

**ORIGINAL RESEARCH: EMPIRICAL
RESEARCH - QUALITATIVE**

Experiences of patients with cancer and their relatives confronted with COVID-19 related delay or change in care: A qualitative study

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Abstract

Aims: To provide in-depth insight into how patients and their relatives experienced change or delay in cancer treatment and care due to COVID-19.

Design: A qualitative study including semi-structured interviews with patients with cancer and their relatives.

Methods: Between July and October 2020, 42 patients who were confronted with a change or delay in cancer treatment or care, and 11 relatives were interviewed. Data collection and analysis were performed according to the most important methods of grounded theory, including iterative data collection and analysis, theoretical sampling, constant comparative analysis and theoretical sensitivity.

Results: This study shows that patients with cancer and relatives experienced paradoxical feelings when confronted with change or delay in treatment or care due to COVID-19. Patients and relatives felt relieved (e.g. less risk of infection), but were also concerned and anxious (e.g. fear for progression, fear for more side effects). Due to these ambivalent feelings, it was difficult for patients and relatives to cope with the change or delay in treatment or care, both when this was decided by the physician and by themselves. In combination with the general impact of COVID-19 on their daily lives, the change or delay led to additional distress. The interviews showed that exploring the meaning of change or delay of care for patients and their relatives and discussing what would help them might prevent or relieve distress.

Conclusion: The findings of our study show that COVID-19 and the associated delay or changes in cancer treatment and care had a major impact on the well-being of patients and their relatives. Person-oriented care is even more important during (emergency) situations in which care might be changed or delayed.

KEYWORDS

cancer, carers, communication, emergency, patient perspectives, psychosocial nursing, qualitative approaches

1 | INTRODUCTION

Since the global outbreak of the coronavirus disease 2019 (COVID-19), almost 194 million COVID-19 cases and 4 million deaths have been confirmed (WHO, 2021). In order to reduce the spread of the virus, limit the pressure on the healthcare system, and save lives, necessary stringent governmental measures such as closing schools, border travel restrictions, and home confinement (nationwide lockdowns) have been taken (European Council, 2020; OECD, 2020). Unfortunately, these measures come at a high economic and social cost (Ammar et al., 2020; European Council, 2020), and negatively impact the management of noncommunicable diseases (WHO, 2020), including the management of patients with cancer (Raymond et al., 2020; The Lancet Oncology, 2020).

1.1 | Background

Patients living with cancer are in most cases more susceptible to an infection with the COVID-19 virus (Lee et al., 2020). Case-fatality rates for patients with cancer who are hospitalized are relatively high, particular for older patients and patients with haematological cancers (Lee et al., 2020). Patients with cancer also seem more susceptible to COVID-19 infection-related complications (ElGohary et al., 2020; Robilotti et al., 2020). According to the systematic review and meta-analysis of ElGohary et al. (2020), patients with cancer are at a higher risk of critical COVID-19 disease, ICU admission, and mechanical ventilation. Moreover, in addition to an increased risk of infection (or related complications), other health risks can arise due to an interruption or change in the cancer treatment or in the provision of care. On the one hand, interruptions or changes in the care process were initiated by patients due to various reasons, such as fear for infection (Brooks et al., 2020). On the other hand, healthcare professionals (HCPs) delayed, reduced or cancelled scheduled appointments or admissions to the hospital, and changed treatment modalities. Moreover, follow-up consults were often postponed or mediated by telephone or video call. The main reasons for these precautions were the prioritization of the care for COVID-19 patients and the reduction of the risk of infection for patients with cancer (Riera et al., 2021; The Lancet Oncology, 2020). Several medical clinical guidelines and recommendations have been developed by professional organizations for oncology and haematology with the aim to guide HCPs in adapting care to the COVID-19 situation, and to guarantee well-considered and uniform decisions across hospitals regarding cancer treatments and related follow-up of patients with cancer (ASCO, 2020; BHS, 2020; BSMO, 2020; EBMT, 2020; ESMO, 2020; ESTRO, 2020). However, guidance on psychosocial counselling and follow-up of patients with cancer and their relatives in times of COVID-19 is still lacking.

COVID-19 and the aforementioned changes or delay in cancer care can influence the psychological well-being of patients and their relatives. In various countries, the effect of COVID-19 on the

Impact

What problem did the study address?

Quantitative studies on distress and anxiety among patients with cancer during the COVID-19 pandemic do not provide in-depth insight into how delay or changes in cancer care impacted patients' well-being. Moreover, these studies did not take into account the perspective of relatives. Experiences and needs of patients and their relatives remain unclear.

What were the main findings?

The importance of listening to the voice of patients and relatives is emphasized by the results of this research. A patient- and family-oriented approach is crucial in all decisions regarding (changed or delayed) care and should not be forgotten in times of emergency.

Where and on whom will the research have an impact?

The findings can be a wake-up call for healthcare professionals to pay more attention to the impact of certain decisions on the psychosocial well-being of patients and their relatives. The advice for healthcare professionals from cancer centres and primary care, formulated in this paper, can make a difference in person-oriented communication and care during pandemics or in other emergency situations.

well-being of patients with cancer was investigated using a survey (Baffert et al., 2021; Ballatore et al., 2021; Chapman et al., 2020; Choobin et al., 2021; Ciężyńska et al., 2020; Ferrara et al., 2021; Jeppesen et al., 2021; Cheli et al., 2021; Swainston et al., 2020; Wang et al., 2020; Yasin et al., 2021). Several of these studies suggest a potentially higher risk for psychological distress and anxiety among patients with cancer during the COVID-19 pandemic. However, these quantitative results do not provide in-depth insight into how COVID-19 and the associated changes in cancer care impacted patients' well-being. Experiences and needs of patients with cancer remain unclear. Moreover, these studies did not take into account the perspective of relatives, who might also be impacted by these changes.

2 | THE STUDY

2.1 | Aims

The aim of this study was to understand how patients with cancer and their relatives experienced delay or change in treatment or care on the initiative of HCPs or on their own initiative. These insights are necessary to provide appropriate guidance on psychosocial

counselling and follow-up by oncology HCPs in times of COVID-19 and beyond.

2.2 | Design

A qualitative study was performed to obtain an in-depth exploration and understanding of the experiences and perceptions of the participants (Holloway & Galvin, 2016; Pope & Mays, 1995). The collected data were used to complement and fully understand previous quantitative research of other authors, mentioned in the introduction. The most important methods of a grounded theory were applied: an iterative process of data collection and analysis, theoretical sampling, a constant comparison method for induction of themes, and theoretical sensitivity of the researchers (Chen & Boore, 2009; Holloway & Galvin, 2016). The COREQ checklist was used to guide the construction of this article (Tong et al., 2007).

2.3 | Sample

Participants were recruited from 11 hospitals across Flanders (Belgium), including two university hospitals. All hospitals also participated in a larger implementation research project to optimize current care processes for patients treated with oral anticancer drugs, called the Collaborative Network to Take Responsibility for oral AntiCancer Therapy (CONTACT). Adult patients (age ≥ 18) with a solid tumour and/or a haematological cancer who were receiving any form of cancer care in the hospital (e.g. active treatment, palliative care, follow-up care) could be included. Patients had to be confronted with a change or delay in their treatment, in their hospital admission/appointment or in their psychosocial (rehabilitation) program. The change or delay could have been initiated by the physician or by the patients themselves. Patients with insufficient knowledge of the Dutch language were excluded. In each hospital, a member of the multidisciplinary team acted as a reference person and identified participants who were eligible for an interview. After being approached by the reference person in the hospital, potential participants were contacted by a member of the research team by telephone and invited for an interview. Relatives (i.e., spouse/partner, family member or caregiver) of patients who met all inclusion criteria were also eligible for the study. At the end of the patient interview, we invited the relative of the patient to participate in the study as well. As recruitment in the hospitals was difficult due to COVID-19, we also made recruitment calls through websites, forums, and social media of cancer patient organizations.

To guarantee maximum variation sampling, we selected participants with variation in age, sex, diagnosis, time since diagnosis, treatment and type of change or delay in care. Based on intermediate analysis, new participants were selected to obtain more information on topics that arose in the previous interviews or to get more insight into certain topics that were not yet covered in previous interviews.

For example at a given moment, we did no longer select patients whose follow-up consultation was postponed or mediated by phone or video call as data saturation was reached for this topic. We then purposefully selected patients who had experienced other changes in their care or treatment.

2.4 | Data collection

Semi-structured interviews took place between June and October 2020. During this period, two waves of the COVID-19 pandemic were observed in relation to the number of positive cases, hospitalisations, and deaths in Belgium. The first wave took place from the 10th of March to the 21st of June. The second wave started on the 31st of August and was still ongoing by the end of 2020 (Healthy Belgium, 2021). However, major changes or delay in treatment and care were foremost observed during the first wave. In the interviews, patients were therefore asked to reflect upon their experiences during this wave.

The research team was composed of eight researchers, four clinical nurse specialists in oncology and a patient expert who all had relevant content- and/or methodological expertise. Most interviews were conducted by the two first authors, who are both female and were PhD candidates at the time of the interviews. Only one of them had prior experience in conducting qualitative research. There was no relationship between the interviewer and any of the participants. Due to social distancing measures, all interviews were conducted by video call. Only when participants were unfamiliar with video call, the interview was carried out by telephone. Prior to the interviews, the researcher briefly introduced herself. All interviewers wrote out their introduction beforehand and considered the impact it could have on the course of the interview and the openness of the participant. All interviews were audio recorded and transcribed verbatim. Additional notes were added to describe non-verbal expressions and contextual factors. Interviews lasted between 20 and 90 min, with a mean duration of 49 min.

A different interview guide was used for each group of participants: (1) patients confronted with a change or delay in treatment or care initiated by their HCP, (2) relatives of the first group of patients, (3) patients who changed or postponed their care or treatment on their own initiative and (4) relatives of the second group of patients. If it was not possible to allocate the participant to one specific subgroup (e.g. when changes in care were initiated by both the patient and HCPs), the interviewer combined questions of both interview guides. All interview guides consisted of open-ended questions to provoke comprehensive answers and allowing participants to openly share their feelings and experiences. The first question was open and broad to introduce the theme of the interview without imposing specific topics and forcing the answer into a certain direction. The following questions were based on the first answer of the participant. Further on in the interview, certain topics derived from literature were addressed by the researcher when they did not come up spontaneously (e.g. when patients did

not report how follow-up by their HCP was performed after the decision to change/delay care was made). As an example, the initial interview guide for semi-structured interviews with patients confronted with a change or delay in treatment or care initiated by their HCP is provided in Appendix S1. Throughout the iterative process of data collection and analysis, new topics were identified. The interview guide was then adapted to further explore these new topics in additional interviews (Charmaz, 2006). For example based on the first analysis, understanding the general meaning of COVID-19 on the daily lives of participants and their relatives proved important to fully grasp the experiences and feelings of patients when care was delayed/changed, and to explain the motives of patients to postpone/change care on their own initiative. Therefore, the impact of COVID-19 on the daily lives and well-being of patients and their relatives was more deeply questioned in the subsequent interviews.

2.5 | Ethical considerations

Ethical approval for this study was obtained by the Ethics Committee Research of University Hospitals Leuven (S63301) and by the local ethics committees of all participating hospitals. All participants were informed verbally and by means of a mailed written informed consent. They received sufficient time to consider their participation. The audio recordings were permanently deleted after transcribing was completed.

2.6 | Data analysis

An inductive qualitative data analysis, using the constant comparative method, was performed (Chen & Boore, 2009; Holloway & Galvin, 2016). Six members of the research team, including four researchers, a clinical nurse specialist and a patient expert, independently read and reread the first set of three interviews to familiarize with the data. An analytical matrix with rows (cases), columns (codes), and cells of summarized data was used for coding the data. Key categories were identified and further refined into themes. The following interviews were analysed similarly. By constant comparison, the first themes were developed. An intermediate meeting was organized to discuss the identified themes with the entire research team ($N = 13$). Based on additional interviews and further intermediate meetings, the themes were adapted and refined. With every new interview that was analysed, the researchers adapted and refined the themes until data saturation was reached or until the end of the study period (Charmaz, 2006; Chen & Boore, 2009).

2.7 | Rigour

Several strategies were used to increase trustworthiness of the data and the analysis. First, an online training was organized for all

members of the research team prior to the start of data collection. An expert in qualitative research explained the basic principles of in-depth interviewing. Moreover, after the first interview an individual feedback session was organized in which every researcher received personal feedback on their interviewing skills from a more experienced member of the research team. Second, all interviewers had to reflect upon previous experiences within the field of psychosocial oncology to make them aware of possible bias that might influence interpretation of the results. This self-reflective process of 'bracketing' enhanced openness and limited preconceived ideas during data collection and analysis (Tufford & Newman, 2010). Third, investigator triangulation was applied throughout the entire analysis. The data, themes and interpretations were discussed in several intermediate meetings by the research team, including researchers, a clinical nurse specialist and a patient expert (Carter et al., 2014). Fourth, an audit trail was developed containing notes of the data collection and analysis procedure. Last, data saturation was reached for the group of patients who were confronted with a change or delay in care initiated by their HCP, meaning that gathering new data did no longer lead to new insights (Charmaz, 2006; Chen & Boore, 2009).

3 | FINDINGS

In total, 53 interviews were conducted, with 42 patients and 11 relatives. We interviewed 33 patients who were confronted with a change or delay in treatment or care initiated by their HCP, and nine relatives of those patients. Furthermore, seven patients who changed or postponed their care or treatment on their own initiative and the relative of four of these patients were also interviewed. In Table 1, information on the nature of the change or delay in care can be found.

The mean age of the patients was 61.3 years (range 39–89) and the majority was female (71.4%). The primary tumour and the oncological treatment of the included patients varied widely. Most patients were diagnosed with breast cancer (47.6%) or colon cancer (16.7%). Treatment with intravenous chemotherapy (26.2%) or oral anticancer therapy (21.4%) were most prevalent. Most patients had a secondary (41.0%) or bachelor's (41.0%) degree and were married (64.3%). The mean age of the included relatives was 53.2 (39–66). Only a minority of these relatives was male (27.3%). Most of them were married to the patient (63.6%) and had a bachelor's degree (45.4%).

An overview of the demographic characteristics of all participating patients and relatives can be found in Tables 2 and 3.

In the results section, we will (1) elaborate on the general meaning of COVID-19 and the associated measures for patients with cancer and their relatives; (2) explain in what way patients with cancer and their relatives experienced a change or delay in treatment or care initiated by their HCP and (3) explore feelings and experiences of patients who changed or postponed their own care or treatment, and the experiences of their relatives. Several themes that were identified in the interviews with patients, also appeared in the

TABLE 1 Type of change or delay in care

	Patients (N = 42)		Relatives (N = 11)	
	HCP's initiative (N = 33)	Patient's initiative (N = 9)	HCP's initiative (N = 7)	Patient's initiative (N = 4)
Type of change/delay in treatment or care				
Modification of treatment ^a	4	/	2	/
Interruption/postponement of treatment ^a	5	5	2	2
Postponement of face-to-face consultation (which was replaced by teleconsultation)	12	/	2	/
Postponement of follow-up investigations	6	2	1	2
Interruption/postponement of (psychosocial) rehabilitation program	3	/	/	/
No change	3	2	/	1

^aCancer treatment, including chemotherapy, immunotherapy, hormone therapy, targeted therapy, radiotherapy and surgery.

interviews with relatives. Each theme is discussed below, first from the perspective of the patient, followed by what we learned from the interviews with the relatives. Meaningful quotes (translated from Dutch) were added to support the results.

3.1 | Meaning of COVID-19 for patients with cancer and their relatives

3.1.1 | Risk perception: A double battle to be fought

The COVID-19 pandemic felt like a new threat to patients that made them feel more vulnerable. Next to their fight against cancer, they now also had to overcome COVID-19. They were afraid for an infection with the virus because they were convinced that COVID-19 would be more severe than in healthy individuals due to the effects of the cancer treatment on their body. Some patients—especially elderly, patients with comorbidities and patients with a long medical oncological history—even thought they would not survive a COVID-19 infection.

'... I felt like my chances of survival were threatened, we had to try to keep it [the virus] out. And then COVID almost got the upper hand because with the chemo, everything was done to get rid of the cancer, but COVID was an unknown factor and the fact that it suddenly crept in made us very alert and scared for months. You're faced with cancer, and with COVID on

top of it, I'm definitely not going to make it ...'—Patient 28, receiving hormone therapy (interruption of psychosocial rehabilitation program [on HCP's initiative]).

By comparing the thoughts and feelings of patients in different disease stages, we found that the risk perception and fear intensity were related to the stage of cancer. Patients in remission, patients with stable disease, or patients who were not on active treatment seemed to experience less fear for COVID-19 infection. Only few patients in remission indicated to be afraid that an infection would cause recurrence of the cancer. Risk perception could be influenced by the need for social contact as well. In some interviews, patients indicated that their strong need for social contact overpowered the fear for infection. The conflict between social well-being and anxiety was most outspoken in patients with poor prognosis or in palliative patients.

Additionally, we found several external factors that might affect how patients perceive the risk for COVID-19 infection. It appeared that patients constantly received warnings and advice from family and friends, and HCPs (including their GP), to be extra careful. Patients' fear was also fuelled by media coverage, that often underlined the more severe course of COVID-19 infection in at-risk patients such as patients with cancer. A last external factor that seemed to negatively influence risk perception was the infection of a relative, especially when this person was a peer with whom the patient could identify.

'... Someone of my friends had COVID and ended up in hospital. And I know that that person also gets

TABLE 2 Demographic characteristics of the participating patients (n = 42)

Characteristics	n (%)
n = 42	
Age (years)	
18–29	/
30–44	3 (7.2)
45–59	15 (35.7)
60–74	19 (45.2)
≥75	5 (11.9)
Sex	
Male	12 (28.6)
Female	30 (71.4)
Level of education ^a	
Primary education	1 (2.6)
Secondary education	16 (41.0)
Higher education: bachelor	16 (41.0)
Higher education: master	6 (15.4)
Marital status	
Single	2 (4.7)
Married	27 (64.3)
Partner, cohabiting	4 (9.5)
Partner, not cohabiting	1 (2.4)
Widowed	8 (19.1)
Primary tumour	
Breast cancer	20 (47.7)
Colorectal cancer	7 (16.7)
Pancreatic cancer	3 (7.1)
Lung cancer	3 (7.1)
Haematological cancer	3 (7.1)
Kidney cancer	2 (4.8)
Other	4 (9.5)
Oncological treatment	
Chemotherapy	13 (30.9)
Hormone therapy	6 (14.3)
Immunotherapy	4 (9.5)
Follow-up care	9 (21.4)
Oral targeted therapy	7 (16.7)
Palliative care	2 (4.8)
Donor lymphocyte infusion	1 (2.4)

^aThree missings.

immunotherapy ... I have witnessed that from very close by and that also feeds your own fear ...'—Patient 10, in follow-up (postponement of follow-up investigation [on patient's initiative]).

The interviews with relatives showed that they were also convinced that patients with cancer were at higher risk for more severe COVID-19

TABLE 3 Demographic characteristics of the participating relatives (n = 11)

Characteristics	n (%)
n = 11	
Age (years)	
18–29	1 (9.1)
30–44	1 (9.1)
45–59	5 (45.4)
60–74	4 (36.4)
≥75	/
Sex	
Male	3 (27.3)
Female	8 (72.7)
Level of education	
Primary education	0 (0.0)
Secondary education	4 (36.4)
Higher education: bachelor	5 (45.4)
Higher education: master	2 (18.2)
Relationship to patient	
Partner, married	7 (63.6)
Partner, cohabiting	1 (9.1)
Son/daughter	3 (27.3)
Primary tumour of patient	
Breast cancer	3 (27.4)
Colon cancer	2 (18.2)
Kidney cancer	1 (9.1)
Lung cancer	1 (9.1)
Leukaemia	1 (9.1)
Cancroid	1 (9.1)
Pancreatic cancer	1 (9.1)
Brain tumour	1 (9.1)
Oncological treatment of patient	
Chemotherapy	5 (45.4)
Immunotherapy	2 (18.2)
Hormone therapy	1 (9.1)
Donor lymphocyte infusion	1 (9.1)
Palliative care	1 (9.1)
Follow-up care	1 (9.1)

disease, possibly leading to death. Relatives were afraid to get infected and pass the virus on to the patient. Their fear, as with patients, was reinforced by media coverage and by warnings and advice of HCPs.

3.1.2 | A need for protection against the threat of the virus

Among patients, the fear of COVID-19 raised questions about how to protect themselves against the virus. These questions seemed

to get more pronounced and complex when the governmental measures were relaxed/lifted (e.g. when their partner had to return to work). Conflicting advice and conflicting signals of HCPs in the hospital (e.g. some HCPs wore a mask, others did not) and in primary care (e.g. in the hospital, the patient was told that she had no increased risk of a more severe COVID-19 disease, while the GP told the patient to be very careful) caused confusion. Some patients were extremely careful and lived in complete isolation from the outside world.

Among relatives we noticed a strong fear to infect the patient. Some relatives indicated that they would blame or not forgive themselves if they would be responsible for infecting the patient. Therefore, relatives felt stressed and challenged in their daily lives. First, relatives tended to constantly monitor the patient for possible symptoms of COVID-19 and contemplate about manners to reduce the risk of infection. Several relatives expressed their worries about whether they were careful enough and not performing any activities that pose a risk. They—therefore—imposed stricter rules on themselves than those for the general population as imposed by the government. For example some relatives indicated wearing a mask when not obligated or meeting less people than the maximum number allowed. One relative even decided to move out temporarily and no longer lived with his partner and children to prevent infection. Relaxation of lockdown conditions and the lack of clear governmental rules instilled fear and uncertainty among relatives as safety was no longer guaranteed. Second, the fear to infect the patient put pressure on friendships and other relationships. Relationships were difficult to maintain when relatives felt little understanding for their fear and concerns from friends and family.

'... That friend is trying to influence me a lot now, [she said:] "I felt excluded because I couldn't come to a restaurant with you because I might have had COVID-19" but I didn't know how to react to that anymore. I told her: "Well, I'd rather you didn't come, I didn't want to take the risk in respect to my husband". Apparently, she resents me for that now. I think I have the right to do so and I think, when you're friends with someone for so many years, they should understand, but apparently that's not the case...'—Relative 3, partner (postponement of follow-up investigation [on patient's initiative])

In several interviews with relatives, it was highlighted that it is important that HCPs and employers acknowledge and understand the concerns of relatives to possibly infect patients. When these concerns were not acknowledged by HCPs, this reinforced fear and impacted the trust in the HCP. To the contrary, support from HCPs (e.g. a conversation with the GP about the risk to infect the patient, advice on how to adjust behaviour to minimize risk for infection) helped relatives to deal with their fear. When the employer showed understanding for the situation of the relative and opportunities were provided to mitigate

the risk for infection (e.g. working from home), this could also ease the fear of relatives. Last, some relatives said that nuanced information provided by the media, such as 'not everyone is seriously ill after infection', had reduced their worries.

3.1.3 | Life is put on hold, again

Many patients felt like COVID-19 and the associated measures had put their lives on hold. They compared it to the feeling they had when they were first diagnosed with cancer. For patients in remission and patients who just passed a severe period of illness or intensive treatment, the prospect of a normal life after cancer was postponed for an undetermined period. For some patients, their (psychosocial) rehabilitation program was interrupted. This felt as the impediment of an important step in their recovery and of a motivation to move on again and look positively at the future. Patients with poor prognosis and palliative patients seemed to experience this differently as future perspectives are limited. They felt like COVID-19 took away their last chances to enjoy life.

'... I still wanted to make a trip and one of my last wishes was to refit my pond later on, but that has also been postponed. This might all seem trivial, but I do not know if I will still be here this summer. When I look in the mirror I say, "don't blabber, of course I'll still be here" but things are what they are.'—Patient 14, in palliative care (postponement of consultation, which was replaced by a teleconsultation [on HCP's initiative]).

Like patients, relatives had the feeling that their lives were on hold, because their perspectives about a normal life after cancer were also taken away from them.

3.1.4 | Impairment of resilience

The interviews with patients revealed that the COVID-19 pandemic had a negative impact on their resilience. Cancellation of psychosocial rehabilitation programs, loss of contact with peers and other social contacts, and no support of relatives during consultations or during (long-term) hospital stay made patients feel like they were on their own. Furthermore, plans and prospects, that gave patients strength to persevere in hard times, were shattered by COVID.

'... The oncological rehabilitation has been stopped. There are also notes on the wall here about meetings, an info-meeting regarding cancer or about ... just to see peers or someone else, you are really alone on your island. Yeah, the contact with peers, the social aspect. Privately everything had been stopped as well. It has been difficult for everyone during that

COVID period: not being allowed to go out, but for us it was even a bit worse I think...’—Patient 27, in follow-up (postponement of consultation and interruption of rehabilitation program [on HCP’s initiative]).

Next to mental resilience, also physical resilience of patients was impacted, for example by the interruption of physiotherapy, or rehabilitation programs.

3.2 | Changes or delay in treatment or care initiated by HCPs

3.2.1 | Patients’ feelings about the decision

The feelings and emotions that patients experienced when their HCP decided to change or delay their treatment or to postpone a consultation or follow-up investigation in the hospital seemed to vary. Some patients had the perception that a hospital stay or visit was dangerous because of the potential exposure to high-risk contacts, such as HCPs, maintenance personnel, and meal service staff. Therefore, they felt relieved when they heard that they did not have to go to the hospital.

‘... Of course I agreed again because I do not like having to go to hospital every week; when you are getting treatment you are a bit more susceptible to all kinds of things. At the moment, it does not look like the best place to be ...’—Patient 1, receiving chemotherapy (modification of treatment; three-weekly instead of weekly chemotherapy [on HCP’s initiative]).

Unlike these patients, others saw the hospital as a safe environment because they were surrounded by HCPs who knew how to handle the threatening situation and who took the necessary safety measures.

In many interviews, patients stated that the change or delay in care enhanced their feeling of vulnerability. When a follow-up investigation was postponed or cancelled, patient felt insecure as they were left in the dark about the status of their cancer. Postponement of a treatment or surgery or changes in the initial treatment also caused uncertainty. Patients, especially those with a more aggressive cancer, were afraid that their tumour would grow or metastasize.

‘... When I received an email that my appointments had been cancelled for an indefinite period of time, I panicked. I thought they were playing with my life. I’ve got a very aggressive type of breast cancer, when it recurs, it might be too late ...’—Patient 29, in follow-up (postponement of consultation, which was replaced by a teleconsultation [on HCP’s initiative]).

Last, the decision to change or delay care could mean prolongation of the patient’s cancer trajectory. Patients looked forward to the end of their treatment, but due to the change or delay, it became unclear when this point would arrive.

3.2.2 | Elements that influence feelings of patients

First, the way the decision to change or delay treatment was communicated to the patient was perceived very important. First, patients would like to hear the decision from an HCP they are familiar with. Impersonal communication by e-mail was not appreciated. Second, it was important that the decision was well framed and motivated. When HCPs provided sufficient information about the reasons for the decision and clearly explained that it was a safe decision in the context of their treatment and disease, patients could more easily accept the decision. Third, it seemed important for patients to have a say in the decision of their HCP. Only a few patients indicated they were involved in the decision. Patients who did not, felt powerless because they had no control over the decision. Fourth, patients wished to receive information about the date on which the treatment will be (re)started or care will return to normal again. Patients said this would help them to accept the delay and offer perspective for the future. Last, showing empathy by acknowledging and understanding their fear and concerns when confronted with the change or delay, would be very helpful.

3.2.3 | Reduced involvement of relatives

Due to the safety measures in the hospital, relatives could no longer accompany the patient when visiting the hospital for a consultation, follow-up investigation or treatment. This caused a shift in the involvement of relatives from a very intense to almost no involvement. Patients indicated that they missed the presence of their partner or family member in the hospital.

‘... You actually make a decision just based on your own emotions and your own feelings, and not go home for a little while, to just give it some thought, just exchange thoughts with your partner, that wasn’t a possibility ...’—Patient 3, receiving chemotherapy (modification of treatment; three-weekly instead of weekly chemotherapy [on HCP’s initiative but patient refused]).

Relatives also indicated they had a hard time dealing with the safety measures that prohibited them to accompany the patient in the hospital. On the one hand, they feared that information that was received in the hospital, would be partially lost. Relatives saw themselves as an important companion in remembering and interpreting the information. Also, relatives felt less informed when they were not present during the consultation.

'... Where otherwise you are supposed to be on the receiving end, now I have to do it with the information he's asking for. And that is less than we are used to because he also likes me to ask things. I think that he cannot convey it as well as when I hear the explanation directly. So basically, you feel a little bit set aside ...'—Relative 4, spouse (postponement of treatment due to COVID-19 infection).

On the other hand, relatives found it difficult that the patient had to go through a part of the cancer process alone without their support. Despite the burden it caused, some relatives showed understanding for the situation and even felt reassured by the strict measures that were applied in the hospital.

3.2.4 | Elements that mitigate the reduced involvement

In the interviews, relatives described certain elements or actions of HCPs that could mitigate their reduced involvement in the cancer process. First, they would have liked to be informed in advance that they were not allowed to accompany the patient. In this way, the patient and relative would get the chance to prepare mentally and practically for the hospital visit (e.g. the patient could bring a notebook). Information about the practical support that was provided in the hospital (e.g. transport of less mobile patients) would also have reassured some relatives. However, in most cases they only found out that they were not allowed to accompany the patient through the media or at the entrance of the hospital without any further explanation. When this safety measure would be lifted, they expected to be proactively informed by the HCP. They found it difficult to contact the HCP themselves because they did not want to be too demanding.

Second, some relatives would have liked to be informed about the decision to change or delay care personally by the HCP, for example a telephone call to explain the reasons for the decision and the possible consequences. Relatives felt this would enable them to support the patient better. They would also have appreciated it when HCPs paid attention to their concerns.

'... Taking that decision of changing that therapy. That it [the decision] is just communicated to my mom in that way. It was like "Yeah, well, and you can tell it to people that you want them to know." Whereas I was like, nowadays: email, text, phone, it's all so easy...'—Relative 2, daughter (modification of treatment; monthly instead of biweekly immunotherapy [on HCP's initiative]).

Moreover, relatives thought it was essential to be present at certain key moments, for example when bad news is delivered. When physical attendance in the hospital was not possible, they suggested

alternatives, such as an appointment at a location outside the hospital or by video call.

3.3 | Changes or delay in treatment or care initiated by the patient

3.3.1 | A well-considered decision that comes with many doubts

The decision of patients to postpone their treatment or consultation themselves always seemed to be well-considered, but hard to make.

Patients struggled with many doubts before and after making the decision. Therefore, patients did not always stand firm on their decision to postpone care. Doubts were reinforced by conflicting advice of HCPs or conflicting stories about the situation in the hospital. Also, the postponement of the end of the therapy and the loss of perspective it brought, made the decision more difficult. To deal with their doubts, patients asked for advice and sought confirmation that their choice was the right one. For this, patients often turned to an oncology nurse or their GP. Doubts could also be reduced when HCPs stated a date for restart of the therapy or confirmed that after postponement the treatment would continue as planned.

3.3.2 | Elements that were considered in the decision-making process

Two elements that played an important role in the decision-making process of patients were the fear for infection and the health consequences of postponement of care. On the one hand, patients were concerned that a hospital visit would increase the risk for COVID-19 infection. Hence, whether strict safety measures were applied in the hospital, was decisive in their decision. On the other hand, they were afraid that postponement of follow-up or treatment could have negative consequences such as risk for recurrence or metastases. They also realized that postponement would extend their treatment trajectory. From the interviews, it was clear that the health condition and quality of life influenced patients' choice. Patients with a stable disease or on maintenance therapy perceived the treatment as less urgent and were more likely to consider postponement. When the patient recently had a normal check-up or when the physician assured that the treatment was not vital, the decision was also easier to make.

To come to a decision, patients engaged with others and asked for their advice. HCPs were their main source of information. Preferably, patients talked to an HCP they knew and trusted, like their treating physician, GP or nurse. Additionally, they also attached great importance to the opinion of peers, as they have been through a similar situation. They also asked for advice from carefully selected family and friends, especially when they worked in health care and could provide 'inside information' on the situation in the hospital.

'... In the end, at that moment you're also like: what are all the precautions in the hospital (...) while two months later you know, okay, they can already assess the risks a bit more, then you have a bit more trust. That also plays a role in your decision to go [to hospital] later on. Now, there has also been consultation with the oncologist, who also, based on my blood results, that had been seen by the GP, had taken the decision that it was okay, we can postpone this for a while. So I did discuss it with a few friends as well. But as I said, my sister-in-law was very much against me going (to hospital). That's why I didn't do it ...'—Patient 10, in follow-up (postponement of follow-up investigation [on patient's initiative]).

4 | DISCUSSION

The results of this qualitative study were consistent with the results of previous quantitative research, showing that patients with cancer experienced more anxiety and distress during the COVID-19 pandemic (Ciążyńska et al., 2020; Sigorski et al., 2020; Yasin et al., 2021; Zhao et al., 2021).

We found that distress arose from fear of infection and was further enhanced by the reduction of social support due to social distancing measures and isolation from family, friends and peers. Furthermore, most patients indicated it was hard to cope with (unwanted) changes or delay in treatment or care due to COVID-19. The feelings described in the interviews were divergent and sometimes paradoxical. On the one hand, the change/delay meant that their fight against cancer was paused, which made them feel powerless and anxious. On the other hand, change/delay of treatment or care provoked feelings of relieve because the risk for infection in the hospital was reduced.

Given the significant level of distress in patients with cancer, and the potential further increase in distress in emergency situations such as the COVID-19 pandemic, it seems necessary to ensure high-quality care that not only focuses on medical aspects but also on the mental health status of the patient. The American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) recommend that all patients with cancer should be screened for symptoms of depression and anxiety at regular time points in their care process (Andersen et al., 2015; Riba et al., 2019). In line with this recommendation, we want to emphasize the importance of (additional) distress screening in emergency situations and at all key moments in the trajectory of care (e.g. when changes or disruption of planned care occur).

From previous research, outside the scope of COVID-19, we knew that relatives of patients with cancer also have a high risk of psychosocial distress (Bevans & Sternberg, 2012; Glajchen, 2004; Hagedoorn et al., 2008; Zwahlen et al., 2008). This study showed that COVID-19 and its impact on cancer care enlarged the psychosocial burden on relatives. As in patients, similar paradoxical feelings

(relief vs. anxiety) were detected among relatives. However, in most cases HCPs seemed to pay remarkably little attention to the relative(s) of the patient. We, therefore, want to raise awareness on potential distress among relatives. Healthcare professionals should pay attention to their needs and questions as well. Distress screening might also be useful among relatives and psychosocial support must be accessible for both patients and their relatives, which is insufficiently reflected in the ASCO and NCCN guidelines (Andersen et al., 2015; Riba et al., 2019).

The interviews stated that the level of distress among relatives rises even more when their involvement in the care of the patient is decreased. Relatives strongly desire to be present at consultations in one or another way, which was not always possible due to protective measures set by the hospital. Patients also made clear that the loss of their partner's support was hard. We, therefore, want to encourage to maintain the involvement and presence of relatives, even and especially in emergency situations which have an impact on planned care. This might require creative solutions (e.g. connecting through video call, a telephone call after the consultation, audio recording of the consultation).

In line with the aforementioned, findings confirm that more attention needs to be paid to the impact of certain decisions on the psychosocial well-being of patients and their relatives. A person-oriented approach is key in high-quality healthcare and should not get lost in times of emergency. A patient-oriented approach entails active participation of the patient in decision-making and giving them the right to take control and power over their care (Castro et al., 2016). This does not only apply to decisions at the start of the therapy when designing the trajectory of care, but also to other decisions that are made along this trajectory (e.g. change or interruption of treatment, postponement of consultation). The importance of listening to the voice of the patient is emphasized by the results of our research. Patients indicated that it is difficult to cope with changes that are simply imposed by their HCP. Next to appropriate framing of the decision, involving the patient in the decision and showing empathy would make it easier for patients to accept the change. Also, it is important that the decision is communicated by an HCP with whom the patient has an existing healthcare relationship. By sharing these results and bringing insight into the effect of certain decisions on patients, we hope to stimulate HCPs to choose for a more patient-oriented approach, even in crisis situations or when confronted with high work pressure and unforeseen circumstances.

When interpreting the results of this study and formulating recommendations for HCPs, we must take into account that COVID-19 was a sudden and unprecedented threat to the health system and HCPs. During the initial wave, HCPs were overwhelmed and had to adapt to this new situation, without any preparation or prior experience. This can be an explanation for some of the shortcomings in communication, psychosocial support and follow-up identified in this study. This probably played less of a role during subsequent waves, as COVID-19 was no longer unknown, and HCPs were better prepared to deal with this situation. During these later waves, however, there was a clear impact of COVID-19 on HCPs themselves, which we should not overlook. A global survey of the European

Society of Medical Oncology (ESMO) Resilience Task Force revealed a large impact of the pandemic on well-being and job performance of oncology professionals, with increased risk of distress and burn-out (Banerjee et al., 2021). Moreover, several studies showed high levels of compassion fatigue among HCPs during the pandemic (Franza et al., 2020; Ruiz-Fernández et al., 2020). A decreased well-being and increased level of compassion fatigue might directly affect the quality of healthcare delivery and impede patient-oriented care practices. This can explain less satisfactory and patient-oriented clinical practices during the entire pandemic. We therefore want to note that supporting the well-being of oncology professionals and improving resilience are important priorities, especially in emergency situations such as the COVID-19 pandemic.

4.1 | Recommendations on psychosocial counselling and follow-up by oncology professionals

The insights gained from this study can be used to provide appropriate guidance on psychosocial counselling and follow-up by oncology professionals in times of COVID-19 and beyond. Based on the interviews, we developed a list of recommendations that are relevant for clinical practice, and can be used in any situation of delay or change to the 'normal' treatment and circumstances. A draft version of the list was discussed in a focus group with several patient experts. The final list of recommendations provides an answer to the following four questions: (a) How do I start the conversation about change/delay?, (b) How do I gain insight into the patient's experiences and feelings?, (c) How do I involve the relative of the patient? and (d) How to further monitor the patient's situation? In Table 4, examples of the recommendations are shown.

We disseminated these recommendations in several Flemish hospitals to guide HCPs on psychosocial counselling and follow-up during the pandemic. At that time, there were no other guidelines on this aspect of care available. Existing guidelines mainly focused on medical aspects of care treatment.

4.2 | Relevance outside the COVID-19 pandemic

Although the COVID-19 pandemic was the incentive to set up this study, the findings can be extrapolated to other (emergency) situations in which deviation from the original care plan is needed. The knowledge provided by this study is needed to give HCPs and policy makers insights into feelings and experiences of patients and relatives when they are confronted with changes in treatment or care. The aforementioned recommendations can be used as general tips and tricks on appropriate psychosocial counselling and follow-up when changes in cancer care are needed. Also, recommendations for policy makers can be made based on the results of this study. This study showed that safety measures taken in emergency situations must be well-considered, taken into account their impact on patients' experiences and well-being.

TABLE 4 Recommendations on psychosocial counselling and follow-up

How do I start the conversation about change/postponement?

The message is best delivered by a healthcare professional with whom the patient has a relationship of trust.

Good framing and motivation of the decision are important: what is the purpose of the change/postponement that you are proposing? What guidelines are you basing your proposal on? Are there other options and what are the advantages and disadvantages?

How do I gain insight into the patient's experiences and feelings?

Be aware that patients experience changing or postponing care differently. Some patients feel relieved (e.g. less risk of infection), others are concerned and anxious (e.g. fear for progression, fear for more side effects).

Ask and discuss with patients what would be helpful in dealing with concerns.

How do I involve the relative of the patient?

Proactively inform patients about the possibility of having relatives present at the treatment or consultation (e.g. by phone or text message before the start of the treatment/consultation). This allows them to prepare practically (e.g. a relative is often an extra pair of ears or eyes), but also emotionally (the relative is a source of mental support).

Consider alternatives to enable the presence of the relative, especially during important conversations that may have an impact on further treatment (e.g. simultaneous teleconsultation, make an audio record of the conversation, follow the conversation by telephone speaker or video call).

How do I further monitor the patient's situation?

Make the follow-up contact including screening for symptoms of COVID-19, personal. Avoid giving the impression that you are going through a standard checklist.

Try to provide perspective on when normal care can be continued. Being given a concrete date is often important to patients.

Encourage patients to share their concerns with healthcare professionals. Patients can be afraid to do so as they do not want to bother their healthcare professional. As a result, patients do not always get the care to which they are entitled.

4.3 | Strengths and limitations

The research team consisted of people with different backgrounds, including one patient expert. We believe this is an important strength of this study. The patient expert was involved throughout the entire research process, from designing of the study to dissemination of the results. The patient expert has made a valuable contribution to the research by bringing in specific knowledge based on personal experiences with cancer and the oncological care process. Patient involvement or participation in health and social research has shown to bring important benefits such as improving relevance and quality of research and increasing the acceptance of the findings (Boote et al., 2002; Whitstock, 2003).

Five strategies were used to increase the trustworthiness of this study. A training and feedback session were organized to improve the interviewing skills of the researchers. Bracketing and investigator triangulation were applied to avoid biased interpretations of the results. The researchers also kept notes of the data collection and analysis in an audit trail.

This study also has four important limitations. First, the achieved sample size was smaller than expected. Overall, participants were difficult to reach as recruitment mainly took place in the hospital, but consultations or treatments were postponed due to COVID-19. The subgroup of patients that decided to postpone their consultation on their own initiative were even harder to reach. Mostly, the appointment was cancelled by telephone via the medical secretary and there was no proper documentation of these cancellations in the electronic health record. Consequently, HCPs had no overview of these patients. In addition, the small sample size of this subgroup may also be due to a limited size of the real total population of patients who postponed/changes their treatment or care on their own initiative. Recruitment of relatives was also challenging as they were no longer allowed to accompany the patient during consultation or treatment in the hospital. Due to the limited number of included patients who changed or postponed their care on their own initiative ($N = 9$) and the scarce number of relatives ($N = 11$), data saturation was not reached for these subgroups of the research population. Therefore, we need to interpret these findings with caution. However, as we were not able to extend the recruitment period due to the rapidly changing context of the COVID-19 pandemic, we tried to create sufficient depth in the executed interviews to be able to thoroughly explore feelings and experiences. Second, the iterative process of data collection and analysis was burdensome. When new topics were identified during analysis, this had to be communicated to the research team as soon as possible to guarantee that these topics could be further explored in following interviews. It was therefore decided to conduct interviews at a slower pace, which probably meant that fewer interviews could be conducted within the allotted time. Third, we should note that although the most important principles congruent with a grounded theory were applied, no grounded theory was developed. Last, due to the rules regarding social distancing and the risk of infection, it was decided to conduct the interviews via an online secured system. The digital interviewing brought several challenges/bottlenecks: technical challenges, danger of not reaching a certain group of patients, decline in participation due to limited digital skills or equipment of eligible patients, less ability to respond to non-verbal communication and the feeling of less personal contact, and disruptive factors in the home environment or the presence of another person in the room. The research team attempted to address these challenges by providing a manual for using the online system, planning the interview well in advance, and conducting the interview by telephone when the participant did not have a computer. However, we tried to limit the number of interviews by telephone to a minimum ($N = 11$) because of the even greater challenges in telephone interviews compared to video interviews.

5 | CONCLUSION

This study shows ambivalence in the feelings and experiences of patients with cancer and their relatives when confronted with change or delay in treatment or care due to COVID-19. Patients and relatives felt relieved (e.g. less risk of infection), but were also concerned and

anxious (e.g. fear for progression, fear for more side effects). Due to these ambivalent feelings, it was difficult for patients and relatives to cope with the change or delay in treatment or care, both when this was decided by the physician and by themselves. Together with the general impact of COVID-19 on their daily lives, this caused more distress in patients. Our study also revealed increased levels of distress among relatives. The inability to accompany the patient to the hospital, caused major difficulties and made them feel less to not involved. The interviews showed that exploring the meaning of change or delay of care for patients and their relatives and discussing what would help them, might prevent or relieve distress. Based on the findings, we can conclude that patient involvement and patient-oriented care are even more important during (emergency) situations in which care might be changed or delayed.

AUTHOR CONTRIBUTIONS

All authors have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; been involved in drafting the manuscript or revising it critically for important intellectual content; given final approval of the version to be published. Each author has participated sufficiently in the work to take public responsibility for appropriate portions of the content; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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