

“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 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 hours 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.

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; Raunkjaer, 2022). 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., 2019; Hansen et al., 2018), and dignity therapy (Houmann et al., 2014; Houmann et al., 2010). 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 & Timm, 2019; Jess et al., 2023). 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 2 for an overview of data material). The field work was conducted by the first 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 non-verbal 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

Table 2: Data material

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

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 re-familiarization 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 3 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.

Figure 1: Example of development of themes:

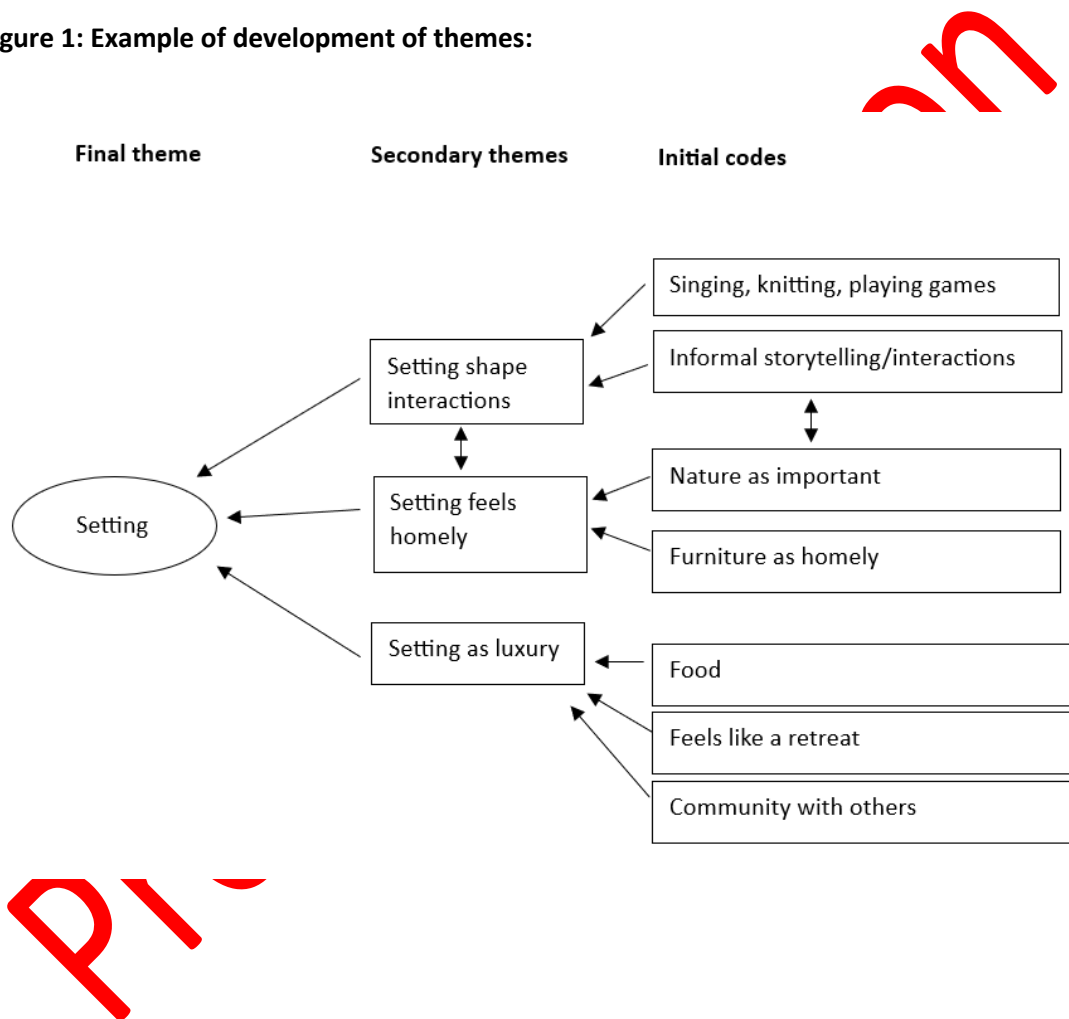


Table 3: Example of the analysis process, inspired by Thomsen (2022).

Data extract	Initial coding (code book)	Development of themes	Theorizing	Final themes
<p>“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).</p>	<p>Community</p> <p>Setting possibilities</p> <p>Non-formal interactions</p>	<p>Setting shaping social interactions</p> <p>Setting feels homely</p>	<p>Context</p> <p>(Hansen et al., 2011)</p> <p>(elements of physical surroundings and behavioral environments)</p>	<p>Setting</p>
<p><i>“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).</i></p>	<p>Trust</p> <p>Professionals</p> <p>Identity</p> <p>Community</p> <p>Acceptance</p>	<p>Being part of a community</p> <p>Context: being chronic</p> <p>Need for new “identity.”</p>	<p>Sense of community</p> <p>(Mcmillan & Charvis, 1986)</p> <p>(elements of membership, belonging and identification)</p>	<p>Community</p>

<p><i>"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."</i></p> <p><i>(Observation excerpt)</i></p>	<p>Joy</p> <p>Courage</p>	<p>Experiencing new ways of thinking</p> <p>Experiencing meaningfulness in life</p>	<p>Existential hope</p> <p>(Graven & Brødslev Olsen, 2018)</p>	<p>Hope</p>

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.

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 (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 et al. (2021), "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 participant 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 (2022) 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.

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