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The cost of living with cancer during the second wave of COVID-19: A mixed methods study of Danish cancer patients' perspectives

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ABSTRACT

Purpose: This study investigated experiences and levels of distress and resilience of Danish cancer patients during the second wave of the COVID-19 pandemic.

Methods: The mixed methods design included a subset of cancer patients who responded to a cross-sectional survey in May 2020. Data were collected through telephone interviews. The National Comprehensive Cancer Network Distress Thermometer (NCCN DT), and Connor-Davidson-Resilience Scale (CD-RISC2) were used to measure distress and resilience. Data were analysed by thematic analysis and descriptive statistics.

Results: Forty patients with lung, breast, colorectal and skin (melanoma) cancer were included; 65% were women. Mean age was 62.2 years (standard deviation [SD], 13.2). Most patients had curable disease (65%); 50% were in treatment and 50% in post-treatment follow up. The interviews revealed four themes: 1) the cost of living with cancer during COVID-19, 2) changes in cancer care delivery, 3) particularly vulnerable, and 4) importance of family support. Mean NCCN DT score was 2.3 (SD, 2.6) while the mean CD-RISC2 score was 7.25 (SD, 1.1). **Conclusion:** Despite drastic changes in daily life imposed by COVID-19 restrictions, Danish cancer patients had remarkably low levels of distress and high levels of resilience. Patients in active treatment, with comorbidities or elderly felt vulnerable. Family support was invaluable in critical times.

1. Introduction

Heading into the second wave of the COVID-19 pandemic, care for vulnerable patients with cancer and their families became more important than ever. The COVID-19 pandemic was from the beginning an international health crisis (World Health Organization, 2020), and the risk of getting an infection with COVID-19 may have increased worries and stress and reduced resilience for patients with cancer and their families. The Danish government closed the country down due to COVID-19 for the first time on March 13, 2020 (Nielsen and Dieperink, 2020), and cancer care delivery has subsequently been influenced by constantly changing recommendations from the Danish Health Authority (Danish Health Authority, 2020). The second wave in Denmark began in the beginning of September 2020, and peaked on December 15th 2020. Restrictions were increased during this period. Face masks became mandatory in all indoor public spaces, the assembly ban was reduced from 50 people to 10 people and restaurants were closed except for take-away. The country shut completely down on December 17th,

when schools and non-essential businesses also were closed. At that time, there was no prospects of vaccination.

In general, cancer is a disease that influences daily and family life (Coyne et al., 2020), and being exposed to an additional threat may be overwhelming. The COVID-19 pandemic has been a reality for less than a year; accordingly, knowledge about cancer and COVID-19 is sparse. A Danish cross-sectional study with $n = 4571$ cancer patients in the department of oncology at Odense University Hospital in May 2020 revealed that 80% of patients were at least somewhat concerned about contracting COVID-19 (Jeppesen et al., 2021). This finding was supported by a recently published quantitative study in which the authors concluded that fears and anxiety related to COVID-19 were high among cancer patients and caregivers (Ng et al., 2020). An Italian survey reported moderate isolation-related suffering concerns among $n = 195$ patients with cancer. Patients who reported more social problems were older, had less education and were living without minor children (Biagioli et al., 2021). However, these surveys provide no detailed insight into the concerns of cancer patients or the influence of the pandemic on

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cancer treatment and daily life.

A few qualitative studies exist of patients with cancer in Western healthcare systems during the pandemic. Hyland and Jim (2020) examined $n = 15$ patients from the US with advanced lung cancer about possible concerns related to COVID-19. They found that patients expressed a sense of loss about what cancer had already taken from them, which was compounded by limitations imposed by COVID-19 (Hyland and Jim, 2020). Moran et al. investigated cancer care delivery during active treatment among $n = 7$ women with gynaecologic cancer from the US. The women experienced attending treatments and appointments alone as one of the primary COVID-19 difficulties (Moran et al., 2020). Haase et al. interviewed $n = 30$ patients with breast or colorectal cancer in Canada, focusing on the needs of older patients during the pandemic. Older cancer survivors appreciated the shift to virtual appointments but needed help with the transition. In addition, older patients needed more written information at discharge when support people could not attend appointments (Haase et al., 2021). In the US, Triantafillou et al. explored the perspectives of $n = 56$ head and neck patients on telemedicine clinic visits during COVID-19. Head and neck cancer patients were generally satisfied with telemedicine, but their concerns included, among other things, the inability to receive a physical examination (Triantafillou et al., 2020). However, these studies were carried out during or just after the first wave of COVID-19. Limited information exists on how European patients perceive the long-term threat of COVID-19 and resulting changes in cancer care and how patients with cancer cope with daily and family life.

2. Aim

The primary study objective was to explore the experiences of Danish patients in relation to the COVID-19 crisis and living with cancer during the second wave of the pandemic. A second objective was to gain insight into their levels of distress and resilience.

3. Methods

3.1. Design

The study used a parallel mixed-methods approach (Chiang-Hanisko et al., 2016). Explorative semi-structured interviews aimed to identify concerns, unmet informational needs and potential resources among Danish cancer patients and provide in-depth understanding of their experiences. In addition, data on their levels of distress and resilience provided insight into the psychological impact of living with cancer during a public health crisis. The Standards for Reporting Qualitative Research (SPQR) was used as a guideline (O'Brien et al., 2014).

3.2. Data collection

Participants were recruited among outpatients who had responded to a cross-sectional survey (COPICADS) about COVID-19 and cancer distributed by the Odense University Hospital oncology department in May 2020 (Jeppesen et al., 2021). A total of $n = 4571$ patients participated in the survey, 1320 of whom were diagnosed with breast, lung, gastrointestinal or melanoma cancer. Of the latter group, patients who had consented to be contacted for an interview were eligible for this study.

Data were collected through telephone interviews. Due to the exploratory nature of the study, the sample size could not be precisely determined *a priori*, but we aimed to include approximately 10 Danish patients with each type of cancer, yielding a total sample size of 40. A purposive sample of eligible patients was selected to ensure maximal variation in age, gender, cohabitation status, and worries (none, mild, moderate or extreme) about COVID-19 reported in the COPICADS study.

3.3. Inclusion criteria

- Aged 18 years and older
- In treatment or follow up after systemic cancer treatment (oral/IV chemotherapy, adjuvant, neoadjuvant or targeted therapy or immunotherapy)
- Diagnosed with breast, lung or colorectal cancer or melanoma
- Danish speaking

Exclusion criteria.

- Inpatient status
- Near the end of life
- Currently receiving radiotherapy or surgical treatment
- Receiving a combination of systemic treatment and radiotherapy
- Positive COVID-19 test at the time of participation
- Inability to understand or follow study procedures
- Inability to give consent

3.4. Study procedures

We conducted in-depth interviews and collected quantitative data about distress and resilience over the phone. We decided to use phone interviews in order to conduct the interviews within a short time frame and eliminate the risk of getting infected with COVID-19. An interview guide was developed to ensure consistency, and interviews were carried out by four interviewers. The semi-structured interview guide was based on information extracted from existing literature on the topic. The interviews covered topics related to COVID-19, such as perceived changes in cancer care, perceived risk of infection with COVID-19, information needs and expectations of healthcare professionals, concerns and worries and influence on daily living and family issues. All interviews were tape recorded and transcribed verbatim.

3.5. Stress and resilience measures

Level of distress was measured with the Danish version of the National Comprehensive Cancer Network Distress thermometer (NCCN DT) (Donovan et al., 2014), and resilience was assessed with the Danish version of the 2-item Connor-Davidson-Resilience Scale (CD-RISC2) (Vaishnavi et al., 2007).

The NCCN DT is used to screen for self-reported psychosocial distress across cancer settings and is a well-validated and reliable screening tool (Donovan et al., 2014). It contains one item: "Please circle the number [0–10] that best describes your level of distress in the past week including today." Patients respond on a vertical visual analogue scale from 0 ("no distress") to 10 ("extreme distress"). If patients reported any distress during data collection, we identified the causes of distress.

The CD-RISC2 measures resilience (Vaishnavi et al., 2007). The two items are: "able to adapt to change" and "tend to bounce back after illness or hardship". The items were selected by the developers as etymologically capturing the essence of resilience, i.e., the ability to spring back and successfully adapt to change. Both items have 5-point response scales (0 = "not at all true", 4 = "true nearly all of the time"), with higher scores reflecting higher resilience. Total possible scores are 0–10.

In addition, we collected patient and disease characteristics: age, gender, cancer diagnosis, current cancer treatment, and cohabitation status. We had data about worries related to COVID-19 during the first outbreak from the COPICADS study (Jeppesen et al., 2021). If not reported by participants, data on treatment modality were gathered from the medical record. All participants signed a written consent form that allowed us to access their medical records for this purpose.

3.6. Analyses

Thematic analysis was chosen to extract data, and to identify and report patterns (Braun and Clarke, 2006). Thematic analysis is a systematic approach comprising six steps: 1) familiarization with data, 2) generating initial codes, 3) searching for themes among codes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the final report (Braun and Clarke, 2006).

We assumed that patients' experiences would vary with treatment intention (curative vs. palliative) and the self-management support they received. Based on these assumptions, we were aware of three subgroups of treatment intention while analysing interview data: cancer treatment with curative intent, cancer treatment with palliative intent, or follow-up care.

We performed descriptive statistical analysis of quantitative data on distress and resilience, including comparing item scores with reference data published for distress scores (Ma et al., 2014; Mehnert et al., 2018) and resilience (NI et al., 2016). Stata 15 was used for statistics.

3.7. Ethical considerations

According to Danish law, approval from the ethical committee was not required, but the study was registered with the Danish Protection Agency (no. 20/25124). All participants received written and verbal information and provided written consent for participation. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2008). Data were secured in Sharepoint.

Before we started interviews, our preconceived notion was that patients would be as concerned about COVID-19 as they had been during the first wave. All four interviewers were skilled in qualitative research, and the three interviewers were experienced in cancer nursing but did not have any care responsibilities for participants.

4. Results

4.1. Participants

September 22nd to November 5th 2020, 40 cancer patients were contacted by phone and asked to participate. No patients declined, but a few patients asked that the interview be conducted at a more convenient time. Participants had lung cancer (10), breast cancer (11), colorectal or rectal cancer (9) or melanoma (10); 26 (65%) were women. The mean age of all participants was 62.2 years (SD, 13.2; range, 31–82). Most (26, 65%) participants had curable disease; 20 (50%) were in treatment and 20 (50%) were in follow up (Table 1). Interviews took an average of 15.3 min (SD, 6.6; range, 7–33). Two patients had not received systemic therapy but were in follow-up after surgery; we included them because they wanted to be interviewed and had experienced changes in their cancer trajectory.

4.2. Themes

We extracted four themes from the 40 interviews (Table 2 presents an example of the analysis). In addition, we asked participants to elaborate on their responses to the NCCN DT and CD-RISC2 scales. The four themes were: 1) the cost of living with cancer during COVID-19, 2) changes in cancer care delivery, 3) particularly vulnerable and 4) importance of family support.

4.3. The cost of living with cancer during COVID-19

The COVID-19 pandemic had a huge impact on participants. Many participants reported their way of life changed completely as the world turned upside down. The majority of participants took many precautions to protect themselves from getting COVID-19 and chose to live in relative isolation from the rest of the world; some had even stopped seeing

Table 1

Participant characteristics, n = 40.

Age, mean (SD)Range	62.2 (13.2) 31–82
Gender, n(%)	
Male	14 (35)
Female	26 (65)
Cancer site, (%)	
Breast	11 (27.5)
Lung	10 (25)
Colorectal or rectal	9 (22.5)
Skin (melanoma)	10 (25)
Cancer status, n(%)	
Curable	26 (65)
Incurable	14 (35)
Treatment status, n(%)	
In active treatment	20 (50)
Survivorship/Follow-up	20 (50)
Past COVID-19 infection, n(%)	
No	40 (100)
Inoculated, n(%)	
Yes	16 (40)
No	24 (60)
Marital status n (%)	
Married/living together	29 (72.5)
Divorced	5 (12.5)
Single	6 (15)
Number of household occupants, n (%)	
1	9 (22.5)
2	22 (55)
3	4 (10)
4	5 (12.5)
Educational attainment, n (%)	
Elementary school	8 (20)
Vocational basic course	2 (5)
General upper secondary education	1 (2.5)
Short-cycle higher education (<3 years)	6 (15)
Medium-cycle higher education (3–4 years)	16 (40)
Long-cycle higher education (>4 years)	6 (15)
Other	1 (2.5)
Employment status, n (%)	
Full-time employment	12 (30)
On sick leave	4 (10)
Early retirement	3 (7.5)
Retirement	18 (45)
Other	2 (5)
Not applicable	1 (2.5)
Worry about COVID-19 in May 2020 n (%)	
Not worried	6 (15)
A little worried	10 (25)
Moderate worried	11 (27.5)
Very worried	9 (22.5)
Extremely worried	3 (7.5)
Not applicable	1 (2.5)

their closest family and friends. One woman described not having been able to see her grandchildren for more than six months, and another expressed sadness because she was not allowed to visit her mother, who suffered from dementia, in the nursing home. Moreover, participants refrained from going to stores or participating in hobbies such as dancing: “I have been completely isolated since March 11th” (man, lung cancer, 69 years). They also thought about the time they might have left. One patient with advanced colorectal cancer said, “I wanted to see Paris, and I have been saying that for 40 years now, and now I am so scared I am not going to see it ...” (woman, 47 years).

Thus, most participants felt restricted by the pandemic in their daily lives. Most had adapted to the new situation and accepted that forced behavioral change was a necessary evil to avoid infection and to curb the pandemic. However, a few participants wished their fellow citizens were more considerate; not all Danes follow government advice and take the recommended precautions or adhere to the imposed restrictions: “I am so tired of young people who go to one party after the other” (man, lung cancer, 55 years). Another participant underscored the point: “People don't take Corona seriously enough” (woman, breast cancer, 46 years). However, a

Table 2
Brief example of data analysis of the importance of family support theme.

Phase 1: Familiarization with data	Phase 2: Creation of initial codes	Phase 3: Search for themes; codes applied across the entire dataset and put into meaningful groups.	Phase 4: Review of whether themes work in relation to the codes	Phase 5: Definition and naming of final themes	Phase 6: Report, pairing findings with selected relevant quotations
The interviews were transcribed and read several times and initial codes were noted.	Nurses are so sweet, but they are not family. Alone with thoughts. Difficult to have life-threatening illness and not have any family visits. Suddenly, I had to sit there alone. It is also hard for them	Patients' need for family involvement in critical times Caregivers' need fprinvolvement	The importance of the family for patients and family caregivers in critical times	The importance of family support	"... it is better to have four ears than two" (b-02) "So it was a little difficult to be life-threateningly ill, and then lie there without getting any family visits. I actually got my mother to visit once, because I was really sick, but we only had half an hour together" (c-03) "... you are very much alone with your own thoughts. You do not have any support from the family. And it's not because you cannot use hospital staff - you can easily. But it's just not the same as the family" (c-03) "... then it is sometimes reassuring to have my husband in hand" (c-06)

few participants reported that the pandemic had also had some positive consequences. For example, it may have brought them closer to their relatives because they spent more time together playing games, organizing photos and taking trips in nature. One respondent commented that the atmosphere of the country had become more tranquil with more time for reflection. Another patient stated that people in general have better hygiene. A few patients were even quite happy that hugs and kissed had almost been abolished. Despite these positive consequences, the impact of the COVID-19 pandemic on participants' quality of life was primarily negative.

4.4. Changes in cancer care delivery

Participants had also experienced significant changes in cancer care delivery. For example, outpatient clinic visits had been replaced by telephone consultations and treatment (e.g., chemotherapy pills) was sent to patients by courier to prevent them from going to the hospital. Some participants viewed this as an advantage because they lived far from the hospital while others believed it was problematic because they preferred face-to-face contact with their treating physician: "To me, human contact actually matters" (woman, melanoma, 52 years). In addition, the fact that their loved ones were not allowed to participate in the consultation or visit during a hospital admission was unsettling for participants. Some also had follow-up consultations postponed due to the risk of infection or limited resources during the pandemic. One woman described her fear that the pandemic would divert resources from cancer care, resulting in fewer follow-up visits and restricted access to the healthcare system that could lead to failure to detect serious conditions. For example, a woman with breast cancer who was to have bilateral mastectomies and reconstruction was told that, due to COVID-19, it would only be possible to remove and reconstruct her cancerous breast and not the other breast, as had been planned for preventive measures: "that seemed completely insane, I would say" (woman, breast cancer, 33 years). Despite their expressed concerns, none of the patients reported that their active cancer treatment had been cancelled or delayed. In addition, the patients felt well informed, reported easy access to news from the Danish Health Authority and expressed no unmet informational needs. If they had questions, they felt they could consult their involved healthcare professionals. In general, patients were satisfied with the delivered cancer care.

4.5. Particularly vulnerable

As Denmark headed into the second wave, most participants expressed having learned to live with COVID-19. In particular, patients in follow up seemed less nervous. One participant said, "the first wave

was very hard due to uncertainty about the disease" (woman, breast cancer, 33 years). However, when asked directly, most patients still felt at greater risk than healthy persons, but this feeling of vulnerability was greatly reduced because the patients took extra safety precautions. Patients undergoing active chemotherapy or those who were facing surgery felt especially vulnerable. One participant whose husband was also suffering from cancer said, "Someone told me that I was not more exposed than so many others, but I think we were, because if we were tested positive with COVID-19 then we could not be able to undergo surgery or get any treatment. So I believe we were extremely vulnerable" (woman, colorectal cancer, 66 years). Furthermore, increasing age and comorbidities increased participants' sense of vulnerability. As one patient put it: "Yes, I feel at risk, due to my age and due to the cancer, so I believe we are at risk of getting COVID-19" (woman, breast cancer, 69 years). Another patient described her concern about the lack of knowledge about risk groups: "My sister turned 30 during that period, and I told the physician that I was going to a birthday party, and he said that he did not know how it (COVID-19) would affect me: 'You may become sick from it, or you may not'. You do not know. You do not take that risk. You get completely scared if you think too much about it" (woman, breast cancer, 33 years). Thus, the patients' level of concern corresponded to the severity of their disease, with the sickest participants being the most concerned.

4.6. Importance of family support

During interviews, participants expressed family support as playing an important role when coping with the COVID-19 crisis. Many participants who visited the outpatient clinic for a follow-up visit were not allowed to bring any caregivers, due to restrictions at the hospital. They accepted the situation, but many family members found other ways of supporting their loved ones, such as waiting in the car in the parking lot during the consultation, highlighting the importance of having family near. Several patients stated that: "four ears are better than two" (man, melanoma, 77 years), and most preferred to have their loved ones at medical consultations. Some participants expressed concerns about receiving bad news without a family member to support them. Patients who were hospitalized, receiving active antineoplastic treatment or undergoing surgery during the first wave described the fact that family caregivers were not allowed to visit the hospital as an even greater challenge. A woman who underwent major surgery said, "It was a little difficult to be life-threateningly ill, and then lie there without being able to get any family visits. I actually did get my mother to visit once, because I was really sick, but we only had half an hour together" (woman, colorectal cancer, 61 years). Another patient explained the consequences of not having family caregivers along: "you are very much alone with your own thoughts. You do not have any support from the family. And it's not because

you cannot use hospital staff - you can easily. But it's just not the same as the family" (woman, colorectal cancer, 47 years). Accordingly, family support is vital, particularly for the most vulnerable patients—those who are hospitalized or receive active treatment—when they are having a treatment status consultation.

4.7. Distress and resilience

Most patients did not experience severe distress; the mean NCCN DT score was 2.3 (SD, 2.6), Table 3. N = 29 (72%) participants reported stress levels < 4, which is considered mild (Riba et al., 2019). N = 11 (28%) participants reported moderate to severe levels of distress (≥ 4), but their distress was generally not caused by the COVID-19 pandemic. Rather, it was related to other factors, such as back pain, work-related stress, and difficulty accepting early retirement due to advanced cancer or waiting for a CT scan result. Only one participant reporting a stress level of 4 blamed COVID-19: "the infection rate the day before had raised, and I have vulnerable family members" (woman, melanoma, 51 years).

Similarly, most patients reported resilience in the upper range (scores of 3 or 4 on each of two items) with a mean CD-RISC2 score of 7.25 (SD, 1.1), Table 3. Most described being able to adapt to changes, cope with stress and deal with whatever comes along. As one patient put it: "I recover, get up again every single time. And I've been through a lot anyway, I think" (woman, colorectal cancer, 47 years). When patients were asked if they were able to adapt when changes occur or tended to bounce back after illness, injury or other hardships, none of the patients responded "not true" (0) or "rarely true (1)." Three patients answered "sometimes true" (2) to one or both questions, whereas the rest (n = 37) responded "often true" (3) or "true nearly all the time" (4). The high levels of resilience on the CD-RISC2 aligned with interview findings.

5. Discussion

The study aim was to explore Danish cancer patients' experiences of living in the midst of the COVID-19 crisis and gain insight into their levels of distress and resilience. We planned to include 40 participants, and all patients we invited agreed to participate. The researchers called from the oncology department and the patients had already given consent to be contacted in the COPICADS study (Jeppesen et al., 2021), both of which undoubtedly made it easier to recruit participants. However, participants were also genuinely interested in this topic. We included a majority of women, primarily because we included breast cancer patients.

Participants experienced daily life and cancer care delivery as extensively changing under COVID-19 restrictions. However, some patients reported that the pandemic had also had some positive consequences, such as more peace in everyday life and stronger cohesion with close family members. This is consistent with a Dutch survey in which almost half of participants responded that they felt more at peace due to the lockdown, and more than a third reported that the pandemic had given them time to reflect positively on their lives (Schellekens and van der Lee, 2020). It can be argued that pandemic-forced isolation increased feelings of tranquility to some extent. However, many participants in the Dutch study also expressed feeling extremely isolated,

Table 3

Distress and resilience among cancer patients during the second COVID-19 wave.

NCCN DT Distress Thermometer, mean score (SD, range)	2.3 (2.6, 0–8)
CD-RISC2 Resilience scale, mean score (SD)	7.25 (1.1)

Abbreviations: CD-RISC2, Connor-Davidson-Resilience Scale; NCCN DT, National Comprehensive Cancer Network Distress Thermometer [0–10]; SD, standard deviation.

Note: Possible scores on both indices are 0–10.

and patients in our study described concerns about future cancer care indirectly caused by a pandemic-strained healthcare system.

Our findings indicated that families played an important role for patients, especially during critical times, i.e., medical consultations, hospitalizations and surgery during the COVID-19 pandemic. It is well documented that families are a significant support during the course of disease (Andersen et al., 2019; Coyne et al., 2020; Luttk et al., 2020). However, hospitals in Denmark chose to close the door on family visits during the pandemic, and families were only allowed to visit if the patient's condition was life-threatening. In Denmark, medical consultations were primarily shifted to telephone consultations (Jeppesen et al., 2021), which also deprived families of the possibility of attending medical consultations with patients. Three Danish studies showed that video consultations in a hospital setting are promising; for example, during ward rounds when families to older patients cannot attend (Ostervang et al., 2019; Vestergaard et al., 2019; Petersson et al., 2020). Other studies reported that video consultations are also suitable in palliative care contexts, where patients and families attend via iPad or computer and talk to physicians or nurses from their homes (Jess et al., 2019; Funderskov et al., 2019). None of these virtual interventions are widely implemented (Jess et al., 2019), but COVID-19 has revealed an urgent need for alternative ways of including families in patients' care. Accordingly, the healthcare system must develop alternative solutions to include families and be able to anticipate and adapt to circumstances such as future pandemics to prevent the exclusion of families.

As we began interviewing participants, we anticipated, on the basis of other studies, that they would report high levels of stress due to the pandemic. According to Jeppesen et al., uncertainty about the pandemic clearly worried patients; 57.5% expressed moderate to extreme worries about COVID-19 (Jeppesen et al., 2021; Rajkumar, 2020). However, this was not the case during the second wave because the patients knew how to deal with the situation. Cancer remained participants' primary concern, as others have also found (Hyland and Jim, 2020). Our findings indicated that the patients coped well. Participants did not report high levels of stress, using a cut-off score of 4 (Riba et al., 2019; Ma et al., 2014; Mehnert et al., 2018). Similarly, in a German COVID-19 cross sectional study also using the NCCN DT, Musche et al. concluded that cancer patients reported levels of distress and anxiety comparable to those of healthy controls. Musche et al. reported that behavioral changes necessitated by the pandemic were given by participants as an explanation for the low level of distress. The patients developed active coping strategies such as physical distancing, disinfecting hands more and avoiding public places (Musche et al., 2020). Thus, adopting needed precautions may very well have contributed to patients' low stress levels. This argument is supported by Hyland and Jim, who argue that cancer patients endorsed the guidelines more intensely than others because of the perceived higher stakes if they were exposed (Hyland and Jim, 2020). It may be argued that cancer patients were more worried in the immediate wake of the pandemic. As they became more used to dealing with COVID-19 in terms of adherence to the recommended precautionary measures, they may feel less stress and better prepared for the second wave. This is also consistent with the high level of resilience participants expressed in interviews. In general, they readily adapted to changes and the fact that they were used to coping with cancer may be a hidden resource making them more resilient to other adversities such COVID-19. However, although patients in this study were interviewed during the second wave and had adapted to pandemic-related circumstances, patients who were older, in active treatment or with comorbid conditions felt more vulnerable, compared to those who were younger, in follow-up care or without comorbidities. This finding was comparable to the first-wave COPICADS study that showed that factors associated with being concerned about contracting COVID-19 were comorbid conditions, incurable cancer, receiving medical cancer treatment and female gender (Jeppesen et al., 2021).

5.1. Strengths and limitations

Patients with breast, lung or colon cancer or melanoma at any stage represent a large number of patients receiving anticancer treatment in the outpatient units. We reached maximal variation in age but included a majority of women (Green et al., 2007). We believe that data saturation was reached with this relatively large number of interviews (Kvale and Brinkmann, 2009), and we considered it a strength to triangulate the interview data with the small descriptive quantitative dataset. Thus, the results regarding distress and resilience confirmed the results from the interview. However, many participants were in follow-up care, and the exclusion of patients receiving radiotherapy or combined systemic treatment and radiotherapy was a limitation because patients increasingly receive combined therapies. They may have different care experiences than those receiving systemic treatment only. The trajectories of these patients are more complex because several departments are involved in their treatment.

We used purposive sampling to select participants for this study. This method secured a variety of participants, but the method may increase the risk of selection bias. This study included four of the most common cancer diagnoses, but the experiences of patients with more infrequent cancers remains unknown. All participants were ethnic Danes, limiting the transferability of study findings to patients from racial and ethnic minority groups. In future studies, our results can be compared with other European cancer populations, which may live with different COVID-19 infection pressures and recommendations. It is important to bear in mind that this study is a snapshot from the second wave and that the threat of the pandemic is constantly changing.

6. Conclusion

Patients were very conscious of the threat from COVID-19 and took many precautions, resulting in comprehensive limitations in their daily and family lives. However, having cancer was still their primary concern. Cancer care delivery was changed with telephone consultations replacing outpatient visits. This was acceptable for many patients, but some preferred face-to-face contact. Patients were also worried that COVID-19 would put a strain on the healthcare system, indirectly resulting in poorer cancer care. Active treatment, comorbidities or older age increased feelings of vulnerability. Family support was essential, and the healthcare system must find new ways to include family virtually, especially during acute illness or important medical consultations.

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CRediT authorship contribution statement

Karin Brochstedt Dieperink: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Writing – original draft, Writing – review & editing. **Tine Ikander:** Conceptualization, Data curation, Formal analysis, Investigation, Validation, Writing – original draft, Writing – review & editing. **Sabina Appiah:** Data curation, Investigation, Validation, Writing – review & editing. **Lærke Kjær Tolstrup:** Conceptualization, Data curation, Formal analysis, Investigation, Validation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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