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# '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 $\geq 18$ 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.	<ul style="list-style-type: none"> <li>• Participant observations (total of 185 hours)</li> <li>• 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.</li> <li>• 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.</li> </ul>
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.	<ul style="list-style-type: none"> <li>• Participant observations (total of 30 hours)</li> <li>• 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.</li> </ul>

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 on) (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). Ethiske overvejelser og utilsigtede konsekvenser i interventionsforskning (Ethical considerations and unforeseen consequences in intervention research). In K. 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/ddYHGCL>
- 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 undersøgelse 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/OHdxfrww>
- 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: Evalueret 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., Vejlgård, 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., Vejlgård, 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., Knauth, F., Wenk, R., Ali, Z., Bhatnagar, 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](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 Palliation (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-kræft.-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/>