chavis, 1986). By membership, the participants have a feeling of belonging, which is strongly connected to the boundaries: who is included and who is not. These boundaries are important for the development of intimacy and feelings of safety. The element of influence refers to how members need to feel influential to be attracted to a community and how communities influence the members through notions of conformity and uniformity. Both dimensions operate concurrently in close communities. The third element of communities, according to Mcmillan and Chavis (1986), is how the community integrates and meets the member's needs, such as through reinforcement. A key concept in this is shared values: "The extent to which individual values are shared among community members will determine the ability of a community to organize and prioritize its need-fulfilment activities" (Mcmillan and Chavis, 1986: 13). Lastly, shared emotional connection rests on elements such as the time spent together, a shared history and shared or similar experiences. A key aspect of the 'sense of community' theory is the dynamic interplay both within and among its elements. I find it important to recognise that this theory is normative; Mcmillan and Chavis (1986) developed the theory not merely to study existing communities, as I have done in this dissertation, but also to guide the creation and facilitation of new communities.

3. Methodology

In the following section, I will elaborate on the chosen research design and methods. A social constructivist position in research does not prescribe a specific set of methods, yet qualitative methods are often considered logical choices when the focus is on context and social meanings (Burr, 2019). In this dissertation, I have adopted such an approach to explore the participants' experiences ethnographically. Given the ambition to explore these experiences in relation to context, I found a qualitative research design inspired by ethnography well suited.

In this chapter of the dissertation, I aim first to account for the chosen research design and to describe how it evolved over the course of the project. Next, I aim to thoroughly reflect upon my position in the field and illustrate how I view my role as a researcher. Then I introduce the data material and the selected methods, concluding with reflections on how I sought to ensure the study's quality.

Research design

A turn to ethnography

I would like to begin this chapter – logically, at the beginning. I believe that a brief exploration of what I initially planned but ultimately *did not* pursue is essential for understanding the rationale behind my final research design. These changes were important for shaping my data generation process and, consequently, impacted the findings presented here.

Like many other research projects, this project was formed years before my enrolment as a PhD student began. Naturally, it evolved. The initial research design was inspired by realist evaluation (Pawson and Tilley, 1997) and based on the same data generation methods of field work, interviews, focus group interviews and documents. Realist evaluation is a theory-driven evaluation approach, centred around context-mechanism-outcomes configurations and may include both quantitative and qualitative methods (Pawson and Tilley, 1997).

I enrolled as a PhD student in August 2021; and just one and a half months later, the first narrative course (Course IV) was held at the municipal rehabilitation centre. This shift encounter with the field ultimately became pivotal for my turn to ethnography and predated the preparation and construction of a rigorous evaluation design. During this first fieldwork, I stumbled upon an 'empirical surprise' (Tavory and Timmermans, 2014) as I learned how some of the participants experienced the courses as harmful (a finding that ended up constituting Sub-study I). I began questioning the very nature of what I was studying. As I engaged with the field and interacted with the participants, I grew increasingly uncertain whether I was even asking the right questions at all. After weeks, maybe months, of trying to force my paths of thinking into the modus of realist evaluation, I consulted senior researchers and my supervisor team to discuss my concerns. In collaboration with them, I decided to abandon the focus on conducting a realist evaluation of the relevance and impact of the narrative exercises and course in general. Instead, I chose to approach the field with less premeditation and more curiosity. Important to note is that although my research approach shifted, the applied research methods remained largely unchanged. What changed was mainly my mindset. My intention in this section is not to suggest that a realist evaluation could not have yielded satisfactory results. Rather, I want to emphasise that, given my background as a researcher and the experiences I had during the fieldwork, ethnography proved to be a better match. I firmly believe that the explorative nature of the ethnographic field study became a strength, allowing me to uncover findings that might have been overlooked had I adopted a more evaluative research approach.

I describe this as a turn to ethnography. For me, the strength of ethnography lies in its ambition and commitment to study *people*; their actions and their accounts as they unfold in everyday life (Hammersley and Atkinson, 2019). I recognise how the settings of the narrative courses do not constitute a classic understanding of 'everyday'; but as highlighted by Kleinmann & Kleinmann (1991), it is central in ethnography to seek to understand what is at play for "particular participants in particular situations" (p.277). Ethnography typically involves different sources of data, and the data generation process is typically not structured strictly around specific objectives for the fieldwork (Hammersley and Atkinson, 2019). For me this meant that after engaging with the field, I reframed my way of thinking and embraced a more open and explorative mindset. Instead of focusing, for example on exploring if and how the narrative exercises functioned as theoretically intended, I embraced my sociological curiosity and asked the field a broader question: What is going on here?

Entering and exploring the field

The field in this study was the empirical settings which is initially described in the Introduction. Getting access to the field was mostly unproblematic for me. Because the narrative courses were developed in cooperation with the research clinic on the basis of the acquired funding, I already had privileged research access to the field. Furthermore, at the research clinic, all participants had already consented to participate in the research as part of their enrolment, where contributing to research is an inclusion criterion. At the municipal rehabilitation centre, I was invited to participate as a researcher by one of the course professionals (the course designer), who served as a gatekeeper.

The description of the research 'clinic' may evoke images of a dental clinic or medical consultations. However, as discussed in Sub-study II, the clinic was an impactful setting. For me, attending the research clinic almost felt luxurious. As already described, despite being located within a hospital, the research clinic was intentionally designed to feel homely with artwork, plants and flowers, calming colours and modern furniture, creating a welcoming atmosphere. Especially the third floor of the clinic, where the participants' private rooms were located, along with the living room, dining room and balcony, to me, felt almost like a hotel. Comfortable chairs were arranged in smaller arrangements and numerous nooks were decorated to encourage participants to sit in smaller groups to engage in conversations. Along with a steady flow of coffee and tea, participants had access to free games, books and bicycles. If participants did not initiate informal social 'hygge' in the evening, the evening host (a clinic professional) would step in to offer additional activities like ping-pong ball or dart (Rasmussen et al., 2020). Food and meals easily became a big deal. All meals were included in the narrative courses at the research clinic, including three primary meals each day (breakfast, lunch and dinner) and all between-meal snacks. Dietary restrictions and limitations were met by the kitchen staff with a welcoming attitude. Each morning, all participants received a 'goodie bag' with various snacks such as fruit, nuts, chocolate and vegetables; and in the afternoon and evening, more fresh fruit and cake were provided. All in all, I experienced how participation in the research clinic was, in many ways, a unique experience.

Creating a homely and inviting atmosphere was also a characteristic of the municipal rehabilitation centre. The use of natural wood and soft chairs, artwork and modern furniture in a newer building helped distinguish the centre from what might otherwise feel like a hospital setting. The narrative course was conducted mainly in a larger meeting room on the first floor; yet, the participants could use other areas of the centre for their individual and group work. The participants brought their own lunch and snacks, but coffee, tea and cake were provided.

Field work positions and reflexivity in the field encounter

During ethnographic fieldwork, the researcher always positions herself in the field. How she should engage with the field during fieldwork is discussed among scholars (Hammersley and Atkinson, 2019; Krogstrup and Kristiansen, 2015). My ambition of being largely in control of my own positioning was often challenged, and dilemmas kept presenting themselves during the fieldwork. Inspired by

Riessman's (2015) take on reflexivity in narrative research, in the next two sections, I aim to foreground my own position, foreclose and disclose what Riessman calls the "situated self" (Riessman, 2015: 233). This section sets the scene for the upcoming section, dedicated to reflecting on the study's quality. Some of the reflections that follow relate to my experiences and field encounters in both empirical settings, while others are specific to my time at the research clinic.

Firstly, I made a choice to try to position myself as 'in between' the participants and the professionals, meaning not representing myself as directly affiliated with the professional staff, while also not trying to represent myself as having the same characteristics as the participants. At times, I found this manoeuvre challenging. As mentioned earlier, before starting my PhD project, I worked at REHPA as a research assistant and therefore I had insider knowledge and a familiarity with the professional staff and this setting. Consequently, I often felt positioned, both by the staff and by the participants, as an information gatekeeper. I sometimes had a deeper knowledge than the participants (and occasionally the professionals) regarding, for example, the narrative course (What's the point?), the given exercises (How do we do this?), the physical surroundings (Where is the nearest toilet?) and the staff (Who do I ask about this?). This sometimes challenged my presence in the field and my ability to participate and observe, yet also imposed specific ethical dilemmas.

Secondly, I do not have cancer, nor have I ever suffered from it. I partook as a researcher, so naturally there were elements during the fieldwork where I needed to step back from actively participating in the courses. In these scheduled sessions, I stepped back to become (mostly) an observer and followed the participants during their group work and talks while remaining silent when they shared their reflections. Otherwise, I engaged in other informal social interactions: joining small-talk conversations in the coffee breaks, enjoying breakfast and late-night knitting, to exchanging hugs and wishes of good luck when parting. Some of the participants joked and said things like "You are almost one of us" (fieldwork), but I also encountered the opposite. One evening, a participant said "You are not one of us, you are not sick" (fieldnotes), but, surprisingly, another participant jumped in the conversation and replied on my behalf "You don't know that" (fieldnotes).

During fieldwork, my foremost intention and priority was to establish a sense of *trust* between me and the participants. The participants needed to trust not only my commitment to confidentiality in a broader ethical and legal sense but also feel comfortable enough with me on a personal level to share openly how they felt and what they experienced during and after the courses. However, also on this matter, I was challenged. At times, the participants misjudged my age, often thinking that I was much younger –

by as much as 10 years. It is well known in ethnographic research that the characteristics of the researcher impact the participants' reactions, imposing a potential problem in the data generation process (Hammersley and Atkinson, 2019). My presumed age sometimes led me to sense that participants would 'tone down the seriousness' (my own phrasing) of their stories when I was present. I quickly realised that this tendency to hold back on the severity of their stories often stemmed from concern for me as they perceived me to be too young to handle stories of such suffering. Sometimes, they uttered things like, *"Now I don't want you to get scared"* (fieldwork) before sharing parts of their life stories.

To meet these challenges, I sometimes utilised my personal experiences of loss strategically, drawing on my experience with former research done on the same kind of target group (Gärtner et al., 2021) to assist me in positioning myself more favourably. By sharing parts of my own life story, most of the participants' reservations about sharing disappeared. I shared stories from my own everyday life, such as being a mother of three and when it felt natural and warranted, I shared the stories of the loss of my mother and father. I found that this personal engagement and honesty on my part fostered meaningful informal talks with the participants and influenced the depth and richness of the data I was able to produce. On the other hand, I also recognise that sharing my personal stories is an example of how all narratives are tailored to a specific audience (Riessman, 1993). What I chose to share was highly dependent on the context, carrying specific meaning in that time and place. Furthermore, it was often necessary to remind participants that the narrative courses were not 'my invention', and that they should feel free to speak their opinions openly. For instance, sometimes participants admitted that they held back negative thoughts because they did not want to hurt my feelings, given the time and effort I invested in being with them. Another aspect of this was my participation in the training course in April 2021, which gave me personal experience with the narrative exercises. This experience influenced both the data generation and the later analysis. Having gone through the narrative exercises myself, I had a preunderstanding of which exercises might be upsetting or painful for the participants, and which could be somewhat confusing. As a result, I was particularly attentive to how the participants reacted when the exercises were introduced by the professionals, and to what happened during their individual and group work.

Overall, these challenges in my fieldwork illustrate that, despite my efforts, I did not always succeed in positioning myself as intended: a professional researcher and participant observer in the field. My outward characteristics, such as appearing young and inexperienced, and my own life experiences, including the loss of my parents and being a mother of relatively older children, became factors that sometimes felt like a symbolic tug-of-war with the field. These methodological reflections on entering and positioning in the field likewise reflect why I view my data as co-produced through the interactions between myself and the participants. They also highlight how my personal experiences became a valuable resource in my work, where both transparency and reflexivity are essential to ensuring the trustworthiness of the study. To maintain this commitment, I will further elaborate on an important dimension of my fieldwork.

The wounded researcher

Studying people in vulnerable situations is not always without risk for the researcher (Liamputtong, 2007). Mallon and Elliott (2019) state that some qualitative research projects pose an emotional risk for the researcher. In this section, I will reflect upon the risks and consequences of qualitatively engaging in a field where suffering is central in both story and body. I hope to address how this impacted this study and contribute meaningfully to a broader discussion on the importance of reflexivity in this area, advocating for its recognition, careful consideration, and acknowledgement within academia.

> I'm just finishing the interview with a younger cancer patient when her phone rings. It is her husband, and I just wait on the other side of the table. I think it's a quick message and that our conversation can continue shortly after.
>
> But just as she answers the phone, it is immediately apparent that something is very wrong. Even from the other side of the table, I can hear her husband on the phone dissolve in tears. And before I can react, I hear his sobbing and desperation in the other end of the phone, as he asks, 'Where are you? I got so scared'. I hear the panic in his voice. My informant had clearly forgotten to tell her husband where she was, and as soon as I sense the mood, I get up and start tidying up after the coffee – and leave the room. My informant and her husband have a long phone conversation before we finish up the interview.
>
> And I am shaken. And most of all, I am shocked by how shaken I actually am.
>
> I cry all the way home from that interview, from Copenhagen to my suburban life in Hvidovre, where cancer does not cast a shadow over our family life. And where I neither appear as the exhausted relative nor the powerless cancer patient. But I cry much for a period afterwards. Because the small, timid voice that I heard a brief snippet of was, in a way, my own. Intimately and invisibly, the threads of her cancer spread into my own life, and my story suddenly became intertwined with hers.

> A tired, distressed relative opened a Pandora's box inside me, which I otherwise painstakingly believed I had found peace with. It reminded me of how many phone calls I have had, with fear lodged in my throat and my heart pounding in my chest, awaiting a voice on the other end calmly indicating 'not yet'. Until suddenly, it was now.
>
> The question is, then, where do I professionally go with my unprofessional vulnerability? What do I do with it? Who do I talk to? Because vulnerability is unprofessional. I see myself as resilient. But not all parts of me can endure being soaked in their suffering, for then I crumble, and my vulnerability peaks through (Notebook entry, 15/11-21).

As I have stressed, a key strength of ethnography is its ability to generate rich, detailed data. However, this richness sometimes comes at a personal cost. As this excerpt illustrates, being immersed in the lives of people suffering from cancer sometimes affected me on a personal level. I do not mean to suggest that this cost was too high; rather, I utilised these experiences to gain a deeper understanding of the participants' experiences and narratives. In this way, it was a worthwhile trade-off.

One might attribute my vulnerability to my personal experience of witnessing severe, life-limiting illness throughout my life, but it was not only the participants' cancer stories that affected me. The participants' lives were, naturally, more complex than just their experience with cancer. I listened to their messy, chaotic stories as well; tales of existential loneliness, financial hardship, the loss of children, infidelity and hurt relationships. These experiences, I believe, would impact any researcher at some level. To be fair, while I often felt a deep empathy that turned my stomach, I also shared moments of such joy with the participants that we laughed until we cried and could hardly breathe. Yet, what stuck with me the most was how little of these experiences I could share with people outside the field, leaving me with limited opportunities for personal relief. First, due to my obligation to maintain confidentiality towards the participants, I was cautious about what I could share with outsiders, although I shared many of my experiences with my closest colleagues and supervisors in an anonymised manner. Next, I experienced a (maybe misunderstood) professional obligation to 'suck it up' as 'yes, research may be hard'. I *did not* want to be seen as professionally weak. But, most surprisingly, I found myself feeling isolated with my research experiences even in my private life. As I discuss in Sub-study III, suffering is tough. It is tough to endure, hard to escape and also hard to listen to. I learned firsthand that the world and our loved ones are not always open to (or capable of) hearing stories of suffering. Experiencing this on my own body created in me what I came to think of as ‘professional loneliness’. I took the initiative to seek supervision from the university’s psychologist to manage this. It is vital for me to stress that my feelings were neither professionally nor personally neglected by the people around me. However, the emotional impact of the fieldwork, which reopened old wounds, was fundamentally a lonely experience. Important though is how these experiences sharpen my analytical lens, allowing me to better understand how the participants’ external circumstances affected their experiences with the narrative courses. In an embodied way, I was reminded that some stories (such as those of suffering) may be silenced in our lives, and therefore we end up carrying these stories of suffering alone.

I understand if this section prompts the question of: Is it feasible for a researcher to be wounded? My point is that the wounds are already there, whether we acknowledge their impact on our research or not. I have tried my best to treat my wounds as an advantage and to utilise my personal experiences with suffering to open the field. My aim with this section is also to highlight that research can sometimes wound us, both personally and professionally. This requires academic attention and curiosity because the researchers’ emotions are to be considered more than mere inconveniences – they can serve as valuable data that enrich our understanding of research.

Data material

The total data material from both empirical settings constituted 215 hours of participant observation, 15 individual interviews, six focus group interviews and three documents, see Table 3 for full data material overview.

Tabel 3: Data material

REHPA				**Municipal rehabilitation centre**	
Course #	**I**	**II**	**III**	**IV**	**Total**
Focus group interviews	n=2	n=2	n=2	/	**6**
(Participants partaking)	(11)	(10)	(7)		**28**
Individual interviews	n=3	n=3	n=3	n=6 (twice with three participants)	**15**
Participatory observations	64.5 hours	59 hours	61.5 hours	30 hours	**215**
Collective story document	2,541 words	2,498 words	2,320 words	/	**3**

Participants

In total, 42 people participated in all or parts of the narrative courses (see Table 4). Six participants had a curable or intendedly curable cancer prognosis and participated at the municipal rehabilitation centre, while the remaining 36 attending the research clinic all had advanced cancer. The majority of the participants were female, counting 34 out of the total 42 participants. Most of the female participants had breast cancer. In contrast, the other participants suffered from various kinds of cancer, such as prostate cancer, lung cancer, bone cancer, multiple myeloma, brain cancer and uterus cancer.

In total, 10 participants did not complete the full narrative course, with reasons counting from experiences of harm to experiencing general illness (Gärtner et al., 2024b). To protect the participants' anonymity, I have chosen to report their age in 10-year intervals, and I have chosen not to disclose any other sensitive information that could potentially jeopardise their anonymity, as further discussed in the next chapter. See Table 5 in Appendix IV for the full participant and data overview.

Tabel 4: Participant overview

	REHPA research clinic			Municipal rehabilitation centre	
Course #	**I**	**II**	**III**	**IV**	**Total**
Participants	Men, n=3 Women, n=10	Men, n=3 Women, n=10	Men, n = 0 Women, n= 10	Men, n=2 Women, n=4	**42 participants**
Participants who withdrew	n=2	n=3	n=3	n=2	**10**
Prognosis	Advanced cancer	Advanced cancer	Advanced cancer	Cured or intended curable cancer	

Methods

As mentioned, the methods used in this project were participant observation, individual interviews, focus group interviews and documents (the collective stories). Figures 4 and 5 illustrate the phases of the narrative courses in which I worked with the different methods. This involved participant observations during the course days, individual interviews between the course days, and focus group interviews on the last day of the courses in the research clinic.

Figure 4: Illustration of the narrative course, including research activities (research clinic)

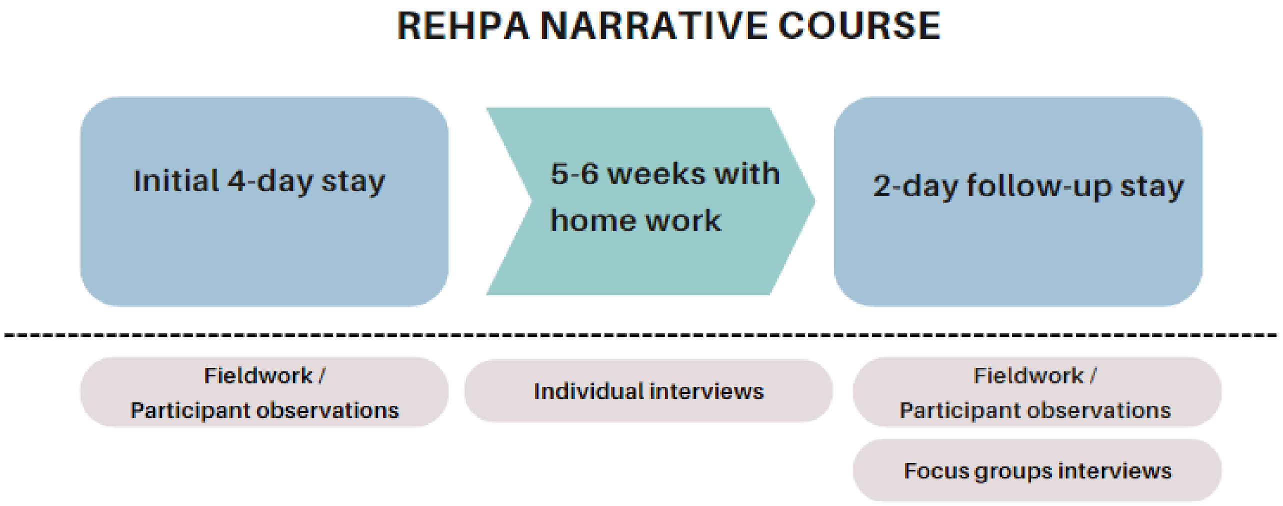
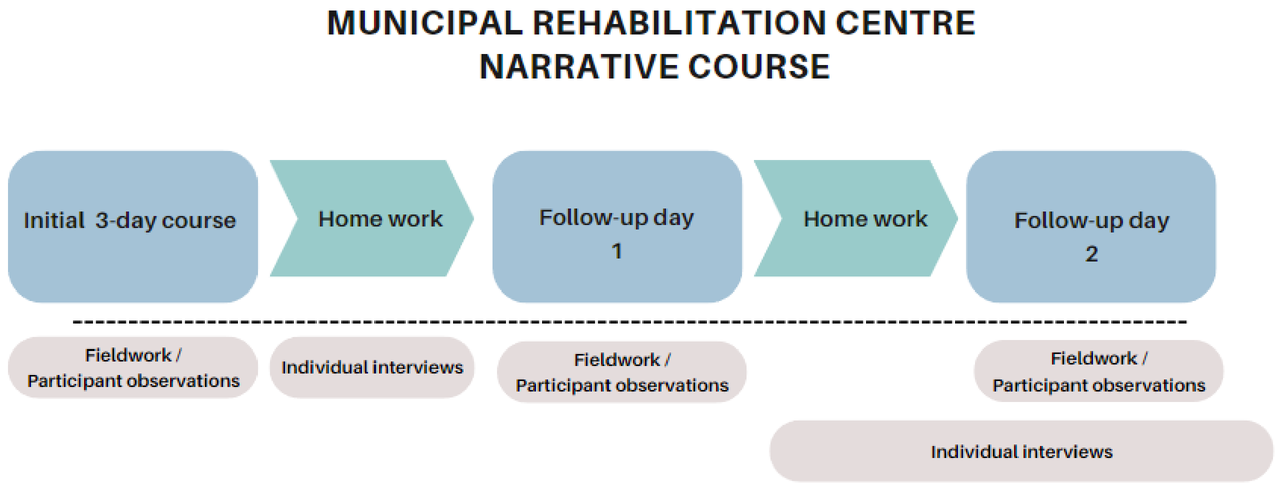


Figure 5: Illustration of the narrative course including research activities (the municipal rehabilitation centre)



Participant observations

Participant observations may be regarded as the heart of ethnographic field work (Emerson et al., 2007) and it has been a central part of this study's empirical foundation. Being present in the field was also a key reason for the change of research design described earlier and I believe that the overall findings in this study support and underline the necessity of doing participant observations.

Observations in research may be carried out in different ways. H. Russell Bernard, an American cultural anthropologist identifies three types of observer roles in research (Bernard, 2018). First, a researcher is a complete observer if this researcher becomes a member of the same group that is studied. This involves deception, as those who are observed are unaware of the researcher's double play. The second option, the participant observer, is the most frequent role in ethnographic fieldwork. It involves a researcher, either an insider or outsider, who partakes in some of the activities they study and records what is possible. A distinction is made here between being an observing participant (insider) and a participant observer (outsider). The third observer role is a complete observer who takes little to no part in interacting with the observed participants (Bernard, 2018).

Although I categorise myself as a participant observer, I shifted between how much I participated and how much I observed. Overall, I did not experience this shift as ambiguous as it was often quite clear to me when and why I needed to take a more participating or observational approach. This strongly relates to my practice of writing fieldnotes and, for instance, how I used my notebook to shift my position in the field.

Constructing fieldnotes

During my observations, I wrote fieldnotes, which I recognise as inherently constructed. Emerson et al. (1995) state that when we write fieldnotes, researchers inevitably select what receives attention in their study. I acknowledge that my influence in constructing these fieldnotes, as with all my general data material, plays a major role in shaping the outcomes of this type of study.

My fieldnotes were written down in a notebook, which I carried around throughout the scheduled programme on the narrative courses. I wrote down the things I observed, along with my reflections or thoughts, such as “It seems like many didn’t really understand how to approach this exercise” (fieldnote excerpt). In this way, I altered between simply writing down descriptions of what happened, to personally engaging in a reflective process with my observations. I tried to stay true to the participants’ use of vocabulary, when possible, because, as Hammersley and Atkinson (2019) states, it is important to record the actual wording of specific actors as they are situated in specific contexts.

At the research clinic, as I engaged with the participants throughout the entire day, I did not bring along my notebook at times when social interactions were informal, such as during breakfast or in the evening. I did this purposely both because it would have been awkward to write down while eating or watching TV, but also to give the participants a break from feeling that they were constantly being observed (although they were). In the evening, I often exchanged my notebook with my knitwear and engaged with the participants in a more casual way. Often, though, I made valuable observations during these hours of informal social activities. Before I went to bed, I went back into my private room after the social gathering and tried to sum up my observations in the notebook. Retrospectively, I realised that these notes, which I reconstructed looking back at what went on, rather than hurriedly scribbling in the moment to capture every observation and wording, had distinct characteristics. These notes were less literal as I was not able to quote the participants, but they were more reflective and thoughtful. At the municipal rehabilitation centre, I refrained from taking notes during lunch or in breaks but reconstructed important observations afterwards.

On occasion, I also intentionally put down my notebook while observing during the scheduled programme and deliberately shifted my position to simply actively listening. I had no systematic reasons or criteria for when I thought this practice change was necessary. I merely relied on intuition and trusted my reading of the situation. Often, my primary goal in putting my notebook aside was to ease the pressure on the participants. It could be in situations where a participant continuously seemed to focus on my writing, and I sensed how it distracted them. Mostly, I intentionally refrained from writing fieldnotes during my observations when the participants engaged in group work. In these two-three person groups, the atmosphere was sometimes highly intimate, and some participants shared vulnerable stories that they did not otherwise share with the larger group. Some of these stories were so personal and of such sensitive nature that I believed it unethical to 'record' them in my notebook. Out of respect, I did not retrospectively write down the contents of these stories but simply tried to capture important observations, such as the atmosphere in the room or how the participants reacted towards each other. During these situations, I sometimes felt like my bodily presence was that of a giant and by putting my notebook down, I tried to shrink my physical presence in the room. I quickly learned that my notebook represented an opportunity to change my position in the field. Many of these episodes of me shifting between writing and not writing fieldnotes extensively intersected with ethical 'on the spot' decisions, which I will elaborate on in the following chapter.

Individual interviews

Another method used in this study was the individual qualitative interview. I also regard the knowledge generated through interviewing as co-constructed between the participant and me as an interviewer. Following Gubrium and Holstein (1995), this approach to interviews disregards the idea of the interviewer getting access to 'knowledge' by questioning the participant. Instead, it acknowledges the impact of the researcher in the construction of knowledge.

I drew on my experiences from participant observations when recruiting participants for individual interviews. Several factors mattered in the selection and recruitment of participants. Foremost, during informal conversations at the course settings, some participants said that they were interested in participating in an individual interview. These participants were therefore, naturally, motivated to contribute further to my research and were easy choices. Yet, I was also cautious about this approach as I recognised that some participants were more outspoken than others during the courses and better at clarifying their opinions in the plenary. Not all participants had the mental or physical capacity to participate in extra activities. Some, whose perspective I would have liked to explore in an individual interview, declined to participate when I asked them directly because they were simply too tired, too sick or too busy. Pragmatic considerations also influenced participant recruitment. Most importantly, I needed to coordinate the initial interview within the interval between their initial stay and subsequent follow-up stays. This primarily affected the distance I could travel across Denmark and, consequently, which participants I could visit for interviews. All in all, the recruitment strategy was formed by the exploratory nature of the ethnographic stance in which sampling is something to be figured out (and changed) as the fieldwork is being conducted (Hammersley and Atkinson, 2019).

As I have defined, I view experience as situated in a specific time and place, and they are therefore dynamic and changing. Consequently, I find choosing the time to conduct the individual interviews significant. In the research clinic, I decided to conduct the interviews between the initial stay and the subsequent follow-up stay, see Figure 5. I interviewed the participants twice at the municipal rehabilitation centre (see Figure 6); the first time between the main three-day programme and the first follow-up day; the second, after they had completed the course (or declined to complete the course as was the case with one of the interview participants). I chose to conduct the interviews after the participants had returned to their ‘everyday lives’ because I believed that this time gap would provide them with an essential distance from their experiences during the courses. This distance, in turn, would make it easier for me to explore whether and how the courses were significant, as presented in Sub-study II.

When I organised an interview, I asked the participants where they wished to conduct the interview. Some of them preferred that I visited them at home, while others came to the university institute in central Copenhagen (my workplace). The recorded interviews were scheduled to last 1-1.5 hours and lasted between 54 minutes and 1 hour and 44 minutes. All interviews were semi-structured in the sense that I initially created an interview guide (primarily informed by experiences I had gained during fieldwork) (Appendix V). However, each interview developed differently, with the guide merely serving as a flexible framework. After introducing the participant to the intention of the interviews and obtaining informed consent, I began each interview with an explorative question in slightly different versions, but with the same meaning:

> “Since you got home after having participated in the initial part of the course, what has affected you the most?” (see interview guide, Appendix V).

How the participants responded to this varied and shaped the rest of the interview. For some, medical treatment or personal issues had completely overshadowed their experiences at the courses, and they needed much reminding of the contents of the course. For others, the initial question served as an initiator for them to express the things that had been on their minds. During the individual interviews, I also gained insight into how (some of) the participants interacted with each other in the time away from the courses. During the individual interviews, I learned of a Facebook group that became key for many participants at the REHPA II course and a means for them to keep contact between the course days/stays.

Focus group interviews

A strength of focus group interviews is how that they aid the researcher in generating data, for instance about how understandings and social norms are produced in social interaction (Halkier, 2016). That the cornerstone in focus groups is social interaction is both a strength and a weakness. Since the data are generated through discussions within the participant group, where understandings and experiences are negotiated among the participants, the researcher is left with richer and more complex data – insights that may be impossible to obtain through individual interviews or participant observations. On the other hand, people may conform to dominant perceptions of the discussed topics, decreasing the variation (Halkier, 2016). For me, the purpose of the focus groups was primarily to explore how the participants collectively negotiated and identified what they perceived as significant during the courses. The focus groups provided me with an opportunity to explore how the participants as a group perceived the narrative exercises and to study the variation in how they interacted in the group discussion.

Focus group interviews were only conducted at the research clinic as too few participants at the municipal rehabilitation centre wished to participate. In total, six focus group interviews were held, lasting approximately 1.5 hours each, including all remaining participants. The focus groups were conducted before noon on the last day of the follow-up stays at the research clinic. The participants were divided into two groups, and while some of the participants attended the focus group interview, the others had individual consultations with the research clinic professionals. Sometimes, the course facilitator sought my input on the selection of participants for the focus groups, particularly regarding which individuals should be placed together. I generally refrained from making such decisions and placed the decision with the course leaders. However, a couple of times, I ended up recommending they split a few participants into two different groups. An example of this was if I, based on my observations, had inside information as to how some participants were generally mistrusting of each other.

The focus groups were audio recorded. I functioned as a moderator and in four out of six focus groups, an observer participated and wrote notes during the interviews. The observer was the course coordinator for the narrative courses (who was not otherwise involved in facilitating the courses) in the research clinic. Her responsibility was primarily to write down important non-verbal actions, such as if someone was crying or when the participants were unrestful. These observations were valuable for contextualising the audio recordings afterwards. For example, the observer noted how intensely two participants looked at each other during group discussions, which reinforced their verbal expressions of feeling like friends.

All focus groups followed roughly the same structure, see Appendix VI for the focus group guide. What surprised me (and the professionals) was that the focus groups unexpectedly served as a sort of evaluation for the participants. These sessions became a forum for them to reflect on their experiences with the course, discussing both positive and negative aspects. Some seized the opportunity to voice their appreciation of the other participants and to thank everybody, and others to evaluate the narrative exercises. After the participants had attended the focus groups, only lunch and oral evaluation were left on the course programme. Yet, many participants expressed that after participating in the focus groups, they felt that they had fully shared their thoughts and had nothing further to add.

Another interesting phenomenon was how the second focus group of the day was very different from the day's first focus group session. I experienced the second focus group as more silent and less engaged, and the participants were more prone to crying or tearing up. Possibly, this was because the second group of participants, before participating in the focus groups, had attended individual sessions with the professionals. In these sessions, the participants could discuss a subject of their own liking with a professional, and it was my impression that these sessions were often intense and emotional, revolving around sensitive subjects.

Documents

In Sub-study III, I discuss the narrative exercise that involved creating a document entitled 'the collective story". I have included these documents as part of the data material in this dissertation as they contribute with perspectives on the participants' experiences that differ from those generated using the other methods. Documents are increasingly being used in qualitative research, with researchers acknowledging different forms of written documents as equally important data resources, as for instance, interview transcripts (Drew, 2006; Prior, 2003). This requires the researcher to view the documents as social, situated and dynamic products, opposing a positivist view of documents as pure contents (Prior, 2003).

The documents of the collective stories are truly unique, and I have struggled to find comparable examples in the international literature that parallel the construction of these collective stories. The documents are not comparable with, for instance, historical documents or reports that may serve to contextualise a research topic (Bowen, 2009). As discussed in Sub-study III, the collective stories documents are constructs, products of a specific narrative exercise involving group interviews based on prompts, following selection, revision and editing by the professionals. I have included the documents with this awareness, viewing them as a social product. However, I have also focused on how the exercise functioned to initiate social interactions between the participants, and I have explored the contents (or main themes) in the collective stories.

The methods combined

Ethnographic and qualitative research is often characterised by its resort to multiple data generation methods, which is sometimes referred to as triangulation (Deegan, 2007) or multimethod research (Mik-Meyer, 2020). Combining the four different methods of participant observation, individual interviews, focus group interviews and documents provided me with the possibility to be more sensitive to the complexity of the participants' experiences, including the influence of context. I have not used the methods in combination to simply check for validity but as an opportunity to explore the same phenomenon (the participants' experiences) from different angles. This approach builds on the idea that the insights shared in focus groups likely differ from those expressed in individual interviews, which, in turn, are distinct from the knowledge generated through participant observations (Halkier, 2016). Likewise, all data generation methods worked to inform and enrich each other. For instance, fieldwork observations often led me to refine my questions in the interviews and focus groups, and vice versa.

Altogether, I consider the various types of methods as integrated components, with each type of data offering a unique contribution to this study. While they may not be represented equally in this study, I believe they are proportionally represented in this study, providing a balanced and comprehensive perspective.

Processing the data

Hammersley and Atkinson (2019) described how data analysis should not be regarded as a separate phase in ethnographic research. As I previously discussed, it became evident to me that potential themes emerged, and unexpected findings arose during my engagement with the field, leading to adjustments in the research design. Therefore, I regard the analysis to begin during the data generation process and extend into the processing of the data.

Media solutions such as NVivo gains traction in qualitative research (Gibbs, 2014). Although I initially had ambitions to learn and utilize the potential of these types of software for transcription and data analysis, I found myself continuously struggling with making it work. Automatised transcriptions in MS Word are likewise an option that I tested, but I found that the process felt too instrumental and that the transcripts were of poor quality. Therefore, I transcribed all the interviews using simple software programs such as Media Player and MS Word. Transcribing the data myself, through the sometimes-tedious countless hours of manual labour, ended up being a valuable initial phase of the data analysis. It provided me with an opportunity to familiarise myself with the data once more. Hearing the participants' voices while I transcribed helped me to be sensitive to the interview atmosphere and to document important reflections I had during this phase. Through the transcription process, I not only became familiar with their words and stories, but I also felt a renewed connection with them as individuals. This connection helped me to recall connections and link the stories from the interviews and focus groups with my field notes and the documents.

I transcribed the material ad verbatim, capturing even subtle details like bursts of laughter and highlighting when words were emphasised by the participant. Often, I observed that such nuances were important for understanding the participants' statements and for providing the necessary context to their accounts. To give an example from Sub-study II:

> "Participant: Yes, it was good, but also extremely hard. But... there is also the positive thing that you can see that you have had a lot of good things and that others are worse off than me [laughs apologetically] (Interview #9)" (Gärtner et al., 2024a).

Including the 'laughs apologetically' remark makes the reader able to recognise her statement as being said with empathy. It provides the reader with a different interpretation frame than if this detail had been omitted, and therefore I found such details in the transcription process important. However, the spoken word is often incoherent and flawed, and the transcriber must make decisions as to how and if to edit such mistakes (McMullin, 2023). During transcription, I often encountered incoherence in the participants' sentence structures that muddled their stories. To be fair to the participants and to increase the readability of the used quotations, I edited most syntax errors and some cases of repetitions.
My commitment to doing things manually continued into the more formalised data analysis process. Armed with the comments option and highlight functions in MS Word together with pen and (much)

paper, highlighters and scissors, I initiated the process of transforming my enormous amount of data into smaller parts.

Data analysis

> "Puzzles are not self-evident in the empirical world but depend on a scholar's background, intuition, and prior theoretical knowledge to identify what is both unexpected and potentially relevant" (Blee, 2019: 741).

The puzzle is, for me, a valuable and honest metaphor for describing what data analysis is. For me, research has its allure in the intriguing process of trying to piece together an understanding of a phenomenon through laying down one piece at a time, without knowing what the image on the puzzle ends up being. I also realise, though, just as Blee (2019) that the image on the puzzle changes depending on which pieces we pick up and put together. This picking up and putting pieces down further depends on personal and professional characteristics and prior understandings.

My overarching approach to data analysis is what I understand as abductive analysis as proposed by Tavory and Timmermans (2014); (Timmermans and Tavory, 2022). By engaging in abductive reasoning, the researcher owns their theoretical predispositions yet seeks out surprises and variations in the data material to reach possible explanations to "what are these observations a theoretical case of?" (Timmermans and Tavory, 2022: 14). For me, this involves analysis as a product of an iterative, dynamic and evolving process, alternating between data generation, theorising and analysis. For example, I entered the field with an existing, though limited, knowledge of the potential of applying narrative methods and familiarity with the assumptions behind the narrative exercises. Yet, surprises in my fieldwork and during data analysis led me to refine my theoretical thinking, seeking out other sorts of theory to aid my analysis. For example, in Sub-study II, I turned to Hansen et al. (2011) for theory to help me explain the influence of context on participants' experiences. I found this iterative approach to correspond well with the ethnographic nature of my research, supporting the notion that analysis is not a separate research phase (Hammersley and Atkinson, 2019; Emerson et al., 1995). Although this style of analysis involves an iterative and creative approach, it is by no means an 'anything goes' approach. Ethnographic analysis requires explication and articulation, careful crafting and organisation (Ballestero and Winthereik, 2021).

I incorporated data from both settings in Sub-study I as the findings of harmful experiences were consistent across the settings. For Sub-study II, I found that the setting and participant groups in the research clinic were distinctly different from those of the municipal rehabilitation centre. Furthermore, although going across the settings for this second sub-study could still have been interesting, only half of the six participants from the municipal rehabilitation centre completed the courses in the group set-up. A data approval technicality regarding my use of the 'collective story' document in the municipality rehabilitation centre meant that I only used data from the research clinic in Sub-study III.

Furthermore, the sub-studies vary regarding the inclusion of different data sources. As this research project involves four different data sources, not every analytical technique or procedure was applied to all data types. However, for the analysis of all data sources, my starting point was to engage in a thorough reading and re-reading of the material. This time-consuming process works to re-familiarise the researcher with the material (Hammersley and Atkinson, 2019) and helped me create a sense of how things developed over time and how to organise events chronologically. As described, my transcription process was a substantial part of this process. My approach to reading the material varied: sometimes I focused on fieldnotes and transcripts from one course at a time, while at other times, I read across transcripts and notes from all courses. Engaging in this iterative process of going back and forth between data (and theory) does not mean that there was no clear progression in my analysis process. To stay true to the puzzle metaphor, it is easier to fill in the gaps when more and more of the puzzle is there to guide the search for the next piece. Through this iterative process, themes emerged as promising and coding followed from that point. Mostly, I engaged in focused coding, which for me meant settling on a promising theme, sometimes during fieldwork and sometimes based on my re-reading of the data material, and then coding according to this. Focused coding does not involve simply settling for the first idea that comes to mind. Instead, it allows the researcher to explore variations in the data, thereby deepening the understanding of the potential theme (Timmermans and Tavory, 2022).

In Sub-study I, I explored the method of coding around an 'index case', which, according to Timmermans and Tavory (2022) is a data excerpt that strikingly captures a potential theme. Variation in the data material is then coded and structured around this index case (Timmermans and Tavory, 2022). As I have already described multiple times, 'experiences of harm' were foremost an empirical finding. Through focused coding, theorising and continued data generation, I was able to explore the phenomenon more thoroughly. This process involved refining my existing theoretical framework and enhancing the theoretical contribution in the analysis, thereby expanding my understanding of the complexity of narratives within the group setting.

Through this process of data analysis, I encountered some pushback to my abductive approach to analysis. Some reviewers and supervisors requested that the data analysis followed a set of fixed steps, ideally illustrated in a nice figure or table. I understand from where this desire for transparency (and control) with the data analysis comes. Failing to rigorously describe how themes emerged exposes qualitative researchers to much criticism and scepticism, often leading to questions about the validity of our research (Green and Thorogood, 2018). Yet, I think that what is often sacrificed on the altar of making the data analysis process transparent through figures and tables is honesty regarding the process of doing analysis. As a junior researcher, I was often cautioned, on courses and by some senior researchers, against taking the ‘easy’ road of doing a thematic analysis, as some might perceive it, particularly in reference to the (earlier) work of Braun and Clarke (2022). However, when submitting my manuscript drafts for supervision and review, I discovered that there was an expectation for step-by-step, chronological and logically illustrated analysis tables, which are characteristic of most thematic analyses. To accommodate these requests in Sub-study II, I found great inspiration in the abductive, thematic analysis proposed by Thompson (2022). This approach incorporates the principle of abductive reasoning with the step-by-step procedures of thematic analysis and included for me, presenting the development of themes in both a figure and table. For me, this approach worked quite well and reduced the resistance I encountered.

In Sub-study III, I was inspired to engage in a more narrative analysis of the documents ‘the collective stories’. As Riessman (1993) suggest, by employing a narrative analysis the researcher considers the story as a whole and contextualises it. Narrative analysis thereby helps the researcher explore not just the contents of a story but why a story was told in the way it was. For me, this meant that I first read and re-read the documents, breaking down the text into smaller stories while identifying key plots, metaphors and variations, leading to the development of initial codes and themes. First, I did this separately for each document; next, across the three documents. For example, stories within the texts were first identified and coded separately, for instance, ‘suffering in the body’ and ‘social suffering’ and thereafter collapsed under the theme of ‘suffering’. Doing this across the three documents, I ultimately ended up with a key narrative (or theme) of ‘suffering and loss’ that functioned as a promising theme for the next part of the analysis.

To examine the context of the documents (how they came about) along with how the participants used them, I utilised the potential theme as a starting point for focused coding of the transcripts and notes, looking for surprises and variations within the data material. To go beyond the contents of the collective stories, I complimented the narrative analysis of the documents with an analysis of the construction process (through fieldnotes) and an analysis of how the participants interacted with and across the documents (Jacobsson, 2016) (through individual interviews and focus group interviews). This process was more abductive. In an iterative process, I explored the patterns and empirical surprises emerging across the data material by interpreting them in relation to the existing theory (Timmermans and Tavory, 2022) and the already identified main story of suffering and loss. This process included rounds of coding and categorisations of emerging themes, re-examinations of the data and re-theorising, along with continuous discussions in the author group. At this stage, I sought out theoretical inspiration to help illustrate the relationship between the collective stories as both contents and a ‘doing’.

To end this section, I wish to add a few last reflections on my data analysis process. In an ideal scenario, the analysis of focus group transcripts should move past simple content coding. It should also take into account how the social reality is constructed through the participants’ social interactions and conversations. This approach recognizes that social reality and meaning are often shaped within the context of these interactions (Halkier, 2016). Regrettably, I have not conducted a specific interaction analysis on the focus group data, which would have been quite interesting. However, this did not *per se* serve my research aim. What I did, whilst coding and theorising, was to stay open, curious and critical as to how, for instance, consensus and conflicts in the focus group were negotiated in the social interactions. Lastly, as put forward by Timmermans and Tavory (2022), I find that much of the data analysis happened in the phase of writing up and discussing the findings with my supervisors and peers. This phase of writing, re-writing and re-coding may sometimes be overlooked or neglected as an essential part of doing data analysis (Timmermans and Tavory, 2022), and for me, this underscores how and why data analysis is a complex, continuous and (practically) never-ending task.

Credibility of the study - Quality criteria

Aligned with my social constructivist position, I accept that I am a part of the entire research process. This chapter of the dissertation aims to describe how and in what ways this has influenced my research process as a whole: from the choice of methods, my adoption of a particular position in the field, my engagement with the participants, the analysis and my thoughts on the matter of research quality.

As extensively debated by scholars, quality measures and criteria such as reliability, generalisation and validity stem from quantitative research and do not transcend effortlessly to qualitative research. As many of these criteria are rooted in a positivist paradigm where the specific focus is matters of precise and reproducible measurements, they do not directly seem to fit ethnographic inquiries in which the matter of context and interpersonal relations are significant for the results (and the becoming of these)(Green and Thorogood, 2018). Rather, the assessment of the quality of qualitative research must rest on a clear understanding of how and in what ways we understand and acknowledge *quality*. These reflections lead me to consider the concept of quality in ethnographic research in line with Hastrup et al. (2011) who emphasise trustworthiness throughout the research process as a fundamental criterion. Trustworthiness, in this context, emphasises how proper and deep descriptions of the field and the decisions made make the analysis and results credible to the reader, who can then follow the line of thought and actions taken in the research process (Hastrup et al., 2011). A way to ensure trustworthiness is through a commitment to reflexivity and transparency.

Transparency and reflexivity

According to Mason (2018), transparency and reflexivity are important elements that must be accounted for when discussing a qualitative study's internal validity. To ensure the validity of methods and interpretations made, the researcher must thoroughly account for and reconstruct which 'routes' were taken and why (Mason, 2018). Likewise, it is equally important to disclose which alternatives were not pursued (Green and Thorogood, 2018). Throughout this dissertation, I have sought a maximum of transparency and reflexivity by providing comprehensive descriptions of the chosen methods, analytical decisions, elements in theorising, changes I have made and challenges I have encountered. Based on these descriptions, I believe the study's overall credibility should be judged.

> "Reflexivity starts by preconceptions brought into the project by the researcher, representing previous personal and professional experiences, prestudy beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests" (Malterud, 2001: 484).

Malterud (2001) emphasises that the researcher's preconceptions are not to be compared to bias if she thoroughly mentions and reflects on them. When adopting a state of reflexivity in the research process, Malterud (2001) further suggests how "personal issues can be valuable sources for relevant and specific research" (484). My descriptions of how I engaged personally with my participants and used my own experiences deliberately to open the field demonstrate my attempts to display my reflexivity in the scholarly product. Furthermore, I believe that the examples I have elaborated on in this chapter demonstrate how and why knowledge generation is a socially situated practice (Alvesson et al., 2008). They show how a detailed context description may demonstrate more clearly to the reader how the data came about and how analytic interferences were made (Green and Thorogood, 2018).

Although I find Malterud (2001) notions of reflexivity to be practically useful, I was intrigued by how Riessman (2015) expanded the concept beyond the simplistic interpretations to which it is sometimes reduced: “adding something personal as a rhetorical flourish” (233). By offering the beautiful metaphor of reflexivity as “entering a hall of mirrors” (233) she elaborates on how we must take great effort in accounting for the entireness of how we are situated in the field of the phenomenon we are studying. How we as researchers must engage in this depends on the specific study (Riessman, 2015). However, it helped me also reflect upon how I (as a person and a researcher) am situated in a larger historical, cultural and social context, which also impacted how I have conducted my research and presented the findings.

To conclude this section on the credibility of the study, it is relevant to reflect upon how the methodological decisions made throughout this project may also enhance its internal validity. First, my use of multiple data methods has provided me with the possibility to approach my research questions from different perspectives. Being physically present with the participants through participant observations worked well as a foundation for exploring emerging themes or uncertainties in later interviews or focus groups. I believe that this has nuanced my understanding of the participants’ experiences. To further increase my reflexivity, I have engaged in discussions with my supervisors, other researchers and PhD students on my empirical data, my analysis and my interpretations. These discussions have not only helped me to assess and strengthen my interpretations and findings, improving my argumentation and confirming my thoughts, but they have also helped me to think differently, see things from alternative perspectives and reflect on my positionality in the field. To provide an example; during discussions with peers and senior colleagues, I discussed the impact of my personal experiences with suffering and how I utilised these experiences during my interaction with the participants. Through productive discussions and continuous encouragement, I was motivated to reflect further on this matter and to write up the section ‘The wounded researcher’ in this chapter.

4. Ethics

In this section, I provide details on how the project was conducted in compliance with the current ethical guidelines and legal procedures. However, my aim is also to discuss the ethical dilemmas that extend beyond the formalities of handling and keeping personal data safe. I will reflect on the ethical challenges I encountered throughout the project and account for how I decided to address them. I draw on the distinction between ‘procedural ethics’ and ‘ethics in practice’ provided by Guillemin and Gillam (2004), which has guided my ethical reflections.

Procedural ethics

The project was approved by the University of Southern Denmark and registered under the university’s personal data register, notification number 11.471. During the initial phases of obtaining data approval, I consulted the university’s legal team to ensure that I followed the right procedures. All data were stored on the university’s approved system for handling sensitive data. The project protocol was assessed by the administration in The Regional Committees on Health Research Ethics for Southern Denmark. Since the project did not include research on the individual subject, such as a collection of tissue or blood samples, it was not necessary to obtain a separate ethical approval. The query to the committee was stored under notification number 20202000-211. The university has its own ethical committee, but due to the limited time between my enrolment and the beginning of the first narrative course, I was unable to pursue approval through that process. However, throughout the project, I have followed the principles of the Helsinki Declaration (WMA, 2022), which I will elaborate on in the following section.

I have generated data from two different settings: the REHPA research clinic and a municipal rehabilitation centre, which have different legal procedures that must be followed. At the research clinic, research is a privileged part of everyday activities and the presence of researchers in the clinic is common. Besides the professional staff that often have research experience or research activities in the clinic, all participants must, as already mentioned, agree to participate in research to be enrolled on the courses at REHPA (Rasmussen et al., 2020). Although acceptance to participate in research is an inclusion criterion for the participants for REHPA in general, I visited the research clinic as an external researcher and the participants could decline to participate in this study. This meant that I needed to explicitly obtain approval for their involvement. All participants, in both settings were provided with oral and written information and provided written consent (see Appendix VII and VIII for forms) before I initiated the data generation process. In consultation with my main supervisor and the course professionals, we decided that if a participant declined to take part in my research, I would still proceed with participant observation of the group. However, I would ensure that any observations or discussions specifically involving the declining participants would be excluded from the research. No participants declined and all participants in all or parts of the narrative courses were included in the study. I recognise how attaining informed content from the participants is a dynamic process and not a 'one-time fix'. My ambition was to continuously be mindful regarding informed consent during my fieldwork. For instance, before I followed the participants into group work, I always checked with them to see if it was okay for me to participate. At the same time, I acknowledge that simply asking for consent does not guarantee that participants fully understood what they consented to, a common dilemma frequently discussed in research (Corrigan, 2003; Hoeyer and Hogle, 2014).

Ethics in handling and presenting the data

Ethical procedures also include ensuring the anonymity of participants. To protect their confidentiality, I have assigned pseudonyms where applicable, as in Sub-study I. This present study included a sample of 42 participants. To protect their anonymity, I found it necessary to avoid including highly detailed information about each participant. For example, as already described, I have grouped their ages into 10-year intervals rather than providing exact figures. Additionally, I have changed, omitted or modified relevant details to make identification more difficult. For the same reasons, I have not reported specific information regarding the participants' individual cancer diagnoses and their civil status.

Besides anonymising all the participants, I also quickly learned that I needed to conceal the location of the municipal rehabilitation centre, although originally it was not my plan. This procedure is sometimes referred to as 'masking' (Jerolmack and Murphy, 2019). I found several reasons for masking the setting. First, only six participants enrolled in the municipal narrative course. They all lived in the same municipality as the centre and their diverse characteristics, such as age and diagnosis/prognosis, made them easily recognisable to outsiders. Second, the narrative course was tested only once in the municipal setting, which made it significantly more challenging to anonymise participants in context-specific situations, as I illustrate an example of in Sub-study I. A third important reason for keeping the municipal setting anonymised was that two out of the six participants experienced harm during the course, an issue I thoroughly explored in Sub-study I. Protecting these participants to the best of my ability was a priority, and concealing the setting was a tool for that.

Another ethical dilemma arose when I began writing up my findings. As suggested by Murphy and Dingwall (2001), even when we as researchers do our best to protect our participants' identities and treat their experiences with respect and sensitivity, our written work may be offensive to those included. This can occur not only because of what we choose to highlight as significant or which stories we include but also due to the omission of details from our findings that the participants themselves may have considered important (Murphy and Dingwall, 2001). My findings represent an interpretation of the participants' experiences, and these interpretations may be at odds with how the participants themselves attribute meaning to their stories, as discussed by Murphy and Dingwall (2001). I have been particularly ethically troubled about how the other participants (besides the four participants whose stories of harm were the centre of Sub-study I) would respond to reading how, for instance, their humour and social interactions were linked to creating harmful experiences for others. In my effort to highlight what I believe is often an overlooked finding of 'harmful experiences', could I inadvertently contribute to harming the other participants? Furthermore, it has been a continuous struggle for me to handle the possibility of the participants recognising each other throughout this dissertation and the published articles. This problem is sometimes referred to as one that concerns internal confidentiality (Tolich, 2004). As stressed by Tolich (2004), it constitutes an often overlooked and potentially harmful ethical dilemma. I found it very likely that the participants in this study risked jeopardising their internal confidentiality as they were part of smaller narrative courses, ranging from six to a maximum of 13 participants. To mitigate this risk, I made an effort to anonymise the participants as much as possible, including strategies such as switching participants from course to course and altering details like their sex. Reflecting on these ethical dilemmas is my way of showcasing that, although I strove to protect the participants' anonymity, ethnographic research inherently carries the risk of exposing participants to harm. While I have approached the study with good intentions and followed ethical procedures, it is important to recognise that no research of this nature is entirely without risk.

Ethics in practice

Procedural ethics may only account for a limited aspect of how research with human participants involves ethical thinking and actions. Notification numbers and applications to research ethics committees do not offer much help when the researcher is put on the spot or needs to take ethical action during research (Guillemin and Gillam, 2004).

While doing fieldwork, it is common for the researcher to encounter situations where something stands out as ethically questionable (Anspach and Mizrachi, 2006), and so it truly was for me. Many of these ethical dilemmas intertwined with my methodological considerations regarding my positioning in the field. Some of the required 'on the spot' ethical decisions have been discussed elsewhere, for example how I refrained from writing very sensitive information down in my notebook and shifted my position in the field. In most of these situations, I found it relatively easy to identify when ethical decisions were needed – I simply listened to and trusted my research gut and intuition. I found the ethical dilemmas and actions related to participants' experiences of harm much more complicated.

How to handle harm

In Sub-study I, I unfolded my findings about the four participants' harmful experiences. Sub-study I represents the most elaborate, ethically challenging episodes; however, episodes of harm occurred in all the narrative courses. I have dedicated this sub-section to reflect further on this aspect.

Protecting the research participants from harm is a fundamental ethical concern in all research (Murphy and Dingwall, 2001). Still, the process of continuously studying the participants while harm occurred became a substantial ethical issue for me. It raised many dilemmas, such as the fairness of the continuation of the study. On the other hand, I found that the participants' experiences of harm, for the most part, had already occurred when I came to recognise them as harmful. Therefore, I needed to weigh the arguments for refraining from the study and continuing the research against each other. In collaboration with my supervisors, I put together a plan for how to address my empirical findings of harm: If I gained critical information on participants' experiences of harm in situations where the professionals were not present (and could take immediate responsibility), such as during individual interviews, it was necessary to seek participants' consent to share this information with the professionals to address my concern on the matter. In this way, I tried to reach an acceptable ethical position, distancing myself from being a passive bystander to the infliction of harm. Most importantly, though, it developed into a moral necessity for me to acknowledge and value the participants' harmful experiences. I therefore dedicated Sub-study I solely to addressing this issue.

However, harmful experiences or adverse consequences occurred in other situations than those illustrated in Sub-study I. As also described in the Methodology Chapter, I experienced how I became a trusted partner during the fieldwork for some of the participants. For these participants, I was the one (among the non-participants) they approached with their worries and concerns, wanting me to be a mediator between them and the professionals. Although my position (as not responsible for the narrative courses) in the project was jeopardised when the participants approached me with their worries, I felt obliged to intervene and play the mediator part when I assessed that the participants' concerns were critical for their general well-being or their willingness to continue at the course. I will provide two examples: one from course II, the other from course III.

One day before lunch I was approached by a participant who pulled me aside because she wished to speak to me in confidence. She explained how she was a little shocked; she had experienced how one of the other participants retold or joked with some of her very private stories, which she had shared during group work. She told me how she felt that her private affairs were being exposed in the course plenum and that she felt violated because of this. I asked her how she wished me to handle this, and she requested me to bring the issue back to the professionals in an anonymous manner. I did so after lunch, and the professionals handled this by initiating the next narrative exercise session with a general reminder that the participants needed to respect each other's confidentiality. In another course, two outside professionals from two municipal rehabilitation centres participated in the course to learn about the narrative course method. One evening before dinner, a participant pulled me aside and described how she experienced the external professionals' presence as dominating, how she felt vulnerable and exposed when they observed her in group interactions and how this kept her from engaging emotionally and contributing to the group's discussions. In her words, to make matters worse, one of these professionals came from the same municipality as the participant and had been involved in her rehabilitation process. The participant asked me how she should handle this, and I replied that I could only help with talking about the issue with the professionals, which she thought was a good idea. She even suggested writing down her experiences. I shared her story with the research clinic professionals the next morning, but this time, it stirred up some tension. It felt as though I had overstepped their professional boundaries and my concern over the participant's experiences seemed to be dismissed. For unknown reasons, the participant later chose not to return for the follow-up stay.

Both examples have led me to reflect upon why the participants approached me and not the professionals directly and whether I intervened too much (or too little?) in my ambition to be ethical in my research practices. The same participant from the first example explained in an individual interview how she felt a sense of 'distance' from the professionals:

> "Well, it was just that I didn't want to approach them, if I had something to say, then I approached you [meaning I, HSG], I didn't feel like going to them [the professionals]. Because they were not part of us, like you are" (interview #12).

As a result of the steps I took to address these potentially harmful experiences for the participants, I deliberately made the decision to alter the research setting. Naturally, ethnographers always impact the setting as they often form relationships with the participants and take part in their community (Dennis, 2009). However, in these cases, I felt morally inclined to actively intervene in ways that impacted the course (although in smaller ways). Mostly, I felt at risk of damaging my relationship with the participants if I had not intervened, and altering the setting became a consequence I regarded as the more acceptable choice.

Navigating ethical field relationships

Ethnographic fieldwork often involves an extended period of time and shared space, during which the researcher and the research participants share experiences and form relationships. Chances are that both parties are changed: the researcher and the researched (Dennis, 2009; Hammersley and Atkinson, 2019). The influence of the researchers' relationships on data generation, final theorising and the presentation of findings (Blee, 2019), raises not only methodological concerns for me but also ethical considerations. For me, practising ethics in my field relations was often tricky and felt ambiguous as the time and the stories I and the participants shared sometimes eradicated the boundaries between researcher and friend. This is a well-known ethical dilemma in qualitative research (Dickson-Swift et al., 2008), which will be further discussed below.

This study was conducted among a group of participants undergoing a sensitive period of their lives. No matter their specific prognosis, their experiences and stories were often about thoughts of dying and suffering in both body and mind. Although their stories resonated deeply with me, I also learned that some of the participants enjoyed that I was neither a healthcare professional nor a family member or friend whom they also needed to protect. I was a willing listener to their stories about cancer and anything else for that matter. Some participants voiced how much they appreciated that I did not shy away from their stories of suffering and illness, and I sensed how it made them feel connected to me on a more personal level. But it was a two-way street: I also felt emotionally connected to some of the participants, and mentally I struggled to let go.

Fieldwork has for me been a continuous motion between engaging and retracting myself, avoiding developing too deep relationships with the participants, yet also not thinking of my research in transactional terms. I did not *want* something from the participants, I hoped we both *gained* something from the encounters. Obviously, as highlighted by Råheim et al. (2016), as a researcher, I acknowledge how the power relation is skewed between me and the participants. Still, it is common for ethnographers to try to minimise the distance between the researcher and the informant to gain access to the field, making reflexive practices paramount to ensuring ethics in research (Råheim et al., 2016).

5. Findings

In this chapter, I wish to present the overall findings of this study as they are presented in the three sub-studies. The sub-studies are written as scientific papers and included in this dissertation as appendices. Furthermore, I wish to present the overall contribution of this dissertation to research by making inferences across the three sub-studies.

Sub-study I: Experiences of harm

This first sub-study was based on data from all narrative courses (I-IV), counting both settings and participant groups, with 42 participants, including 215 hours of fieldwork, 15 interviews and six focus-group interviews. The focus of Sub-study I was to explore some participants' harmful experiences. The analysis was based on the principles of abductive analysis and drew on the theoretical contribution to illness narratives offered by Frank (2013), concerning the narrative typology of restitution, quest and chaos.

This sub-study presents the perspectives of the four participants who made their harmful experiences apparent during/after the courses and who chose to withdraw before the course was finished. The findings demonstrate that some participants had limited room to share their stories of suffering, while other more positive stories were encouraged – through a complex interplay between the participants, the professionals and the focus of the narrative exercises. This dynamic resulted in harmful experiences for those whose stories of anxiety, sorrow and suffering were suppressed.

Overall, I found that the participants' experiences of harm illustrate how a rehabilitation approach, encouraging certain stories, ended up dominating over a palliative care approach where relief from suffering is central. While the participants' stories could be understood as chaotic, this sub-study contributes to the field of narrative research with valuable knowledge on the value of equally acknowledging all illness narratives. The sub-study further contributes with perspectives on certain areas of attention and concern when rehabilitation and palliative care approaches are combined. Additionally, the study contributes with an example highlighting the importance of carefully considering potential adverse consequences in healthcare interventions. This attention is crucial at every stage: design, implementation and evaluation of health care interventions.

The sub-study is drafted as a paper entitled "'There is nothing beautiful or life-affirming in it': experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer" and is published in Mortality (Gärtner et al., 2024b).

Sub-study II: Setting, community and hope

This sub-study was based on data from the narrative courses I-III, conducted at the research clinic for people with advanced cancer. The sub-study included 185 hours of fieldwork, nine individual interviews and six focus groups. The purpose of this sub-study was to explore if the narrative courses in the research clinic were perceived as significant by the participants and, if so, in what ways. The analysis was inspired by abductive thematic analysis, involving three theoretical perspectives to analyse the participants' experiences of significance. I first drew inspiration from Hansen et al. (2011) when analysing the influence of context. Next, I turned to the theoretical perspective on the significance of belonging to a community offered by Mcmillan and Chavis (1986). Finally, I incorporated the perspective of hope offered by Graven and Brødslev Olsen (2018).

The findings indicate that the courses were generally experienced as significant for the participants but that, notably, the setting, the community and the gaining of hope were the dominant elements. The course context, including the setting, played into how the participants interacted with each other, encouraging them to spend social time together and share their personal stories. The narrative course appeared to represent a significant break from everyday life for them, and the findings further illustrate the significance of community for most participants. Forming this community, especially sharing the same illness prognosis, fostered intimacy and a close interpersonal connection between the participants. The sub-study demonstrates how, for example the community seemed to outweigh the participants' perceptions of the 'life story' theme of the courses, which they often found vague and unclear. Finally, the study indicated that some participants experienced a shift in their outlook on life, characterised by a renewed sense of hope. By comparing their life situation and stories with others and by meeting other cancer patients who had lived extensive lives with an incurable cancer diagnosis, some participants acquired more existential hope.

I discuss the findings of this sub-study in relation to existing research from similar studies that report comparable results. On this basis, I suggest that the narrative course contents may have been overshadowed by factors such as setting and community, illustrating the influence of context on the participants' experiences in residential courses like the narrative courses.

This sub-study is drafted as a paper entitled "The most fantastic thing is coming here as an individual and going to bed as part of a group": participants' experiences from a residential course for people with advanced cancer". The paper is published in Omega – Journal of Death and Dying (Gärtner et al., 2024a).

Sub-study III: Shared experience

Sub-study III is based on data generated at the research clinic during the narrative courses I-III. This included 185 hours of fieldwork, nine individual interviews, six focus groups and three documents entitled 'collective stories about life with advanced cancer', focused on the specific narrative exercise. The sub-study aimed to determine the experiences with the collective story exercise for participants with advanced cancer participating in the narrative courses.

The data analysis contains a narrative analysis of the 'collective stories' document, along with more abductive approaches to the fieldnotes, the individual interviews and the focus group interviews, to explore how the participants experienced the constructing phase of the exercise and how they engaged with the document afterwards. In terms of theory, I incorporated perspectives offered by Gubrium and Holstein (2009) to analyse the social situatedness of storytelling and the perspectives of Kleinman and Kleinman (1991) on the understanding of experience in relation to the specific setting of the course, understood in terms of 'local moral world'. Additionally, I was inspired by Steffen (1997) and her perspective on the significance of storytelling in groups and shared experiences.

This sub-study demonstrates how the 'collective stories' revolved around the theme of suffering and loss in living with advanced cancer. The ability to share their illness stories and experiences in the exercise allowed the participants to integrate their individual experiences into a shared experience and story. The narrative exercise therefore legitimatised the participants' experiences of suffering and loss, providing them with feelings of healing and relief. The study further demonstrates how the reading of the collective story was an essential part of the exercise, illustrating the performative and embodied nature of telling and listening. Furthermore, this sub-study illustrates how the collective stories were primarily valuable in the specific setting of the courses, making them challenging for some participants to share with outsiders. The findings likewise illustrate how the construction of the collective stories was impacted by the broader social and cultural context, impacting how expressing and experiencing living with advanced cancer is possible.

This paper is entitled “Sharing stories: Experiences of sharing personal stories and creating a collective story about living with advanced cancer”. The paper is submitted to Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine (Gärtner et al. forthcoming).

Overall contribution

The overall aim in this dissertation was to explore the participants’ experiences during and after participating in a narrative course for people who have or have had cancer.

This dissertation contributes new knowledge on an applied narrative method for people who have or have had cancer in Denmark. It demonstrates the complexity of applying a narrative method like the narrative courses in group set-ups. It underscores how working with narrative may lead to both positive and negative (harmful) experiences. Furthermore, this study stresses how the participants’ experiences were impacted by other parameters than the narrative exercises. Based on the three sub-studies, I argue that contextual parameters, such as the setting, the role of the professionals, and the group setup, were essential factors that influenced and shaped the participants’ experiences. The finding of ‘influence of context’ is a key contribution of this dissertation that may contribute to and nuance the current understanding of the influence of context in healthcare research and interventions.

Furthermore, the findings show that the participants’ experiences must be understood within the broader social and cultural context, particularly in relation to the narrative focus of the courses. Likewise, the dissertation contributes with perspectives on how ‘cancer’ is profoundly embedded in public discourse and stresses how specific attention to this in research is needed as it influences the way living with cancer is experienced and narrated. The findings therefore demonstrate the complexity of factors that shaped the participants’ experiences in the narrative courses.

Moreover, the narrative courses were designed to coordinate rehabilitation and palliative care approaches. This dissertation contributes to existing research, with new perspectives on relevant areas of attention and concern when coordinating rehabilitation and palliative care by applying narrative methods. Especially, the findings contribute to new perspectives on how a rehabilitation approach may dominate in combined courses, suppressing the palliative care principle of offering relief from suffering. Findings from Sub-study III indicate that the participants experienced relief from suffering during this specific narrative exercise, highlighting how the dominance of the rehabilitation and palliative care approaches varied across the narrative exercises and course programme. Yet, as illustrated in Sub-study

III, the relief from suffering was specific to the context (the setting and community of the courses), underscoring once more the influence of context on the participants' experiences.

Methodologically, contributing with ethnographic perspectives focused on the participants' experiences at four narrative courses, this study highlights the need for ethnographic fieldwork, including participant observations to explore the participants' experiences as they unfold in interaction in specific contexts. Likewise, this study contributes with new perspectives on the dilemmas of harmful experiences, navigating 'ethics in practice' and the influence of the researcher in establishing field relationships.

6. Discussion

The overall aim in this dissertation was to explore the participants' experiences during and after participating in a narrative course for people who have or have had cancer. Having conducted three sub-studies, I explored these experiences from different angles, demonstrating diverse perspectives on the participants' experiences at the courses. As presented, one of the main findings that transcends the three sub-studies is that the participants' experiences were very much influenced by context, including the course settings. The importance of this finding is further underscored by the fact that most participants found forming a community with people with the same illness prognosis to be highly meaningful. This sense of connection was closely linked to the specific context of the courses and the composition of the participant group. Furthermore, as previously described, I was unable to conclude that the narrative exercises (overall) were a significant element of the courses. An exception to this was the 'collective stories' exercise, which is discussed in detail in Sub-study III. However, findings from this study underscore the influence of context on the significance of the exercise. Another key finding is that although most of the participants had positive experiences with the courses, some experienced harm during and after the narrative courses. This finding highlights the complexity of courses involving narrative and shows that narratives and storytelling may lead to both positive and harmful experiences – in this study, in relation to coordinated rehabilitation and palliative care. Lastly, this study's contribution is largely guided by the ethnographic fieldwork which has been shown to be essential for exploring the participants' experiences in interaction.

To discuss these key findings and contributions, I have chosen to structure the discussion into three main themes: narrative as an applied method, the influence of context, and methodological strengths and limitations. The first theme 'narrative as an applied method in rehabilitation and palliative care' concerns the narrative courses, including the narrative exercises in relation to the approaches of rehabilitation and palliative care, the potentials and limitations of the applied narrative method, including the influence of the applied narrative method in groups of peers. Next, I discuss important elements in relation to context, comprising a discussion regarding the settings, the participants' life circumstances and the peer/social support element of the courses. Furthermore, I will discuss the methodological strengths and limitations of this study. Finally, I will reflect on how the overall contribution and findings presented in this dissertation could have implications for research and practice.

Narrative as an applied method

I have not been able to conclude that the narrative exercises in themselves were experienced as significant by the participants. It raises the possible question as to what happened, since the narrative exercises did not work as assumed? To discuss this, I turn to three sub-themes. First, I address the participants' ambiguity and a general misalignment with the expectations and purposes of the courses and exercises. Second, I explore the potential of storytelling among peers for people with cancer, with specific attention to the benefits and possible harms of narrative. Lastly, I discuss how the narrative courses coordinated rehabilitation and palliative care, and what this dissertation contributes to this area of research.

Ambiguity and misalignment in expectations

In health interventions in general, the participants' motivation for participation varies and their expectations and goals may not be aligned with the intention of the intervention and the chosen outcomes (Bruhn, 2001; Broholm-Jørgensen, 2022). A key finding, discussed in Sub-study II, was that the participants generally found the narrative exercises related to the 'life story' theme of the courses to be confusing and ambiguous. Many voiced their confusion as to what a 'life story' was, what the purpose of the specific exercises was and how things were connected. Furthermore, some of the participants voiced how they had expected an opportunity to create a written life story to pass on to their families or simply to receive more tangible tools to handle their life situation. Some requested more elaboration of the theoretical assumptions behind the exercises, while others expressed a need for more physical exercises and breaks from working with the exercises. Generally, the participants' expectations and the intent of the courses were often not aligned. Additionally, while some of the narrative exercises worked well for some of the participants, the same exercise could be distressing for others. These findings correspond well with the research clinic professionals' experiences, as described in the REHPA report no.27 (Rasmussen et al., 2023).

I have intentionally avoided labelling the narrative courses an 'intervention' to align this study with ethnographic research practice rather than an evaluative framework. However, the participants' ambiguous experiences with the narrative course may stem from its design, specifically the absence of an elaborate programme theory. As described by Pope et al. (2019), 'weak programme theory' contrasts with 'strong programme theory' by lacking a solid theoretical base that may provide plausible explanations to how the programme (or course) links to the effect. The narrative courses *were* designed on the basis of extensive narrative theory, along with practical professional experiences; however, the findings indicate how the link between the overall theoretical assumption and the specific narrative exercises was inconsistent. The problem with a weak programme theory is not just that it complicates the assessment of whether a programme 'works' as it was originally intended (Pope et al., 2019), but also that the programme mechanisms may fail to work or work in adverse ways. If I were to regard the narrative courses as an 'intervention', they should have been considered a 'complex intervention' (Skivington et al., 2021) since they took place in a complex environment with multiple paths of change. A key issue with the theoretical assumptions behind the narrative course could be that they did not fully cover these complex paths of change. I do not intend to go deeply into this area of evaluative research; rather, my aim is to underscore that the lack of significance of the narrative exercises could be explained by this lack of programme theory.

Although I could not conclude that the narrative exercises were overall experienced as significant, the narrative courses as a whole were regarded as meaningful and significant, as detailed in Sub-study II. While ambiguity and misalignment in expectations were at play regarding the contents of the courses, other significant elements of the courses seemed to outweigh these challenges.

Storytelling among peers – benefits and harms

As I have previously discussed, narrative and applied narrative methods are often found to be meaningful for people living with life-threatening illnesses (Roikjær et al., 2021; Chochinov et al., 2005; Cepeda et al., 2008; Houmann et al., 2014; la Cour et al., 2016). Especially sharing experiences in groups of peers has often been perceived as important (la Cour et al., 2015; Hansen et al., 2011; Steffen, 1997). An essential part of the narrative courses was that they provided the participants with an opportunity to share their stories and experiences with peers with similar illness prognoses. As presented in Sub-study II, the setting in and around the narrative courses at the research clinic especially encouraged participants to engage in storytelling and share their stories and illness experiences. Coupled with the general focus on storytelling during the formal sessions and narrative exercises in the courses, sharing became a significant element of the participants' experiences.

Although the narrative courses were not designed as a social/peer support programme alone, participation in the courses were equal to group interactions with peers. An anticipated benefit for the participants was that the group setup could create positive community feelings (Raunkiaer, 2022; Gärtner et al., 2021; Rasmussen et al., 2023). This expectation was confirmed especially in Sub-studies II and III, highlighting how sharing their illness experiences in a group of peers was perceived as meaningful and beneficial to most participants. Thus, this study is consistent with former research underlining the positive effects of social support and peer support among cancer patients (Adamsen, 2002; Docherty, 2004; Davison et al., 2000; Applebaum et al., 2014; Ussher et al., 2006; Jablotschkin et al., 2022; Aizpurua-

Perez et al., 2024; Høybye et al., 2005). Another finding related to how the social interactions among the participants fostered feelings of hope, for instance, particularly through social comparison. As discussed in Sub-study II, the sharing of experiences and storytelling within peer groups provided participants with an opportunity to compare their situations and experiences. For some, this process contributed to gaining a new perspective on their lives. As highlighted by scholars, social comparison is a common strategy, not reserved for cancer patients, that may have both positive and negative outcomes (Arigo et al., 2014; Nierop-van Baalen et al., 2016; Bennenbroek et al., 2002; Rottmann et al., 2012). This present study suggests that the narrative courses overall functioned well as arenas for both sharing and social comparison. However, consideration of their potentially negative effects should also be considered. Overall, this study contributes to perspectives on how storytelling among peers was generally experienced as meaningful. This finding aligns with a large amount of research on the benefits of storytelling and shared experiences among people with the same illness prognosis (Lewis et al., 2024; Harkin et al., 2017; Høybye et al., 2005; Knox and Svendsen, 2015; la Cour et al., 2016). In line with Raunkiaer (2022) this present study demonstrates how sharing experiences at the research clinic fostered community feelings that contributed to making the participants' experiences at the courses meaningful.

This present study demonstrates how group processes and member-group fit influenced the benefits of social support in the narrative courses. Coreil et al. (2004) found that the 'matching' of participants in support groups is essential to positive experiences, indicating a need for attention to how support groups are composed. Others have explored how social support may inflict harmful experiences as group dynamics, loss of group members and witnessing suffering may impose harm and distress (Walsh et al., 2024; Jablotschkin et al., 2022).

One of the most unexpected findings of this project was that, for some participants, the narrative courses, due to their contextual complexity – caused experiences of harm. As presented in Sub-study I, one identified cause of harm was the dominance of a rehabilitative logic in the courses. The primary focus in most of the narrative exercises, reinforced by the professionals, was on identifying resources and personal strengths. This emphasis left little room for the participants to share stories of distress and suffering. Frank (1998) warns that professionally used narrative techniques or interventions risk biomedical reductivism and dehumanisation of patients' illness experiences. Frank (1998) writes:

> "My strong assumption is that people tell the stories they need to tell in order to work through the situation they are in. As long as a story continues to be told, the work of that situation continues to need doing. This assumption hardly obviates the desirability of

> change. It does suggest that for the deeply ill, change cannot be hurried by external intervention; if anything, the processes that nurture change may become confused and set back” (Frank, 1998: 206-207).

What Frank (1998) points to is that patients’ stories, such as those of suffering, should simply be listened to. The professionals should not seek to fix them, for example through interventions, but just honour them. The objective of the narrative courses and the logic of the narrative exercises were overall guided by this approach of ‘fixing’ the participants’ stories in order to help the participants maintain or improve their quality of life. Yet, following Frank’s logic, by not listening to these stories, the suffering of being deeply ill is not honoured (Frank, 1998) and as argued in Sub-study I, storytelling may lead to harmful experiences.

Scholars have highlighted the importance of ‘the narrative turn’ in social sciences and humanities, which has been confirmed in an abundance of research into the narratives of people living with illness (Frank, 2013; Hydén, 1997; Bury, 2001). Yet, insisting on pursuing ‘the story’, by imposing a narrative framework over people’s illness experiences, may suppress some experiences, perhaps mostly those of suffering (Charmaz, 2002). Recently, scholars such as Donnelly (2021) and Nielsen (2019) contested the dominance and overall favour of narratives structured around ‘restitution’. The restitution narratives are unavailable to people living with chronic illnesses and disabilities, and their stories may be left untold. As highlighted in a recent study by Lewis et al. (2024), specific challenges come from living with incurable cancer that differs from normative expectations of ‘cancer survivors’ or other patient groups with better prognoses. In their study, the authors report that the patients often needed to conceal or silence their experiences to maintain social bonds. Broom et al. (2019) illustrated how people living with or surviving beyond cancer may experience a normative pressure to thrive no matter the odds of surviving or their sufferings, limiting their possibility for expressing their experiences. Challenging this proposed “narrative hegemony of the positive” (Segal, 2012: 307), this dissertation demonstrates findings that support the claims of scholars advocating for a more cautious and reflective approach regarding which narratives are favoured and which are silenced, both in research and healthcare practices (Donnelly, 2021; Woods, 2011; Woods, 2014; Wasson, 2018). Like the above-mentioned researchers, this dissertation contributes perspectives on valuing all illness narratives, including those which lack a plot, the uncomfortable ones and those that scare us.

Narrative in coordinated rehabilitation and palliative care

The narrative courses were designed to coordinate/combine rehabilitation and palliative care. As previously mentioned, I considered all participants to be ‘deeply ill’ (Frank, 1998) with needs that would benefit from a combination of rehabilitative and palliative care approaches. However, this study also demonstrates how the applied narrative method did not easily work to coordinate these two approaches. As highlighted in Sub-study I, the logic of rehabilitation seemed to suppress the palliative care approach of offering relief from suffering. In Sub-study III, I demonstrated how the exercise of constructing a collective story about life with advanced cancer could provide relief from suffering. Important though is how this particular exercise was unique compared with the other exercises by revolving around the participants’ illness and symptom burden, making it stand apart from the other exercises. This study points to some areas of concern when combining rehabilitation and palliative care, as was done in the narrative courses. It raises important questions about the potential costs of attempting to coordinate these approaches through narrative methods.

This dissertation’s findings support the concerns of other scholars, like Timm et al. (2021a) who discuss the possible consequences of combining the approaches. For instance, they discuss how it may lead to harm for the patients if one approach comes to undermine the other. As demonstrated by an international scoping review by Gärtner et al. (2023), few studies have elaborately reported on interventions that combine the two approaches. The authors conclude that in the evaluation of combined interventions, the individual, integral goals of rehabilitation and palliative care are not evenly assessed, and a focus on social and spiritual dimensions is often lacking. Applied narrative methods are not novel within rehabilitation and palliative care (Roikjær et al., 2021). However, I have not discovered studies reporting on a similar approach as the narrative courses that also aim to coordinate rehabilitation and palliative care. This study’s findings on this matter should therefore be interpreted with caution. It is important to bear in mind that this study primarily contributes to understanding the complexity of factors that shaped participants’ experiences during courses like the narrative ones. These factors include, but are not limited to, the influence of combining rehabilitation and palliative care.

The influence of context

Context has been a major dimension of exploring the participants' experiences throughout this study. The findings have demonstrated how context became important in several ways. In this section, I will organise the discussion of context by focusing on some of the key elements that were particularly significant.

The research settings

The narrative courses were conducted in two different research settings: the research clinic and a municipal rehabilitation centre. I have described how much the two settings differed; most importantly, in terms of how the courses were organised: one as a residential stay and the other as a day course.

A notable feature of the research clinic is the unique way its physical space is designed to feel homely. As highlighted in Sub-study II, participating in the research clinic represented a break from the participants' everyday lives, making the clinic's setting a significant factor in shaping their experiences. As mentioned earlier, the research clinic shares a history with the former RcDallund, and many physical features of the clinic and RcDallund are comparable. Based on extensive fieldwork at RcDallund and analysed through an analytical lens of rituals, Tjørnhøj-Thomsen and Hansen (2013) illustrated how significant the rehabilitation site was for the participant's experiences. With food, extensive professional attention, storytelling and community explained as transformative activities connected to the rehabilitation setting (Tjørnhøj-Thomsen and Hansen, 2013), the present study's findings confirm and extend our knowledge on the influence of context. Just as Hansen et al. (2011) illustrated in their study, all these contextual elements of residential rehabilitation influenced the participant's experiences, accounting for much of the intervention's effect.

As discussed in Sub-study II, contextual parameters, particularly the setting in the research clinic, may have had a greater impact on the participants' experiences than the specific course contents itself. Key elements of the research clinic setting were not available to the participants at the municipal rehabilitation centre, such as free food and extensive time to socialise with the other participants (and foster community). This raises the question as to which degree the settings of the research clinic and municipal rehabilitation centre are too different to be meaningfully compared. This study further underscores the uniqueness of the setting in the research clinic and emphasises the importance of considering how the research clinic differentiates from municipal rehabilitation centres, when developing and implementing new courses and programs.

Within implementation research, context is increasingly acknowledged as directly related to the success of interventions (Mielke et al., 2022; Daivadanam et al., 2019). Also, within the Medical Research Council's (MRC) framework for the development and evaluation of complex interventions, contextual factors play a major role in determining how and why interventions work (Skivington et al., 2021). This study's findings stress the importance of attention to context. It therefore supports the growing body of research that emphasises the importance of considering the influence of setting and contextual factors in healthcare interventions (Pettegrew, 2017; Poland et al., 2009; Skivington et al., 2021; Hansen et al., 2011).

Participants' life circumstances and the context of peers

As discussed in Sub-studies I and II, the participants' life circumstances seemed to influence their experiences with the narrative courses. Exploring the characteristics of the participants and how these characteristics influenced their experiences offers potential for further understanding the findings.

First, I find it relevant to this discussion to stress that the narrative course participants were not necessarily representatives of the general cancer population in Denmark. Participants in health care initiatives like the narrative courses are not equally distributed among the population, with inequality in health being one explanation – and it is well established that inequality exists in health in Denmark (Lauridsen et al., 2018; Olsen et al., 2023). Social inequalities regarding cancer are widespread, ranging from inequality in terms of the risk of getting diagnosed with cancer to differences in treatment and chances of survival (Olsen et al., 2023). A Danish population-based study conducted by Oksbjerg Dalton et al. (2019) showed how cancer patients' socioeconomic position differs in terms of referral and attendance to rehabilitation. The authors found that a higher education level translated into higher referral and attendance rates for rehabilitation for both males and females. Moreover, the narrative courses had a female preponderance, with 34 out of 42 participants being female. This skewness mirrors research in a similar context (Høybye et al., 2008; Raunkiaer, 2022; la Cour et al., 2016; Hansen et al., 2011), where female participants also dominated. Gender variation in cancer is a dimension of the general problem of inequality in healthcare in Denmark (Handberg et al., 2014). Scholars have shown how notions of masculinity may influence men's illness perception, possibly causing a lower attendance to rehabilitation among males than among females (Maersk et al., 2022; Michaelsen and Kristiansen, 2017). In the present study, I was not particularly concerned with the participants' sociodemographic characteristics. Yet, when exploring the participants' experiences (and before the findings from this study potentially inform future practice and research), it is important to recognise and disclose that the individuals who attend these courses and contribute to research tend to represent a specific subset of patients. This is a critical consideration as the courses in the present study were predominantly attended by white, middle-class, middle-aged women.

Another important finding is how the participants' experiences were influenced by dimensions of their life circumstances, such as age, social network and relationship status. As discussed in Sub-study I, experiences of harm seemed partly related to the participants' life circumstances. Moreover, Sub-study II also demonstrated how the participants' experiences with the courses as significant were influenced by their life circumstances. A further examination of these findings will guide two sub-discussions, first, on the relevance of the concept 'biographical disruption', and second, on the importance of 'vulnerability'.

The concept of 'biographical disruption' is a well-established theoretical perspective, widely recognised as suitable for studying the illness experiences of people living with disablement, chronic conditions or life-threatening illnesses (Hubbard and Forbat, 2012; Morgan et al., 2020; Larsson and Grassman, 2012). Although the concept is often perceived as a suitable framework for analysing illness experiences, several scholars have also indicated the need for refining the concept (Williams, 2000; Reeve et al., 2010). A key argument is that the concept of 'biographical disruption' indicates that illness disrupts elements of life understood as 'normal' (Reeve et al., 2010). However, for some individuals, illness may be anticipated rather than unforeseen and may not necessarily cause the disruption of life that the concept of 'biographical disruption' is intended to describe (Larsson and Grassman, 2012). Aside from individuals living in such great hardships that illness is just one of many challenging life events (Atkinson and Rubinelli, 2012), scholars have explored the relevance of the concept 'disruption' in older age, where illness is often more expected. A central argument is that age may mediate the disruptiveness of illness (Pound et al., 1998; Engman, 2019). As discussed in Sub-study I, age also seemed to play a role in the narrative courses, especially in influencing the participants' ability to adopt a cheerful and thankful attitude towards living with the consequences of cancer. As the participants ranged in age from the early 30s to the late 80s, their life situations differed: from being in the middle of establishing a career and family life, such as having smaller kids in the preschool years to participants who had already lived long lives, now having grandchildren and/or great-grandchildren. In recent years, there has been a growing attention to how younger cancer patients' needs differ from those of older patients (Aagesen et al., 2022; Andersen et al., 2022). Scholars who critically appraise the concept of 'biographical disruption' stress the need for researchers to pay greater attention to context, timing and circumstances around illness (Larsson and Grassman, 2012; Williams, 2000; Cluley et al., 2023). This dissertation's findings contribute with new perspectives on why such nuances are warranted as the participants' experiences with the narrative courses in general (and narrative exercises in particular) varied based on their life circumstances, such as age.

Another perspective on the influence of the participants' life circumstances on their experiences, could be illuminated through the concept of 'vulnerability'. As I have described in the methodology chapter, and demonstrated in sub-studies I-II, the participants' lives were naturally more complex than their illness and prognosis. In general, there were great differences in the participants' life circumstances. Specific participants seemed to struggle financially, socially and mentally, whereas others felt 'lucky' due to their favourable life circumstances, despite their unfavourable prognosis (Gärtner et al., 2024a). These differences in life circumstances are likely representative of many group interactions in general. However, for this study, it is particularly relevant to note how some participants' experiences were influenced by their vulnerability during the narrative courses.

The term 'vulnerability' is both a highly contested and complex concept (Traianou and Hammersley, 2024). It often concerns marginalised and disadvantaged groups in society, encompassing attention to ethnic and sexual minorities, yet it also captures people living with chronic and terminal illnesses (Liamputtong, 2007). The traditional understanding of the term views it as a characteristic of a specific group of people, such as people suffering from mental illnesses (Victor et al., 2022; Faissner et al., 2023; Gordon, 2020). Yet, taking a situational and relational approach to vulnerability allows researchers to assess how vulnerability is produced in social structures and interactions (Faissner et al., 2023). One way to understand the dynamic nature of vulnerability is to envision it as consisting of metaphorical 'layers' that may be triggered, for instance by social context or age (Victor et al., 2022; Faissner et al., 2023). I regard this approach to vulnerability as reflective of this study's findings. In Sub-study I, the participants' experiences of harm appeared to result from specific layers of vulnerability being triggered within the specific context of the courses. Furthermore, this study contributes ethnographic perspectives to recent epidemiological research, highlighting how (social) vulnerability is a dynamic concept, which also changes during the cancer trajectory (Møller et al., 2023b). Overall, I consider this study to contribute to a line of research that addresses 'vulnerability' in a contextual and dynamic way. This has implications for how group courses should be organised and underscores, yet again, the need for understanding the complexity of what influences participants' experiences.

Methodological strengths and limitations

So far, I have provided details on how this study contributes to international literature. In the following section, I discuss the methodological strengths and limitations of this study.

In line with Hansen et al. (2011), I believe that the findings presented in this dissertation demonstrate how well-suited ethnographic methods, including fieldwork, were for exploring the participant's experiences in the narrative courses. Ethnographic methods are suited for exploring the complexity of 'the social situatedness' of experience, including attentiveness to context (Kleinman and Kleinman, 1991). By building strongly on the participants' experiences, this dissertation aligns with research in which the participants' (or patients') views and stories of illness and health initiatives are favoured over surveys and statistics. Within healthcare, it is now considered essential to explore these experiences to provide evidence for necessary improvements and/or changes in healthcare services, shaping not just policy but also driving changes in practices (Oluoch et al., 2023). Adopting an open and explorative approach to participants' experiences, which I have done in this study, is not revolutionary. Yet, it may challenge a healthcare paradigm in which measurements, such as Patient Reported Outcome Measures (PROM) or Patient Reported Experience Measures (PREM) are widely recognised as the dominant forms of evidence (Male et al., 2017). As presented in Sub-study I in particular, the extensive fieldwork and attention to the participants' experiences in context fostered findings in this study that did not transcend into evaluative measures at the courses. This finding underscores the strength of conducting ethnographic fieldwork. Both quantitative and qualitative research have formerly been conducted at RcDallund, mainly under the more extensive research programme FOCARE (Rix et al., 2011). Of especially interest to this methodological discussion is that the quantitative randomised trials done at RcDallund were unable to show any significant effects on the participants' quality of life, well-being and health behaviour (Rottmann et al., 2012; Ross et al., 2015). This further supports the need for explorative, ethnographic research focusing on patients' experiences rather than on quantitative measures.

The chosen research design, which consists of four different yet complementary methods, is a strength of this present study. While the participant observations allowed me to observe the participants as they engaged with each other throughout the courses, individual – and focus group interviews made it possible to explore in greater depth the participants' experiences with the courses and exercises. For Sub-study III, document analysis, in combination with the other research methods, allowed me to examine the significance of this particular narrative exercise from multiple angles, highlighting not just the contents of the documents but also the construction process, the reading and how the participants used and engaged with the document afterwards.

Throughout this dissertation, I have thought of myself as an ‘abductive researcher’ or even, sometimes, like an ambassador for abductive reasoning. As previously described, my reliance on an analytical style that may seem confusing and ‘closed off’ was sometimes challenged during my academic experiences. I have often struggled with structuring the creative process and dynamics of abductive analysis and this has led me to engage in discussions in the field about how to make abductive interferences more transparent and how to legitimise the resulting interpretations (Thompson, 2022). Discussions of my methods and abductive reasoning with scholarly peers, supervisors and senior professors throughout this study period have significantly contributed to enhancing analytical transparency, refining the presented findings and engaging with relevant theories. These exchanges have also been instrumental in my development and maturation as a researcher.

A key strength of the abductive approach, in my view, is that although I aspired to be curious, open and explorative in my fieldwork, I also acknowledge and embrace the fact that as a sociologist, I have a “head full of theories” (van Hulst and Visser, 2024: 3). I also acknowledge that what the researcher finds ‘surprising’ in the field also relies strongly on this predisposition towards theory and the researcher’s previous experiences (Blee, 2019; van Hulst and Visser, 2024). My pre-dissertation experiences with the target group of participants with advanced cancer and the importance of ‘community’, as reported in Gärtner et al. (2021), were naturally part of the abductive process in this dissertation. Although this may present itself as a major limitation, it is actually part of the process:

> “Abduction intervenes in the tension between knowing what you are interested in by chasing usual subjects and remaining open to new unexpected findings for which a usual-suspects explanation is inadequate” (Timmermans and Tavory, 2022: 3)

For example, when I encountered the participants who experienced the courses as harmful, I instantly thought of the ‘surprise’ as a case of exclusion from a community as the participants were not conforming to the group’s shared norms and behaviour. However, such a ‘usual-suspects’ explanation did not suffice to explain the complexity of the empirical findings, and by abstracting the findings in light of narrative theory, I found better, more plausible explanations for the cases of harm.

What *is* a limitation in this choice of style for me was that, as underscored by Timmermans and Tavory (2022), abductive reasoning requires the researcher to have "in-depth familiarity with a broad range of theories" (Timmermans and Tavory, 2022: 3). Although I felt attuned to thinking theoretically about, for instance, the importance of community, I was not very familiar with the 'broad range' of narrative theory. Although theorising is always a work in progress (van Hulst and Visser, 2024; Timmermans and Tavory, 2022), I felt underprepared when I understood the need to immerse myself in such a complex theoretical landscape. Yet, surprises in the fieldwork forced me to spend countless hours of pedalling between reading previous scholars' papers and looking closely at the data material, and this process naturally shaped my use of theory. Following the logic of Timmermans and Tavory (2022), throughout this present study, I have tried to engage theory that could both open up the field (for me) and help my inferences "travel" (32) beyond the locality of narrative courses and the people involved. For this latter purpose, I found a great strength in narrative theory, for instance as proposed by Frank (2013). It helped contextualise the participants' experiences (and narratives) in both the local and broader social and cultural contexts. Adopting a critical perspective on both theory and practice of how narratives are produced, this study contributes to the literature on the potentials and limitations of narrative. Theoretical frameworks on the influence of community and shared experience (Mcmillan and Chavis, 1986; Steffen, 1997) and the influence of context (Hansen et al., 2011; Duranti and Goodwin, 1992; Gubrium and Holstein, 2009) have been essential for the potential transference of this study's findings to other context of practice and research. Therefore, in this study, I adhere to the notion of analytical generalisation, as outlined by Halkier (2011), by applying theory and theoretical concepts to the findings. This approach allows the study to contribute to the international literature.

Additional limitations arise from the methodology discussed. For instance, several participants did not complete the narrative courses (10 out of 42 participants). Follow-up interviews with the participants who did not complete the courses, as performed by Ussher et al. (2008), could have contributed to a broader understanding of the participants' experiences, such as those of harm. I cannot rule out that more participants than the four participants who verbally expressed their experiences of harm, as reported in Sub-study I, actually did experience some elements of harm during the courses. Additionally, interviews with all participants could have shed new light on their experiences and contributed to a more equal distribution of the participants' voices in this study. Furthermore, a longitudinal approach could possibly have contributed to a deeper understanding of the participants' experiences and the significance of the courses beyond the immediate time during and after the courses. This study could likely have benefitted from the development of a ‘dark logic’ model, as presented by Bonell et al. (2015) in conjunction with a more evaluative approach. Such a model might have provided a more comprehensive framework for exploring and explaining the experiences of harm.

‘The wounded researcher’ re-visited

Reflexivity has played a significant role in this study, relating closely to ensuring the study’s reliability and validity. To end this methodological discussion, I wish to re-visit the section in Chapter 3 entitled ‘The wounded researcher’ and reflect further on the consequences of my positioning in the field and the findings of this study. My aim in this section is to contribute to the growing body of recent research focused on the concept of ‘the vulnerable researcher’ (Traianou and Hammersley, 2024; Liamputtong, 2007; Warden, 2013) and the role of the researcher in ethnographic research.

As highlighted by Liamputtong (2007), researcher self-disclosure is vital in qualitative research as it establishes trust and heightens the participants’ level of commitment and willingness to exchange experiences. As discussed earlier, I experienced how sharing my personal experiences with loss helped foster more open and honest expressions of the participants’ experiences in the narrative courses. My personal ‘wounds’ became a methodological advantage, so to speak. Yet, my perspective on this matter goes a bit further than simply acknowledging the advantage of ‘disclosure’ or embracing the fact that I was, indeed, a ‘vulnerable researcher’. As I discussed in Chapter 4, field relationships represented both a methodological and ethical challenge to me. However, in my position as neither a participant nor a professional in the courses, I also experienced that I became a resource for some of the participants. Some participants used my listening ears in ways that seemed unique to the conversations they had in other ways during the courses. It is reasonable to consider that the engagement of a listening researcher like me, in courses like the narrative could become an important part of the overall experience for some participants. It again demonstrates the importance of transparency in ethnographic research, taking the situatedness of the researcher into account (Riessman, 2015). On the other hand, researchers risk harm while researching the vulnerable (Traianou and Hammersley, 2024) and I have aimed to illustrate this dilemma also. Like Warden (2013), who paid a great personal price conducting her ethnographic PhD study among vulnerable participants in a dangerous environment, I too have learned that there is a “vulnerability that accompanies empathy” (Warden, 2013: 152) that needs to be acknowledged within academia.

Implications for practice and research

Exploring the participants' experiences, like those unveiled in this study, is of course not enough. The knowledge generated should be applied as a base for modifications and improvements in healthcare services (Coulter et al., 2014; Oluoch et al., 2023). Based on the findings in this dissertation, I will now propose several key implications for practice, such as for healthcare professionals working in rehabilitation and/or with palliative care for people with cancer, as well as for further research.

Implications for practice

The findings of this study highlight the importance of appropriate visitation when enrolling participants in courses similar to the narrative courses. As this study has demonstrated, the participants' life circumstances, such as being younger or having small kids, influenced their course experiences and, for some, led to negative experiences. Others benefited from feeling that they belonged to a community and/or through social comparison to others who were facing greater challenges. This illustrates the complexity of how group courses function and the diverse range of implications they can have. Furthermore, this suggests that vulnerability can be triggered by social context. These findings imply that practitioners should be mindful of this complexity when recruiting participants for group courses to ensure that the participants have the mental and physical resources to participate and benefit equally. This could include the development of strategies for managing group dynamics and handling participants who experience harm/distress. Likewise, professionals should be mindful of potential negative experiences in participant groups, including the potential and limitations of narratives.

Furthermore, in this dissertation, I explored and illustrated how an applied narrative method, such as the narrative courses, harboured both a potential for positive experiences and adverse consequences for the participants. In particular, dominant master narratives, such as that of rehabilitation, were shown to potentially limit the extent to which people with cancer were able to experience their illness and express these experiences. The study contributes with knowledge on why caution is needed when adapting a narrative approach. It should be acknowledged that such an approach harbours a risk that some illness narratives become legitimate and may dominate at the expense of those who suffer. It is therefore of relevance to professionals who aim to work with narrative methods to be cautious not to adopt an uncritical approach to working with narrative and to value all illness narratives equally. This could include attention towards how the course contents are communicated and critical attention towards how the professionals themselves could reproduce dominant metaphors or master narratives of illness.

Overall, this study has demonstrated the influence of context on the participants' experiences. Many of this study's findings, such as the significance of the setting and the importance of social interactions with peers, align with previous research from similar settings, such as in the REHPA research clinic and former RcDallund. Professionals who design and implement interventions, such as those in municipal cancer rehabilitation centres, should integrate this knowledge into their programs, acknowledging that the course context, such as fostering a sense of community, could be just as important as the programme contents itself.

Furthermore, this study's findings regarding the influence of context raise important questions about the purpose of 'testing' a course like the narrative course in the research clinic with the intention of implementing it (if found meaningful) in a municipality rehabilitation programme. The importance of context warrants further consideration before transferring a course 'design' tested in the research clinic to a municipality rehabilitation centre.

Implications for research

The narrative courses were structured around narrative exercises. However, this study has not been able to demonstrate the significance of the narrative exercises in general. The contextual dimensions of the courses, such as community and the influence of the setting, were found to be more significant than the course contents *per se.* However, the narrative exercises could harbour potential that would be interesting to investigate more thoroughly. Future research should take a comprehensive research approach when studying applied narrative methods, considering the influence of contextual parameters, such as group dynamics, the setting and the broader social and cultural context.

A next step in research could be to combine ethnographic field studies with a more systematic assessment of the relationship between course contents and course context, identifying the effectiveness of applied narrative methods across different contexts, practices and cultures. This might very well include a more elaborate intervention and evaluation design, possibly informed by the MRC framework for the development and evaluation of complex interventions (Skivington et al., 2021). Furthermore, this study's findings point to how attention to 'dark logic' mechanisms in designing and implementing healthcare interventions must be prioritised and continuously developed. This study has also emphasised how experiences of harm may go unnoticed without the presence of the ethnographic researcher, who can observe and document these harmful experiences as they unfold. This underscores why also future research should incorporate and acknowledge the uniqueness of knowledge generated during ethnographic fieldwork. A longitudinal ethnographic design could further inform a more profound understanding of how the courses impacted the participants after returning to their everyday lives, along with investigating how the participants' experiences change over time.

This study underscored the importance of exploring the influence of social interactions among participants in group courses. While there is much research concerning the benefits and positive experiences with social support through peer interaction, it is important to investigate further the dark side of social/peer support. Future research could critically analyse member-group fit and the participants' life circumstances before and after enrolment in interventions to contribute with more comprehensive knowledge on this matter. Building on the findings of this study, further qualitative research is needed into why some participants decline to complete rehabilitation courses to uncover the causes and complexity behind this more fully.

Given the importance of context, this study raises the question of whether it is feasible to 'test' interventions/courses at a research clinic if the end goal is to inspire courses offered in a municipality cancer rehabilitation centre. Further studies could specifically investigate the differences and similarities between these two settings, to establish a stronger foundation for the design and implementation of future interventions.

This study highlights how the coordination of rehabilitation and palliative care through an applied narrative method was not a straightforward undertaking. Future research should consider the logic and goals of both approaches when designing and evaluating interventions in which the two approaches are combined. Further research is needed to uncover how normative assumptions about living with cancer, along with discourses from both rehabilitation and palliative care, shape participants' experiences and the practice of healthcare professionals in combined interventions.

7. Conclusion

In this study I set out to overall explore the participants' experiences during and after participating in a narrative course for people who have or have had cancer.

Primarily, this dissertation demonstrates the complexity of the participants' experiences with the narrative courses. It highlights how influential factors beyond the narrative exercises themselves were, yielding both positive and negative course experiences. The dissertation shows how contextual parameters, like the setting and the social interactions in the groups, were perceived as significance for the participants. Furthermore, it underscores the need to interpret these experiences in both the local and broader social and cultural contexts. The dissertation sheds light on how some narratives in the courses were encouraged and legitimatised, while others were supressed. It underscores the need for specific attention towards how an illness like cancer is narrated about, and how this affects individual illness experiences and the expression of such experiences. In addition, this study has identified some areas of concern and a need for further attention when coordinating rehabilitation and palliative care through an applied narrative method. Methodologically, this ethnographic field study contributes to the knowledge of experience's social situatedness, emphasising the need for exploring these experiences as they unfold in specific interactions and contexts. The study further contributes with perspectives on the role of the researcher, strengthening the knowledge of the significance and use of researcher reflexivity.

In conclusion, this dissertation contributes to the current body of knowledge of applied narrative methods in cancer rehabilitation and palliative care. The study provides a tangible example of how narrative methods could be applied in group courses for people living with cancer while emphasising the complexity of the contextual factors influencing participants' experiences. The dissertation demonstrates the need for careful and critical consideration of contextual parameters and the potentials and limitations of narrative when developing, implementing and exploring the significance of courses like the narrative.

Summary

This dissertation is an ethnographic field study, based on the experiences of 42 participants who had or have had cancer and who participated in one of four narrative courses, combining rehabilitation and palliative care approaches in Denmark.

Worldwide, the incidence of cancer increases and in Denmark, cancer is the leading cause of death. People who have cancer often suffer from a variety of complex symptoms, extending beyond the body to also include psychological, social and existential issues. Cancer may cause a ‘biographical disruption’, causing patients to lose their sense of who they are and their sense of coherence in life. The question of how to best relieve the suffering of people with cancer is a central focus for both researchers and healthcare professionals and is the motivator for this dissertation. Research into the potential of narrative for people with life-threatening illnesses has shown promising results as narratives may help those who are ill to regain or recreate a sense of meaning and coherence in life. Furthermore, research has shown that patients benefit from combined rehabilitation and palliative care approaches.

In 2021, Danish professionals designed a narrative course based on narrative exercises with a focus on selected life story elements and storytelling in groups for people with cancer. Three narrative courses were conducted as residential stays in the REHPA research clinic for people with advanced cancer, and one course was conducted in a municipal rehabilitation centre for people who were cancer free or whose prognosis for becoming cancer free was favourable. This dissertation has aimed to explore the participants’ experiences, specifically how contextual parameters influenced these experiences. This aim has been explored through three sub-studies written as scientific papers.

In Sub-study I, I explored how and in what ways the participants in the narrative courses reported experiences of harm. This sub-study’s findings demonstrated that some participants experienced limited opportunities to share stories of suffering while other stories were encouraged. The sub-study demonstrated how this occurred in a complex interplay involving the other participants, the professionals and the narrative exercises. Furthermore, the sub-study illustrated how the harmful experiences were connected to how the rehabilitation approach came to dominate the palliative care approach, where relief of suffering is central.

Sub-study II aimed to explore if the narrative courses in the research clinic were perceived as significant by the participants and, if so, in what ways. This sub-study demonstrated how the narrative courses were generally perceived as significant for the participants. The participants expressed how the community, the setting and the gaining of hope were central. The findings indicated that contextual parameters were more important to the participants than the narrative exercises.

Sub-study III revolves around a specific narrative exercise named ‘the collective story about life with advanced cancer’. This sub-study aimed to determine the experiences with the collective story exercise for participants with advanced cancer participating in the narrative courses. The study illustrated how the exercise legitimised the participants’ experiences of suffering and loss by embedding their individual illness stories into a shared experience. Furthermore, this study illustrated how sharing the collective stories with the outside world could be challenging, which made them particularly valuable in the specific setting where they are created.

Overall, this dissertation contributes knowledge on the significance of applied narrative methods to people with cancer. Based on the findings from the three sub-studies, I show how contextual parameters influenced the participants’ experiences in significant ways, for instance, through the group set-up and the setting. This dissertation demonstrates the significance of interpreting the participants’ experiences and narratives in the local context and the broader social and cultural context in which they are embedded. Furthermore, this dissertation contributes knowledge on specific areas of attention and concern relevant for researchers and healthcare professionals when narrative methods are applied to groups in coordinated rehabilitation and palliative care programs.

Resumé

Denne afhandling er bygget på et etnografisk feltstudie, der er baseret på erfaringer fra 42 deltagere, der havde eller havde haft kræft, og som deltog i ét af fire danske narrative kurser, der kombinerede rehabilitering og palliation.

På verdensplan stiger forekomsten af kræft, og i Danmark er kræft den hyppigste dødsårsag. Mennesker, der har kræft, lider ofte af en kompleksitet af symptomer, der strækker sig ud over fysiske symptomer til også at omfatte psykologiske, sociale og eksistentielle problemer. Kræft kan forårsage en 'biographical disruption', hvor patienten kan miste sin følelse af, hvem han/hun er, samt miste en følelse af sammenhæng i livet. Hvordan man bedst hjælper mennesker med kræft til at leve de bedst mulige liv, er både i fokus for forskere og sundhedspersonale, ligesom det motiverer denne afhandling. Forskning i narrativers potentiale for mennesker med livstruende sygdom har vist lovende resultater, da narrativer kan hjælpe syge til at genvinde eller genskabe en følelse af mening og sammenhæng i livet. Yderligere har forskning vist, at patienter drager fordel af kombinerede rehabiliterings- og palliative tilgange.

I 2021 designede danske professionelle narrative kursuser, baseret på narrative øvelser med fokus på udvalgte livshistorieelementer og fortælling i grupper for mennesker med kræft. Tre narrative kurser blev gennemført som internatophold i REHPA's forskningsklinik for mennesker med fremskreden kræft, og ét forløb blev gennemført på et kommunalt rehabiliteringscenter for mennesker, der var kræftfrie eller med en prognose om at blive kræftfrie. Formålet med denne afhandling har været at udforske deltagernes oplevelser med særlig opmærksomhed på, hvordan kontekstuelle parametre påvirkede disse oplevelser. Dette formål er undersøgt gennem tre delstudier, der er udformet som videnskabelige artikler.

I delstudie I undersøgte jeg, hvordan og på hvilke måder deltagerne i de narrative kurser rapporterede om negative oplevelser, beskrevet som 'harm'. Resultaterne af denne delundersøgelse viste, hvordan nogle af deltagerne oplevede begrænsede muligheder for at dele deres historier om lidelse, mens andre historier generelt blev opmuntret. Delstudiet viste, hvordan dette skete i et komplekst samspil, der involverede både de andre deltagere, de professionelle og de narrative øvelser. Desuden illustrerede delstudiet, hvordan de negative oplevelser bl.a. skyldtes, at en rehabiliteringslogik kom til at dominere over den lindring af lidelse, der er central i palliation.

Formålet med delstudie II var at undersøge, om de narrative forløb i forskningsklinikken blev opfattet som betydningsfulde af deltagerne og i givet fald på hvilke måder. Dette delstudie viste, hvordan de narrative kurser generelt blev opfattet som betydningsfulde for deltagerne. Især gav deltagerne udtryk for, hvordan fællesskabet, omgivelserne og en øget følelse af håb var centralt. Resultaterne viste, at kontekstuelle parametre var vigtigere for deltagerne end de narrative øvelser.

Delstudie III omhandler en specifik narrativ øvelse kaldet 'den kollektive fortælling om livet med fremskreden kræft'. Formålet med denne delundersøgelse var at undersøge deltagernes erfaring med øvelsen. I dette del-studie har jeg belyst, hvordan øvelsen fungerede til at legitimere deltagernes oplevelser af lidelse og tab ved at indlejre deres individuelle sygdomsfortællinger i en fælles fortælling og 'shared experience'. Yderligere viste dette delstudie, hvordan det kunne være udfordrende at dele de kollektive fortællinger med omverdenen, hvilket gjorde dem særligt værdifulde i den specifikke sammenhæng.

Overordnet bidrager denne afhandling med viden om den anvendte narrative metodes betydning for mennesker med kræft. Med udgangspunkt i resultaterne fra de tre delstudier argumenterer jeg for, hvordan kontekstuelle parametre påvirkede deltagernes oplevelser på væsentlige måder, for eksempel gennem gruppeinteraktioner og den særlige kontekst i forskningsklinikken. Dermed understreger fundene i denne afhandling betydningen af at fortolke deltagernes oplevelser og fortællinger i både den lokale såvel som den bredere sociale og kulturelle kontekst, som de er indlejret i. Desuden bidrager denne afhandling med viden om specifikke opmærksomheds- og bekymringspunkter, der er relevante for både forskere og sundhedsprofessionelle, når narrative metoder anvendes i gruppeforløb, der kombinerer rehabilitering og palliation.

References

- Adamsen L (2002) From victim to agent': the clinical and social significance of self-help group participation for people with life-threatening diseases. *Scandinavian Journal of Caring Sciences* 16(3): 224-231.
- Adamsen L, Rasmussen JM and Pedersen LS (2001) 'Brothers in arms': how men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. *Journal of Clinical Nursing* 10(4): 528-537.
- Ahlzen R (2019) Narrativity and medicine: Some critical reflections. *Philosophy, ethics, and humanities in medicine : PEHM* 14(1): 9-9.
- Aizpurua-Perez I, Arregi A, Gonzalez D, et al. (2024) A randomized controlled trial of the effectiveness of a one-to-one peer support intervention on resilience, social support, and salivary cortisol in recently diagnosed women with breast cancer. *European Journal of Oncology Nursing* 71: 102616.
- Alvesson M, Hardy C and Harley B (2008) Reflecting on reflexivity: Reflexive textual practices in organization and management theory. Journal of management studies, 05/2008 45(3):480-501
- Andersen NH, Christiansen JA, Cour K, et al. (2022) Differences in functioning between young adults with cancer and older age groups: A cross-sectional study. *European Journal of Cancer Care* 31(6): e13660-n/a.
- Andersen S (2007) Smid ikke metoderne ud med badevandet. Epistemologisk konstruktivisme og dens metodiske konsekvenser. *Dansk Sociologi* 16.
- Anspach RR and Mizrachi N (2006) The field worker's fields: ethics, ethnography and medical sociology. *Sociology of Health and Illness* 28(6): 713-731.
- Applebaum AJ, Stein EM, Lord-Bessen J, et al. (2014) Optimism, social support, and mental health outcomes in patients with advanced cancer. *Psycho-oncology (Chichester, England)* 23(3): 299-306.
- Arigo D, Suls JM and Smyth JM (2014) Social comparisons and chronic illness: research synthesis and clinical implications. *Health Psychology Review* 8(2): 154-214.
- Atkinson S and Rubinelli S (2012) Narrative in cancer research and policy: voice, knowledge and context. *Critical Reviews in Oncology/Hematology* 84(2): S11-S16.
- Ballestero A and Winthereik BR (2021) Introduction. Analysis as Experimental Practice. *Experimenting with Ethnography*. United States: Duke University Press.

- Bamberg MGW (2007) *Narrative, state of the art.* Amsterdam;Philadelphia: J. Benjamins Pub. Co.
- Bamberg MGW and Andrews M (2004) *Considering counter narratives: narrating, resisting, making sense.* Amsterdam;Philadelphia;: J. Benjamins Pub. Co.
- Bell K (2012) Remaking the Self: Trauma, Teachable Moments, and the Biopolitics of Cancer Survivorship. *Culture, Medicine, and Psychiatry* 36(4): 584-600.
- Bell K and Ristovski-Slijepcevic S (2013) Cancer survivorship: Why labels matter. *Journal of Clinical Oncology* 31(4): 409-411.
- Bennenbroek FTC, Buunk BP, van der Zee KI, et al. (2002) Social comparison and patient information: what do cancer patients want? *Patient Education and Counseling* 47(1): 5-12.
- Berendonk C, Blix BH, Hoben M, et al. (2020) A Narrative Care approach for persons living with dementia in institutional care settings. *International Journal of Older People Nursing* 15(1): e12278-n/a.
- Berg-Sørensen A (2013) Hermeneutik og fænomenologi. In: Jacobsen MH, Lippert-Rasmussen K and Nedergaard P (eds) *Videnskabsteori i statskundskab, sociologi og forvaltning*. Hans Reitzels Forlag, pp.215-244.
- Bergquist Røberg A-S, Ploug Hansen H, Feiring M, et al. (2017) Rehabilitation in momentum of Norwegian coordination reform: From practices of discipline to disciplinary practices. *Alter* 11(3): 193-207.
- Bernard HR (2018) *Research methods in anthropology: qualitative and quantitative approaches.* Lanham, Maryland: Rowman & Littlefield.
- Blee K (2019) How Field Relationships Shape Theorizing. *Sociological Methods & Research* 48(4): 739-762.
- Blix B and Sorly R (2017) *Fortelling og forskning: Narrativ teori og metode i tverrfaglig perspektiv.* Orkana akademisk.
- Blix BH, Berendonk C and Caine V (2019) Theoretical foundations of narrative care: Turning towards relational ethics. *Nursing Ethics* 26(7-8): 1917-1927.
- Bo IG (2016) Den narrative tilgang - erkendelsesmåder og identitetsforståelser. In: Bo IG, Christensen A-D and Thomsen TL (eds) *Narrativ forskning. Tilgange og metoder*. København: Hans Reitzels Forlag.
- Bo IG, Christensen A-D and Lund Thomsen T (2016) *Narrativ forskning: tilgange og metoder.* København: Hans Reitzels Forlag.

- Bonell C, Jamal F, Melendez-Torres GJ, et al. (2015) ‘Dark logic’: theorising the harmful consequences of public health interventions. *Journal of epidemiology and community health (1979)* 69(1): 95-98.
- Bowen GA (2009) Document Analysis as a Qualitative Research Method. *Qualitative research journal* 9(2): 27-40.
- Braun V and Clarke V (2022) *Thematic analysis: a practical guide.* Los Angeles: SAGE.
- Broholm-Jørgensen M (2022) The practice of hope in public health interventions: a qualitative single-case study. *Health Promotion International* 37(5).
- Broom A, Kenny K, Kirby E, et al. (2019) The collective/affective practice of cancer survivorship. *The British journal of sociology* 70(4): 1582-1601.
- Brown C and Augusta-Scott T (2007) *Narrative therapy: making meaning, making lives.* Thousand Oaks: Sage Publications Ltd.
- Bruhn JG (2001) Ethical Issues in Intervention Outcomes. *Family and Community Health* 23(4): 24-35.
- Bruner J (2004) Life as Narrative. *Social research* 71(3): 691-710.
- Burr V (2019) Social Constructionism. In: Liamputtong P (ed) *Handbook of Research Methods in Health Social Sciences*. Singapore: Springer Singapore, pp.117-132.
- Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4(2): 167-182.
- Bury M (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* 23(3): 263-285.
- Bäckman CG and Walther SM (2001) Use of a personal diary written on the ICU during critical illness. *Intensive Care Medicine* 27(2): 426-429.
- Cepeda M, Chapman C, Miranda NRN, et al. (2008) Emotional Disclosure Through Patient Narrative May Improve Pain and Well-Being: Results of a Randomized Controlled Trial in Patients with Cancer Pain. *Journal of Pain and Symptom Management* 35(6): 623-631.
- Charmaz K (2002) Stories and Silences: Disclosures and Self in Chronic Illness. *Qualitative inquiry* 8(3): 302-328.
- Charon R (2008) *Narrative medicine: honoring the stories of illness.* New York: Oxford University Press.
- Charon R, DasGupta S, Hermann N, et al. (2017) *The principles and practice of narrative medicine.* New York, NY: Oxford University Press.
- Chochinov HM, Hack T, Hassard T, et al. (2005) Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology* 23(24): 5520-5525.

- Cluley V, Burton JO, Quann N, et al. (2023) Biographical dialectics: The ongoing and creative problem solving required to negotiate the biographical disruption of chronic illness. *Social science & medicine (1982)* 325: 115900-115900.
- Coreil J, Wilke J and Pintado I (2004) Cultural Models of Illness and Recovery in Breast Cancer Support Groups. *Qualitative Health Research* 14(7): 905-923.
- Coret M and Martimianakis MAT (2023) Conceptualizations of "good death" and their relationship to technology: A scoping review and discourse analysis. *Health Sci Rep* 6(7): e1374.
- Corrigan O (2003) Empty ethics: the problem with informed consent. *Sociology of Health and Illness* 25(7): 768-792.
- Coulter A, Locock L, Ziebland S, et al. (2014) Collecting data on patient experience is not enough: they must be used to improve care. *BMJ* 348
- Czarniawska B (2006) *Narratives in social science research.* London: Sage.
- Daivadanam M, Ingram M, Annerstedt KS, et al. (2019) The role of context in implementation research for non-communicable diseases: Answering the 'how-to' dilemma. *PloS One* 14(4): e0214454-e0214454.
- Danesi G, Bourquin C, Stiefel F, et al. (2020) The isolation of cancer survivors. *European Journal of Cancer Care* 29(2): e13194-n/a.
- Davison KP, Pennebaker JW and Dickerson SS (2000) Who Talks?: The Social Psychology of Illness Support Groups. *The American psychologist* 55(2): 205-217.
- De Fina A (2015) Narrative and Identities. *The Handbook of Narrative Analysis*. pp.349-368.
- Deegan MJ (2007) The Chicago School of Ethnography. In: Atkinson P, Coffey A, Delamont S, et al. (eds) *Handbook of ethnography*. SAGE Publications Ltd, pp, pp.11-25.
- DeKruyf L (2007) AN INTRODUCTION TO NARRATIVE THERAPY. In: Jordan K (ed) *The Quick Theory Reference Guide: A Resource for Expert and Novice Mental Health Professionals*. United States: Nova Science Publishers, Incorporated, pp.445-460.
- Dennis B (2009) What does it mean when an ethnographer intervenes? *Ethnography and Education* 4(2): 131-146.
- Dickson-Swift V, James EL and Liamputtong P (2008) *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks.* Cambridge: Cambridge University Press.
- Dieperink KB, Pilegaard MS, Jespersen E, et al. (2021) Rehabiliterende palliation til den livstruede patient og familie. In: Ilkjær I and Kragh CF (eds) *Palliation og rehabiliterende palliation*. Gad, pp.25-45.

- Dietz JH, Jr. (1969) Rehabilitation of the cancer patient. *Medical Clinics of North America* 53(3): 607-624.
- Docherty A (2004) Experience, functions and benefits of a cancer support group. *Patient Education and Counseling* 55(1): 87-93.
- Donnelly C (2021) Claiming chaos narrative, emerging from silence. *Disability & society* ahead-of-print(ahead-of-print): 1-15.
- Drew P (2006) When Documents 'Speak': Documents, Language and Interaction. *Talk and Interaction in Social Research Methods*. n5. 63-80.
- Duranti A and Goodwin C (1992) *Rethinking context: Language as an interactive phenomenon.* Cambridge: Cambridge University Press.
- Egerod I, Christensen D, Schwartz-Nielsen KH, et al. (2011) Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine* 39(8): 1922-1928.
- Emerson RM, Fretz RI and Shaw LL (1995) *Writing ethnographic fieldnotes.* Chicago: University of Chicago Press.
- Emerson RM, Fretz RI and Shaw LL (2007) Participant observation and fieldnotes. In: Atkinson P, Coffey A, Delamont S, et al. (eds) *Handbook of ethnography*. SAGE Publications Ltd, pp.352-368.
- Engman A (2019) Embodiment and the foundation of biographical disruption. *Social science & medicine (1982)* 225: 120-127.
- Faissner M, Werning A, Winkelkötter M, et al. (2023) Situational vulnerability within mental healthcare - a qualitative analysis of ethical challenges during the COVID-19 pandemic. *BMC Medical Ethics* 24(1): 31.
- Falk K and Timm H (2018) Arkitektur & Lindring. Reportno.7. Place Published: Nyborg. Institution: REHPA
- Floriani CA and Schramm FR (2012) Routinization and medicalization of palliative care: Losses, gains and challenges. *Palliative and Supportive Care* 10(4): 295-303.
- Frank A (2012) Varieties of Narrative Analysis. Thousand Oaks, California: SAGE Publications, Inc.
- Frank AW (1998) Just Listening: Narrative and Deep Illness. *Families systems & health* 16(3): 197-212.
- Frank AW (2003) Survivorship as Craft and Conviction: Reflections on Research in Progress. *Qualitative Health Research* 13(2): 247-255.
- Frank AW (2013) *The wounded storyteller: body, illness, and ethics.* London;Chicago;: The University of Chicago Press.

- Freeman M (2015) Narrative as a mode of understanding: Method, theory, praxis. *The Handbook of Narrative Analysis*. pp.21-37.
- Frello B (2012) *Kollektiv identitet - kritiske perspektiver.* Frederiksberg: Samfundslitteratur.
- García-Rueda N, Carvajal Valcárcel A, Saracíbar-Razquin M, et al. (2016) The experience of living with advanced-stage cancer: a thematic synthesis of the literature. *European Journal of Cancer Care* 25(4): 551-569.
- Gergen M and Gergen K (2006) Narratives in action. *Narrative Inquiry* 16: 112-121.
- Gibbs GR (2014) The SAGE Handbook of Qualitative Data Analysis. London: SAGE Publications Ltd.
- Gordon BG (2020) Vulnerability in research: Basic ethical concepts and general approach to review. *The Ochsner journal* 20(1): 34-38.
- Graff L, Timm H and Thuesen J (2023) Organizational narratives in rehabilitation-focused dementia care – Negotiating identities, interventions and personhood. *Dementia (London, England)* 22(4): 709-726.
- Graven V and Brødslev Olsen J (2018) *Hvor der er håb: fra teori til sundhedsfaglig praksis.* Frederiksberg: Samfundslitteratur.
- Green J and Thorogood N (2018) *Qualitative methods for health research.* Los Angeles: SAGE.
- Gubrium JF and Holstein JA (2009) *Analyzing narrative reality.* London: SAGE.
- Guillemin M and Gillam L (2004) Ethics, Reflexivity, and "Ethically Important Moments" in Research. *Qualitative inquiry* 10(2): 261-280.
- Gärtner HS, Blix BH, Raunkiær M, et al. (2024a) "The Most Fantastic Thing is Coming Here as an Individual and Going to Bed as Part of a Group": Participants' Experiences From a Residential Course, for People With Advanced Cancer. *OMEGA - Journal of Death and Dying* 0(0): 00302228241264876.
- Gärtner HS, Blix BH, Raunkiær M, et al. (2024b) 'There is nothing beautiful or life-affirming in it': experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer. *Mortality*. DOI: 10.1080/13576275.2024.2360521. 1-17.
- Gärtner HS, Shabnam J, Aagesen M, et al. (2023) Combined rehabilitation and palliative care interventions for patients with life-threatening diseases – PREGOAL. A scoping review of intervention programme goals. *Disability and Rehabilitation* 46(14): 2989–2998
- Gärtner HS, Timm HU and Raunkiær M (2021) Meningsfulde fællesskaber for mennesker med kronisk, fremadskridende kræft (Meaningful communities for people with advanced cancer). *Omsorg* 38(4): 55-59.

- Halkier B (2011) Methodological Practicalities in Analytical Generalization. *Qualitative inquiry* 17(9): 787-797.
- Halkier B (2016) *Fokusgrupper.* Frederiksberg: Samfundslitteratur.
- Hammersley M and Atkinson P (2019) *Ethnography: principles in practice.* London: Routledge.
- Hanahan D (2014) Rethinking the war on cancer. *The Lancet* 383(9916): 558-563.
- Handberg C, Nielsen CV and Lomborg K (2014) Men's reflections on participating in cancer rehabilitation: a systematic review of qualitative studies 2000-2013. *European Journal of Cancer Care* 23(2): 159-172.
- Hansen HP, Laursen SS, Zwisler A-D, et al. (2019) I'm sure that there is something healing in the writing process: Creative Writing Workshops for People with a Cancer Disease. *Tidsskrift for Forskning i Sygdom og Samfund* 16(31).
- Hansen HP, Rasmussen AJ and Zwisler ADO (2018) Skriving som heling?:De første danske erfaringer med skrivning som del af rehabilitering. *Månedsskrift for Almen Praksis*, *96*(5), 359-366
- Hansen HP and Tjørnhøj-Thomsen T (2007) Rehabilitering og Kræft i et kritisk perspektiv. *Klinisk Sygepleje* 21(1): 4-12.
- Hansen HP and Tjørnhøj-Thomsen T (2008) Cancer Rehabilitation in Denmark: The Growth of a New Narrative. *Medical Anthropology Quarterly* 22(4): 360-380.
- Hansen HP, Tjørnhøj-Thomsen T and Johansen C (2011) Rehabilitation interventions for cancer survivors: The influence of context. *Acta Oncologica* 50(2): 259-264.
- Hansen PK (2018) Illness and heroics:On counter-narrative and counter-metaphor in the discourse on cancer. *Frontiers of narrative studies* 4(1): 213-228.
- Haraway D (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist studies* 14(3): 575-599.
- Harkin LJ, Beaver K, Dey P, et al. (2017) Navigating cancer using online communities: a grounded theory of survivor and family experiences. *Journal of Cancer Survivorship* 11(6): 658-669.
- Hart B, Sainsbury P and Short S (1998) Whose dying? A sociological critique of the 'good death'. *Mortality (Abingdon, England)* 3(1): 65-77.
- Hastrup K, Rubow C and Tjørnhøj-Thomsen T (2011) *Kulturanalyse: kort fortalt.* Frederiksberg: Samfundslitteratur.
- Hoeyer K and Hogle LF (2014) Informed Consent: The Politics of Intent and Practice in Medical Research Ethics. *Annual review of anthropology* 43(1): 347-362.
- Holmgren A (2006) Identitet som historier - eksternaliserende, dekonstruerende og flerkonstruerende sprogbrug. In: White M *Narrativ teori*. Hans Reitzels Forlag, pp.9-23.

- Houmann LJ, Chochinov HM, Kristjanson LJ, et al. (2014) A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. *Palliative Medicine* 28(5): 448-458.
- Houmann LJ, Rydahl-Hansen S, Chochinov HM, et al. (2010) Testing the feasibility of the Dignity Therapy interview: Adaptation for the Danish culture. *BMC Palliative Care* 9(1): 21-21.
- Hoybye MT and Tjornhoj-Thomsen T (2014) Encounters in Cancer Treatment: Intersubjective Configurations of a Need for Rehabilitation. *Medical Anthropology Quarterly* 28(3): 305-322.
- Hubbard G and Forbat L (2012) Cancer as biographical disruption: constructions of living with cancer. *Supportive Care in Cancer* 20(9): 2033-2040.
- Hui DMDM, Nooruddin ZMD, Didwaniya NMD, et al. (2014) Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review. *Journal of Pain and Symptom Management* 47(1): 77-89.
- Hulse SB, Balogun Z, Rosenzweig MQ, et al. (2024) I'm still me, I'm still a person: war metaphor use and meaning making in women with metastatic breast cancer. *Supportive Care in Cancer* 32(2): 108.
- Hyden L-C (2008) Narratives in Illness: A Methodological Note. *Qualitative sociology review : QSR* 4(3): 49-58.
- Hyden L-C (2017) *Entangled narratives: collaborative storytelling and the re-imagining of dementia.* New York, NY: Oxford University Press.
- Hyden LC (2010) Identity, self, narrative. In: Hyvärinen M, Hydén L-C, Saarenheimo M, et al. (eds) *Beyond Narrative Coherence*. John Benjamins Publishing Company, pp.33-48.
- Hydén LC (1997) Illness and narrative. *Sociology of Health and Illness* 19(1): 48-69.
- Hydén LC and Brockmeier J (2008) *Health, Illness and Culture: Broken Narratives.* Routledge.
- Hyvärinen M (2012) "Against Narrativity" Reconsidered. In: Rossholm G and Johansson C (eds) *Disputable Core Concepts of Narrative Theory* Peter Lang, pp.327-346.
- Hyvärinen M, Hyden LC, Saarenheimo M, et al. (2010a) *Beyond narrative coherence.* Amsterdam;Philadelphia;: John Benjamins Pub. Co.
- Hyvärinen M, Hyden LC, Saarenheimo M, et al. (2010b) Beyond narrative coherence. An introduction. In: Hyvärinen M, Hyden LC, Saarenheimo M, et al. (eds) *Beyond narrative coherence*. pp.1-15.
- Høybye MT, Dalton SO, Christensen J, et al. (2008) Research in Danish cancer rehabilitation: Social characteristics and late effects of cancer among participants in the FOCARE research project. *Acta Oncologica* 47(1): 47-55.

- Høybye MT, Johansen C and Tjørnhøj-Thomsen T (2005) Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-oncology (Chichester, England)* 14(3): 211-220.
- Jablotschkin M, Binkowski L, Markovits Hoopii R, et al. (2022) Benefits and challenges of cancer peer support groups: A systematic review of qualitative studies. *European Journal of Cancer Care* 31(6): e13700-n/a.
- Jacobsen MH (2010) Dødens sociologi: Udfordringer for sociologi, selv og samfund. In: Andersen PT and Timm H (eds) *Sundhedssociologi - en grundbog*. Hans Reitzels Forlag, pp.251-287.
- Jacobsson K (2016) Analysing documents through fieldwork. In: Silverman D (ed) *Qualitative Research*. 5 ed.: SAGE Publications, pp.167-183.
- Jarlbæk L, Mikkelsen TB, Hansen RS, et al. (2024) Appendiks - Dødssted og dødsårsager blandt voksne i Danmark – i perioden 2012-2020. Place Published: Nyborg. Institution: REHPA
- Jarvinen M (2000) The Biographical Illusion: Constructing Meaning in Qualitative Interviews. *Qualitative inquiry* 6(3): 370-391.
- Jerolmack C and Murphy AK (2019) The Ethical Dilemmas and Social Scientific Trade-offs of Masking in Ethnography. *Sociological Methods & Research* 48(4): 801-827.
- Jess and Timm (2019) Hiv og liv gennem 25 år:Evaluering af et rehabiliteringsophold med fokus på fortællinger mellem mennesker der har levet et langt liv med hiv (Life with HIV the last
- 25 years). Reportno. 18. Published: Nyborg Institution: REHPA
- Jess M, Nielsen SP, Rasmussen A, et al. (2023) Stories of a long life with HIV: A qualitative study of a narrative intervention. *Scandinavian Journal of Caring Sciences* 37(3), 777-787
- Järvinen M and Mik-Meyer N (2005) *Kvalitative metoder i et interaktionistisk perspektiv: interview, observationer og dokumenter.* Kbh: Hans Reitzels forlag.
- Kleinman A (1998) *The illness narratives: suffering, healing, and the human condition.* New York: Basic Books.
- Kleinman A and Kleinman J (1991) Suffering and its professional transformation: toward an ethnography of interpersonal experience. *Culture, Medicine and Psychiatry* 15(3): 275-275.
- Knaul FM, Farmer PE, Krakauer EL, et al. (2018) Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet (British edition)* 391(10128): 1391-1454.
- Knox JB and Svendsen MN (2015) Authoring experience: the significance and performance of storytelling in Socratic dialogue with rehabilitating cancer patients. *Medicine, Health Care, and Philosophy* 18(3): 409-420.

- Krogstrup HK and Kristiansen S (2015) *Deltagende observation (Participant observations).* Kbh: Hans Reitzels Forlag.
- Kaasa S, Loge JH, Aapro M, et al. (2018) Integration of oncology and palliative care: a Lancet Oncology Commission. *The lancet oncology* 19(11): e588-e653.
- la Cour K, Ledderer L and Hansen HP (2015) 'An Arena for Sharing':Exploring the Joint Involvement of Patients and Their Relatives in a Cancer Rehabilitation Intervention Study. *Cancer Nursing* 38(2): 1-9.
- la Cour K, Ledderer L and Hansen HP (2016) Storytelling as part of cancer rehabilitation to support cancer patients and their relatives. *Journal of Psychosocial Oncology* 34(6): 460-476.
- Langellier KM and Peterson EE (2004) *Storytelling in daily life: performing narrative.* Philadelphia, Pa: Temple University Press.
- Larsson AT and Grassman EJ (2012) Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness? *Sociology of Health and Illness* 34(8): 1156-1169.
- Lauridsen SMR, Dal L and Paldam Folker A (2018) Retfærdighed og social ulighed I sundhed i det kommunale sundhedsvæsen. *Klinisk Sygepleje* 32(2): 111-122.
- Lee JL and Jeong Y (2023) The Effect of Dignity Therapy on Terminally-Ill Adult Patients: A Systematic Review and Meta-Analysis. *Iranian Journal of Public Health* 52(1): 10-22.
- Levy JM (2005) Narrative and Experience: Telling Stories of Illness. *Nexus* 18(1): 8-33.
- Lewandowska A, Rudzki G, Lewandowski T, et al. (2020) The problems and needs of patients diagnosed with cancer and their caregivers. *International Journal of Environmental Research and Public Health* 18(1): 1-19.
- Lewis S, Newton G, Kenny K, et al. (2024) The incurable self: Negotiating social bonds and dis/connection with metastatic breast cancer. *Sociology of Health and Illness* 46(2): 295-314.
- Liamputtong P (2007) Researching the Vulnerable. London: SAGE Publications, Ltd.
- MacDonald C, Theurer JA and Doyle PC (2021) “Cured” but not “healed”: The application of principles of palliative care to cancer survivorship. *Social science & medicine (1982)* 275: 113802-113802.
- Maersk JL, Rosted E and Lindahl-Jacobsen L (2022) ‘When I can ride my bike, I think, am I at all as sick as they say?’ An exploration of how men with advanced lung cancer form illness perceptions in everyday life. *European Journal of Cancer Care* 31(6): e13751-n/a.

- Male L, Noble A, Atkinson J, et al. (2017) Measuring patient experience: a systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision. *International Journal for Quality in Health Care* 29(3): 314-326.
- Mallon S and Elliott I (2019) The Emotional Risks of Turning Stories into Data: An Exploration of the Experiences of Qualitative Researchers Working on Sensitive Topics. *Societies (Basel, Switzerland)* 9(3): 62.
- Malterud K (2001) Qualitative research: standards, challenges, and guidelines. *The Lancet (British edition)* 358(9280): 483-488.
- Maribo T, Ibsen C, Thuesen J, et al. (2022) *Hvidbog om rehabilitering.* Rehabiliteringsforum Danmark.
- Martínez M, Arantzamendi M, Belar A, et al. (2017) 'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review. London, England: SAGE Publications, 492-509.
- Marzorati C, Riva S and Pravettoni G (2017) Who Is a Cancer Survivor? A Systematic Review of Published Definitions. *Journal of Cancer Education* 32(2): 228-237.
- Mason J (2018) *Qualitative researching.* Sage Publications Ltd.
- Mattingly C (2012) *Healing dramas and clinical plots: the narrative structure of experience.* Cambridge University Press.
- Mattingly C and Garro LC (2000) *Narrative and the cultural construction of illness and healing.* Berkeley, Calif: University of California Press.
- Mcmillan DW and Chavis D (1986) Sense of Community: A Definition and Theory. *Journal of Community Psychology* 14(1): 6-23.
- McMullin C (2023) Transcription and Qualitative Methods: Implications for Third Sector Research. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations* 34(1): 140-153.
- McNamara B (2004) Good enough death: autonomy and choice in Australian palliative care. *Social Science and Medicine* 58(5): 929-938.
- Meyer T, Kiekens C, Selb M, et al. (2020) Toward a new definition of rehabilitation for research purposes: A comparative analysis of current definitions. *European Journal of Physical and Rehabilitation Medicine* 56(5): 672-681.
- Michaelsen JJ and Kristiansen M (2017) Maskulinitet og sygdom: Mænds håndtering af kræft og deres erfaringer i mødet med sundhedsvæsenet, et kvalitativt studie. *Nordisk sygeplejeforskning* 7(3): 182-194.

- Mielke J, Brunkert T, Zúñiga F, et al. (2022) Methodological approaches to study context in intervention implementation studies: an evidence gap map. *BMC Medical Research Methodology* 22(1): 320.
- Mik-Meyer N (2020) Multimethod qualitative research. In: Silverman D (ed) *Qualitative Research*. London: Sage, pp.357-374.
- Mollica MA, Smith AW, Tonorezos E, et al. (2022) Survivorship for Individuals Living With Advanced and Metastatic Cancers: National Cancer Institute Meeting Report. *Journal of the National Cancer Institute* 114(4): 489-495.
- Morgan DJ and Burholt V (2020) Loneliness as a Biographical Disruption—Theoretical Implications for Understanding Changes in Loneliness. *The journals of gerontology. Series B, Psychological sciences and social sciences* 75(9): 2029-2039.
- Murphy E and Dingwall R (2001) Handbook of Ethnography. SAGE Publications Ltd.
- Møller JJK, La Cour K, Pilegaard MS, et al. (2023a) The use and timing of rehabilitation and palliative care to cancer patients, and the influence of social vulnerability - A population-based study. *BMJ supportive & palliative care*. DOI: 10.1136/spcare-2023-004487. spcare-2023-004487.
- Møller JJK, la Cour K, Pilegaard MS, et al. (2023b) Social vulnerability among cancer patients and changes in vulnerability during their trajectories – A longitudinal population-based study. *Cancer Epidemiology* 85: 102401-102401.
- Neo HY, Yap CW, Teo LM, et al. (2021) Palliative Rehabilitation Improves Health Care Utilization and Function in Frail Older Adults with Chronic Lung Diseases. *Journal of the American Medical Directors Association* 18: 18.
- Neubauer BE, Witkop CT and Varpio L (2019) How phenomenology can help us learn from the experiences of others. *Perspect Med Educ* 8(2): 90-97.
- Nielsen E (2019) *Disrupting breast cancer narratives: stories of rage and repair.* London;Toronto;Buffalo;: University of Toronto Press.
- Nierop-van Baalen C, Grypdonck M, van Hecke A, et al. (2016) Hope dies last . A qualitative study into the meaning of hope for people with cancer in the palliative phase. *European Journal of Cancer Care* 25(4): 570-579.
- Nordentoft S, Dieperink KB, Johansson SD, et al. (2022) Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers. *Scandinavian Journal of Caring Sciences* 36(3): 815-829.

- Nottelmann L, Jensen LH, Vejlgaard TB, et al. (2019) A new model of early, integrated palliative care: palliative rehabilitation for newly diagnosed patients with non-resectable cancer. *Supportive Care in Cancer* 27(9): 3291-3300.
- Oksbjerg Dalton S, Halgren Olsen M, Moustsen IR, et al. (2019) Socioeconomic position, referral and attendance to rehabilitation after a cancer diagnosis: A population-based study in Copenhagen, Denmark 2010-2015. *Acta Oncologica* 58(5): 730-736.
- Olsen MH, Kjær TK and Dalton SO (2023) Social Inequality in Cancer in Denmark - White Paper 2.edition. Kræftens Bekæmpelse
- Oluoch D, Molyneux S, Boga M, et al. (2023) Not just surveys and indicators: narratives capture what really matters for health system strengthening. *The Lancet global health* 11(9): e1459-e1463.
- Paulsen MK (2020) Appearance of Experience as Form and Process. *Integrative Psychological & Behavioral Science* 54(4): 861-879.
- Pawson R and Tilley N (1997) *Realistic evaluation.* Thousand Oaks, Calif: Sage.
- Peterson EE and Langellier KM (2007) The performance turn in narrative studies. In: Bamberg M (ed) *Narrative – State of the Art*. The Netherlands: John Benjamins Publishing Company.
- Pettegrew LS (2017) An ethnography of humor, ritual and defiance in a cancer care setting. *Journal of organizational ethnography* 6(3): 159-176.
- Plage S (2020) Cancer survivorship reimagined: A qualitative study on evolving interpretative repertoires of cancer and survivorship using participant-produced photography. *European Journal of Cancer Care* 29(6): e13320-n/a.
- Plage S and Kirby E (2022) Reconfiguring time: optimisation and authenticity in accounts of people surviving with advanced cancer. *Health sociology review* 31(1): 96-111.
- Plummer K (2007) The Call of Life Stories in Ethnographic Research. In: Atkinson P, Coffey A, Delamont S, et al. (eds) *Handbook of ethnography*. SAGE Publications Ltd, pp.395-406.
- Plummer K (2020) “Whose Side Are We On?” Revisited: Narrative Power, Narrative Inequality, and a Politics of Narrative Humanity. *Symbolic interaction* 43(1): 46-71.
- Poland B, Krupa E and McCall D (2009) Settings for Health Promotion: An Analytic Framework to Guide Intervention Design and Implementation. *Health promotion practice* 10: 505-516.
- Pope AM, Finney SJ and Bare AK (2019) The Essential Role of Program Theory: Fostering Theory-Driven Practice and High-Quality Outcomes Assessment in Student Affairs. *Research & practice in assessment* 14(1): 5.
- Pound P, Gompertz P and Ebrahim S (1998) Illness in the Context of Older Age: The Case of Stroke. *Sociology of Health and Illness* 20(4): 489-506.

- Prior L (2003) *Using documents in social research.* London: Sage Publications.
- Proulx K and Jacelon C (2004) Dying with dignity: The good patient versus the good death. *American Journal of Hospice & Palliative Medicine* 21(2): 116-120.
- Radbruch L, De Lima L, Knaul F, et al. (2020) Redefining Palliative Care—A New Consensus-Based Definition. *Journal of Pain and Symptom Management* 60(4): 754-764.
- Rasmussen A, Søsted D and Rottmann N (2023) Livsfortællinger, mening og sammenhæng i liv med uhelbredelig kræftsygdom - Kliniske erfaringer fra en metodisk afprøvning i REHPA Forskningsklinik. Reportno.27. Place Published: Nyborg. Institution: REHPA
- Rasmussen AJ and Sodemann M (2020) Narrativ medicin som nyt, interdisciplinært felt. *Ugeskrift for Laeger* 182: 1-5.
- Rasmussen Ar, Jespersen Er, Backmann Tr, et al. (2020) Praksisbeskrivelser – Forskningsklinik REHPA. Standard rehabiliteringsforløb for mennesker med eller efter kræft. (Practice descriptions research clinic REHPA – standard rehabilitation programme for people with or after cancer). Place Published: Nyborg. Institution: REHPA
- Raunkiaer M (2022) The Experiences of People With Advanced Cancer and Professionals Participating in a Program With Focus on Rehabilitation and Palliative Care. *Omega: Journal of Death and Dying* 88(4):1383-1402
- Raunkiaer M and Gärtner HS (2020) Rehabilitering og palliation til mennesker med kronisk fremadskridende kræft – erfaringer fra to REHPA-forløb 2019-2020 (Rehabilitation and Palliative care to people with advanced cancer - experiences from two REHPA courses 2019-2020). Reportno. 19 Place Published: Nyborg. Institution: REHPA
- Reeve J, Lloyd-Williams M, Payne S, et al. (2010) Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health* 14(2): 178-195.
- Riessman CK (1993) *Narrative analysis.* London: Sage.
- Riessman CK (2015) Entering the Hall of Mirrors. In: De Fina A and Georgakopoulou A (eds) *The Handbook of Narrative Analysis*. Hoboken, NJ: John Wiley & Sons, Inc, pp.219-238.
- Rix B, Bøjlerehauge L, Juul S, et al. (2011) *10 års forskning og udvikling på RehabiliteringsCenter Dallund.* Kræftens Bekæmpelse.
- Roikjær SG, Gärtner HS and Timm H (2021) Use of narrative methods in rehabilitation and palliative care in Scandinavian countries: A scoping review. *Scandinavian Journal of Caring Sciences* 36(2): 346-381.

- Ross L, Rottmann N, Andersen KK, et al. (2015) Distress after a psychosocial cancer rehabilitation course. Main effects and effect modification in a randomised trial at 12 months of follow-up. *Acta Oncologica* 54(5): 735-742.
- Rottmann N, Dalton SO, Bidstrup PE, et al. (2012) No improvement in distress and quality of life following psychosocial cancer rehabilitation. A randomised trial. *Psycho-oncology (Chichester, England)* 21(5): 505-514.
- Råheim M, Magnussen LH, Sekse RJT, et al. (2016) Researcher-researched relationship in qualitative research: Shifts in positions and researcher vulnerability. *International journal of qualitative studies on health and well-being* 11(1): 30996-30912.
- Saillant F (1990) Discourse, knowledge and experience of cancer: A life story. *Culture, Medicine and Psychiatry* 14(1): 81-104.
- Sarah R (2013) The Narrative Turn: Interdisciplinary Methods and Perspectives. *Student anthropologist* 3(3): 64-80.
- Schoenau MN (2022) Dominant restitution narratives of 'being lucky': An ethnographic exploration of narratives about operable lung cancer. *European Journal of Cancer Care* 31(5): e13633-n/a.
- Segal J (2012) Cancer Experience and its Narration: An Accidental Study. *Literature and Medicine* 30(2): 292-318.
- Sidenius A, Manderson L, Mogensen O, et al. (2019a) "But this is a good cancer":Patient perceptions of endometrial cancer in Denmark. *Journal of Clinical Nursing* 28(1-2): 245-256.
- Sidenius A, Mogensen O, Rudnicki M, et al. (2019b) Feeling lucky:hierarchies of suffering and stories of endometrial cancer in a Danish context. *Sociology of Health and Illness* 41(5): 950-964.
- Skivington K, Matthews L, Simpson SA, et al. (2021) A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ (Online)* 374: n2061-n2061.
- Skowronski M (2019) *'Will I get cancer again?' An ethnography of worries, healing landscapes and sensation-to-symptom processes among people living in the aftermath of cancer in rural Norway*. The Arctic University of Norway, Norway.
- Sontag S (1991) *Illness as metaphor and AIDS and its metaphors.* Harmondsworth: Penguin.
- Steffen V (1997) Life stories and shared experience. *Social science & medicine (1982)* 45(1): 99-111.
- Stegmann ME, Geerse OP, van Zuylen L, et al. (2021) Improving care for patients living with prolonged incurable cancer. *Cancers* 13(11): 2555.

- Strang P, Strang S, Hultborn R, et al. (2004) Existential pain—an entity, a provocation, or a challenge? *Journal of Pain and Symptom Management* 27(3): 241-250.
- Strawson G (2004) Against Narrativity. *Ratio (Oxford)* 17(4): 428-452.
- Sundhedsdatastyrelsen (2023a) Dødsårsagsregisteret 2022. Institution: Sundhedsdatastyrelsen
- Sundhedsdatastyrelsen (2023b) Nye kræfttilfælde i Danmark. Institution: Sundhedsdatastyrelsen
- Sundhedsstyrelsen (2017) Anbefalinger for den palliative indsats. Institution: Sundhedsstyrelsen
- Sundhedsstyrelsen (2018) Forløbsprogram for rehabilitering og palliation i forbindelse med kræft. Institution: Sundhedsstyrelsen
- Sung H, Ferlay J, Siegel RL, et al. (2021) Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA: A Cancer Journal for Clinicians* 71(3): 209-249.
- Tavory I and Timmermans S (2014) *Abductive analysis: theorizing qualitative research.* Chicago: The University of Chicago Press.
- Thompson J (2022) A Guide to Abductive Thematic Analysis. *Qualitative report* 27(5): 1410-1421.
- Thomsen LL (2016) Fortællinger om sygdom og død - mellem kaos og restitution (Stories of illness and death - between chaos and restitution). In: Bo IG, Christensen A-D and Thomsen TL (eds) *Narrativ Forskning. Tilgange og metoder*. Hans Reitzels Forlag.
- Thomsen LL, Bo IG and Christensen A-D (2016) Narrativ forskning: tilgange og metoder. In: Bo IG, Christensen A-D and Thomsen TL (eds) *Narrativ Forskning. Tilgange og metoder*.Hans Reitzels Forlag, pp.13-33.
- Thuesen J, Mikkelsen TB and Timm H (2016) Koordinering af rehabilitering og palliation til mennesker med livstruende sygdomme (Coordination of rehabilitation and palliation to people with life-threatening diseases). Place Published: Nyborg. Institution: REHPA
- Thuesen J, Rossau HK, Frausing S, et al. (2017) Kræftrehabilitering i Danmark – kortlægning af praksis på hospitaler og i kommuner. Place Published: Nyborg. Institution: REHPA
- Thuesen J and Timm HU (2014) Palliation og rehabilitering: begrebslige og praktiske forskelle og ligheder. *Omsorg* 31(3): 30-35.
- Timm H, Thuesen J and Clark D (2021a) Rehabilitation and palliative care: histories, dialectics and challenges. *Wellcome Open Research* 6: 171.
- Timm H, Thuesen J and la Cour K (2021b) Modeller for rehabiliterende og palliativ tilgang – ICF og Total Pain. *Omsorg* 4: 11-15.
- Timmermans S and Tavory I (2022) *Data analysis in qualitative research: theorizing with abductive analysis.* Chicago: University of Chicago Press.

- Tjørnhøj-Thomsen T and Hansen HP (2013) The Ritualization of Rehabilitation. *Medical Anthropology* 32(3): 266-285.
- Tolich M (2004) Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants. *Qualitative Sociology* 27(1): 101-106.
- Tonnesen M, Nielsen CV and Andersen RS (2022) What Are Your Goals? Goal-Setting Logics in Danish Parkinson's Rehabilitation. *Medical Anthropology* 41(5): 574-590.
- Traianou A and Hammersley M (2024) Interrogating the concept of vulnerability in social research ethics. *Diametros* 80: 1-16.
- Ussher J, Kirsten L, Butow P, et al. (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social science & medicine (1982)* 62(10): 2565-2576.
- Ussher JM, Kirsten L, Butow P, et al. (2008) A Qualitative Analysis of Reasons for Leaving, or Not Attending, a Cancer Support Group. *Social Work in Health Care* 47(1): 14-29.
- van Hulst M and Visser EL (2024) Abductive analysis in qualitative public administration research. *Public Administration Review*. DOI: 10.1111/puar.13856.
- VeluxFonden (2022) Available at: https://veluxfonden.dk/en/content/new-white-paper-identifies-new-paths-better-life.
- Victor E, Luna F, Guidry-Grimes L, et al. (2022) Vulnerability in practice: Peeling back the layers, avoiding triggers, and preventing cascading effects. *Bioethics* 36(5): 587-596.
- Wackers DYM, Plug HJ and Steen GJ (2020) Violence metaphors for cancer: Pragmatic and symptomatic arguments against. *Metaphor and the social world* 10(1): 121-140.
- Walsh CA, Currin-McCulloch J, Faris NR, et al. (2024) "Living with Loss": A qualitative exploration of existential fears among people with advanced lung cancer in online lung cancer support groups. *Palliative and Supportive Care*. Epub ahead of print 2024/02/29. DOI: 10.1017/S147895152400004X. 1-6.
- Warden T (2013) Feet of clay: confronting emotional challenges in ethnographic experience. *Journal of organizational ethnography* 2(2): 150-172.
- Wasson S (2018) Before narrative: episodic reading and representations of chronic pain. *Medical Humanities* 44(2): 106-112.
- White M (2006) *Narrativ teori.* København: Hans Reitzels Forlag.
- WHO (2001) *ICF: The International Classification of Functioning, Disability and Health*. Available at: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health.

- WHO (2020) *Palliative Care*. Available at: https://www.who.int/news-room/fact-sheets/detail/palliative-care.
- WHO (2023) Policy brief on integrating rehabilitation into palliative care services. Place Published: Copenhagen. Institution: WHO Regional Office for Europe
- Williams S (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness* 22(1): 40-67.
- Wind G and Vedsted P (2008) Om kronisk sygdom. *Tidsskrift for Forskning i Sygdom og Samfund* 5(9).
- Wise M, Marchand LR, Roberts LJ, et al. (2018) Suffering in Advanced Cancer: A Randomized Control Trial of a Narrative Intervention. *Journal of Palliative Medicine* 21(2): 200-207.
- WMA (2022) *WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS*. Available at: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/.
- Wood J (2022) Cicely Saunders, 'Total Pain' and emotional evidence at the end of life. *Medical Humanities* 48(4): 411-420.
- Woods A (2011) The limits of narrative: provocations for the medical humanities. *Medical Humanities* 37(2): 73-78.
- Woods A (2014) Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience. In: Carel H and Cooper R (eds) *Health, Illness and Disease : Philosophical Essays*. Routledge, pp.113-128.
- Aagesen M, Pilegaard MS, Hauken MA, et al. (2022) Users' perspective on rehabilitation interventions for young adult cancer survivors: A group concept mapping study. *European Journal of Cancer Care* 31(6): e13734-n/a.

REHPA-FORLØB 2022

KALENDER

Forløb 1
Uge 4 Ophold den 24.-27. januar 2022
Uge 8 Opfølgning den 24.-25. februar 2022

Forløb 2
Uge 13 Ophold den 28.-31. marts 2022
Uge 19 Opfølgning den 10.-11. maj 2022

Forløb 3
Uge 34 Ophold den 22.-25. august 2022
Uge 39 Opfølgning 27.-28. september 2022

SÅDAN SØGER DU OM OPHOLD

- Du kan downloade og printe henvisningsskemaet fra www.rehpa.dk under REHPA-forløb.
- Du medbringer skemaet til din læge, der kan henvise dig ved udfyldelse af skemaet eller via sygehushenvisning.
- Når vi har modtaget henvisningen fra lægen, modtager du et ansøgningsskema i din e-boks, der skal udfyldes elektronisk på internettet.
- Vi gennemgår løbende ansøgninger til REHPA-forløbet, og du får svar på din ansøgning ca. 4 uger før forløbet.
- Vær opmærksom på, at hvis holdet er overtegnet, får du afslag på din ansøgning.
- Har du spørgsmål til forløb eller ansøgning, så kontakt os gerne på telefon 30 57 10 59 eller mail rehpa.ophold@rsyd.dk

REHPA
Vestergade 17, 5800 Nyborg
Telefon 30 57 10 59, mail: rehpa.ophold@rsyd.dk, www.rehpa.dk

STÅ BEDRE FAST I LIVET MED ALVORLIG SYGDOM - VIA EGNE OG ANDRES FORTÆLLINGER

Et forløb for dig, der lever med kronisk og/eller uhelbredelig kræft

REHPA
Videncenter for
Rehabilitering og Palliation

Region Syddanmark SDU

FORTÆLLINGER SOM AFSÆT FOR BÅDE BEDRE FUNKTIONSEVNE OG LINDRING

Forskningsklinikken REHPA tilbyder tre gruppebaserede forløb i 2022 for mennesker, der lever med kronisk og/eller uhelbredelig kræft. I forløbene arbejdes især med deltagernes individuelle og fælles fortællinger om livet før, nu og i fremtiden. Målet er at forbedre livskvaliteten for den enkelte deltager.

Mennesker med kronisk og/eller uhelbredelig kræft og deres pårørende har ofte udfordringer med at opretholde livskvalitet i hverdagen. Mange oplever store forandringer, og det kan være svært at opretholde følelsen af sammenhæng og meningsfuldhed i hverdagen. Identitet, roller og relationer kan forandre sig og være årsag til fortvivlelse og lidelse. Bekymringer for ens nære, for fremtiden og frygt for døden kan fylde.

Følelsesmæssigt kan du opleve store skift. Glæden over at være i live og ved det liv, du har levet, kan nemlig også fylde meget. Ligesom håbet om, at der er mere godt i vente.

Om livsfortællingsforløbet

Fortællinger er dynamiske og mangfoldige og kan hjælpe os til at forstå os selv, hvem vi er og gerne vil være. Ved deltagelse i REHPAs livsfortællingsforløb får du mulighed for:

- At få øje på omstændigheder og mening i dit liv
- Hjælp til at se på fremtiden. Hvor er der håb? På langt sigt/på kort sigt?
- At få øje på relationer, som er vigtige for dig
- At få kontakt til værdier, der er vigtige for dig
- At få kontakt til – og måske lære af – andre i samme situation
- At finde glæde og lethed

Deltagelse i et forløb er helt uafhængigt af eventuelle tidligere erfaringer med fortællinger. Indholdet veksler mellem fortælleværksteder og blide kropslige aktiviteter. Du bliver guidet af REHPAs personale, som er særligt trænet i livsfortællingsmetoden.

HVEM KAN DELTAGE?

Du kan deltage, hvis du:

- Har brug for at finde fodfæste i livet i forbindelse med kronisk og/eller uhelbredelig kræft.
- Kan og vil deltage aktivt i forløbet, som omfatter et ophold på 4 dage, 5-6 uger hjemme og 2 dages opfølgning.
- Kan og vil bidrage til REHPAs forskning via spørgeskemaer, interviews mv.
- Kan tale og forstå dansk
- Kan klare dig selv, da REPHA ikke rummer mulighed for personlig pleje, behandling eller lægefaglig behandling.
- Din eventuelle behandling ikke står i vejen for, at du kan deltage aktivt i rehabiliteringsforløbet.

Forskning

Der foregår løbende forskellige forskningsaktiviteter hos REHPA, og derfor indsamler vi oplysninger om, hvordan du har det før, under og efter dit ophold.

Livsfortællingsforløbene er en del af REHPAs arbejde med koordinering af rehabilitering og palliation til mennesker med kronisk og/eller uhelbredelig kræft. Ønsket er at udvikle metoder – her arbejde med fortællinger – som kan hjælpe deltagerne til bedre livskvalitet.

Når den indsamlede viden bliver offentliggjort, er det i anonymiseret form, så du og de øvrige deltagere ikke kan genkendes. Du underskriver i den forbindelse en samtykkeerklæring ved ansøgningen om deltagelse i et forløb på REHPA.

Fagpersoner tilknyttet REHPA

Under dit forløb på REHPA møder du: Psykolog, sygeplejerske og fysioterapeut. De står for oplæg, samtaler, aktiviteter og er dine værter gennem opholdene.

Lægehjælp og behandling

Det er fortsat din egen praktiserende læge eller hospitalslæge, der har ansvaret for din behandling og medicin. Hvis du har brug for lægelig assistance under opholdene, vil det være din egen læge, vagtlæge eller behandlende afdeling, som kontaktes.

Hvis du får afslag

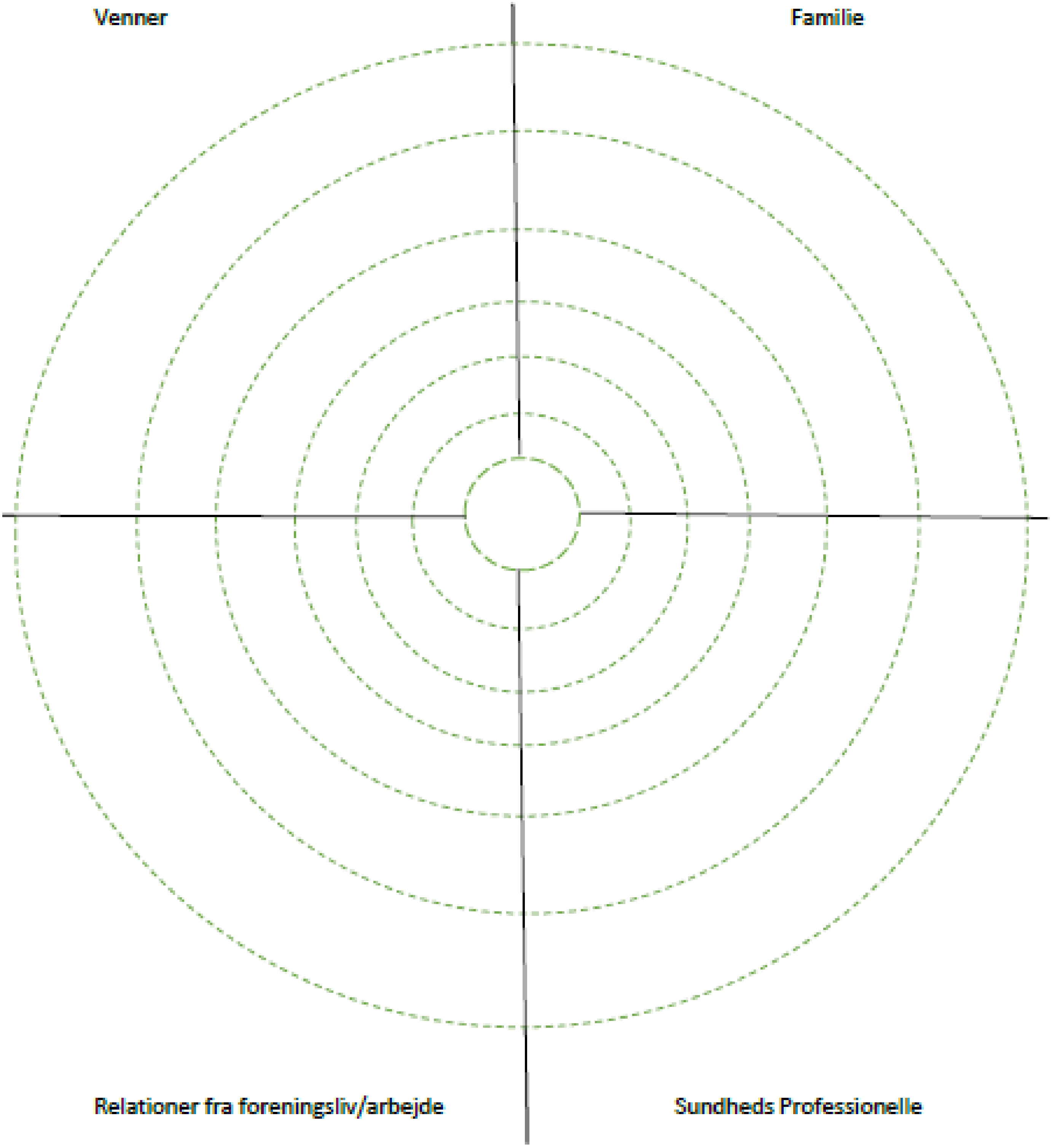
Kræftrehabilitering i Danmark er placeret hos din kommune. REHPA-forløb har til formål at bidrage med viden og forskning på dette område. Hvis du modtager afslag fra REHPA, anbefaler vi dig at kontakte din kommune.

PRAKTISKE FORHOLD

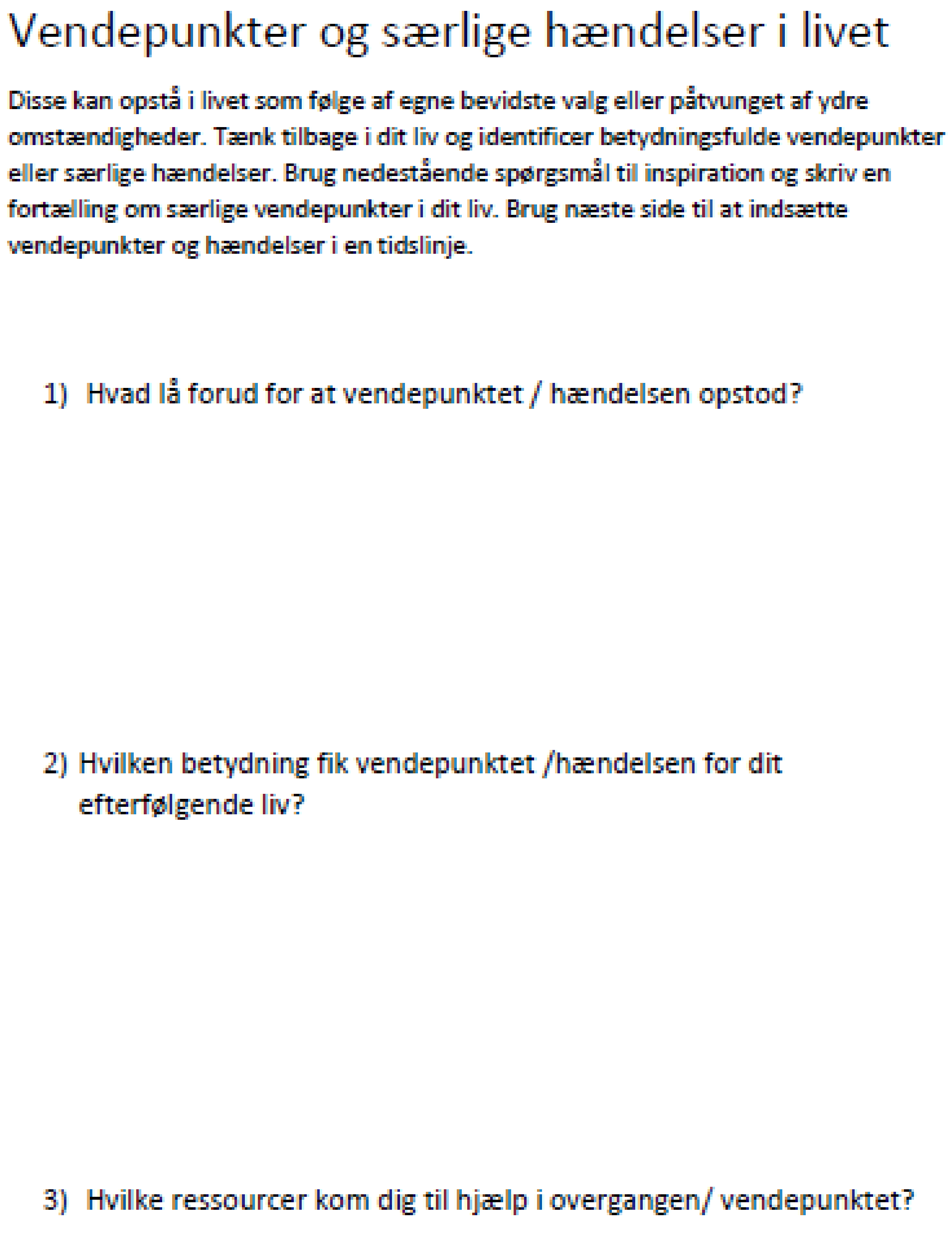
- REHPA-forløb er gratis.
- Forløbene afvikles som internatophold, hvor du overnatter i enkeltværelse på REHPA i Nyborg.
- Vores lokaler er røgfrie.
- Der er plads til op til 20 deltagere på hvert hold.
- REHPA overholder alle forholdsregler ifm. med COVID-19.
- Du skal selv sørge for og betale transport til og fra REHPA.
- Du medbringer selv alt din ordinerede medicin og evt. hjælpemidler. Du er selv ansvarlig for medicinering under dit ophold. REHPA udleverer ikke medicin.
- Som deltager på REHPA-forløb bliver du administrativt registreret som indlagt, fordi REHPA er en del af Odense Universitetshospital.

Appendix II

NETVÆRKSKORT



Appendix III



Vendepunkter og særlige hændelser i livet

Disse kan opstå i livet som følge af egne bevidste valg eller påtvunget af ydre omstændigheder. Tænk tilbage i dit liv og identificer betydningsfulde vendepunkter eller særlige hændelser. Brug nedestående spørgsmål til inspiration og skriv en fortælling om særlige vendepunkter i dit liv. Brug næste side til at indsætte vendepunkter og hændelser i en tidslinje.

1) Hvad lå forud for at vendepunktet / hændelsen opstod?

2) Hvilken betydning fik vendepunktet /hændelsen for dit efterfølgende liv?

3) Hvilke ressourcer kom dig til hjælp i overgangen/ vendepunktet?

Table 5. Full participant and data overview

Participants ID number	Sex	Age	Setting	Interview (number)	Focus group (number)	Withdrew	_reason
#1	Male	60-70	Municipal rehab.		/		
#2	Female	50-60	Municipal rehab.		/	x	Experience of harm
#3	Female	70-80	Municipal rehab.	#1, #4	/		
#4	Male	30-40	Municipal rehab.	#2, #5	/		
#5	Female	30-40	Municipal rehab.	#3, #6	/	x	Experience of harm
#6	Female	60-70	Municipal rehab.		/		
#7	Male	70-80	REHPA I		#2		
#8	Male	60-70	REHPA I		#1		
#9	Male	50-60	REHPA I	#7	#2		
#10	Female	80-90	REHPA I		#2		
#11	Female	40-50	REHPA I			x	Illness (follow-up stay)
#12	Female	60-70	REHPA I		#1		
#13	Female	50-60	REHPA I	#8	#1		
#14	Female	50-60	REHPA I			x	Illness (went home at night on the follow-up stay)
#15	Female	50-60	REHPA I		#2		
#16	Female	70-80	REHPA I		#1		
#17	Female	40-50	REHPA I		#2		
#18	Female	40-50	REHPA I		#1		
#19	Female	50-60	REHPA I	#9	#2		
#20	Male	60-70	REHPA II		#3		
#21	Male	50-60	REHPA II		#3		
#22	Male	50-60	REHPA II			x	Died
#23	Female	50-60	REHPA II	#10	#3		
#24	Female	50-60	REHPA II	#11	#4		
#25	Female	40-50	REHPA II	#12	#3		
#26	Female	40-50	REHPA II			x	Experience of harm
#27	Female	50-60	REHPA II			x	Experience of harm
#28	Female	50-60	REHPA II		#4		
#29	Female	40-50	REHPA II		#3		
#30	Female	50-60	REHPA II		#4		
#31	Female	40-50	REHPA II		#4		

#32	Female	50-60	REHPA II		#4		
#33	Female	50-60	REHPA III		#5		
#34	Female	60-70	REHPA III		#6		
#35	Female	60-70	REHPA III	#13	#5		
#36	Female	60-70	REHPA III		#6		
#37	Female	60-70	REHPA III		#5		
#38	Female	60-70	REHPA III	#14		x	Unknown (follow-up stay)
#39	Female	50-60	REHPA III			x	Unknown (follow-up stay)
#40	Female	40-50	REHPA III			x	Unknown (goes home during the main stay)
#41	Female	70-80	REHPA III		#6		
#42	Female	50-60	REHPA III	#15	#6		

Interviewguide, første interview

Semi-struktureret individuelt interview med deltagere

Før interviewet:

- Velkommen
- Information om projektet, interviewets formål, lydoptagelse mm.
- Mundtligt informeret samtykke (skriftligt foreligger)

Spørgsmål	**Tema og begreber**
Siden du var på kurset, hvordan har du så haft det? Hvad har fyldt? *Hvordan har det været for dig at deltage i det her kursus?* *Hvad har det betydet?*	(åben, eksplorativ)
Kan du fortælle mig om grunden til, at du meldte dig på dette Livsfortællingskursus? *Hvad gjorde du dig af tanker om indholdet og betydningen af indholdet på kurset? Hvad tænkte du om begrebet "livsfortælling"?* *Hvad var dine forventninger?* *Havde du nogle bekymringer ift. din deltagelse?*	Selvvurderet behov, (for rehabilitering og palliation), motivation
Kan du fortælle mig om din oplevelse af at arbejde med den kollektive fortælling? *Var der noget der føltes svært eller let ift. øvelsen med spørgsmålene?* *Hvordan oplevede du at få læst den kollektive fortælling op på tredje dagen?* *Var der noget i arbejdet med den kollektive fortælling, der gjorde et særligt indtryk på dig?* *Har du gjort dig tanker om, hvordan (hvis overhovedet) du kan bruge den kollektive fortælling i dit videre liv?*	Den kollektive fortælling
Hvordan oplevede du arbejdet med opgaverne i materialet? (vendepunkterne og livslinjen, roller, værdier, handlinger mm.) *Hvordan oplevede du det, når du skulle fortælle om dine egne oplevelser i mindre grupper? Og plenum?* *Hvordan oplevede du det at lytte til de andres fortællinger? At se dem blive berørt?*	Individuelle fortællinger

Hvad synes du om det udleverede kursusmateriale? Og hvordan arbejdede du med mappen kontra den udleverede notesbog? *Hvordan oplevede du omgivelserne? Lokalerne, serviceringen mm.* *Hvordan oplevede du holdstørrelsen og sammensætningen?* *Hvordan oplevede du Steen og Mettes roller under kurset? (deres tilstedeværelse, deres opsamlinger mm)* *Var der noget ved rammerne om kurset, som du villet have ønsket var anderledes?*	Implementering
Siden du havde sidste dag på kurset, er der gået x antal dage. *Har du brugt materialet fra kurset i dit liv? Har du f.eks. talt med dine pårørende eller sundhedsprofessionelle om noget af det, som du har arbejdet med?* *Har du fået arbejdet med dine værdier og handlinger, sådan som det var meningen? (hvis ja: hvordan? hvis ikke: hvorfor?)* *Hvad er dit helhedsindtryk af kurset indtil videre? Hvad er særligt godt og hvad fungerer mindre godt?*	Outcome (Livskvalitet, mening)
Nu er interviewet ved at være slut. *Derfor vil jeg blot høre dig ad, om der er noget du synes, jeg har glemt at spørge om, eller om der er noget du har lyst til at tilføje eller bemærke?*	Afrunding

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Statens Institut for Folkesundhed

Interviewguide - fokusgruppeinterviews		
	Spørgsmål	**Formål**
Intro	Kort om mig og min position Kort om observatørens rolle Et fokusgruppeinterview er et anderledes interview end det man normalt forbinder med et interview. Ideen i fokusgruppen her er, at det er jer, der taler mest, men jeg vil gerne have jer til at diskutere nogle emner/temaer, som jeg løbende introducerer for jer for og som relaterer sig til dette forløb hos REHPA. I skal så tale med hinanden om emnet og give udtryk for, om I er enige eller uenige med det, de andre siger, samt kommentere det, give input mv. Husk - at der ikke er nogle rigtige eller forkerte svar, eller nogle rigtige eller forkerte holdninger eller fortolkninger af de spørgsmål, jeg stiller. I er eksperterne på jeres egne liv og holdninger og jeg er her interesseret i jeres erfaring/oplevelser med at være her på kurset hos REHPA. Jeg vil forsøge at lade jer snakke så meget som muligt, det er jeres indbyrdes samtale der er i centrum her - og selvom det er meget naturligt, at nogle mennesker snakker mere end andre, så må I gerne hjælpe mig med at være opmærksomme på, at alle får sagt noget. Interviewets struktur: Det vil tage maks. 1 ½ time og her vil vi snakke om nogle emner der relaterer sig til det kursus I har været på her i REHPA. Det hele optages på diktafonen. Det er kun for at kunne huske bedre, hvad I siger. Det er kun mig, der kommer til at høre det. I vil selvfølgelig være anonyme i projektet. Spørgsmål?	
Præsentation af deltagerne	Selvom I kender hinanden til en vis grad, så vil jeg gerne bede jer alle om lige at præsentere jer for hinanden – navn, hvor I kommer fra og hvor længe I har været syge	
Startspørgsmål	Hvad har optaget jer mest siden I kom hjem fra kurset? - Hvilke tanker har I gjort jer om indholdet på kurset?	
Evaluerende spørgsmål	Foran jer ligger alle de øvelser, I var igennem på det forløb I var på i uge 4. Hvilke øvelser oplevede I gjorde mest indtryk på jer? Underspørgsmål: - Hvad var jeres oplevelse af at arbejde med øvelserne? - Var der øvelser som oplevedes særligt gode – eller særligt udfordrende? – og hvorfor	Øvelserne på print

Evaluerende spørgsmål	Hvad forbinder I med begrebet ***livskvalitet***? (Eksempler: frihed til at vælge, glæde, oplevelse af mening mm.) Skriv ord på post it´s sammen og se, om I sammen kan finde frem til de væsentligste 3 ord.	Post its Tuscher
Evaluerende spørgsmål	Hvad forbinder I med ordet "livsfortælling"? - Hvad er fortællinger for jer? - Hvordan har det været at høre andres fortællinger her på kurset?	
Evaluerende spørgsmål	Hvad har det sociale betydet for jer, under opholdet her? - Hvordan var det at være sammen med andre med kronisk kræft? - Hvordan har I oplevet samspillet mellem indholdet i øvelserne og så tiden til at snakke og være sammen socialt?	
Outro (5 min)	Nu er denne lille seance ved at være forbi. Derfor vil jeg lige høre jer ad, hvordan det har været at deltage i? Er der nogen af jer det har noget, I føler I gerne lige vil have sagt eller har spørgsmål til inden vi slutter?	

Ekstra øvelser		
		Materialer
Øvelse	Skriv korte sætninger ned om det væsentligste I har fået ud af kurset – 5 min til hver.	Post-its

Oplysning om deltagelse i projekt

I forbindelse med ph.d.-projektet ”**Meningsskabende fortællinger for mennesker der har eller har haft kræft**”, følger ph.d.-studerende Henriette Søby Gärtner kurset ’Livsfortællinger’ i REHPA - Videncenter for Rehabilitering og palliation. Deltagelse i forskningsprojektet kræver deltagernes skriftlige samtykke.

Ph.d.-projektet gennemføres på Syddansk Universitet. Syddansk Universitet er ansvarlig for beskyttelsen af personoplysninger, der anvendes i forskningsprojekter. Det er frivilligt at deltage i projektet. Indsamlingen sker via deltagende observationer, gruppefortællingen (dokument), samt eventuelle interviews og fokusgruppeinterviews.

Formål med behandlingen af oplysninger til projektet
Det overordnede formål med projektet er at evaluere nogle forløb, hvori der arbejdes med både de individuelle og kollektive fortællinger hos mennesker der har eller har haft kræft. Der evalueres på kursernes evne til at forbedre livskvaliteten, forstået som bl.a. sammenhæng, mening og håb for deltagerne.

De oplysninger som indhentes, relaterer sig til det at finde/skabe mening i livet med alvorlig sygdom. Herunder arbejdes der med den individuelle livshistorie samt kollektive fortælling, hvorfor følgende oplysninger kan være relevante: vendepunkter i livet, familieforhold, helbredsudfordringer, arbejdsliv, religiøse eller spirituelle forhold.

Sådan bruger vi oplysningerne
Syddansk Universitet behandler personoplysninger fortroligt - i overensstemmelse med gældende ret. Oplysningerne vil kun blive brugt til forskning og formidling af forskningsresultater. Vi sørger for at opbevare dem sikkert, så det kun er de relevante forskere på SDU, der har adgang til dem. Oplysningerne bliver gemt så længe, de er relevante for forskningen – det kan også være andre forskningsprojekter. Herefter vil de blive slettet eller anonymiseret.

Ønske om at deltage
Når der skal bruges personoplysninger til forskningsprojektet, er der nogle særlige bestemmelser i lovgivningen, som giver mulighed for at indsamle og bruge personoplysninger uden samtykke fra deltageren. Den findes i databeskyttelseslovens § 10 og databeskyttelsesforordningens art. 6, stk. 1, litra e.

Bestemmelsen giver os lov til at bruge dine personoplysninger til forskning uden dit samtykke, men forbyder også, at bruge oplysningerne til andre formål end forskning og statistik. Du risikerer derfor ikke, at dine oplysninger vil blive brugt til andre formål. Endvidere vil offentliggørelse af dine oplysninger i videnskabelige tidsskrifter kun ske med Datatilsynets tilladelse.

Databeskyttelseslovens § 10 og databeskyttelsesforordningens art. 6, stk. 1, litra e giver også mulighed for, at vi kan videregive oplysningerne til andre forskningsprojekter, men der vil fortsat være tale om sundhedsvidenskabelig forskning.
Du skal derfor beslutte dig for, om du vil deltage i projektet, så vi kan bruge dine oplysninger. Ved at indvillige i deltage, vil vi indsamle de oplysninger, som er nævnt ovenfor, og anvende dem i projektet. Skulle du, på et tidspunkt i forløbet, ikke længere have lyst til at deltage, kan du trække dig fra projektet. Det

medfører at vi ikke længere vil indsamle nye oplysninger om dig, men vi har fortsat lov til at bruge de oplysninger, vi allerede har fået.

Yderligere information
Hvis du har spørgsmål til undersøgelsen, kan du til enhver tid, kontakte ph.d.-studerende Henriette Søby Gärtner på tlf. 60194322 eller hsg@sdu.dk.

Hvis du har spørgsmål omkring databeskyttelse og dine rettigheder kan du kontakte vores Databeskyttelsesrådgiver, Simon Kamber på tlf. 6550 3906 eller dpo@sdu.dk.

Ønsker du at klage over behandlingen af personoplysninger til Datatilsynet på www.datatilsynet.dk.

Ønske om at deltage

☐ Jeg forstår, at det er frivilligt at deltage i projektet.

☐ Jeg forstår, at oplysninger om mig, fortsat bliver brugt, selvom jeg ikke længere ønsker at deltage.

☐ Jeg forstår, at mine personoplysninger kun vil blive anvendt til forskning.

Dato Navn Underskrift

Information om deltagelse i projektet: Meningsskabende fortællinger til mennesker der har eller har haft kræft

Du inviteres hermed til at deltage i et forskningsprojekt. Projektet går ud på at evaluere nogle kurser, hvori der arbejdes aktivt med fortællinger hos mennesker der har eller har haft kræft.

Hvad er formålet med projektet og hvad bruges resultaterne til?

Det overordnede formål med projektet er at evaluere nogle særlige forløb/kurser, hvori der arbejdes aktivt med fortællinger hos mennesker der har eller har haft kræft. Der evalueres på forløbenes mulighed for at forbedre livskvaliteten for deltagerne, forstået som bl.a. øget følelse af sammenhæng i livet, mening og håb. Projektet skal hjælpe med at udvikle fremtidige indsatser med brug af fortællinger, til gavn for mennesker ramt af livstruende sygdom og deres pårørende.

Hvordan deltager jeg?

Du bestemmer selv, om du har lyst til at deltage i projektet, og du kan til enhver tid trække din deltagelse tilbage. Takker du ja til at deltage, vil jeg bede dig om at underskrive en samtykkeerklæring. Deltagelse i dette forskningsprojekt har *ingen* indflydelse på din behandling og deltagelse i andre forløb.

Hvad kræver det af mig?

Jeg vil under kurset observere, tage noter og måske snakke med jer deltagere uformelt, men der kræves intet særligt af dig. Har du lyst til at deltage i et interview eller en fokusgruppe, så har du også mulighed for det.

Hvordan behandles mine oplysninger?

Alle dine oplysninger bliver behandlet fortroligt efter gældende lovgivning. Det betyder, at dine oplysninger bl.a. anonymiseres, hvorfor du ikke vil kunne genkendes som enkeltperson i de resultater, som vil blive formidlet.

Hvem udfører forskningen og hvem har godkendt det?

Projektet er et ph.d.-projekt og udføres af mig (Henriette Søby Gärtner), som er uddannet sociolog og ph.d.-studerende på Syddansk Universitet, Statens Institut for Folkesundhed.

Projektet er økonomisk støttet af Kræftens Bekæmpelse – Knæk Cancer midler og REHPA, Videncenter for Rehabilitering og Palliation.

Yderligere information og spørgsmål?

Hvis du har spørgsmål til projektet, kan du til enhver tid kontakte Henriette Søby Gärtner på tlf. 60 19 43 22 eller hsg@sdu.dk.

Jeg håber, at du har lyst til at deltage.

Med venlige hilsner,

Henriette Søby Gärtner, Sociolog og ph.d.-studerende. Syddansk Universitet, Statens Institut for Folkesundhed

Sub-study I

MORTALITY
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Routledge
Taylor & Francis Group

‘There is nothing beautiful or life-affirming in it’: experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer

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ABSTRACT

Narrative methods have been shown to help people with cancer to create meaning, find hope and restore a sense of coherence in life. Likewise, the combination of rehabilitation and palliative care for people with life-threatening illness is receiving increasing interest and is generally perceived as beneficial for patients. Four narrative courses combining rehabilitation and palliative care approaches for people who have or have had cancer were carried out in Denmark between 2021 and 2022. An ethnographic field study revealed that some of the course participants experienced harm during the courses and therefore chose to withdraw. Findings show that a rehabilitation approach dominated in the courses and that the participants’ experiences of harm occurred in a complex interplay between the participants, the professionals and the specific narrative exercises. While some participants’ stories were recognised as legitimate and meaningful and were continuously supported and encouraged, other participants’ stories of suffering were suppressed.

KEYWORDS

Storytelling; narratives; cancer; rehabilitation; palliative care

Introduction

Being diagnosed with cancer may cause a disruption in life. In parallel with the illness in the body, people with cancer are affected psychologically, socially and spiritually (Lewandowska et al., 2020), and sustaining a satisfying quality of life may be challenging (Peoples et al., 2021).

This study is based on an ethnographic field study exploring the experiences reported by the participants during four narrative courses in Denmark that combined rehabilitative and palliative care approaches. The focus of the study is on the participants’ experiences

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of harm, drawing on Lorenc and Oliver's (2014) understanding of harmful effects in public health interventions in which harm is understood as unintended, adverse effects.

Narrative methods and narrative research

Illness narratives are a special genre of narrative that places the patient's experiences with their illness at the centre of attention (Thomsen, 2016). Although patients' narratives are often explored as analytical objects in research, other methods of actively working with various forms of narratives are frequently utilised (Egerod et al., 2011; Jeppesen, 2013; Kirkevold et al., 2014; la Cour et al., 2016). Within the fields of rehabilitation and palliative care in Scandinavia, narrative methods are used by professionals in their care of people living with a life-threatening illness and their significant others. Generally, these methods are by the patients perceived as meaningful in increasing or maintaining quality of life (Roikjær et al., 2021). Narrative methods used in clinical practice can include patient diaries in intensive care units (Egerod et al., 2011), dignity therapy with terminally ill patients (Chochinov et al., 2005) and narrative therapy (White, 2006).

In narrative analysis, the narratives of the research subjects are examined, often with the intention of understanding both the content of the story and how the narrative is constructed (Bo et al., 2016). In our understanding, narrative methods apply narrative theory in a specific method or form. In this study, we explore the participants' experiences using an applied narrative method (the narrative course), and we analyse the narratives constructed during the courses and represented in the fieldwork.

Combined approaches of rehabilitation and palliative care for people with cancer

Rehabilitation and palliative care have traditionally constituted two separate healthcare approaches, yet proposals for how the two may be combined for the benefit of the patient have gained increasing interest (Thuesen et al., 2016; Timm et al., 2021). Whereas rehabilitation has traditionally been concerned with functioning and the subjective goals of increasing quality of life and well-being (Meyer et al., 2020; Stucki & Bickenbach, 2017), palliative care utilises the concept of 'total care' with the overall goal of improving the patient's quality of life towards the end of life (Timm et al., 2021; WHO, 2020). Relief from suffering, including all four and equal 'total pain' dimensions of suffering (physical, mental, social and existential-spiritual), is a core concept in palliative care (WHO, 2020). While palliative care has formerly been understood as end-of-life care, it is now considered best practice to implement palliative care early in the illness trajectory (Radbruch et al., 2020). Likewise, it is recognised that patients with life-threatening illness benefit from rehabilitation approaches in combination with palliative care approaches (Thuesen et al., 2016; Tiberini & Richardson, 2015; Timm et al., 2021). Evidence-based knowledge on the most beneficial ways to integrate or combine the two approaches are still underrepresented in research (Nottelmann et al., 2019), and interventions that combine the two approaches often focus on the findings and measures of outcome (Gärtner et al., 2023; Nottelmann et al., 2021; Timm et al., 2021). Although rehabilitation and palliative care both aim to enhance the patient's quality of life (Meyer et al., 2020; WHO, 2020), the two specialities differ in focus and approach. While the focus of rehabilitation is on functioning in day-to-day life and the ability to do things, the focus of palliative care is the relief of suffering in all its senses, for example physical pain, loss, meaninglessness (Timm et al., 2021). Whereas *doing/activity* is at the centre of rehabilitation, *being/presence* can be said to be at the centre of palliative care (Thuesen et al., 2016).

Methodology

The narrative courses

Design and implementation

The narrative courses were designed by a psychologist and a family therapist, respectively, and were previously tested and found to be meaningful for the participants in a narrative intervention for people living with HIV (Jess & Timm, 2019; Jess et al., 2023). The narrative courses were developed in collaboration with the Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA), to fit the format of their standard rehabilitation courses for people who have or have had cancer (Rasmussen et al., 2020). Before this, two pilot courses were successfully carried out at the end of 2019 and in early 2020 to test the feasibility and acceptability of a course combining rehabilitative and palliative approaches for participants with incurable and advanced cancer in the REHPA setting (Raunkiaer, 2022; Raunkiaer & Gärtner, 2020). Prior to the narrative courses, relevant members of the clinical team at the REHPA research clinic (nurses, physiotherapists and one psychologist) underwent training by the course designers on how to conduct the courses. Two of the authors (HSG and HT) participated in this training to familiarise themselves with the narrative exercises and the field.

Theoretical assumptions behind the courses

The narrative courses were informed by a broad range of narrative theories (Chochinov et al., 2005; Frank, 2013; White, 2006) and designed to enhance or maintain the participants' quality of life by enabling the participants to create meaning, foster hope and restore a sense of coherence in life with cancer. A crucial element in the theoretical framework informing the courses is the assumption that narration is a social practice and that the stories we tell help us create meaning in our lives and shape our sense of self (Frank, 2013; Kleinman, 1998). Drawing on insights from narrative therapy, the courses were based on the assumption that when working actively with our narratives, it is possible to identify and compose alternative and perhaps less-used narratives that may help and guide us in the future (Chochinov et al., 2005; White, 2006). However, although the courses were inspired by narrative therapy, they were not regarded as therapy per se. Rather narration was seen as a common social practice, which was structured and managed within the framework of the course programme. The narrative courses rest upon theories and practices that consider storytelling and reflecting and working with key elements of one's life history as an overall benign practice (Hyvärinen, 2010).

Course content

The narrative courses included both oral and written narrative exercises and group work. The participants were encouraged to share, work with and reflect upon some key components in their current life stories, such as identifying former turning points in their life and identifying important relationships.

The participants received a compendium consisting of six narrative exercises and small written introductions and a blank notebook. Each session in the course programme was paired with an exercise connected to a life story theme, such as identifying and reflecting on a social network and turning points in life. Every exercise started with individual writing, followed by oral group work and ended with a plenum conversation. The courses also included an exercise of constructing a collective story about life with cancer, inspired by comments and reflections in the plenum talk, which was compiled into a written document by the course leaders (henceforth referred to as 'the professionals'). Some elements of light, physical activity such as yoga or mindful walking were implemented to give the participants breaks from the narrative exercises.

Setting and participants

The narrative courses were carried out in two different settings (a national residential centre and a municipal day centre) with different target groups and with minor variations regarding content and duration (see Table 1). The courses were tested four times. In both

Table 1. Overview of the narrative courses.

Narrative courses	Setting	Participants/professionals	Study design
I-III (held three times in 2022)	REHPA research clinic 4-day residential course with a 2-day residential follow-up course after 5–6 weeks	Participants with incurable cancer (n=36) Participants were from all of Denmark and considered eligible for inclusion if they: 1) were aged ≥ 18 years and diagnosed with incurable, advanced cancer, 2) had the ability to speak and understand Danish and 3) needed no professional assistance regarding personal hygiene and medicine. All participants were formally referred to the course by their treating doctor or general practitioner, thereafter, underwent visitation from the REHPA staff and were telephoned before their attendance. The courses were carried out by a psychologist, nurses and physiotherapists.	● Participant observations (total of 185 hours) ● 9 individual interviews, conducted in the interval between the main course and the follow-up days and revolved around the participant's experiences with the course as an overall experience and the narrative exercises in particular. ● 6 focus group interviews were conducted on the last follow-up day of each course in the research clinic and included 28 participants, divided into smaller groups of three to six participants. Focus was primarily on the themes from the individual interviews.
IV (held one time in 2021–2022)	Municipal rehabilitation centre The main part was held on 3 consecutive days, from 9.00–16.00. Two follow-up days were planned to be held with a one-month interval (delayed due to COVID-19)	Participants had been successfully treated for cancer or had a good prognosis (n=6) Participants were recruited within the municipality by the centre professionals from existing users of the centre and underwent visitation from the professionals. The course was carried out by the course developer (a psychologist) and a social worker.	● Participant observations (total of 30 hours) ● Due to too few participants willing to participate in a focus group interview, 2 individual interviews were conducted with 3 of the participants: the first interview in the interval between the main part of the course and the second after the course was completed.

settings, the courses were modified by the professionals to fit with the current practices and the aim of the setting, but the main elements of the participants' involvement in the same narrative exercises were not changed significantly. The courses were advertised as 'life story courses' with a focus on helping the participants to regain or rediscover meaning in life through exercises such as identifying important relationships, key values in life or future desired actions. Except for transportation to and from the course settings, participation was of no cost to the participants.

In total, 42 participants attended all or most of the courses. This study is based on the stories of four participants (two from each setting) who clearly expressed their experiences of harm and who declined to complete the narrative courses.

Study design

The study consisted of 215 hours of fieldwork involving participant observations and informal conversations, 15 in-depth qualitative interviews and six focus group interviews carried out by the first author (HSG). Focus during the observations was on exploring concrete actions, the language used and non-verbal and bodily expressions (Hastrup, 2010; Krogstrup & Kristiansen, 2015). The fieldwork provided essential insights into how the participants acted, talked and engaged with each other, as well as important understandings of how harm was experienced. Extensive field notes were written during the courses and included in the data material.

Data analysis

Our analysis was based on the principles of abductive analysis. An abductive analysis is a dialogical process between empirical data and theory in which the data influence choices of theory, and theory guides the approach to the data (Thompson, 2022; Timmermans & Tavory, 2022). Through the data-generating process, the first author gradually became aware of stories indicating experiences of harm during the courses. The first author became familiar with the data through extensive reading and rereading of the transcribed individual interviews and focus group discussions as well as the field notes. This step helped confirm that elements of the harmful experiences were not deviant cases with little relevance to the courses in general. Next, HSG looked more closely into the parts of the data material initially labelled as 'something went wrong for someone'. Later, we named this as the analytical theme 'experiences of harm', and HSG searched purposively in the material for data that related specifically to this theme. Finally, HSG coded these parts of the material in a search for variation across situations and time (Tavory & Timmermans, 2014; Timmermans & Tavory, 2022) and engaged in a continuous iterative process, going back and forth between the data, the theory and previous research (Thompson, 2022; Timmermans & Tavory, 2022). In our analysis of the data, we were inspired by Frank's three narrative plots that may serve as ideal types for stories of illness (Frank, 2013; Thomsen, 2016). Frank suggests that the 'restitution narrative' is the most frequent, and also the culturally preferred, illness narrative. Restitution narratives revolve around returning to being healthy after falling ill (Frank, 2013). In contrast to the restitution narrative, Frank proposes the 'chaos narrative', which lacks the order and coherence we anticipate in a good story (Frank, 2013). The chaos narrative is fragmented and discouraging to both the teller and the listener. According to Frank, people living out chaotic narratives lack control and connection to others and the self (Frank, 2013). The third ideal type of narrative, the 'quest narrative', encompasses the transition and transformation. In quest narratives, the teller becomes the 'hero' in their own story and embodies the agency to view illness as a personal journey (Frank, 2013).

Ethics

The study was approved by The University of Southern Denmark (Notification number: 11.471). All participants received both oral and written information before providing their written consent. Participants were anonymised and given pseudonyms, and sensitive personal information was omitted in field notes and the included citations. The study was conducted in accordance with the principles of the Helsinki Declaration (WMA, 2022). The Committee on Health Research Ethics in the Region of Southern Denmark reviewed the study protocol and determined that the study was not required to obtain ethical approval (case number: 20202000–211).

Nonetheless, we experienced ethical dilemmas that extended beyond informed consent and ethical codebooks. Our awareness of the participants' experiences of harm on the narrative courses required situational, motivated actions as the courses unfolded, and HSG felt ethically inclined to go beyond ordinary procedural ethics and was obliged to navigate ethics in practice (Broholm-Jørgensen & Tjørnhøj-Thomsen, 2022; Guillemin & Gillam, 2004). This required making on-the-spot ethical decisions and acting to reduce the psychological stress and harm the participants were experiencing (Broholm-Jørgensen & Tjørnhøj-Thomsen, 2022; Müller et al., 2022). In most of these situations, the course professionals were present and could address the situation as it unfolded. On other occasions, some participants approached HSG in person and shared sensitive information they wished to be brought to the professionals, as they were not comfortable sharing their frustrations with the professionals themselves. Some of this information was, in the participants' own words, critical for their further participation in the course. HSG was given consent to bring forth these concerns to the professionals, which was done as soon as possible to help reduce the harmful experiences for the participants.

Findings – a lack of room for suffering

In the following sections, we present different accounts of the participants' experiences of harm. The overall finding is that for some of the participants there was a lack of room for their suffering that caused them to experience harm. Our findings suggest that circumstances beyond the participants' cancer treatment, sequelae and prognosis also influenced the participants' experiences. Circumstances such as age, marital status and having children living at home mattered, especially concerning the adoption of a cheerful and grateful attitude.

Nevertheless, the focus here is the harm experienced relating to the narrative courses, further described in two sub-themes: the approach of rehabilitation and the dominant stories of cancer.

The approach of rehabilitation

Our findings suggest that a rehabilitation approach, including encouraging the participants to be aware of important values in life and to reflect and act on significant roles in their lives, dominated on the courses. Generally, the exercises and how they were framed focused on life beyond the consequences of the cancer illness and encouraged the participants to identify and tell stories based on their resources, hopes and dreams. Little room was left for participants to express feelings of sorrow, sadness or anxiety, or to find relief from their suffering.

Hanne was a young mother of three small children. Her situation differed from most of the participants, as most of the other participants were >50 years of age and had adult children and/or grandchildren. Hanne shared her diagnosis of incurable, advanced cancer with the other participants at REHPA, but she could not participate in the way some of the others talked and joked. On this course, many of the participants experienced the group as harmonic and inclusive, yet the humour quickly evolved and became dark – perhaps even morbid. Some participants joked extensively in the plenum about the participants' imminent demise and problems of not having an intimate partner, for instance stating that 'If we find someone to be with, we can just say to them that they won't have to put up with us that long anyway' (field notes). Although such 'jokes' often sparked laughter in the room and contributed to a generally cheerful atmosphere, some participants felt alienated.

In a plenum conversation, Hanne voiced her frustration: 'I've felt so lonely among you. I wanted to go home multiple times and yet I stayed. The way you talk and joke, I'm just not there yet. I'm so scared of dying and leaving my children alone' (field notes). In the oral plenum evaluation at the end of the four-day residential stay, Hanne elaborated on her experience:

> I felt wrong, and I didn't get any great epiphanies. And I felt lonely during the exercises, I have been very close to going home and I cried enormously but I also faced some things. It's been extremely hard for me, sometimes too hard. (Field notes)

The group dynamic in this course, which made some participants experience a 'tight-knit community' (field notes), made Hanne feel 'wrong' and 'lonely'. The severity of her situation conflicted with the cheerful atmosphere that evolved through the group dynamics.

Theresa, a female in her 50s who participated in the same course as Hanne, voiced similar challenges with the atmosphere and humour. In the same plenum evaluation session, Theresa said to the other participants and clinical staff:

> I recognise some of the things that Hanne says, I've also had a sense of reinforcement of the loneliness that was there. It has been extremely hard, too intense . . . . And it can be nice with a little humour but not if it becomes a general mood (cries). (Field notes)

Theresa felt that the 'too cheerful vibe' was not only created and reinforced by the participants but also by the professionals and in the narrative exercises. Theresa also addressed what she experienced as expressions of 'overwhelming gratitude' that dominated both the formal sessions and non-formal gatherings during the course, which did not leave room for her to express her feelings of anxiety and sorrow. Hanne and Theresa's sense of being alone was reinforced by not being able to comply with the perceived vibe and humoristic approach. Consequently, they both called the research clinic after the first part of the course and declined to participate in the two-day follow-up, as the initial part of the course had caused them too much distress.

Most of the participants complied with the course's premise of zooming in on themes such as values, relationships and finding new paths in life. They were able to tell stories based on humour, gratitude and hope. Yet some participants failed to comply – either intentionally because they felt the exercises or dominating stories were 'non-sense' as one participant put it, or unintentionally because they simply could not. Some participants were not able to deliver the reflections and answers as anticipated in the exercises because their current life situations were dominated by suffering.

Lotte, a female participant in the municipal rehabilitation centre course, openly shared her challenges with finding out 'what is now in life' (field notes). Although having been successfully treated for cancer, Lotte suffered from long-term sequelae and personal challenges. On the second day of course IV, the participants were given an exercise in which they used a timeline to identify key turning points and reflect upon how these turning points had influenced their lives. While introducing the exercise, the professionals' emphasised that seemingly negative turning points in life may also lead to some positive outcomes.

In a short break after the participants had worked individually with the exercise, Lotte said to the group that it was 'brutal to see your life on paper like that. Why am I here?' (field notes). On the third day, before the day's programme commenced, Lotte described to the group how she had experienced the previous day: 'Yesterday morning was very brutal, actually, I've never felt that bad in my entire illness trajectory. I couldn't keep myself together' (field notes). Lotte furthermore expressed that she 'felt dropped on the floor' (field notes) and she questioned the meaning of the course. She stated that although she found the exercises interesting, she felt that it was inappropriate to initiate an exercise that made her feel so bad and that she was then expected to move on to the next exercise shortly thereafter: 'It's like having an open wound. Like something was ripped to pieces, without being patched back together. It's still bleeding' (field notes). Not only in the turning point exercise, but at multiple times during the course, Lotte struggled to comply with the professional framing of finding possibilities and mobilising her past resources to recover from her illness. Looking back at her life became a source of frustration for Lotte, causing her to confront previous disappointments and sorrows in life. This process of revisiting previous experiences seemed to work against Lotte rediscovering meaning in her current life situation and turned out to be counterproductive for her. Lotte's narrative had some chaotic and non-linear characteristics that she felt were dismissed in the professional framing of the course and by the professionals who encouraged her 'to move on' from the exercise (field notes).

Dominating stories of life with cancer

Jenny, a younger female treated for cancer, was interviewed twice: once during and once after the course. In the second interview, Jenny expressed how she was 'tired' of the course and the rehabilitation centre in general. She had grown very unsatisfied with the narrative course. Jenny originally joined the course because she 'wanted to come and talk to somebody who was in the same boat' (Interview 1), and she longed to be 'honest' and be able to say whatever she wanted. This desire for honesty in the group setting became a struggle for Jenny:

> I just struggled to figure out what the convention was because we need to be open and honest, but not too honest and open. We must be personal, but not too personal, most definitely not private. You know, I couldn't figure it out. (Interview 1)
>
> I probably just expected that here you were allowed to be wherever you were and that all feelings were okay. That nothing was inconvenient. (Interview 1)

Struggling to find a level of honesty and disclosure aligned with the other participants, Jenny jokingly described herself as 'the one who went naked to a party'. As the course progressed, Jenny experienced more and more undesirable consequences, which made her feel that her stories and perspectives on her illness were not legitimate. In one specific exercise (unique to the setting), the participants were requested to bring two pictures: one that characterised them right now and one that showed something they wanted more of. Jenny felt excluded and made to feel different, as she felt she could not comply with the exercise. Consequently, she declined to participate in the last follow-up day:

Jenny: I think it became an admission ticket, you should bring something nice and something beautiful and something life-affirming and something lovely and something wonderful. And I felt provoked and, actually, I couldn't solve the assignment.

Interviewer: You didn't know what to bring?

Jenny: No. No, I didn't know what to bring, because the thing that has characterised me lately, well then I should take a picture of a toilet and bring it, and I thought, I can't do that because it's such an unspoken admission ticket on this course, at least I feel that there is a vibe that it must be inspiring, it must be beautiful, it must be life-affirming. (Interview 2)

Jenny suffered from the side effects of radiation to her bowels, causing her everyday life to be spent partly on the toilet or in constant alertness about when she needed to go next. She shared openly with the group that this affected her everyday life tremendously.

During the interviews, Jenny became increasingly annoyed with the whole organisation of the course, possibly because she found a willing listener and understanding counterpart in the interviewer. Throughout the interviews, her stories developed into a more coherent counter-narrative through which Jenny legitimised her resistance and feelings of otherness, as she was able to position herself in opposition to the narrative course and professionals.

Jenny described how she felt that the focus on the beautiful and life-affirming elements of being successfully treated for cancer was a form of 'currency' that could be exchanged for positive attention on the course: '[A]nd the currency is absolutely the beautiful, the inspiring, the giving. And I became majorly indignant about how you needed to give such things when you are at your most difficult place' (Interview 2). Jenny elaborated and explained how she felt pressured to tell positive stories 'to ease the anxiety of the outside world' (Interview 1) and that this pressure provoked her: 'It's not enough that I have had cancer, now I need to come and confirm other people's lives, I don't want to do that. Because there is nothing beautiful or life-affirming in it' (Interview 2).

When asked by the interviewer, in the second interview, whether the course had not helped her at all, Jenny replied, 'No. I just realised that I am more wrong than I thought', (Interview 2) and continued that she wished that she had never attended the course or had never been referred to the rehabilitation centre at all.

Jenny's resistance to focusing on the positive aspect corresponds with the findings highlighted in the previous section. Hannes's stories of fear and her stress about the future conflicted with the cheerful stories of some of the other participants, and she felt alienated and wrong when her stories were not recognised as legitimate in the group. Likewise, Theresa contested how the telling of some stories was favoured for contributing to the cheerful atmosphere, and she felt that an existing sense of loneliness was reinforced.

Discussion

The risk of doing harm

Targeted interventions aim to alter the behaviour, structures or practices of target groups to enhance or maintain a health-related area (Broholm-Jørgensen & Tjørnhøj-Thomsen, 2022). Although health interventions may take the form of an experiment, limited attention has been paid to possible unintended and harmful consequences when designing, implementing or evaluating the interventions, in spite of the fact that public health interventions may cause harm (Bonell et al., 2015; Broholm-Jørgensen & Tjørnhøj-Thomsen, 2022). Lorenc and Oliver (2014) proposed a framework for categorising the potentially harmful effects of interventions (Lorenc & Oliver, 2014), and Bonell et al. (2015) argued that evaluators should not just document harm but also explore the mechanisms behind the harm. They recommended that in addition to intervention logic models, evaluators should develop 'dark logic models' in which all mechanisms, contexts, interactions, inputs and processes should be considered to better help evaluators anticipate and assess potential harm caused by the intervention (Bonell et al., 2015).

We find it possible that this lack of attention to the possible 'dark logic mechanisms' in the narrative courses led to some of the findings we have presented. As these mechanisms were unforeseen, no countermeasures were built into the course programme. However, the professionals mitigated the expressed harm by offering participants an individual debriefing conversation.

Furthermore, research has emphasised the necessity of selecting the right target group when designing health interventions (Aagaard-Hansen et al., 2023). In the context of research, vulnerability is a widely discussed concept. The concept of situational vulnerability indicates that participants may be vulnerable in one specific situation, yet not in other situations (Gordon 2020). We find it plausible that the experiences of harm reported in this study may be related to the participants' situational vulnerability. It is possible that having young, dependent children represent a specific challenge regarding the creation of meaning and hope when living with incurable cancer. Similarly, Lotte had struggled with social relations after she fell ill (field notes), which possibly influenced her experiences of harm on the narrative course.

Age is an important factor in the specific experiences of cancer patients, as supported by previous research. Earlier adulthood is a period in life that differs from older age: for instance, establishing a family and entering the workforce often dominate in earlier adult life (Aagesen et al., 2022). Although the participants underwent internal screening by the professionals, some participants might have experienced everyday struggles in such a way that their needs for rehabilitation and palliative care were not aligned with the aim and organisation of the course. Likewise, it is possible that the degree to which the participants experienced harm varied because of elements outside of the course. These findings indicate how 'cancer patients' are a diverse target group with varying challenges and life circumstances.

A key element of the courses was the group composition. Throughout the courses, the participants engaged with each other, as all exercises involved group work. Previous research has demonstrated that in the rehabilitation of cancer patients, group interventions or social peer support groups are often associated with high satisfaction among the participants (Gärtner et al., 2021; Midtgaard et al., 2006; Nordentoft et al., 2022). Yet participants in group courses may experience harm. A recent systematic review of the benefits and challenges of cancer support groups found that although peer support has various benefits for the participants, certain challenges are also reported, such as tensions arising from group dynamics and the confrontation with other participants' suffering (Jablotschkin et al., 2022). This study supports these findings, indicating that the group dynamics involving dark humour and overall cheerfulness became a source of experiences of harm for some of the participants.

Combined approaches

Scholars have discussed what happens when rehabilitation and palliative care are combined, as it seems likely that both fields undergo a change when merged. Timm et al. (2021) argue that 'when rehabilitation is integrated in palliative care, it may be transformed in favour of function-focused and one-dimensional needs, while the complexity and interrelation of needs may be more difficult to articulate and are therefore silenced' (p.12). Normative values from the field of rehabilitation might put pressure on patients who are suffering and need to be cared for (Timm et al., 2021) . Our findings support these concerns. Combining the two approaches into one course is a complex matter, and specific attention is required to ensure that the two approaches supplement each other rather than one approach suppress the other.

In addition to the focus on rehabilitation and palliative care, the narrative courses draw on knowledge from several fields and practices, not least psychiatry and psychology (Chochinov et al., 2005; White, 2006). Although the courses had no explicit therapeutic intent, the professionals acknowledged that the courses may have therapeutic effects (field notes). Several participants expressed positive experiences with the courses as being 'therapeutic', especially after successful group work (field notes). Yet our findings illuminate that some participants' experiences deviated from this. Within group psychotherapy, it is also recognised that adverse consequences may arise from psychosocial treatments, as upsetting social interactions in peer groups may cause distress (Roback, 2000; Strauss, 2021). Our findings suggest that combining psychological theories and methods, narrative exercises and practices and assumptions from the fields of rehabilitation and palliative care might require a more thoroughly described model to deal with and ease harmful experiences among participants.

Dominating narratives of illness

The stories that dominated the courses shared traits with ‘the quest narrative’ (Frank, 2013) in which the narrator typically undergoes a transformation to become the hero of their own story and from that position shares deeper insights and meaning gained from being ill (Frank, 2013). When participants openly resisted the quest narrative plot, as did Hanne, Jenny and Theresa, it was accompanied by a personal cost of feeling rejected, lonely and ‘being wrong’, thereby resulting in unforeseen and harmful experiences.

In this study, we draw on accounts from the participants who in some way made their experiences of harm noticeable during or after the course by talking about their experiences openly in the plenum conversations or communicating their views to the interviewer in the individual interviews. In contrast to the dominant stories of the courses, these were often stories of suffering and hopelessness. Following Frank’s terminology, Lotte’s stories could be recognised as having chaotic narrative traits, as her stories were often disordered and without clear coherence. Yet true chaos narratives are non-stories and often remain untold (Frank, 2013). According to Frank (2013), people who tell stories in the form of a chaos narrative lack distance from their own stories and the ability to reflect critically on their situation. The future is presented as bleak or non-existent, and this challenges the listener, who often seeks to establish a sense of meaning and a form of comfort (Frank, 2013). Although useful as a frame for understanding illness narratives as a genre, Frank’s typology of restitution, quest and chaos narratives lacked the necessary dimension and nuance required for the purposes of our analysis.

Although some of the participants’ stories are reminiscent of the chaos narratives described by Frank (2013), they are not *only* chaotic. The stories were often rooted in critical self-reflection and displayed an understanding of the participants’ positioning in life (and in the social scene of the course). And while Frank’s typology recognises the value of letting people voice these chaos narratives and the need for chaos narratives to be acknowledged (before one may move one) (Frank, 2013), the participants in our study insisted on being heard and understood. Our findings demonstrate that Hanne, Theresa, Lotte and Jenny insisted that their stories of suffering and despair should be acknowledged, legitimised and equally valued as stories of life with or after a life-threatening illness.

Frank reminds us: ‘To deny a chaos story is to deny the person telling this story, and people who are being denied cannot be cared for’ (Frank, 2013, p. 109). Yet our findings call for a theoretical advancement of our understanding of illness narratives and their place in narrative methods and research, as Frank’s typology (2013) did not suffice in our case. Therefore, we suggest a fourth type: a narrative of suffering.

The narrative courses rest on theories and practices in which narrative methods are considered mainly as a benign process, yet Lotte’s experiences illustrate how the focus of narrating one’s life can also constitute a harmful process. Our findings support those of scholars who state that the focus on the narrating self or the benefits of narrating one’s life may not always be for the good (Strawson, 2004). Furthermore, the ‘coherence paradigm’ of narrative studies – encouraging linear and coherent narratives and indicating that coherent life stories make people live better and more ethical lives – has been contested (Hyvärinen, 2010). Other scholars have discussed how Frank’s typology favours the quest narratives and dismisses the suffering in illness narratives (Donnelly, 2021; Nielsen, 2019). Nielsen and others call for counter-narratives that legitimise feelings of anger and encourage stories that rebel against dominating discourses of cancer (Nielsen, 2019). Yet our findings suggest that the participants felt a need to voice and dwell on their feelings of suffering and distress without being forced to find meaning or hope. This resonates with the findings of scholars who have criticised the focus on the transformative powers of illness narratives and the endeavour to find meaning within suffering (Aaltola, 2019; van Hout et al., 2022; Wasson, 2018). Cancer as a serious illness is heavily embedded in public discourse. Metaphorically, cancer is often portrayed as a battle to either win or lose (Hansen, 2018; Nielsen, 2019). How one is expected to feel as a 'proper' cancer patient is often wrapped in terminology revolving around hope and positivity, which creates a normative pressure for the patient to endure the suffering or even flourish during difficult circumstances (Broom et al., 2019; Nielsen, 2019). We find it plausible that suffering needs to be witnessed in its inherent meaninglessness, and if not narration might result in harmful experiences.

Strengths and limitations

The ethnographic method provided us with the opportunity to explore experiences of harm as they unfolded in specific social contexts. The first author was present in situations in which the participants voiced their experiences of harm. The choice of methods was specifically productive for uncovering aspects of the course that perhaps would not otherwise have been noticeable. Dissatisfaction with elements of the course was not evident in the written evaluation forms completed by all participants in the REHPA course. Overall, the participants expressed general gratitude both on a micro level: the helpful staff and wonderful settings, as well as on a macro level: the welfare state for providing them with the opportunity to participate in such courses.

As the narrative courses were complex, we could have utilised an evaluation framework to strengthen our findings. The study could also have benefited from developing a dark logic model (Bonell et al., 2015). Our study includes a relatively small study sample, and the testing of the courses was carried out only four times in total. Our results point to the need for further research, and they suggest the importance of taking a cautious approach to participants' experiences and that this should be taken into account in the planning, testing and assessment of health care interventions.

Conclusion

Our findings illustrate that a rehabilitation approach dominated the narrative courses, which suppressed the palliative principle of offering relief from suffering. We have shown how some stories were continuously supported and encouraged, while stories of suffering were suppressed in a complex interplay involving the participants, the narrative exercises and the professionals. Furthermore, it seems plausible that the experiences of harm were related to the participants' situational vulnerability and that harmful mechanisms are produced in specific group constellations.

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References

Aagaard-Hansen, J., Hindhede, A. L., & Maindal, H. T. (2023). A conceptual framework for selecting appropriate populations for public health interventions. *Frontiers in Public Health*, 11. https://doi.org/10.3389/fpubh.2023.1161034

Aagesen, M., Pilegaard, M. S., Hauken, M. A., Wæhrens, E. E. E., & Cour, K. (2022). Users' perspective on rehabilitation interventions for young adult cancer survivors: A group concept mapping study. *European Journal of Cancer Care*, *31*(6), e13734–n/a. https://doi.org/10.1111/ecc.13734

Aaltola, E. (2019). Confronting suffering with narrative theory, constructed selfhood, and control: Critical perspectives by Simone Weil and Buddhist metaphysics. *Journal of Disability & Religion*, *23*(3), 227–250. https://doi.org/10.1080/23312521.2019.1567296

Bo, I. G., Christensen, A.-D., & Lund Thomsen, T. (2016). *Narrativ forskning: tilgange og metoder* (Vol. 11). Hans Reitzel. https://go.exlibris.link/znssyyBB

Bonell, C., Jamal, F., Melendez-Torres, G. J., & Cummins, S. (2015). 'Dark logic': Theorising the harmful consequences of public health interventions. *Journal of Epidemiology & Community Health*(*1979*) *69*(1), 95–98. https://doi.org/10.1136/jech-2014-204671

Broholm-Jørgensen, M., & Tjørnhøj-Thomsen, T. (2022). Etiske overvejelser og utilsigtede konsekvenser i interventionsforskning (Ethical considerations and unforeseen consequences in intervention research). InK. S. Petersen, H. T. Maindal, L. Ledderer, & C. Overgaard (Eds.), *Komplekse interventioner* (pp. 245–266). Aalborg Universitetsforlag.

Broom, A., Kenny, K., Kirby, E., & Lwin, Z. (2019). The collective/affective practice of cancer survivorship. *The British Journal of Sociology*, *70*(4), 1582–1601. https://doi.org/10.1111/1468-4446.12616

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, *23*(24), 5520–5525. https://doi.org/10.1200/JCO.2005.08.391

Donnelly, C. (2021). Claiming chaos narrative, emerging from silence. *Disability & Society*, *ahead-of-print*(ahead-of-print), *39*(1), 1–15. https://doi.org/10.1080/09687599.2021.1983420

Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Ågård, A. S. (2011). Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, *39*(8), 1922–1928. https://doi.org/10.1097/CCM.0b013e31821e89c8

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (Second ed.). The University of Chicago Press. https://go.exlibris.link/kyDYTLz1

Gärtner, H. S., Shabnam, J., Aagesen, M., Guldin, M.-B., Vind, A. B., Marsaa, K., Bergenholtz, H. M., Graven, V., Sampedro Pilegaard, M., & Thuesen, J. (2023). Combined rehabilitation and palliative care interventions for patients with life-threatening diseases – PREGOAL. A scoping review of intervention programme goals. *Disability and Rehabilitation*, 1–10. https://doi.org/10.1080/09638288.2023.2246373

Gärtner, H. S., Timm, H. U., & Raunkiær, M. (2021). *Meningsfulde fællesskaber for mennesker med kronisk, fremadskridende kræft (Meaningful communities for people with advanced cancer)*. https://go.exlibris.link/cw8frLJ4

Gordon, B. G. (2020). Vulnerability in research: Basic ethical concepts and general approach to review. *The Ochsner Journal*, *20*(1), 34–38. https://doi.org/10.31486/toj.19.0079

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, *10*(2), 261–280. https://doi.org/10.1177/1077800403262360

Hansen, P. K. (2018). *Illness and heroics: On counter-narrative and counter-metaphor in the discourse on cancer*. https://go.exlibris.link/R9j5hcgk

Hastrup, K. (2010). *Ind i verden: En grundbog i antropologisk metode (In the world: A handbook of anthropological method)* (2. udgave ed). Hans Reitzel. https://go.exlibris.link/ddYHGYCL

Hyvärinen, M. (2010). *Beyond narrative coherence* (Vol. 11). John Benjamins Pub. Co.

Jablotschkin, M., Binkowski, L., Markovits Hoopii, R., & Weis, J. (2022). Benefits and challenges of cancer peer support groups: A systematic review of qualitative studies. *European Journal of Cancer Care*, *31*(6), e13700–n/a. https://doi.org/10.1111/ecc.13700

Jeppesen, J. (2013). *Rehabilitering Med Historier: En Socio-Narratologisk unersøgelse Af Journalistisk fortælling Som Metode Til at forstå Patienten Som Medmenneske (Rehabilitation with stories: A socio-narratological study of journalistic narrative as a method to understand the patient) [Publication number dissertation/thesis Syddansk Universitet]*. Odense. https://go.exlibris.link/0Hdxfrww

Jess, M., Nielsen, S. P., Rasmussen, A., Skov-Pedersen, J., & Timm, H. (2023). Stories of a long life with HIV: A qualitative study of a narrative intervention. *Scandinavian Journal of Caring Sciences*, *37*(3), 777–787. https://doi.org/10.1111/scs.13161

Jess, M., & Timm, H. U. (2019). *Hiv og liv gennem 25 år:Evaluering af et rehabiliteringsophold med fokus på fortællinger mellem mennesker der har levet et langt liv med hiv (Life with HIV the last 25 years)*. https://go.exlibris.link/jRSR7F8H.

Kirkevold, M., Martinsen, R., Bronken, B. A., & Kvigne, K. (2014). Promoting psychosocial wellbeing following stroke using narratives and guided self-determination: A feasibility study. *BMC Psychology*, *2*(1), 4–4. https://doi.org/10.1186/2050-7283-2-4

Kleinman, A. (1998). *The illness narratives: Suffering, healing, and the human condition*. Basic Books. https://go.exlibris.link/s0w6V8B3

Krogstrup, H. K., & Kristiansen, S. (2015, Invalid Date). *Deltagende observation (Participant observations)* (Vol. 6). Hans Reitzel. https://go.exlibris.link/MFz5TDrv

la Cour, K., Ledderer, L., & Hansen, H. P. (2016). Storytelling as part of cancer rehabilitation to support cancer patients and their relatives. *Journal of Psychosocial Oncology*, *34*(6), 460–476. https://doi.org/10.1080/07347332.2016.1217964

Lewandowska, A., Rudzki, G., Lewandowski, T., & Rudzki, S. (2020). The problems and needs of patients diagnosed with cancer and their caregivers. *International Journal of Environmental Research and Public Health*, *18*(1), 1–19. https://doi.org/10.3390/ijerph18010087

Lorenc, T., & Oliver, K. (2014). Adverse effects of public health interventions: A conceptual framework. *Journal of Epidemiology & Community Health*(*1979*)*68*(3), 288–290. https://doi.org/10.1136/jech-2013-203118

Meyer, T., Kiekens, C., Selb, M., Posthumus, E., & Negrini, S. (2020). Toward a new definition of rehabilitation for research purposes: A comparative analysis of current definitions. *European Journal of Physical and Rehabilitation Medicine*, *56*(5), 672–681. https://doi.org/10.23736/S1973-9087.20.06610-1

Midtgaard, J., Rorth, M., Stelter, R., & Adamsen, L. (2006). The group matters: An explorative study of group cohesion and quality of life in cancer patients participating in physical exercise intervention during treatment. *European Journal of Cancer Care*, *15*(1), 25–33. https://doi.org/10.1111/j.1365-2354.2005.00616.x

Müller, M., Olesen, A., & Rømer, M. (2022). Social work research with marginalized groups - navigating an ethical minefield. *Nordic Social Work Research*, *12*(1), 63–75. https://doi.org/10.1080/2156857X.2020.1756388

Nielsen, E. (2019). *Disrupting breast cancer narratives: Stories of rage and repair*. University of Toronto Press. https://go.exlibris.link/9KX8YhSV

Nordentoft, S., Dieperink, K. B., Johansson, S. D., Jarden, M., & Piil, K. (2022). Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers. *Scandinavian Journal of Caring Sciences*, *36*(3), 815–829. https://doi.org/10.1111/scs.13019

Nottelmann, L., Groenvold, M., Vejlgaard, T. B., Petersen, M. A., & Jensen, L. H. (2021). Early, integrated palliative rehabilitation improves quality of life of patients with newly diagnosed advanced cancer: The Pal-Rehab randomized controlled trial. *Palliative Medicine*, *35*(7), 1344-1355. https://doi.org/10.1177/02692163211015574

Nottelmann, L., Jensen, L. H., Vejlgaard, T. B., & Groenvold, M. (2019). A new model of early, integrated palliative care: Palliative rehabilitation for newly diagnosed patients with non-resectable cancer. *Supportive Care in Cancer*, *27*(9), 3291–3300. https://doi.org/10.1007/s00520-018-4629-8

Peoples, H., Nissen, N., Brandt, Å., & la Cour, K. (2021). Perceptions of quality of life by people with advanced cancer who live at home. *The British Journal of Occupational Therapy*, *84*(11), 723–730. https://doi.org/10.1177/0308022620976839

Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, K., Goh, C. . . . Pastrana, T. (2020). Redefining palliative care—A new consensus-based definition. *Journal of Pain and Symptom Management*, *60*(4), 754–764. https://doi.org/10.1016/j.jpainsymman.2020.04.027

Rasmussen, A. R., Jespersen, E. R., Backmann, T. R., & Jarlbæk, L. R. (2020). *Praksisbeskrivelser – Forskningsklinik REHPA. Standard rehabiliteringsforløb for Mennesker Med Eller Efter kræft. (Practice Descriptions Research Clinic REHPA – Standard Rehabilitation Programme for People with or After Cancer)*. REHPA. https://www.rehpa.dk/wp-content/uploads/2020/04/Rehpa_praksisbeskrivelser_020420_enkelt.final_.pdf

Raunkiaer, M. (2022). The experiences of people with advanced cancer and professionals participating in a program with focus on rehabilitation and palliative care. *Omega: Journal of Death and Dying*, 302228211058307–302228211058307. https://doi.org/10.1177/00302228211058307

Raunkiaer, M., & Gärtner, H. S. (2020). *Rehabilitering og palliation til mennesker med kronisk fremadskridende kræft: erfaringer fra to REHPA forløb 2019-2020. REHPA, Videncenter for Rehabilitering og Pallation (Rehabilitation and Palliative care to people with advanced cancer - experiences from two REHPA courses 2019-2020)* (Report No. 19). REHPA. https://www.rehpa.dk/wp-content/uploads/2020/09/Notat.-Rehabilitering-og-palliation-kraeft.-KRP-forloeb.-final.pdf

Roback, H. B. (2000). Adverse outcomes in group psychotherapy: Risk factors, prevention, and research directions. *The Journal of Psychotherapy Practice and Research*, *9*(3), 113–122. https://go.exlibris.link/hk8pyZfC

Roikjær, S. G., Gärtner, H. S., & Timm, H. (2021). Use of narrative methods in rehabilitation and palliative care in Scandinavian countries: A scoping review. *Scandinavian Journal of Caring Sciences*, (*n/a*(n/a). *36*(2), 346–381. https://doi.org/10.1111/scs.13050

Strauss, B. (2021). "You can't make an omelet without breaking eggs": Studies on side effects and adverse events in group psychotherapy. *International Journal of Group Psychotherapy*, *71*(3), 472–480. https://doi.org/10.1080/00207284.2021.1890089

Strawson, G. (2004). Against narrativity. *Ratio (Oxford)*, *17*(4), 428–452. https://doi.org/10.1111/j.1467-9329.2004.00264.x

Stucki, G., & Bickenbach, J. (2017). Functioning: The third health indicator in the health system and the key indicator for rehabilitation. *European Journal of Physical and Rehabilitation Medicine*, *53*(1), 134–138. https://doi.org/10.23736/s1973-9087.17.04565-8

Tavory, I., & Timmermans, S. (2014). *Abductive analysis: Theorizing qualitative research*. The University of Chicago Press. https://go.exlibris.link/8g7qpD15

Thompson, J. (2022). A guide to abductive thematic analysis. *The Qualitative Report*, *27*(5), 1410–1421. https://doi.org/10.46743/2160-3715/2022.5340

Thomsen, L. L. (2016). Fortællinger om sygdom og død - mellem kaos og restitution (Stories of illness and death - between chaos and restitution). In I. G. Bo, A.-D. Christensen, & T. L. Thomsen (Eds.), *Narrativ Forskning. Tilgange og metoder* (pp. 239–256). Hans reitzels Forlag.

Thuesen, J., Mikkelsen, T. B., & Timm, H. (2016). REHPA. https://www.rehpa.dk/wp-content/uploads/2017/04/Koordinering-af-rehabilitering-og-palliation-til-mennesker-med-livstruende-sygdom.pdf

Tiberini, R., & Richardson, H. (2015). *Rehabilitative palliative care. Enabling people to live fully until they die*. https://www.hospiceuk.org/publications-and-resources/rehabilitative-palliative-care-enabling-people-live-fully-until-they-die

Timmermans, S., & Tavory, I. (2022). *Data analysis in qualitative research: Theorizing with abductive analysis*. University of Chicago Press. https://go.exlibris.link/k9ySGyvJ

Timm, H., Thuesen, J., & Clark, D. (2021). Rehabilitation and palliative care: Histories, dialectics and challenges. *Wellcome Open Research*, *6*, 171. https://doi.org/10.12688/wellcomeopenres.16979.1

van Hout, F., van Rooden, A., & Slatman, J. (2022). Chronicling the chronic: Narrating the meaninglessness of chronic pain. *Medical Humanities*, *49*(1), 1–8. https://doi.org/10.1136/medhum-2021-012331

Wasson, S. (2018). Before narrative: Episodic reading and representations of chronic pain. *Medical Humanities*, *44*(2), 106–112. https://doi.org/10.1136/medhum-2017-011223

White, M. (2006). *Narrativ teori*. Reitzels. https://go.exlibris.link/q46xsDhq

WHO. (2020). *Palliative care*. https://www.who.int/news-room/fact-sheets/detail/palliative-care

WMA. (2022). *WMA declaration of Helsinki – ethical principles for medical research involving human subjects*. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Sub-study II

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"The Most Fantastic Thing is Coming Here as an Individual and Going to Bed as Part of a Group": Participants' Experiences From a Residential Course, for People With Advanced Cancer

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Abstract

People who suffer from advanced cancer may experience a loss of ability to participate in everyday life and meaningful activities, challenging their sense of identity and social relations. Social support in patient-to-patient interactions and the sharing of experiences with people in similar situations may help alleviate distress. This article is based on an ethnographic field study carried out in relation to three residential narrative

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courses, which included 36 persons with advanced cancer. In this study, we aimed to explore whether the courses were perceived as significant by the participants and, if so, in what ways. The field work included 185 hr of observations, six focus group interviews and nine individual interviews. The data were analyzed using an abductive thematic approach. Our findings indicate that the residential courses were generally experienced as meaningful and that in particular the setting, the community, and gaining hope were experienced as significant.

Keywords

rehabilitation, life stories, advanced cancer, narratives, palliative care

Introduction

Individuals living with advanced cancer can experience extended lifespans thanks to early diagnosis and sophisticated medical treatments (Arantzamendi et al., 2020). Nevertheless, chronic illness can lead to a "biographical disruption" (Bury, 1982, p. 169), which encompasses alterations in identity and interpersonal relationships. Living with cancer may therefore be challenging, and the issue of how to sustain or redefine oneself in terms of identity, everyday life, and the future becomes pivotal (Hubbard & Forbat, 2012; Montali et al., 2022).

It is widely recognized that people living with advanced cancer need support to help ease their distress (García-Rueda et al., 2016; Newton et al., 2021). Social support is generally regarded as being important in the process of adjusting to life with a life-threatening illness (Applebaum et al., 2014; Tao et al., 2022). Social support is a complex concept, including emotional support from family members, support from healthcare professionals and from peers (Drageset et al., 2016; Helgeson, 2003). In the Scandinavian setting, experiences from diverse group-based interventions for individuals facing life-threatening illnesses indicate that interactions between patients are both advantageous and meaningful (Gärtner et al., 2021; Hansen et al., 2011; la Cour et al., 2015; Midtgaard et al., 2006; Nordentoft et al., 2022; Raunkiaer, 2024). For example, Missel et al. (2019) found that participants in a group-based exercise intervention for people with operable lung cancer perceived a sense of community and belonging in the group as being essential for managing their illness (Missel et al., 2019). A synthesis of international, qualitative literature, examining the role of social support in physical activity interventions for cancer survivors illustrated how patient-to-patient interactions were often recognized as contributing to strengthening relationships and reduce feelings of distress, such as of isolation (McDonough et al., 2021). Although there are significant differences between how social support through patient-to-patient interventions is organized and implemented, they all facilitate social interaction between people in similar life circumstances.

Narrative methods may facilitate reflections, support a sense of identity, and aid in the meaning-making process for individuals living with life-threatening illnesses (Roikjær et al., 2021). In Scandinavia, examples of narrative methods include the implementation of patient diaries in intensive care units (Bäckman & Walther, 2001; Egerod et al., 2011), creative writing courses inspired by narrative medicine (Hansen et al., 2018, 2019), and dignity therapy (Houmann et al., 2010, 2014). International examples may include a life review and illness narrative intervention for people with advanced cancer (Wise et al., 2018), an emotional disclosure writing intervention (Cepeda et al., 2008) and expressive writing for hospice patients (Imrie & Troop, 2012). Three residential group-based courses applying narrative methods (hereafter called narrative courses) for people with advanced cancer were conducted in 2022. The narrative courses were informed by a theoretical framework drawing mainly on dignity therapy (Chochinov et al., 2005) and narrative therapy (White, 2006). Additionally, the courses operated on the premise that narratives are socially constructed and that individuals forge and continually reshape their identities through the acts of storytelling and active listening (Frank, 2013; Jess et al., 2023; White, 2006). The narrative courses aimed to enhance the participants' ability to rediscover or construct meaning and coherence in their lives, as well as to foster hope amidst the challenges of living with advanced cancer.

In this study, we aimed to explore whether the courses were perceived as significant by the participants and, if so, in what ways.

The Narrative Courses

The narrative courses were designed and carried out in the research clinic of REHPA, the Danish Knowledge Center for Rehabilitation and Palliative Care. REHPA is publicly funded, and the research clinic is placed in a hospital ward in Nyborg, Denmark. The narrative courses were developed within the framework of REHPA's standard rehabilitation courses for people who have or have had cancer (Rasmussen et al., 2020). The narrative courses were based on a previous, successfully tested and evaluated narrative course for long-term survivors of HIV (Jess et al., 2023; Jess & Timm, 2019). The course designers, comprising a psychologist and a nurse and family therapist who were originally involved in the HIV course, modified the course to cater to individuals living with advanced cancer. This effort was in collaboration with REHPA professionals, including a psychologist, nurses, and physiotherapists, who would later conduct the three adapted courses. The adaptation focused mainly on practical aspects to accommodate any potential constraints in the participants' resources. In April 2021, the course designers provided training to the REHPA professionals on how to effectively facilitate the revised courses. Authors HSG and HT were present at this training session to obtain a more in-depth understanding of the narrative exercises involved.

In line with REHPA's general courses, the narrative courses included an initial, four-day residential stay and a two-day residential follow-up stay after 5–6 weeks. Upon arrival, all participants received a notebook and a compendium consisting of six narrative exercises with short introductions. All exercises included individual, written work, followed by smaller group discussions, and ended in plenary conversations including all participants (see Table 1, Supplementary, for an overview of the narrative exercises on the four-day stay). The narrative exercises required personal engagement, as in every exercise the participants had to reflect on elements from their life stories and share their thoughts with the group. Sessions with physical activity were also included.

Participants were >18 years and diagnosed with advanced cancer, were self-reliant, could speak and understand Danish, and were willing to partake in the narrative exercises and the research conducted at the clinic. The participants were referred to REHPA by their treatment doctor and underwent internal assessment by telephone from the REHPA staff to align expectations before enrollment in the course. Participants came from all over Denmark and participation was free of charge, apart from individual transportation. The participants were predominantly female (30 out of 36 participants) and ranged in age from 39–87 years. A total of 28 participants completed the narrative courses. Reasons for not completing the course varied. One participant died, two did not complete the courses due to general illness, three due to unknown reasons, and two participants declined to attend the follow-up days due to harmful experiences at the initial stay (Gärtner et al., 2024).

Although located on the third floor of a hospital, the research clinic is placed near historic architecture and nature, and the research clinic is designed to be calming and inspiring, for instance, by means of colors from nature (Falk & Timm, 2018; Rasmussen et al., 2020). All participants had private rooms and all meals were provided, which fulfilled nutritional requirements and dietary preferences and restrictions. The staff was professionally trained and had experience in dealing with people living with life-threatening illness.

Methods

Study Design

This study is based on ethnographic field work (Hammersley & Atkinson, 2019), including participant observations, individual interviews, and focus group interviews (see Table 1 for an overview of data material). The field work was conducted by the first

Table 1. Data Material.

REHPA Course no.	I	II	III	Total
Focus groups (groups of 3–6 participants) (Number of participants, total)	*n* = 2 (11)	*n* = 2 (10)	*n* = 2 (7)	*N* = 6 (28)
Individual interviews	*n* = 3	*n* = 3	*n* = 3	*N* = 9
Participatory observations	64.5 hours	59 hours	61.5 hours	185 hours

author, HSG. In total, 36 persons who participated in all or parts of the narrative courses at REHPA were included. The focus of the field work was on actions, language and nonverbal expressions. The field notes written throughout the fieldwork are part of the data material (Emerson et al., 1995). Three participants were recruited from each course group for individual interviews. Participants were sampled on the basis of interest in participating and pragmatic reasons (was it feasible within the timeframe, and did the participant have the mental resources). The interviews were conducted between the initial and the follow-up stays, in the participants' homes or at the university. The six focus group interviews were carried out on the last day of the follow-up stays and included all remaining participants, amounting to 28 participants in total. Both the individual interviews and the focus groups focused on the participants' overall experiences with the course and the narrative exercises in particular.

Ethics

Oral and written information was provided to the participants before they gave their written consent. We have conducted this study in accordance with the principles of the Helsinki Declaration (WMA, 2022), and the participants were informed about their right to withdraw from participation in the study. All participants have been given pseudonyms, and identifying information was changed or left out to protect anonymity. The study was approved by the University of Southern Denmark (Notification number: 11.471) and the Committee on Health Research Ethics in the Region of Southern Denmark determined that the study did not require separate ethical approval (case number: 20202000-211).

Data Analysis

We conducted an abductive thematic analysis (Thompson, 2022). In abductive reasoning, the researcher makes sense of the patterns in the data by interpreting them in relation to existing theories, while still looking for new interpretations (Thompson, 2022; Timmermans & Tavory, 2022). In this way, abductive reasoning represents a middle ground between inductive and deductive methods of analysis (Thompson, 2022), building on the knowledge of others while still looking for empirical surprises in the material (Timmermans & Tavory, 2022).

All of the data material was included in the analysis. We were inspired by Thompson's (2022) eight-step process for abductive thematic analysis: Transcription and Familiarization, Coding, Codebook, Development of themes, Theorizing, Comparison of Datasets, Data Display, and Writing up (Thompson, 2022). First, HSG transcribed the audiotapes. During this process, initial notes were made, and a refamiliarization with the data and deep reading were conducted. HSG coded the material and developed a codebook in an iterative process. Themes were developed from sorting and investigating the relationships between the codes. Next, HSG began theorizing, a process in which the researcher's theoretical perspective guides the search for an understanding of the relationship between the themes and the dataset, as well as being open to instances in which existing literature or theory does not suffice (Thompson, 2022). An example of the analysis process is presented in Table 2 and an example of the development of a final theme is illustrated in Figure 1. A continuous refinement, including refinement of themes, took place through discussions in the author group.

Theoretical Inspiration

In line with the final themes found in the first analysis of the empirical data, theory on "Context," "Sense of community," and "Existential hope" further inspired the analysis.

According to Hansen et al. (2011), the outcome of interventions is influenced by the specific context. Hansen et al. analyzed context as being the setting, the physical surroundings, the behavioral environment, including professional staff, and the language environment (Hansen et al., 2011). This broad understanding reflects the significance of setting put forward in the empirical data.

Table 2. Example of the Analysis Process, Inspired by Thomsen (2022).

Data extract	Initial coding (code book)	Development of themes	Theorizing	Final themes
"you don´t feel like you are in an institution, it feels so homely (…) It was easy to push the furniture together so we could sit together when we sang. I think the setting was great, you could sit two and two or you could sit all together" (Interview #10).	Community Setting possibilities Non-formal interactions	Setting shaping social interactions Setting feels homely	Context (Hansen et al., 2011) (elements of physical surroundings and behavioral environments)	Setting
"*And then the whole identity thing, it just gave me a boost in terms of identity now being a chronic. Because you found this community, but also the experience of acceptance from you guys [the professionals], that we are who we are" (Interview #11).*	Trust Professionals Identity Community Acceptance	Being part of a community Context: being chronic Need for new "identity."	Sense of community (Mcmillan & Charvis, 1986) (elements of membership, belonging and identification)	Community
"*I have become a lot more courageous than before. I think it is going well and it gives me a joy of life. I feel stronger than I have for a long time." (Observation excerpt)*	Joy Courage	Experiencing new ways of thinking Experiencing meaningfulness in life	Existential hope (Graven & Brødslev Olsen, 2018)	Hope

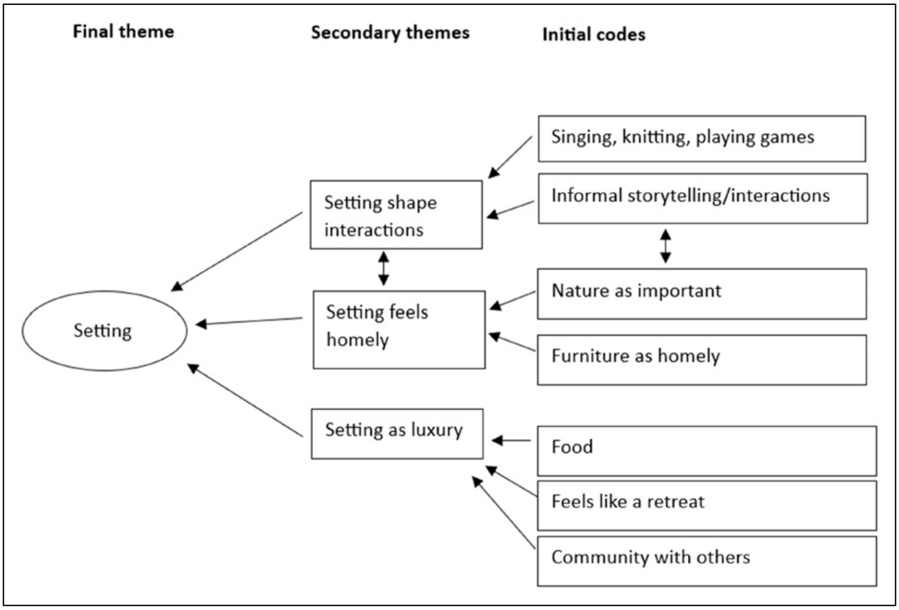

Figure 1. Example of development of themes.

To unfold the findings concerning the significance of the community, Mcmillan and Chavis' (1986), concept of "Sense of community" (p. 9) was helpful. Mcmillan and Chavis define sense of community as "a feeling that members have of belonging, a feeling that members matter to one another and the group, and a shared faith that members´ needs will be met through their commitment to be together" (Mcmillan & Chavis, 1986, p. 9), and the theory is still a widely acknowledged model for understanding how communities function and operate (Redman & Fisher, 2002).

Finally, to capture the empirical findings on how the participants experienced a changed view of life, in the sense of hope, courage, and pride, we use a theoretical concept of existential hope. Following Graven and Brødslev Olsen (2018), hope as an existential phenomenon should be seen as being tied to the social world, rather than as an individual, psychological capacity (Graven & Brødslev Olsen, 2018), and as a phenomenon connected to one's expectations in life (Szabat & Knox, 2021). According to Graven & Brødslev Olsen (2018), "to hope" (p. 75) in this existential sense is not connected to specific goals in life, but instead captures a way of being in the world.

Setting, Community, and Hope

In an exploration of the experiences of participants in the residential narrative courses, the analysis identified three themes: the setting, the community, and hope. While these themes naturally intersect, for clarity we discuss each one individually.

The Setting

The REHPA research clinic was a unique setting for the course, which was perceived as significant by the participants. In general, they felt “pampered” (Interview #14) throughout the course and talked in positive terms about the clinic. The food in particular was described as “luxury” (Interview #13), while others emphasized the joy of not having to cook for themselves: “Well, the cooking was so exclusive. I couldn´t eat my way through it all, including the goodie bag. We got so much good food. We haven’t talked that much about the setting, but it was fantastic” (Interview #14).

Yet the setting was not just a comfortable frame around the narrative courses. It influenced how the participants acted and engaged with each other during their stay. The professionals motivated the participants to go for walks between formal sessions to enjoy the surrounding nature. Little nooks with comfortable chairs inspired the participants to sit down in small groups to continue talking during breaks and to sit for extended hours in the living room to knit, sing, or watch TV together. A participants explained: “you don´t feel like you are in an institution, it feels so homely (…) It was easy to push the furniture together so we could sit together when we sang. I think the setting was great, you could sit two and two or you could sit all together” (Interview #10).

In addition to the narrative exercises in the day program, encouraging the sharing of personal stories, the setting, and the amount of free time in the course programme also allowed the participants to engage in informal storytelling. In this way, the setting played a part in how much time the participants were encouraged to spend together and why the exercise-initiated storytelling often blended into and continued beyond the sessions.

> During the evening, almost all participants gather in the living room. Some knit and small talk about yarn and other hobbies, but three participants push the lounge chairs together and seem to continue a conversation they had earlier. It appears intimate. When the staff brings in coffee and cake half an hour later, they push their chairs apart and engage with the others and participate in the more social and cheerful atmosphere. (field note excerpt)

Participation in the course was a break from normal everyday life. Physically, socially, and mentally, the participants were detached from their everyday routines, such as caring for family, doing everyday chores, and receiving medical treatment. During the course, they had the opportunity to care for themselves, engage in discussions rooted in their cancer diagnoses, and join a new community. For some, getting a break from everyday life was the primary reason to participate:

> I thought about it as a, well I allowed myself to call it a luxury retreat. You have a lot of people who understand you and you don’t have to explain a lot, and we talk a lot! [someone laughs], but I don´t have to convince anyone about how it feels, because we all know. It´s really, really easy. So, I haven’t taken it so seriously [the narrative exercises] and I haven’t worked with it at home. (Focus Group Interview #4)

The excerpt above illustrates that the course theme of life stories was less important than the setting for some of the participants.

Community

The community formed during the courses was of great significance to the participants. All participants shared the experience of living with advanced cancer and were able to identify with the stories and struggles of the other participants. Some expressed the need to talk to others who could more easily understand their illness experience or to speak in ways about their illness that they were not able to with their families and friends. For some participants, satisfaction with the course was linked to the other participants having similar prognoses. The topic of being incurable, or chronically ill, as some preferred to say, was frequently talked about as an exceptional situation that differed from their previous experiences with cancer. Some expressed having experiences of entering a group with "immediate understanding" (Interview #7). For some participants, this differed from attending rehabilitation courses in the municipalities, in which they were often mixed with cancer patients with a better prognosis. On the narrative course, the participants felt free to speak honestly and felt no need to hold anything back, expressed as "we are in the same boat" (field notes).

During the courses, the participants found that their point of view was valued and recognized by the others, as well as by the professionals, and that their status (as a distinct group of cancer patients) and special challenges were taken seriously. Many participants stated that they struggled to find new ways of thinking about themselves in terms of identity. Some experienced sadness and a loss of "identity" (field notes) from having to leave their jobs and retire, and they shared their struggles with figuring out how to live life in the best way, considering their prognosis and physical and mental limitations. One participant felt validated in her new identity as "incurably ill with cancer," not just by the community, but also by the course structure and setup:

> And then, the whole identity thing, it just gave me a boost in terms of identity now being chronic. Because you found this community, but also the experience of acceptance from you guys [the professionals], that we are, who we are. (Interview #11)

Our findings indicate that the course inclusion criteria effectively fostered a sense of intimacy among participants, which contributed to the development of a strong community. Moreover, this sense of belonging evolved into a source of personal identity as participants identified with the group.

The content of the narrative exercises, coupled with the group format and the overall setting of the courses, prompted the participants to share life events and tell personal stories. Through sharing, the participants made personal investments in the community, which contributed to their emotional connection to the group. One of the professionals checked in with the participants in plenary sessions every morning, asking them what they had taken with them from the day before. After only having attended the course for one day, one participant quickly replied: “The most fantastic thing is coming here as an individual and going to bed as part of a group” (field notes).

During the courses, some participants formed close relationships and friendships that extended into everyday life after the courses. In one case, a participant died between the initial and the follow-up stay. Some of the other participants had visited him in the hospital and attended his funeral. Later, one participant explained in a plenary session: “In those four days he became a friend, and an even better friend than some of my old friends” (field notes).

In one of the courses, the participants talked about how they had quickly formed a Facebook group and stayed in touch between the initial and the follow-up stay. The participants referred to having supported each other in the online group and helping each other follow up on the goals they had set for themselves. One female participant explained that she felt comfortable sharing poems and feelings of distress online because she felt “known” (Interview #11) by the other participants after the first stay. Another participant elaborated on the community in the online group:

> We are incredibly supportive, crazily open and honest. It’s like we’re just sure that nobody wants to hurt us and all that we say will be accepted and embraced. So, REHPA did something to us that makes us trust each other and that we want to help each other. It is rare for me to have a place where I don’t feel like I need to show ‘I handle it well’ but where I can just… [exhales deeply in relief]. (Interview #10)

For some, meeting and engaging with the other participants became a way to attribute meaning to their illness experience: “If I were to say something positive about the illness, I would say that I wouldn´t have met you if it weren’t for that. I have never experienced such a thing, and I have experienced a lot” (Focus Group Interview #2).

Our findings also showed that the majority of participants were confused by the theme of the narrative courses, finding it vague and unclear. Overall, the participants shared the perception that the theme of “life stories” was unclear and that they were not always sure how the exercises related to the theme. Mostly, the participants expressed uncertainty about the definition of life stories. One participant said: “I didn’t know what a life story was, so I just made up my own idea of what it was” (Interview #10).

Some participants requested more tools to handle the mental strain of having a life-threatening illness and some felt disappointed by not having their expectations met. In one of the courses in particular, several participants stated that they felt unprepared for working so intensively with their life story, and some had expected a standard REHPA rehabilitation stay. One participant voiced that she felt a lack of coherence between the life story theme and the exercises. Nonetheless, she stated:

> If you would have asked me if I wanted to come back and start all over again next week then I would have said yes, 100%. It has been super, super good. It´s just so apparent, it could have been better. (Focus Group Interview #3)

Participants who were critical of the delivery of the courses nonetheless emphasized their satisfaction with the group format, adamantly stating “don´t change that” (Focus Group Interview #3). Our findings suggest that the sense of belonging to the community in general overruled the ambiguity concerning the narrative theme.

Hope

Some participants voiced the opinion that attending the courses fostered feelings of “hope,” “courage,” and “pride,” while some expressed this in terms of “getting my dreams back” (Interview #9). The participants´ experiences of a changed view of life were either connected to starting projects that they otherwise had put off or of more existential hope, such as believing that “there still a life to live” (field notes).

> Interviewer: You said that you left with a sense of pride. What kind of pride was that?
>
> Participant: Well, it was the feeling, as I said, that I’ve found my hope again and courage to dare be me again and to dare to say, that I’ve still got something to offer, I still have things I can and will, I’m not disappearing tomorrow. (Interview #11)

Another participant explained that after the course she had started on new projects:

> I have become a lot more courageous than before. I think it is going well and it gives me a joy of life. I feel stronger than I have for a long time. (field notes)
>
> Instead of being in the process of settling my life, and instead of trying to make peace with the limitations, which is fine, you need to do that also, but after I got home, it’s like the world is opening itself up again. (Interview #10)

The time from when the course participants received their cancer diagnosis ranged from a few months to 14 years prior to the course. Particularly for the participants who had recently been diagnosed with advanced cancer, meeting other participants who had lived for longer with their illness was a source of inspiration that promoted a sense of hope and courage. For example, one recently diagnosed participant explained:

> When I went home, I felt really stuffed. Yet I was also extremely happy and filled with courage and energy. And I think that came from being with 13 other people who were in the same boat as me (…). I was so happy when I got home because of all of you who I met here, who have had cancer for many years. And it was so life-affirming for me, to bring that home. Because I have had some thoughts about that I would probably be dead within six months. But I’m still alive, soon it´s for one year. It gave me such a sense of hope, to hear and meet you guys. The energy I got from you, I brought along into everyday activities. (Focus Group Interview #4)

The increased or newfound hope expressed by the participants was not a hope of being cured, but rather an existential hope, which was connected to experiencing a sense of meaningfulness in life.

Many participants stated having had an initial apprehension about meeting the others, as they feared the confrontation with people being at the end of life. After having attended the course, some expressed relief that only a few participants were obviously disabled due to their illness and treatment: "I was prepared, I already told my husband 'if they are all very sick, I can't do that, then I´m going home', but it wasn´t like that at all" (Interview #12).

Another participant expressed her worries like this: "I thought that [laughs], well, all sorts of ugly scenes in my head of a lot of old people with walking frames and that kind of things [laughs]. That was really discredited" (Focus Group Interview #4).

While many participants shared the opinion that the community was strengthened by how similar their physical and mental capacities were, some also expressed being inspired by the participants who had specific challenges.

Some participants praised the positivity and optimism of the few participants who had physical limitations and used a walking frame, for instance. When the participants were confronted with the stories of suffering and traumatic life circumstances, some rethought their own life situations and were able to see their lives from a new perspective. One participant shared how she was deeply touched by the story of a younger participant who was recently divorced, had experienced a rapid deterioration in her health, and was alone with her children. All participants felt sympathy for the woman and stated that she was "an inspiration" to them, as she overcame such hardships and still "kept going with dignity" (Interview #7).

> Participant: I´m very privileged, if you can be that when you are going to die, but I think so. And the others' [life situations] put that into perspective. You know, I´m really sick to my stomach, what are they going to do?
>
> Interviewer: So, if I understand you correctly, it was good for you?
>
> Participant: Yes, it was good, but also extremely hard. But... there is also the positive thing that you can see that you have had a lot of good things and that others are worse off than me [laughs apologetically]. (Interview #9)

Another participant experienced similar thoughts and found comfort in knowing that others experienced similar or even worse hardships than herself:

> Those who live alone, they were going home to nothing. I´m just going home to my husband who embraces me the whole time and who carries me in his arms, right? It gave me such a feeling "God damn it, I´m lucky." (Interview #13)

The participants each brought experiences and knowledge to the group, engaging in a mutual exchange where they took turns contributing to and benefiting from the community. This was often done through storytelling. Although there was not always a consensus on how deeply their discussions should delve into sensitive subjects like death and dying, some participants found inspiration in meeting others who could speak candidly about preparing for their own passing, such as choosing a final resting place or writing farewell letters. Some explained how they, after the initial stay, found the courage to reach out to their local pastor, while others started writing their life stories for their families.

Many participants further expressed that listening to others' stories helped them put their own thoughts and feelings into words. "There are not so many words in us," as a male participant put it during group work, yet gradually he expressed how it became easier for him to explain what was on his mind (field notes). Another participant jokingly described herself as experienced in "everything cancer related," describing her illness in terms of an activity that she practiced: "I attended cancer for a long time, I´ve become quite good at it" (field notes). Another participant replied positively to her wording: "it´s nice for me to experience that you can 'attend' cancer, to use your phrase. It´s actually a great expression that I will remember" (Focus Group Interview #4).

Notably, the shared experiences were often specific to this community, as everyone suffered from advanced cancer. The shared stories might not have been equally valued outside of the courses. Thus, the narrative courses became a specific setting for the participants to both be inspired and inspire others in ways that might otherwise be inaccessible to them.

Discussion

Findings from this study concerning narrative residential courses for people with advanced cancer show that the participants perceived the setting, the community, and the gaining of hope as significant.

Hansen et al. (2011) found that the effectiveness of interventions is significantly affected by their context, which they defined as the setting, physical surroundings, behavioral environment—including the presence of professional staff—and the linguistic environment (Hansen et al., 2011). Our results support the notion that the context of a course plays a crucial role in shaping participants' experiences. Similarly, the concept of "sense of community" is sensitive to the setting in which it is fostered (Mahan et al., 2002), and in this study we have shown how the specific setting in the research clinic impacted how the community was formed and experienced. Our study demonstrates the way in which the particular setting of the clinic influenced the formation and perception of the community among the participants.

Chronic and life-threatening illness may cause the patient challenges in terms of identity (Bury, 1982; Nanton et al., 2016; Palmer-Wackerly et al., 2018). In this study we find that the participants´ experiences with belonging to a community helped foster new ways to identify oneself as a person with advanced cancer. These findings are supported by research highlighting the importance of peer-support and group identification in people with advanced cancer (Chambers et al., 2012; Karlsson et al., 2014) and they suggest that belonging to a community of fellow cancer patients may serve as social support and aid in recognizing a sense of identity.

According to Mcmillan and Chavis (1986), the amount of time that individuals spend together influences the formation and perceived strength of a community (Mcmillan & Chavis, 1986). The narrative courses provided the participants with an opportunity to engage in identification with others and the group as well as to compare their own situations to those of others with similar challenges over an extended period, spanning several full days and nights.

Our results show that individuals with advanced cancer experienced a sense of belonging within a significant community. This is in line with Mcmillan and Chavis' (1986) observation that bonding over critical events often fosters a strong sense of community. The group sessions allowed participants to identify with one another and the group, as well as to assess their own circumstances in relation to those facing similar challenges. Engaging in social comparison has been described as a typical coping strategy among people living with cancer (Van der Zee et al., 2000), and our study supports previous research indicating that social comparison can be a source of hope and well-being (Bennenbroek et al., 2002; Nierop-van Baalen et al., 2016).

Hope can be seen as a social phenomenon, emerging from interactions within significant relationships and communities where the individual may encounter and nurture "hopeful experiences" (Graven & Brødslev Olsen, 2018). Our findings imply that the narrative courses became such a source of "hopeful experiences," which influenced the participants' perspectives on life with advanced cancer. Following Graven et al. (2021), our findings confirm that existential hope is about meaning, whereas unlike this, medical hope is about the control of disease, death, and dying. Our findings further align with previous research concerning meaningful relationships which, through social support, assist the individual's experiences of hope (Benzein et al., 2001; Mahon & Yarcheski, 2017; Tao et al., 2022).

In this study, we explored the participants' experiences with narrative courses where the sharing of personal stories was emphasized. We found that the boundaries between formal and informal storytelling were often blurred, with participants being afforded the opportunity to engage in community building through storytelling. Our findings align with those from previous studies conducted at the REHPA research clinic and similar environments, even when storytelling was not a formal part of the course program. For instance, in their study of a multimodal rehabilitative and palliative care intervention for patients with high-grade glioma and their family caregivers Nordentoft et al. (2022) observed that patient satisfaction was closely linked to the sense of community, despite narrative exercises not being formally included. The patients reported an increased capacity to maintain hope in their daily lives, which echoes the results of our study. Similarly, La Cour et al. (2015) found that a residential rehabilitation course provided a valuable "arena for sharing," (p. 7) highlighting the importance of the setting itself. Raunkiaer (2024) also noted the significance of the course community in a combined rehabilitation and palliative care course for individuals with advanced cancer. The narrative courses in this study were conducted in a context similar to those described in previous research (Hansen et al., 2011; Jess et al., 2023; la Cour et al., 2015; Nordentoft et al., 2022). As put forward in the result section, our findings point to how the feeling of belonging to the community in general overruled the ambiguity of the narrative theme. Reflecting on the findings from other studies, we might even suggest that the setting and the community sometimes overrule the significance of the specific content of a course. While we do not dismiss the value of the narrative exercises, we could not conclusively determine their significance on their own. Based on previous research and our findings, we propose that narrative methods applied in group courses and encouraging the forming of community may be one of many effective approaches to support the well-being of individuals living with life-threatening illnesses.

We argue that ethnographic fieldwork was a suitable approach for exploring the aspects of the residential narrative courses that participants found significant. Through participant observation across three courses, we were able to explore both structured and informal interactions among participants. We discovered that employing both individual and focus group interviews enhanced and expanded the observations. However, the study design would have been more robust with a longitudinal approach, which would have allowed an examination of the participants' experiences over an extended period. It is important to note that the study relies on a limited dataset, as the courses were conducted only three times within a specific setting. This limitation impacts the transferability of our findings to different contexts.

Conclusion

In this study, we found that participants in the narrative residential courses primarily valued the experience of the setting, the community, and the gaining of hope. These aspects were generally deemed more significant than the specific content related to working with narratives. This study highlights the importance of conducting ethnographic field studies to explore participants' perceptions of what they experience as significant. Exploratory research into participants' experiences may provide a more comprehensive understanding of the value and limitations of group courses and interventions within health research.

Author Contributions

HSG was responsible for data generation and analysis and first draft of the manuscript. HT was responsible for the idea of the narrative courses, BHB, MR and HT have contributed into data analysis through discussions and have continuously read and commented drafts of the manuscript.

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Supplemental Material

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References

Applebaum, A. J., Stein, E. M., Lord-Bessen, J., Pessin, H., Rosenfeld, B., & Breitbart, W. (2014). Optimism, social support, and mental health outcomes in patients with advanced cancer. *Psycho-Oncology*, *23*(3), 299–306. https://doi.org/10.1002/pon.3418

Arantzamendi, M., García-Rueda, N., Carvajal, A., & Robinson, C. A. (2020). People with advanced cancer: The process of living well with awareness of dying. *Qualitative Health Research*, *30*(8), 1143–1155. https://doi.org/10.1177/1049732318816298

Bäckman, C. G., & Walther, S. M. (2001). Use of a personal diary written on the ICU during critical illness. *Intensive Care Medicine*, *27*(2), 426–429. https://doi.org/10.1007/s001340000692

Bennenbroek, F. T. C., Buunk, B. P., van der Zee, K. I., & Grol, B. (2002). Social comparison and patient information: What do cancer patients want? *Patient Education and Counseling*, *47*(1), 5–12. https://doi.org/10.1016/S0738-3991(02)00018-6

Benzein, E., Norberg, A., & Saveman, B.-I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, *15*(2), 117–126. https://doi.org/10.1191/026921601675617254

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Cepeda, M. S. M. D. P., Chapman, C. R. P., Miranda, N. R. N., Sanchez, R. M. D. M., Rodriguez, C. H. M. D., Restrepo, A. E. M. D., Ferrer, L. M. M. D., Linares, R. A. M. D., & Carr, D. B. M. D. (2008). Emotional disclosure through patient narrative may improve pain and well-being: Results of a randomized controlled trial in patients with cancer pain. *Journal of Pain and Symptom Management*, *35*(6), 623–631. https://doi.org/10.1016/j.jpainsymman.2007.08.011

Chambers, S. K., Foley, E., Galt, E., Ferguson, M., & Clutton, S. (2012). Mindfulness groups for men with advanced prostate cancer: A pilot study to assess feasibility and effectiveness and the role of peer support. *Supportive Care in Cancer: Official Journal of the Multinational*

Association of Supportive Care in Cancer, *20*(6), 1183–1192. https://doi.org/10.1007/s00520-011-1195-8

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *23*(24), 5520–5525. https://doi.org/10.1200/JCO.2005.08.391

Drageset, S., Lindstrøm, T. C., Giske, T., & Underlid, K. (2016). Women's experiences of social support during the first year following primary breast cancer surgery. *Scandinavian Journal of Caring Sciences*, *30*(2), 340–348. https://doi.org/10.1111/scs.12250

Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Ågård, A. S. (2011). Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, *39*(8), 1922–1928. https://doi.org/10.1097/CCM.0b013e31821e89c8

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes*. University of Chicago Press.

Falk, K., & Timm, H. (2018). Arkitektur & lindring.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). The University of Chicago Press. https://go.exlibris.link/kyDYTLz1

García-Rueda, N., Carvajal Valcárcel, A., Saracíbar-Razquin, M., & Arantzamendi Solabarrieta, M. (2016). The experience of living with advanced-stage cancer: A thematic synthesis of the literature. *European Journal of Cancer Care*, *25*(4), 551–569. https://doi.org/10.1111/ecc.12523

Gärtner, H. S., Blix, B. H., Raunkiær, M., & Timm, H. (2024). 'There is nothing beautiful or life-affirming in it': Experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer. *Mortality*, 1–17. https://doi.org/10.1080/13576275.2024.2360521

Gärtner, H. S., Timm, H. U., & Raunkiær, M. (2021). Meningsfulde fællesskaber for mennesker med kronisk, fremadskridende kræft (Meaningful communities for people with advanced cancer). https://go.exlibris.link/cw8frLJ4

Graven, V., & Brødslev Olsen, J. (2018). Hvor der er håb: fra teori til sundhedsfaglig praksis [Where there is hope: from theory to practice] (1. udgave ed.). Samfundslitteratur.

Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice* (4th ed.). Routledge. https://doi.org/10.4324/9781315146027

Hansen, H. P., Laursen, S. S., Zwisler, A.-D., & Rasmussen, A. J. (2019). I'm sure that there is something healing in the writing process: Creative writing workshops for people with a cancer disease. *Tidsskrift for Forskning i Sygdom og Samfund*, *16*(31), 167–185. https://doi.org/10.7146/tfss.v16i31.116963

Hansen, H. P., Rasmussen, A. J., & Zwisler, A. D. O. (2018). Skriving som heling? De første danske erfaringer med skrivning som del af rehabilitering. https://go.exlibris.link/nSX40pC0

Hansen, H. P., Tjørnhøj-Thomsen, T., & Johansen, C. (2011). Rehabilitation interventions for cancer survivors: The influence of context. *Acta Oncologica*, *50*(2), 259–264. https://doi.org/10.3109/0284186X.2010.529460

Helgeson, V. S. (2003). Social support and quality of life. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *12*(Suppl 1), 25–31. https://doi.org/10.1023/A:1023509117524

Houmann, L. J., Chochinov, H. M., Kristjanson, L. J., Petersen, M. A., & Groenvold, M. (2014). A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. *Palliative Medicine*, *28*(5), 448–458. https://doi.org/10.1177/0269216313514883

Houmann, L. J., Rydahl-Hansen, S., Chochinov, H. M., Kristjanson, L. J., & Groenvold, M. (2010). Testing the feasibility of the dignity therapy interview: Adaptation for the Danish culture. *BMC Palliative Care*, *9*(1), 21. https://doi.org/10.1186/1472-684X-9-21

Hubbard, G., & Forbat, L. (2012). Cancer as biographical disruption: Constructions of living with cancer. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *20*(9), 2033–2040. https://doi.org/10.1007/s00520-011-1311-9

Imrie, S., & Troop, N. A. (2012). A pilot study on the effects and feasibility of compassion-focused expressive writing in Day Hospice patients. *Palliative & Supportive Care*, *10*(2), 115–122. https://doi.org/10.1017/S1478951512000181

Jess, M., Nielsen, S. P., Rasmussen, A., Skov-Pedersen, J., & Timm, H. (2023). Stories of a long life with HIV: A qualitative study of a narrative intervention. *Scandinavian Journal of Caring Sciences*, *37*(3), 777–787. https://doi.org/10.1111/scs.13161

Jess, & Timm (2019). Hiv og liv gennem 25 år:Evaluering af et rehabiliteringsophold med fokus på fortællinger mellem mennesker der har levet et langt liv med hiv (Life with HIV the last 25 years). https://go.exlibris.link/jRSR7F8H

Karlsson, M., Friberg, F., Wallengren, C., & Öhlén, J. (2014). Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: A life-world phenomenological study. *BMC Palliative Care*, *13*(1), 28. https://doi.org/10.1186/1472-684X-13-28

la Cour, K., Ledderer, L., & Hansen, H. P. (2015). 'An arena for sharing': Exploring the joint involvement of patients and their relatives in a cancer rehabilitation intervention study. https://go.exlibris.link/qJcZLJRk

Mahan, B., Garrard, W., Lewis, S., & Newbrough, J. (2002). Sense of community in a university setting: Campus as workplace. In *Psychological sense of community: Research, applications, and implications* (pp. 123–140). Boston, MA: Springer US.

Mahon, N. E., & Yarcheski, A. (2017). Parent and friend social support and adolescent hope. *Clinical Nursing Research*, *26*(2), 224–240. https://doi.org/10.1177/1054773815619881

McDonough, M. H., Beselt, L. J., Kronlund, L. J., Albinati, N. K., Daun, J. T., Trudeau, M. S., Wong, J. B., Culos-Reed, S. N., & Bridel, W. (2021). Social support and physical activity for cancer survivors: A qualitative review and meta-study. *Journal of cancer survivorship: Research and Practice*, *15*(5), 713–728. https://doi.org/10.1007/s11764-020-00963-y

Mcmillan, D. W., & Chavis, D. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, *14*(1), 6–23.

Midtgaard, J., Rorth, M., Stelter, R., & Adamsen, L. (2006). The group matters: An explorative study of group cohesion and quality of life in cancer patients participating in physical exercise intervention during treatment. *European Journal of Cancer Care*, *15*(1), 25–33. https://doi.org/10.1111/j.1365-2354.2005.00616.x

Missel, M., Borregaard, B., Schoenau, M. N., & Sommer, M. S. (2019). A sense of understanding and belonging when life is at stake—operable lung cancer patients' lived experiences of participation in exercise. *European Journal of Cancer Care*, *28*(5), Article e13126. https://doi.org/10.1111/ecc.13126

Montali, L., Zulato, E., Frigerio, A., Frangi, E., & Camussi, E. (2022). Mirroring, monitoring, modelling, belonging, and distancing: Psychosocial processes in an online support group of breast cancer patients. *Journal of Community Psychology*, *50*(2), 992–1007. https://doi.org/10.1002/jcop.22696

Nanton, V., Munday, D., Dale, J., Mason, B., Kendall, M., & Murray, S. (2016). The threatened self: Considerations of time, place, and uncertainty in advanced illness. *British Journal of Health Psychology*, *21*(2), 351–373. https://doi.org/10.1111/bjhp.12172

Newton, J. C., O'Connor, M., Saunders, C., Moorin, R., Ali, S., Nowak, A. K., & Halkett, G. K. B. (2021). The role of psychosocial support in the experiences of people living with advanced cancer: A qualitative exploration of patients' perspectives. *Psycho-Oncology*, *30*(3), 287–295. https://doi.org/10.1002/pon.5569

Nierop-van Baalen, C., Grypdonck, M., van Hecke, A., & Verhaeghe, S. (2016). Hope dies last. A qualitative study into the meaning of hope for people with cancer in the palliative phase. *European Journal of Cancer Care*, *25*(4), 570–579. https://doi.org/10.1111/ecc.12500

Nordentoft, S., Dieperink, K. B., Johansson, S. D., Jarden, M., & Piil, K. (2022). Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers. *Scandinavian Journal of Caring Sciences*, *36*(3), 815–829. https://doi.org/10.1111/scs.13019

Palmer-Wackerly, A. L., Dailey, P. M., Krok-Schoen, J. L., Rhodes, N. D., & Krieger, J. L. (2018). Patient perceptions of illness identity in cancer clinical trial decision-making. *Health Communication*, *33*(8), 1045–1054. https://doi.org/10.1080/10410236.2017.1331189

Rasmussen, A., Jespersen, E., Backmann, T., & Jarlbæk, L. (2020). Praksisbeskrivelser – Forskningsklinik REHPA. *Standard rehabiliteringsforløb for mennesker med eller efter kræft. (Practice descriptions research clinic REHPA – standard rehabilitation programme for people with or after cancer)*.

Raunkiaer, M. (2024). The experiences of people with advanced cancer and professionals participating in a program with focus on rehabilitation and palliative care. *Omega*, *88*(4), 1383–1402. https://doi.org/10.1177/00302228211058307

Redman, T., & Fisher, A. T. (2002). Sense of community of young women in custody. In A. T. Fisher, C. C. Sonn, & B. J. Bishop (Eds.), *Psychological sense of community: Research, applications, and implications* (pp. 87–108). Springer US. https://doi.org/10.1007/978-1-4615-0719-2_5

Roikjær, S. G., Gärtner, H. S., & Timm, H. (2021). Use of narrative methods in rehabilitation and palliative care in Scandinavian countries: A scoping review. *Scandinavian Journal of Caring Sciences*, *36*(2), 346–381. https://doi.org/10.1111/scs.13050

Szabat, M., & Knox, J. B. L. (2021). Shades of hope: Marcel's notion of hope in end-of-life care. *Medicine, Healthcare & Philosophy*, *24*(4), 529–542. https://doi.org/10.1007/s11019-021-10036-1

Tao, Y., Yu, H., Liu, S., Wang, C., Yan, M., Sun, L., Chen, Z., & Zhang, L. (2022). Hope and depression: The mediating role of social support and spiritual coping in advanced cancer patients. *BMC Psychiatry*, *22*(1), 345. https://doi.org/10.1186/s12888-022-03985-1

Thompson, J. (2022). A guide to abductive thematic analysis. *Qualitative Report*, *27*(5), 1410–1421. https://doi.org/10.46743/2160-3715/2022.5340

Timmermans, S., & Tavory, I. (2022). *Data analysis in qualitative research: Theorizing with abductive analysis*. University of Chicago Press. https://go.exlibris.link/k9ySGyvJ

Van der Zee, K., Buunk, B., Sanderman, R., Botke, G., & van den Bergh, F. (2000). Social comparison and coping with cancer treatment. *Personality and Individual Differences*, *28*(1), 17–34. https://doi.org/10.1016/s0191-8869(99)00045-8

White, M. (2006). Narrativ teori. Reitzels. https://go.exlibris.link/q46xsDhq

Wise, M., Marchand, L. R., Roberts, L. J., & Chih, M. Y. (2018). Suffering in advanced cancer: A randomized control trial of a narrative intervention. *Journal of Palliative Medicine*, *21*(2), 200–207. https://doi.org/10.1089/jpm.2017.0007

WMA. (2022). *Wma declaration of HELSINKI – ethical principles for medical research involving human subjects*. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

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Sub-study III

Sharing Stories: Experiences of Sharing Personal Stories and Creating a Collective Story about Living with Advanced Cancer

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Abstract

Narration may offer healing to people living with life-threatening illnesses by its ability to help people maintain or re-create a sense of meaning, re-create their life histories and restore an experience of consistency in life that may have been lost when falling ill. Three times during 2022, a Danish rehabilitation research clinic offered narrative courses for people with advanced cancer, with the focus on working with elements of the participants' life stories and to further create a collective story based on the individual participants' stories. Our aim in this study was to explore the experiences of participants with advanced cancer who took part in the collective story exercise during the narrative courses. This study is based on ethnographic fieldwork, comprising 185 hours of participant observation, nine individual interviews and the three collective stories documents. We demonstrate how the exercise functioned to integrate the participants' individual illness experiences into a shared story of shared experience, and how this integration helped legitimatize the participants' experiences of suffering and loss, offering healing and relief. We have further illustrated how the participants' experiences with the collective stories were primarily valuable within the specific course community, identified as a 'local moral world', and how the collective stories were also influenced by dominant cultural and social narratives, underscoring the embeddedness of all narratives in a wider context.

Keywords

Cancer and palliative care, Experiencing illness and narratives, Chronic illness and disability, Ethnography, Death dying and bereavement

Introduction

Narratives exist on multiple levels of everyday life and society; from the stories we tell our loved ones in intimate moments, to organizational narratives shaping institutional practices and procedures, to grand stories of our culture and national identity (Blix and Sorly, 2017). Narratives are not simply stories communicated to someone (Gubrium and Holstein, 2009). They originate from social interactions which shape the course and content of the story itself. Narratives are always embedded in a specific social and local context and display an interconnectedness to dominant macro narratives (de Fina, 2008). Therefore, narratives must be understood as a social practice, and attention must be paid to the socially shared resources and analysed within a larger, social and cultural context (Atkinson, 2009; Frank, 2013; Gubrium and Holstein, 2009). Severe illness is a call for narrative (Frank, 2013) and illness narratives have been of much interest in social and health care research (Bury, 2001; Hydén, 1997; Charon et al., 2017). Through narration, people living with illness can (re)construct their life history and "recreate a temporal context that had been lost" (Hydén 1997, p.53), and express their experiences of suffering (Hydén, 1997; Kleinman, 1998; Frank, 2013). Narration may offer healing in its capacity to maintain or re-create a sense of meaning and restore an experience of consistency in life that may have been lost when falling ill (Bury, 2001; Bury, 1982; Hydén, 1997).

Although illness narratives often concern an individual illness experience, narrating illness is a social event (Hydén, 1997). Illness stories told in clinical settings are naturally impacted by this context, affecting the form and purpose of the stories (Hydén, 1997). Within the field of cancer, dominant cultural narratives and moral imperatives of cancer rehabilitation and survivorship shape patients' lived and told experiences of living with cancer (Broom et al., 2019; Hansen and Tjørnhøj-Thomsen, 2008; Segal, 2012). Scholars have demonstrated how people with cancer adapt cultural and biomedical discourses when telling stories about their illness. In a Danish context, Sidenius et al. (2019) have demonstrated how women with endometrial cancer internalized healthcare professionals' framing of their prognosis as favourable, leading them to tell about their illness in terms of 'feeling lucky' (Sidenius et al., 2019b) or to describe their cancer in terms of being 'good' (Sidenius et al., 2019a). Another recent Danish study exploring the illness stories of people with operable lung cancer had similar findings (Schoenau, 2022). Furthermore, scholars have found how organizational narratives within the field of rehabilitation may favour some stories over others, underscoring why attention to the institutional and structural context of storytelling is crucial (Graff et al., 2023). Thus, illness narratives are more than individual expressions of experience and they may collectivize individual illness experience (Hydén, 1997).

Listening to patients' illness stories has traditionally been part of clinical work, and within the last decade patients' individual and personal illness experiences has gained more interest in both research and clinical interventions (Roikjær et al., 2021). A literature review showed that storytelling in rehabilitation and palliative care interventions are perceived as meaningful for the participants and their next of kin (Roikjær et al., 2021). In line with this, a Danish rehabilitation research clinic offered narrative courses for people with advanced cancer. The courses focused on working with elements of the participants' life stories and composing a collective story based on the individual participants' stories. In this article, we explore the participants' experiences with being part of this specific collective storytelling exercise, answering the research question: What were the experiences with the collective story exercise for participants with advanced cancer participating in the narrative courses?

How to distinguish between the concept of 'narrative' and 'story' continues to be debated within the narrative research field, and often the two terms are used interchangeably (Mattingly and Garro, 2000). In this study, we deliberately use the terminology of 'stories' to primarily describe the specific narrative exercise of constructing collective stories about life with advanced cancer, whereas we otherwise do not distinguish between the two.

Narrative courses for people living with advanced cancer in a Danish rehabilitation context

Three narrative courses were conducted in 2022 in the Danish Knowledge Centre for Rehabilitation and Palliative Care in Denmark (REHPA) research clinic, as a part of a combined rehabilitation and palliative care program for people with advanced cancer. The courses were organized as residential stays and were further modelled after the general courses in this clinic (Rasmussen et al., 2020) to include an initial 4-day residential stay and a two-day follow-up stay after 5–6 weeks. The aim of the courses was to support the participants to construct and re-construct meaning and a sense of a coherence in life, when living with advanced cancer (Rasmussen et al., 2023; Gärtner et al., 2024a). The courses were based on the understanding that individuals continuously shape and reshape their identities through storytelling and attentive listening and that narratives are shaped by social processes (Frank, 2013; White, 2006; Jess et al., 2023). The courses were guided by a theoretical framework inspired by dignity therapy (Chochinov et al., 2005) and narrative therapy (White, 2006). While dignity therapy includes a constructed document summarizing the life story of the patient, narrative therapy encompasses the assumption that actively working with storytelling may help patients identify alternative stories about life which may alter their perceptions about the future. Both these dimensions were an inspiration for the construction of a collective story document at the courses (Rasmussen et al., 2023).

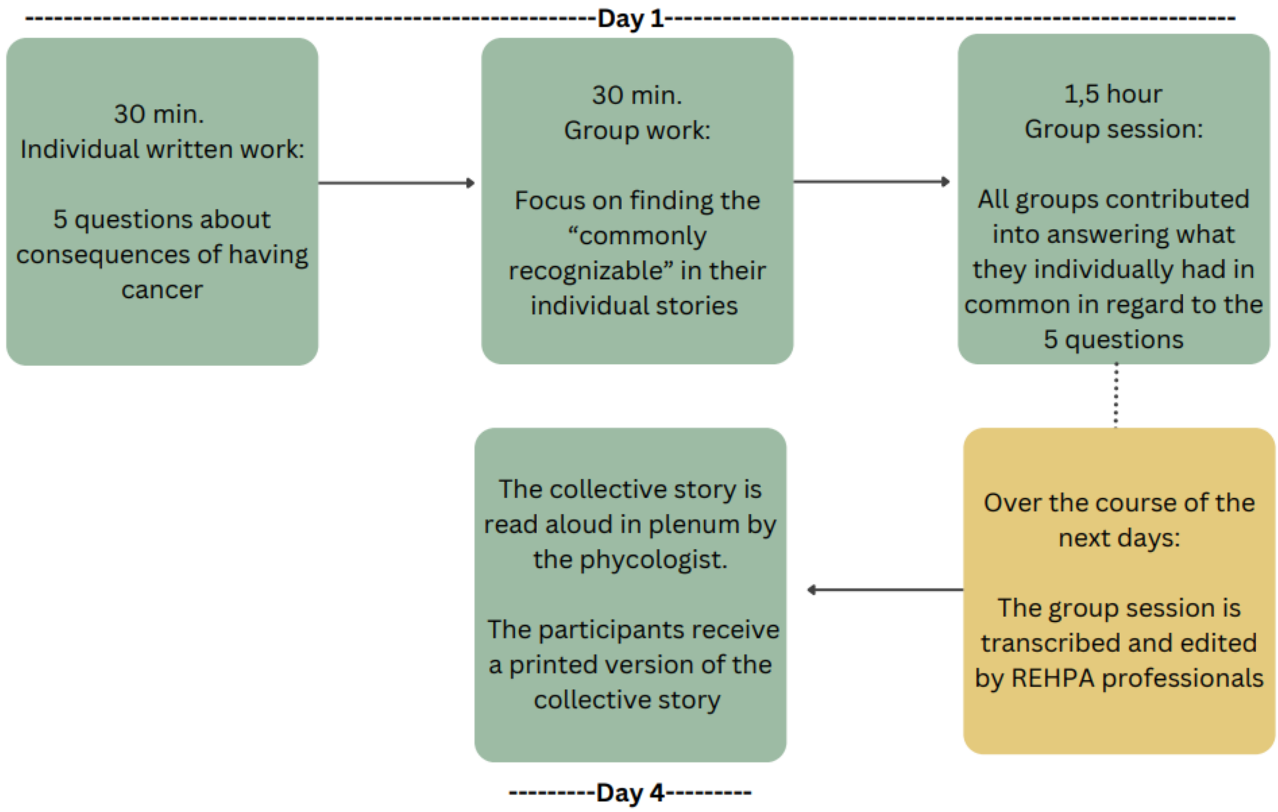
Constructing collective stories

The construction of the collective story was the first of six narrative exercises presented to the participants at the narrative courses (Gärtner et al., 2024a). The exercise aimed to help the participants identify individual and shared experiences with advanced cancer. While this exercise explicitly revolved around the participants' illness and illness trajectory, the other narrative exercises focused on other aspects of the participants' lives, such as their resources, social roles and social networks (Rasmussen et al., 2023; Gärtner et al., 2024a). The flow of the exercise is illustrated in Figure 1. At the beginning of the exercise, the participants were invited to reflect and write down their thoughts based on five questions/prompts:

- How do you experience your body's reaction to treatment?
- How has living with a chronic and incurable illness affected you mentally?
- How would you describe your encounters with the healthcare system?
- How has living with a life-threatening illness affected your relationships with the social world (working life, social network, sport, community engagement through clubs and associations etc.).
- How does your chronic illness affect themes in your life, such as thoughts about isolation, loss of meaning, the constant choices, mortality.

Next, the participants were invited to share their reflections on the five questions in small groups of two-three participants, identifying what was 'commonly recognizable' and which parts of their experiences and stories were shared. During the next step, all groups were all gathered in one room to share their reflections in a plenum session which was audio recorded. The professionals, comprising a psychologist, a nurse and physiotherapists, ensured that all groups shared their reflections on all questions and that divergent opinions were acknowledged. After completion of the plenum session, the audio recordings were transcribed and later edited by a student worker and the professionals, resulting in an approximately six-page-long document. In the document, the collective storytelling process was edited to fit into a shared story, dominated by the personal pronouns of primarily 'we' and 'us'.

Figure 1: Flow of the collective stories exercise



On the last day of the initial stay (in one case, on the follow-up days due to the COVID-19 Pandemic), the participants gathered in plenum again, and the collective story was read aloud to them by one of the professionals involved in the course. The participants were then invited to share immediate reflections, and all participants received a printed version of the collective story to take home with them.

Methods

Study design, participants, and data material

Of the 36 people who joined the courses, 28 completed it. Reasons for non-completion varied (Gärtner et al., 2024b). Participants were deemed eligible to participate if they were over 18 years old, had been diagnosed with advanced cancer, were fluent in Danish and willing to participate in both the narrative course and the clinic's research activities, and were self-reliant. Most of the participants (n=30) were female with ages ranging from 39 to 87 years.

The study was designed as an ethnographic field study. *The field work* included 185 hours of participant observation with all enrolled participants. Nine *individual interviews* were conducted in the interval between the initial and the follow-up stay, counting nine participants, three from each course. Six *focus group interviews* were conducted, two on the last day of each of the courses. All 28 participants who completed the courses took part in a focus group interview (3–6 people in each and a duration of about 90 min.). Furthermore, the three constructed collective stories were included as data material, with word counts ranging from 2320 to 2541 words.

All participants received oral and written information before providing a written consent for participation in this study. This study follows the principles of the Helsinki Declaration (WMA, 2022), and the Committee on Health Research Ethics in the [left out for review] established that this study did not require an ethical approval [left out for review]. The study was approved by The University of [left out for review], stored under notification number [left out for review].

Data analysis

Guided by our research question, the first step of our analysis was an exploration of the collective story documents, which we approached inductively through narrative analysis (Riessman 1993). Our aim was to explore the content of the stories by identifying and analysing stories within the text, leading to identifying the key stories of the documents. This process involved reading each document multiple times to become familiar with the stories. In the next step of the analysis, we searched for similarities and differences between the documents, as well as variation in how the stories were structured. Metaphors and story plots were also identified. Based on this analysis, we generated the key story (or main theme) of 'suffering and loss'. Furthermore, we focused our analysis on how this key story was embedded in (and impacted by) a larger frame of dominant social and cultural narratives of cancer and rehabilitation.

To explore the participants' experiences with the narrative exercise, we went beyond the content of the collective stories. Additionally, we complemented the narrative analysis of the documents with an analysis of the construction process (through field notes) and of how the participants interacted with and over the documents (Jacobsson, 2016), through individual interviews and focus group interviews. This was an abductive and iterative process, through which we explored the patterns and empirical surprises across the data material by interpreting them in relation to existing theory (Timmermans and Tavory, 2022) and the already identified key story in the documents of suffering and loss. This process involved multiple rounds of coding and categorizing emerging themes, re-examinations of the data and developing new perspectives on theory, along with ongoing discussions among the authors.

Theoretical perspectives on illness narratives and their embeddedness in the context of social and cultural life, informed our analysis. Analysis of the 'socially situated practice of storytelling' (Gubrium & Holstein 2009, p. 9) and shared experience was inspired by Vibeke Steffen´s work on illness narratives (Steffen, 1997). Further, Kleinmann and Kleinmann's (1991) work on understanding human experiences of suffering as an intersubjective medium and their notions of local moral worlds (Kleinman and Kleinman, 1991) informed our analysis.

Findings

To ensure clarity, we will present the findings in the same chronological order and organization as the exercise. First, we will discuss the key story identified within the documents, its significance, and the construction process for the participants. Next, we will explore findings related to the performance of the reading and its context within a specific setting. Finally, we address findings from the last phase of the exercise, which involved sharing of the document – a phase often found challenging by the participants. The overarching finding of this study is that through sharing individual illness narratives and through the constructing and sharing of the collective stories, participants found relief in expressing their experiences with suffering and loss due to advanced cancer. This overall finding emerged from the various elements of the exercise, which together formed a significant whole.

Collective stories about suffering and loss

The collective stories were based on the participants' individual stories and the group work. The purpose was to accentuate shared experiences. Through the construction of the collective stories, participants were invited to engage in sharing their cancer experiences with others with presumed similar experiences and prognoses. The structure of the exercise and the narrative course overall created an obligation for the participants to engage in listening and commenting on co-participants' stories.

Prompted by the five questions, the collective stories were mostly about suffering. The stories revolved around loss in all forms imaginable: of bodily functions, identity, relationships, trust, participation in everyday activities, and loss of happiness and the ability to dream about the future:

> 'We experience different losses. We experience sorrow over the loss of our ability to work, our children, loss of… It is just one sorrow after the other. Loss.'
>
> (Excerpt of the collective story, course II).

> 'There is also great sorrow connected to different losses. Partially, loss of identity and control over your life, to do things and accomplish many goals in life. The loss of opportunity to have

> experiences in the future like growing old or having grandchildren, things we might not get to experience. And then the sorrow it is to lose, lose an active lifestyle'.
>
> (Excerpt of the collective story, course I).

Suffering in form of pain, fatigue, anxiety, and loneliness were also dominant themes:

> 'When we think about how it has affected us psychologically to have a chronic, incurable illness, there is now a seriousness in life. There is a lost faith in life. It feels like getting slapped and 'well, I can also fall ill'.
>
> Then, the loneliness sets in, too. When you sit alone and maybe find yourself surrounded by peace, then your thoughts are allowed to run free. Even though we are many people at home, we may feel incredibly lonely. They are there, but they don't know how it feels to be us.
>
> And then there is the anxiety. For some of us, it is about dying from our children all too soon. For others among us, the anxiety is about how you can't trust your body'.
>
> (Excerpt of the collective story, course II).

Although the collective stories predominantly revolved around suffering and loss, the participants found the exercise of the collective story exercise to be significant. A key to these experiences of significance was rooted in the specific context of the course and the exercise's foundation in a group of 'fellow sufferers' (Steffen, 1997 p. 105).

Telling and listening to each other's stories created a community between the participants, and the setting played into how stories of loss and suffering were legitimatized and valued. A participant explained how the reciprocity of telling and listening mediated the severity of the stories:

> 'Even though it is tough, it's the recognizability in it. To meet and hear others who had the same experiences. It's also a gift to receive, I think' (Excerpt from focus group four, course II).

By constructing collective stories, participants were able to integrate their individual experiences with advanced cancer into a shared story. This sharing of struggles and acknowledgement of each other's stories appeared to enhance their sense of community and, for some, alleviated feelings of loneliness:

> 'Again, it's the recognizability in it, that you are not alone, because you recognize yourself in the collective story (..) I had such a lonesome feeling - that I was alone in this, and it disappeared a little' (Excerpt from focus group four, course II).

Recognizing their experiences within a group of fellow sufferers (Steffen, 1997) helped to validate the participants' individual illness stories of suffering, transforming individual suffering into shared stories of suffering. These findings echo the work of anthropologist Vibeke Steffen on Alcohol Anonymous (Steffen, 1997), emphasizing the transformative power of storytelling in turning individual illness stories into shared experiences.

In the research setting, as previously mentioned, the process of collectivizing illness stories emerged from both the storytelling practice and the professional intension. This involved a professionally lead session and editing process that emphasized the transition from the individual 'I' to the collective 'we'. According to Frank (2009), all stories create a distinction between the 'I' that narrates and the 'I' that suffers. This distinction is a crucial reason why sharing stories of illness can be experienced as healing:

'What I can affirm is how stories can bring existential or spiritual healing, and crucial to that healing is the capacity of stories to open a distance between the patient living in a diseased body and the ill person who is able to narrate illness' (Frank, 2009: 6).

The collective stories illustrated this process. By providing participants with an opportunity to create distance from their own experiences, the collective story exercise appeared to alleviate, or perhaps heal, the participants' feelings of loneliness in their suffering.

The impact of dominant narratives about cancer and rehabilitation

The collective stories were not just stories of suffering and loss, but also expressions of how the participants' stories about health, illness, and suffering were shaped by cultural and social narratives available to them. This influence is evident in how participants discuss their relationships with their bodies:

> 'Some of us had a feeling, until now, until we got sick, that we were a team with our body. We could exercise and eat healthy and in return, we could trust our body that it would take us through a half-marathon or whatever you want. But suddenly we can't trust it, it just falls ill and gets cancer' (Excerpt of the collective story, course II).
>
> 'A lot of us have the experience that, in the midst of life, that we are made very old. At a time when we should feel strong and beautiful and sexy. And it happened very suddenly (Excerpt of the collective story, course I).

These excerpts illustrate that the sick body is portrayed as more than just 'wounded' by illness, as described by (Frank, 2013). Additionally, the excerpts show that participants' stories about the body are embedded within social and cultural narratives that suggest we should be able to control our bodies (Nettleton and

Watson, 1998). This theme is also reflected in sections of the collective stories that were 'emplotted' (Steffens, 1997, p. 105) with positive conclusions:

> 'It is like the body, in some ways, becomes used to all the medicine you get. Like, think of all the drugs and stuff we get into our bodies, but it just keeps going and going. It's crazy. It's incredible how strong the body actually is'.
>
> (Excerpt of the collective story, course III).

Other scholars have highlighted how discourses in cancer rehabilitation can influence individuals with life-threatening illness to feel obligated to persevere and thrive despite their suffering. Managing the suffering of illness well can seem like a moral imperative (Hansen and Tjørnhøj-Thomsen, 2008), a theme that is also emphasized in the collective stories:

> 'And then you find that you lose your motivation and faith but at the same time, you feel that you must have it – faith and motivation. To keep living the way you do. But at the same time, it is lost, right? It is like you are in a bit of a conflict there'.
>
> (Excerpt of the collective story, course II)
>
> 'Some of us find that you need to accomplish many things. That now you need to live a lot, but actually you can't live a lot all of a sudden. Because maybe you're working, or your kids are going to school and it's a normal everyday life'.
>
> (Excerpt of the collective story, course II)

These excerpts show how the participants, now confronted with their own mortality, continued to shape their stories based on their own expectations and what was 'expected' of them. This places the collective stories within frame of dominant illness narratives. They serve not only as testimonies about experiences with advanced cancer, but also how these experiences are shaped by the social and cultural context surrounding the storytellers.

Reading and listening to the collective story

> 'It is the last day of the four-day main stay at REHPA. The participants are sitting around the tables in the room. I feel how the anticipation is palpable; there is hardly any chitchat. I long to go home. Probably the participants do as well? The professionals introduce what this session is about. Everyone is very silent. The psychologist places herself on the edge of her table, one leg touches the ground while the other hovers in the air. In her hands is the now transcribed and edited collective story and she is about to read it out loud. The room is silent,

> and she starts to read. I feel a chill running down my spine, and while she is reading the story out loud, I look around at the participants. Some are visually moved. They tear up. They look out the window in concentration or down at their hands. I struggle to suppress my own tears. Rarely have I been in a room this loaded with emotions. For several minutes, everything is silent expect from the voice carrying the collective story from paper to the present' (field notes, course II).

The third phase of the exercise involved reading the collective aloud, which was a crucial component for the participants. As illustrated above, the atmosphere in the room was charged even before the reading began. Mattingly (2010) suggests that the meaning of a story is influenced not only by its content but also by the context and the storyteller. Therefore, attention to both the story and the situational and conditional practices of storytelling, including its embeddedness in practice, is essential (Peterson and Langellier, 2007).

The reading was performed by a professional who intentionally moved from her seat at the professionals' table to a position closer to the participants, adopting a relaxed posture. She took her time and spoke slowly. For some, this performance of the collective story was key to the significance of the exercise, as illustrated in this interview dialogue:

> 'Participant: (…) it really gave such an experience of being understood, to be seen. That someone gets it. So actually, I experienced it as ultra-important. One of the things that resonated most with me at home was hearing that story.
>
> Interviewer: Have you looked it at home or re-read it?
>
> Participant: Yes, and that was a bad idea.
>
> Interviewer: It was a bad idea?
>
> Participant: Yes, well (…) when I read it myself, then it's just words. Not because I'm bad at it, but because I didn't feel embraced and heard compared to when it was read out loud, because I thought I could do that [laughs]. But it was different (…) It was delivered in a way that felt emphatic; I think it felt like being cared for, because the tone of voice was soft (…) I don't know if I would have felt differently if someone else had read it out loud, but I still think that a large part of the effect came from having it read out loud' (interview, course III).

The reading of the collective stories connected the participants' initial storytelling in the first phase of the exercise to a more embodied experience during the reading, integrating all phases of the exercise into a cohesive whole. A participant explained that she was initially very confused about what the professionals meant by 'the collective story', as she had not thought much about the first phase of the exercise. However, the reading transformed her understanding and moved her deeply (focus group two, course I).

For others, hearing the collective story read aloud was a profound, almost spiritual experience. As illustrated by the field note excerpt, some participants, typically reserved with their emotions during the course, either teared up or visibly cried during the reading. These experiences extended beyond the specific moment and context of the reading: they were impactful memories that participants carried with them, as expressed weeks later at the follow-up course:

> 'Participant 1: What made the biggest impression on me was the collective story [many verbally agree]. It's ridiculous. We sat there, 13 different people with very different [cancer] illnesses and were in completely different places in this and then it was spot on. I mean, I think that's crazy.
>
> Participant 2: It's a good startup exercise because it created an instant bond between us because you could relate to everybody (…).
>
> Participant 3: It was so crazy, almost like a spiritual experience, having it read aloud (..). It was such an experience where you think, and it isn't going to happen, that maybe there is something more between heaven and earth. At least that was how I felt, and it was something I brought home with me, to think that I became so emotional. Such a large and strong man like me, it was such a crazy experience' (Excerpt from focus group 3, course II).

One participant tearfully described the reading as having a 'therapeutic effect', feeling 'healing', and making her feel 'recognized' as a person, despite also feeling sorrowful (fieldnotes, course III). Another participant noted that after hearing the collective story read aloud, she felt more empathetic towards herself, as the story reflected the struggles she had experienced. In this way, the collective stories helped the participants not only to express but also to understand their struggles and suffering.

Advanced cancer calls for narratives about the body that is ill (Frank, 2013), but storytelling also occurs through bodily, communicative practices among relations (Langellier and Peterson, 2004). As we have shown, it is important to explore the significance of the collective stories as both 'a making and a doing' (Peterson and Langellier, 2007: 205).

Sharing the collective stories in everyday life

The final phase of the exercise involved the participants receiving a physical printout of the collective story, along with the opportunity to share it. The professionals emphasized that this document was personal and could be used as the participants wished, but the highlighted the option of sharing it with friends and family. Some participants chose to share the collective story with loved ones, while others discussed it in other cancer support groups they attended. For some, taking the collective story home to share with their friends and family was seen as a significant benefit of participating in the exercise:

> ‘Participant: Well, I brought the collective story with me back home, of cause, and I read it out loud for my family. And it was really lovely for me. Because they hadn’t grasped the point the way we do. I hadn’t been able to explain or word it, and people always just said ‘I pity you’, but shut up, I don’t want to be someone you pity! But, when I had read it aloud, it just.. I don’t know if was as meaningful for them as it was for me, but it just made so much sense to me, because now they know what it’s really like’ (Excerpt from focus group four, course II).

Although the excerpt describes a meaningful shared experience, it also notes that the significance of sharing the collective story was primarily felt by the participant and perhaps less so by the recipients. Other participants reported that when they shared the collective story with outsiders, the document’s meaningfulness to them was not always acknowledged by those recipients:

> “I had my neighbour read it, but I didn’t get that much feedback. I think I’ll use it for myself from now on, as a way of offering myself comfort. I can always take it out again and remind myself that I’m not alone in this’ (Field notes, course III).

Other participants described instances where their loved ones rejected the collective story because the content was too painful:

> ‘The collective story we made; it moved me a lot. And I have tried to show it to my husband, and he was touched by it, but it was too much for him, he just couldn’t. I thought that maybe he could use it to understand where I am on my trajectory, but it was too much for him’ (Interview, course II).

Participation in the course represented inclusion into a ‘local moral world’ (Steffen, 1997; Kleinman and Kleinman, 1991). As previously demonstrated, participants’ accounts of suffering and loss were legitimized and valued within this community of fellow sufferers. However, sharing these stories with people outside this group proved challenging. Stories of suffering can burden the listener, and generally, listeners prefer illness narratives that emphasize hope and positivity (Frank, 2013). The difficulty the participants experienced in sharing the collective stories illustrate how the course created a unique local world. Within this setting, the participants could share stories of suffering and loss that might not be accepted or understood in their everyday interactions.

Discussion

Our study demonstrates that the exercise of constructing collective stories was experienced as significant for the participants, particularly because it allowed them to integrate their individual experiences of living with advanced cancer into a shared story. This process helped alleviate feelings of suffering, loss, and loneliness. We found that the reading was a crucial part of the exercise, and we also noted the challenges participants faced when sharing the collective story document in their everyday lives. The literature supports the idea that sharing stories of suffering related to illness can be healing (Hydén, 1997; Kleinman, 1998; Frank, 2013). However, these findings do not directly align with the primary goals of the narrative courses, which aimed to help participants maintain and rediscover meaning and a sense of a coherence in life despite the challenges of advanced cancer.

The collective stories differ from individual illness stories in that they generally do not prescribe a model for future actions for the participants (Steffen, 1997; Mattingly and Garro, 2000). This aspect set the exercise apart from other narrative exercises in the courses, which often included a professionally introduced notion for the participants to focus on aspects of meaning, life values, future actions, or utilizing past life resources. Through constructing collective stories about life with advanced cancer, a community was also formed – a local moral world in which participants' experiences of suffering and loss were not only accommodated but also valued and legitimatized. Simply being recognized and acknowledged in their experiences of suffering seemed to provide healing and relief for the participants.

Additionally, we have demonstrated how the collective stories were influenced by the social and cultural context in which they were embedded (Bury, 2001; Langellier and Peterson, 2004; Kleinman and Kleinman, 1991). It is well-established that cancer is deeply entrenched in public discourse (Plage and Olson, 2021; Garden, 2010; Nielsen, 2019). Frank (2013) discusses three ideal types of illness narrative: restitution, quest, and chaos, noting that restitution narratives are favoured in everyday life stories as well as by society and social media (Frank, 2013; Donnelly, 2021). Consequently, individual stories of suffering from an incurable and life-threatening illness may remain untold in everyday life (Broom et al., 2019; Donnelly, 2021), a challenge that our study participants faced when sharing the collective stories. Our study further supports this observation, revealing how dominant narratives not only shape the expression but also the experience of living with advanced cancer. This highlights the importance of understanding both individual and collective illness stories within the context of cultural and social narratives. In this study, we found that the exercise of constructing collective stories, within the specific context of fellow sufferers, created a space for sharing stories of suffering that may be suppressed by dominant illness narratives in participants' everyday lives.

We argue that the construction of the collective stories represented a unique storytelling opportunity for participants that is not directly comparable to other forms of formal or informal storytelling activities known from everyday life or narrative research. This suggests the method's feasibility for further application in rehabilitation and palliative care interventions for people with life-threatening illnesses. This study also underscores the importance of recognizing the socially situated nature of the collective stories (Steffen, 1997; Gubrium and Holstein, 2009) and how the meaning attributed to them was related to the performance of the reading and the embodied nature of listening (Mattingly and Garro, 2000; Mattingly, 2010).

An aim of the exercise concerning the collective story was to create a document that could be shared, drawing theoretical inspiration from dignity therapy (Chochinov et al., 2005). However, unlike dignity therapy, which is based on participants' own accounts of what matters most to them, the collective stories were heavily influenced by five specific prompts and focused on identifying the 'commonly recognizable' elements in their stories. The collective stories explored in this study are essentially *constructed*; they are the result of a creative, collaborative storytelling and editing process involving both the participants and the professionals. Central to understanding the collective stories is recognizing how the five prompts contributed to creating a unique arena where sharing experiences of having cancer and undergoing treatment were not only encouraged but expected.

We have not conducted an analysis of the construction of the collective stories per se, which is crucial to addressing the question of 'whose voice is really represented in the collective stories?' Such an analysis would include exploring changes in the story from day one and day four, examining the professionals' role in facilitating the storying process, and investigating the steps and consequences of the editing process. As a result, the analysis of the construction process of the collective stories is based only on the participants' experiences and the observations of the first author. Nevertheless, the different research methods complemented each other well. This study's findings highlight the importance of conducting explorative ethnographic fieldwork to assess the significance of rehabilitation efforts like the exercise of constructing collective stories. By adopting this perspective, we gained a deeper understanding of how and why the exercise was significant, while also examining the complexities involved in constructing, listening to, receiving and sharing the document.

Conclusion

In this study, we aimed to explore the experiences of participants with advanced cancer who took part in the collective story exercise during the narrative courses. We demonstrated how the exercise of constructing these stories provided the participants with significant healing experiences, such as alleviating feelings of loneliness when their individual illness stories were integrated into a collective story of shared experience. This integration helped legitimatize the participants' experiences of suffering and loss, making their experiences valuable within the specific course community, which we identified as 'a local moral world'. We also illustrated that sharing the collective stories was often experienced as challenging, further emphasizing that their significance was tied to this specific local moral world. Additionally, we highlighted how the collective stories were influenced by dominant cultural and social narratives and must be understood within this context of embeddedness.

References

Atkinson P (2009) Illness Narratives Revisited: The Failure of Narrative Reductionism. *Sociological research online* 14(5): 1-10.

Blix B and Sorly R (2017) *Fortelling og forskning: Narrativ teori og metode i tverrfaglig perspektiv. Orkana akademisk*

Broom A, Kenny K, Kirby E, et al. (2019) The collective/affective practice of cancer survivorship. *The British journal of sociology* 70(4): 1582-1601.

Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4(2): 167-182.

Bury M (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* 23(3): 263-285.

Charon R, DasGupta S, Hermann N, et al. (2017) *The principles and practice of narrative medicine.* New York, NY: Oxford University Press.

Chochinov HM, Hack T, Hassard T, et al. (2005) Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology* 23(24): 5520-5525.

de Fina A (2008) Who tells which story and why? Micro and macro contexts in narrative. *Text & talk* 28(3): 421-442.

Donnelly C (2021) Claiming chaos narrative, emerging from silence. *Disability & society* ahead-of-print(ahead-of-print): 1-15.

Frank AW (2009) Tricksters and Truth Tellers: Narrating Illness in an Age of Authenticity and Appropriation. *Literature and Medicine* 28(2): 185-199.

Frank AW (2013) *The wounded storyteller: body, illness, and ethics.* London;Chicago;: The University of Chicago Press.

Garden RE (2010) Telling Stories about Illness and Disability: The Limits and Lessons of Narrative. *Perspectives in Biology and Medicine* 53(1): 121-135.

Graff L, Timm H and Thuesen J (2023) Organizational narratives in rehabilitation-focused dementia care – Negotiating identities, interventions and personhood. *Dementia (London, England)* 22(4): 709-726.

Gubrium JF and Holstein JA (2009) *Analyzing narrative reality.* London: SAGE.

Gärtner HS, Blix BH, Raunkiær M, et al. (2024a) "The Most Fantastic Thing is Coming Here as an Individual and Going to Bed as Part of a Group": Participants' Experiences From a Residential Course, for People With Advanced Cancer. *OMEGA - Journal of Death and Dying* 0(0): 00302228241264876.

Gärtner HS, Blix BH, Raunkiær M, et al. (2024b) 'There is nothing beautiful or life-affirming in it': experiences of harm in a narrative course combining rehabilitative and palliative care approaches for people who have or have had cancer. *Mortality*. DOI: 10.1080/13576275.2024.2360521. 1-17.

Hansen HP and Tjørnhøj-Thomsen T (2008) Cancer Rehabilitation in Denmark: The Growth of a New Narrative. *Medical Anthropology Quarterly* 22(4): 360-380.

Hydén LC (1997) Illness and narrative. *Sociology of Health and Illness* 19(1): 48-69.

Jacobsson K (2016) Analysing documents through fieldwork. pp.155-170.

Jess M, Nielsen SP, Rasmussen A, et al. (2023) Stories of a long life with HIV: A qualitative study of a narrative intervention. *Scandinavian Journal of Caring Sciences*. DOI: 10.1111/scs.13161.

Kleinman A (1998) *The illness narratives: suffering, healing, and the human condition.* New York: Basic Books.

Kleinman A and Kleinman J (1991) Suffering and its professional transformation: toward an ethnography of interpersonal experience. *Culture, Medicine and Psychiatry* 15(3): 275-275.

Langellier KM and Peterson EE (2004) *Storytelling in daily life: performing narrative.* Philadelphia, Pa: Temple University Press.

Mattingly C (2010) *The paradox of hope: journeys through a clinical borderland.* Berkeley: University of California Press.

Mattingly C and Garro LC (2000) *Narrative and the cultural construction of illness and healing.* Berkeley, Calif: University of California Press.

Nettleton S and Watson J (1998) *The body in everyday life.* London: Routledge.

Nielsen E (2019) *Disrupting breast cancer narratives: stories of rage and repair.* London;Toronto;Buffalo;: University of Toronto Press.

Peterson EE and Langellier KM (2007) The performance turn in narrative studies. In: Bamberg M (ed) *Narrative – State of the Art*. The Netherlands: John Benjamins Publishing Company.

Plage S and Olson RE (2021) Surprise Reveals the Affective-Moral Economies in Cancer Illness Narratives. *Qualitative Health Research* 31(14): 2730-2742.

Rasmussen A, Søsted D and Rottmann N (2023) Livsfortællinger, mening og sammenhæng i liv med uhelbredelig kræftsygdom - Kliniske erfaringer fra en metodisk afprøvning i REHPA Forskningsklinik. Reportno. 27. Place Published: Nyborg Institution: REHPA.

Rasmussen Ar, Jespersen Er, Backmann Tr, et al. (2020) Praksisbeskrivelser – Forskningsklinik REHPA. Standard rehabiliteringsforløb for mennesker med eller efter kræft. (Practice descriptions research clinic REHPA – standard rehabilitation programme for people with or after cancer). Place Published: Nyborg Institution: REHPA

Roikjær SG, Gärtner HS and Timm H (2021) Use of narrative methods in rehabilitation and palliative care in Scandinavian countries: A scoping review. *Scandinavian Journal of Caring Sciences* n/a(n/a).

Schoenau MN (2022) Dominant restitution narratives of 'being lucky': An ethnographic exploration of narratives about operable lung cancer. *European Journal of Cancer Care* 31(5): e13633-n/a.

Segal J (2012) Cancer Experience and its Narration: An Accidental Study. *Literature and Medicine* 30(2): 292-318.

Sidenius A, Manderson L, Mogensen O, et al. (2019a) "But this is a good cancer":Patient perceptions of endometrial cancer in Denmark. Journal of clinical nursing 28(1-2):245-256

Sidenius A, Mogensen O, Rudnicki M, et al. (2019b) Feeling lucky:hierarchies of suffering and stories of endometrial cancer in a Danish context. Sociology of Health and Illness 41(5):950-964

Steffen V (1997) Life stories and shared experience. *Social science & medicine (1982)* 45(1): 99-111.

Timmermans S and Tavory I (2022) *Data analysis in qualitative research: theorizing with abductive analysis.* Chicago: University of Chicago Press.

White M (2006) *Narrativ teori.* København: Hans Reitzels Forlag.

WMA (2022) *WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS*. Available at: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/.