

## Research Article

# Patient-Reported Experiences of Supportive Cancer Care during the COVID-19 Pandemic

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**Background.** During the COVID-19 pandemic, people affected by cancer were in need of information about the virus and about the (self-) management of cancer symptoms and treatment. It is important to understand how patients with cancer navigated through the pandemic and to explore their experience relating to their supportive care needs. **Aim.** This study aimed to describe the experience of Swiss oncological patients during the COVID-19 pandemic with additional supportive cancer care. **Methods.** A single-center study was conducted in 2021. Patients with melanoma, breast, lung, or colon cancer who received active systemic anticancer treatment at the time of the COVID-19 pandemic and who were additionally seeing either oncology clinical nurse specialists, integrative medicine physicians, or both were included. We conducted semistructured interviews alongside the patient-reported quantitative assessment of distress and resilience. Thematic analysis was performed for the qualitative data and descriptive statistics for the quantitative data. **Results.** Eighteen patients with cancer were interviewed. Patients seeing an integrative medicine physician highlighted that they positively felt being addressed as a whole person during the consultations. The oncology clinical nurse specialists were perceived as the first point of contact for the patients and had more time during the pandemic compared to what the patients normally received. In general, patients did not experience delays or disruptions in their cancer treatment. As immunosuppressed and fatigued patients with cancer, they felt supported by the restrictions and hygienic measures. Access to vaccination reassured patients against the risk of infection. These results were reflected in the quantitative data, as we found moderate distress levels ( $M=4.1$ ;  $SD=2.5$ ) and high resilience scores ( $M=7.5$ ;  $SD=0.9$ ) in this patient population. **Conclusion.** During the COVID-19 pandemic, patients with cancer felt particularly supported by integrative medicine and cancer nurse consultations. Secured resources for nursing consultations and integrative medicine services can help to address the supportive care needs of patients with cancer.

## 1. Introduction

Fostering the quality of life in people affected by cancer through physical, psychological, social, and spiritual support

across every phase of the illness trajectory is basic to supportive cancer care in general [1, 2]. Nursing and integrative medicine provide holistic personalized care and are relevant services within supportive cancer care disciplines [3–6]. The

challenges of the COVID-19 pandemic, such as the restrictions and uncertainties, amplified the need for supportive cancer care in patients with cancer [7–9].

In the rising COVID-19 pandemic, people affected by cancer were concerned about the impact of COVID-19 on cancer care [8, 10]. Patients with cancer were in need of information about the virus itself and about cancer treatment during the pandemic, including supportive cancer care services [8–10].

Distress levels in patients with cancer [11] varied from moderate to severe at the beginning of the COVID-19 pandemic in 2020 [12–14] to lower distress levels in the following pandemic years [10, 15, 16] but remained higher compared to the general population [11]. In contrast, resilience levels were high throughout the COVID-19 pandemic in patients with cancer [10, 15, 17, 18]. Ayubi, Bashirian, and Khazaei [12] provided an overview of the measurement instruments and the statistics in their systematic review and meta-analysis in terms of the comparability of depression and anxiety measurement instruments including distress, and performed statistical analyses in the reviewed studies. In addition, the authors conclude that depression, anxiety, and distress are relevant outcomes for research and cancer care relating to the COVID-19 pandemic [12].

Cancer centers worldwide were reorganized to limit the dissemination of the SARS-CoV-2 virus and to reduce the risk of infection for patients with cancer, caregivers, and health professionals [19]. In the course of these reorganizations due to the COVID-19 pandemic, supportive cancer care services have also been restructured [8, 20–22].

The Comprehensive Cancer Center Zurich [23] provides cancer care in 17 specialized organ centers and conducts more than 20 interdisciplinary tumor boards weekly. Every year, around 2000 newly diagnosed cancer patients are treated. The integrative medicine consultations and the cancer nurse consultations of the Comprehensive Cancer Center of the University Hospital Zurich provide holistic supportive cancer care services, addressing the mind and body of the patients with cancer, i.e., symptoms, mental health, and resources. Both types of consultations also aim to support patients' self-management of symptoms and draw on their personal resources. In preparation for a possible COVID-19 emergency, the Comprehensive Cancer Center of the University Hospital Zurich was reorganized during the pandemic. Before, the nurse consultation was offered once per week, mainly providing a single prechemotherapy education consultation. During the pandemic, the service was extended to a daily offer and transformed into a continuous counseling service for patients. The integrative medicine consultation was extended to an online offer.

With the changes in healthcare delivery, it is important to understand how people with cancer navigated the COVID-19 pandemic and to explore their experience relating to their supportive care needs [2, 7, 8, 20, 22].

This study aimed to describe the experience of Swiss German oncological patients during the COVID-19 pandemic, who, in addition to their active systemic anticancer treatment, received nursing and/or integrative medicine

consultations at the Comprehensive Cancer Center of the University Hospital Zurich. This study was part of a national multicenter study including five hospitals covering the three main language regions of Switzerland [10].

## 2. Materials and Methods

This explorative study was conducted in 2021 by applying qualitative methods complemented by quantitative data.

We used the consolidated criteria for reporting qualitative studies (COREQ) [24]. The checklist is provided in the appendix and further information about the qualitative approach is provided in the publication of the national multicenter study [10].

*2.1. Inclusion and Exclusion Criteria.* Adult patients ( $\geq 18$ ) undergoing active systemic anticancer treatment for melanoma, breast, lung, or colon cancer were included in this study. These cancer types were selected due to their prevalence in outpatient settings and to minimize variability in care experiences due to multiple treatments or involving multiple departments [10]. Further inclusion criteria were receiving active oral or intravenous systemic anticancer treatment, including chemotherapy, targeted therapy, and immunotherapy with adjuvant or palliative intent at the time of the COVID-19 pandemic, and being able to speak German [10]. Exclusion criteria included hospitalized patients, patients in an end-of-life situation (defined by the oncologist via the "surprise question": "Would I be surprised if the patient dies in the next 6 months?"), patients currently receiving radiotherapy or surgical treatment (even if combined with systemic therapy), patients who had laboratory-confirmed infection with SARS-CoV-2 virus or clinically/radiologically diagnosed COVID-19 infection, and patients not able to follow study procedures [10].

The participants either received, in addition to consultations with oncology physicians, a cancer nursing consultation, an integrative medicine consultation, both consultations, or none of the two consultations within the Comprehensive Cancer Center of the University Hospital Zurich at the time of the COVID-19 pandemic. Participants who did not receive an additional supportive cancer care service were included in this substudy regarding their general experiences with cancer treatment during the COVID-19 pandemic.

Either the consulting oncologists, cancer nurse specialists, or the integrative medicine physicians at the Comprehensive Cancer Center of the University Hospital Zurich invited potential participants and referred them to the study coordinator for final inclusion in the study.

*2.2. Data Collection.* We conducted semistructured qualitative interviews of a duration of approximately 40–60 minutes by phone or on-site, depending on the patients' preferences [10]. We asked the patients about their experiences during the pandemic, how they were affected in their illness trajectory, and how they experienced integrative medicine and cancer nursing consultations (the interview

guideline can be found in the publication of the national multicenter study) [10]. The original interview guideline in German can be obtained from the corresponding author upon request).

At the end of the interviews, patients answered questions about self-reported distress and resilience [10]. Distress was measured using the German version of the National Comprehensive Cancer Network Distress Thermometer (NCCN-DT) [25]. Resilience was evaluated via the German version of the 2-item Connor–Davidson Resilience Scale [26]. We additionally collected patients' sociodemographic data and clinical characteristics, including age, gender, responsibilities as a caregiver, cancer diagnosis, current cancer treatment, and comorbidities [10].

**2.3. Data Analysis.** We performed a thematic analysis of the qualitative interview data using MAXQDA Software (Release 20.4.2) [27]. Based on the interview data, we inductively created a coding tree that was then collapsed into themes and subthemes in an intersubjective validation and synchronization process among the research team of the national multicenter study [10]. Further details about the approach to analyses, the themes and subthemes, their definition, and illustrative quotes can be found in the publication of the national multicenter study [10]. Patients' experiences with integrative medicine consultations and cancer nursing consultations were two additional questions of the interview guideline at the University Hospital Zurich and subsequently were two additional site-specific subcodes within the national synchronized coding tree.

The quotes in the results chapter, which illustrate the findings, are verbatim transcriptions from the interviews, which were originally in Swiss German and German and were then translated into English by the authors. The numbers at the end of the quotations identify the participants and their position in the transcript.

Using Stata Software (Version 17.0), we performed descriptive statistics on the patients' distress and resilience scores, sociodemographic data, and clinical characteristics [10].

### 3. Results

61 patients were screened, from which 21 were included in the study and provided informed consent. There were three dropouts due to hospitalization, migration/lack of time, and not being reachable after informed consent. Eighteen patients with cancer were interviewed, and the same eighteen participants answered the questionnaire about distress and resilience. Four of them saw an oncology clinical nurse specialist, five saw an integrative medicine physician, five received both consultations, and four received routine cancer care without a nursing or an integrative medicine consultation. Their sociodemographic and clinical characteristics are displayed in Table 1.

**3.1. Integrative Medicine Consultations.** The interviewed patients highlighted that they positively felt acknowledged as complete individuals during the integrative medicine consultations, with their symptoms, mental health challenges, worries, and fears.

*"I know few doctors who are like her. Because she is so emphatic. In addition, acupuncture can absorb many side effects. Be it physical or psychological. So yes, I am very happy that I can use this offer. (...) Now with these appointments, they also care in a way or affection. (...) For example, nausea, or I have had a lot of water in the face Or also fear, so fears of the next chemo (...) I have always had relatively a lot of vertigo. I also have such a neuro/, how do you say it, in the fingers. I have had pain. In addition, also the circulation (...) I have a very low blood pressure" (5-06, 31-37).*

*"It felt so good to have someone that looked me in the eyes (...), and talked to me as if I were a human being" (5-10, 90-93).*

Most patients appreciated the time the integrative physicians had to talk to them. Some patients felt that this provided the space for finding holistic treatment solutions.

*"I am also glad that there is always slightly more time available (...) unlike other medical visits. (...) I think (...) it is also important (...) that you can put your worries and fears there. (...) It is always good to find solutions" (5-09, 103).*

One patient added that she appreciated the evidence-based consultation.

*"And it felt so good that someone simply listened to me and tried to do something. (...) Additionally, with these side effects, with the chemobrain, with these nails, that started to fall out. With the neuropathies, where you have to deal (...) with doctors (...) that just say yes, it is normal; and it is kind of like, yeah, stop whining around. It is normal and it will go away. However, for me, it felt anything but normal. (...) You all of a sudden do not feel your body like a part of yourself anymore, (...) or you all of a sudden forget things, where you did not before. I have to admit, I was very skeptical. I'm someone who does not do a lot of complementary medicine otherwise. I have truly been very pleasantly surprised. In addition, what has been important for me is that it is scientifically supported. That you're doing something where it is kind of verified and that is not bordering on magic. However, that it is something where someone has tried to look at in a study once" (5-10, 96).*

A patient mentioned positively the possibility of a phone consultation that was installed during the pandemic.

*"I mean, yesterday I could not go to acupuncture because I was not feeling well; and then we talked on the phone for half an hour" (5-06, 57).*

**3.2. Nursing Consultations.** Most of the patients with cancer who received a nursing consultation stated that the oncology clinical nurse specialist seemed to have more time during the pandemic than they would have normally had for their patients.

TABLE 1: Sociodemographic and clinical characteristics of the participants [10].

Variables	N = 18 n (%)
Age (mean (SD))	53.3 (13.5)
<i>Gender</i>	
Male	3 (16.7)
Female	15 (83.3)
<i>Living situation</i>	
Single/living alone	4 (22.2)
Living with partner	12 (66.7)
Living separated from partner/husband/wife	2 (11.1)
Widowed/partner deceased	—
<i>Children and/or relatives in need of care living in the same household</i>	
Yes	3 (16.7)
No	14 (77.8)
Missing	1 (5.6)
<i>Education</i>	
No degree	—
Compulsory education	—
Vocational training	4 (22.2)
Higher technical education/University of Applied Sciences	10 (55.6)
University	4 (22.2)
<i>Current main professional activity</i>	
Employed	4 (22.2)
Self-employed	4 (22.2)
Retired	4 (22.2)
Homemaker	1 (5.6)
Disability due to illness or accident	5 (27.8)
Other	—
<i>Cancer type</i>	
Breast	8 (44.4)
Lung	2 (11.1)
Colon	5 (27.8)
Melanoma	3 (16.7)
<i>Currently receiving systemic treatment</i>	
Yes	15 (83.3)
No	3 (16.7)
<i>Comorbidities</i>	
Diabetes mellitus	1 (5.6)
Heart failure	—
Mental health illness	1 (5.6)
Other comorbidity	6 (33.3)

“And that made me feel so good. Or even just during the first chemo, the nursing staff had more time to simply stand by you; what someone else might have done otherwise (before the pandemic)” (5–10, 27).

In addition to having more time, the patients often described the oncology clinical nurse specialist as their first point of contact and referring point for their questions and symptom management. As visitors and companions were restricted in the hospital during the pandemic, some patients perceived the oncology clinical nurse specialist as being able to fill this gap by taking care of them, for example, during chemotherapy.

“Well, I had a breast cancer nurse, and she was, well, super, super, super helpful and truly sweet and accompanied me very well through the time. Therefore, I could also call her at any time and take her with me to treatments if necessary, for example, and, (...) that also (...) helped me well through the time. (...) She was (...) a bit of a thread through everything and sometimes kept me company during the chemotherapies, for example. (...) I would say, a breast cancer nurse is worth her weight in gold (...) especially because you’re not allowed to take anyone with you to the hospital and stuff. (...) She was also always there and I never felt alone” (5-03, 59-61.)

The patients pointed out that they could address symptoms and side effects of their therapies with the oncology clinical nurse specialist for which otherwise there may not have been the time to discuss them with their oncologists. They highlighted how helpful these additional cancer nursing consultations have been for them.

*“I had several nursing consultations with her (...) before chemo, before surgery, before radiation, and then also now during the antihormone therapy. I can also always contact her and ask her questions. That helps a lot, because many doctors do not have as much time to answer questions or to deal with the side effects of cancer treatment” (5-03, 65).*

**3.3. General Experiences with Cancer Treatment during the COVID-19 Pandemic.** In general, patients (including those who did not receive an additional supportive cancer care service) did not experience delays or disruptions in their cancer treatment nor felt additionally burdened by the pandemic [10].

*“Interviewee: I think the cancer treatment itself has not changed for me. (...) Because it was life-sustaining, it was carried out as it would have been, I think, in non-pandemic times.*

*Interviewer: so no appointments have been cancelled or therapies postponed or anything like that?*

*Interviewee: no, I think rather the opposite. I could benefit, like I said before, (...) because the nursing staff had more time to listen to you” (5-10, 59-61).*

As immunosuppressed and fatigued patients with cancer, they felt supported by the restrictions and hygienic measures [10].

*“I got my cancer diagnosed two weeks before the lockdown (...). However, I would now say that the coronavirus crisis, the lockdown, was actually more of a blessing than a curse for us (...). It went (...) hand in hand. (...) I had to completely isolate myself anyway because of the immunosuppressing effect (of the chemotherapy). In addition, with me also my whole family because my husband was then in the home office, the childcare closed and so on and immediately, quite a lot of risk factors for me actually fell away (...). I actually hardly had to clear any stones out of the way (...). Yes, it all worked out/this may sound stupid now, but it all fell into place quite happily” (3-04, 6).*

Access to vaccination reassured patients against the risk of infection [10].

*“The fact that I was vaccinated (...) is like a security. I still protect myself the same way. (...) I feel more liberated after the vaccination. (...) I have also been told that you do not know how the vaccine works when you have chemotherapy but anyway, I just felt better. I felt more secure” (3-08, 45).*

**3.4. Distress and Resilience.** The results from the interviews are reflected in the quantitative data, as we found moderate distress levels ( $M = 4.1$ ;  $SD = 2.5$ ) and high resilience scores ( $M = 7.5$ ;  $SD = 0.9$ ) in the patients (Table 2).

## 4. Discussion

A holistic personalized approach with more time resources for the patients was the predominant experience of the participants relating to supportive cancer care services (integrative medicine and/or cancer nursing consultations) during the pandemic at the University Hospital Zurich. Being seen, heard, and treated as a whole and individual person was especially important for most interviewed patients with cancer, and this seemed to be independent of being in the situation of a pandemic. The need for a personalized holistic approach with sufficient time resources is in line with research about supportive cancer care in general [1, 2, 29, 30]. In relation to this, there is a consensus that the aims of supportive cancer care are best achieved by interprofessional collaboration accompanied by good coordination and communication between the involved disciplines and health professionals [1, 2].

A more holistic approach with more time resources for the patients was supported by the restructuring of the Comprehensive Cancer Center of the University Hospital Zurich in response to the COVID-19 pandemic. It is now a chance to reflect on how the positive experiences during this time (holistic care, staff, and financial resources) can be incorporated into usual cancer care after the pandemic. At the Comprehensive Cancer Center of the University Hospital Zurich, the daily offer of a nursing consultation for patients with cancer was permanently installed as a consequence of the good experiences during the pandemic. Moreover, the nurse consultation now acts as a coordinator between the different health professionals involved in supportive cancer care, by identifying the needs of the patients and by referring the patients to the specific services, including the integrative medicine service. Therefore, the collaboration between nurses and integrative medicine physicians during the pandemic was a role model. However, it should be considered that nursing was the only health profession that during the pandemic (and also before and after) had no legal foundation to switch to telephone or online consultations and to bill adequately, although there was a catalog of the Federal Office of Public Health in Switzerland, which authorized other health professional groups to do so [31]. Compared to other countries within which such nurse-led services are the standard of care, Switzerland is persisting in a physician-dominated tariffication system [6]. This is concerning considering the importance of supportive cancer care for patients with cancer. As a consequence, only those patients with cancer who went to the hospital had the option for cancer nurse consultations during the COVID-19 pandemic.

A general experience of the study participants was that the conditions of the COVID-19 pandemic (i.e., hygienic measures, social distancing, home offices, and online

TABLE 2: Distress and resilience scores [10].

	N	Mean	SD	Median	Min	Max
Distress (0–10) NCCN-DT	17*	4.1	2.5	3	1	8
Resilience (0–8) CD-RISC2	18	7.5	0.9	7.5	5	8

\*1 data missing. The NCCN practice guideline recommends that a DT score of 4 or higher indicates moderate-to-severe distress and mild distress corresponding to a DT score of <4 [25]. Validation of the German version of the NCCN-DT identified a score of  $\geq 5$  on the visual analog scale as a cutoff for a clinically significant level of distress [28].

consultations) provided a supportive environment for patients with cancer under active systemic anticancer treatment.

**4.1. Distress and Resilience.** Our results are similar to those of other studies measuring distress and resilience during the COVID-19 pandemic [15, 16, 18]. This might be explained by the time when these studies were conducted, during the second COVID-19 wave in 2021, when the first scientific insights and vaccines started to be available and provided reassurance for people [10]. It is already known that supportive cancer care, including integrative medicine services and cancer nurse services, positively influences the quality of life, including resilience and distress, in people affected by cancer [3–5]. This might also help patients with cancer face the challenges of the COVID-19 pandemic.

**4.2. Limitations.** The study population predominantly included middle-aged, well-educated women (83.3%) and women with breast cancer (44.4%). Although this population is known as the predominant users of supportive cancer care [32], more people of younger ages, different socioeconomic backgrounds, different sex and gender identities, and with different types of cancers might have provided a broader spectrum of experiences and distress and resilience scores. In addition, the participants were limited to patients with cancer under active systemic anticancer treatment in hospitals. People with untreated cancer were not included, that is, those who might have avoided visits to their medical doctors and the hospital due to the COVID-19 pandemic and their fear of infection. The experiences of those patients might have been significantly different compared to our study participants. In addition, a longitudinal follow-up study would have provided a more differentiated picture of the patients' experiences.

Although nursing and integrative medicine are relevant services in supportive cancer care, the inclusion of other supportive cancer care services in our study during the COVID-19 pandemic (e.g., psycho-oncology, palliative care, physiotherapy, and ergotherapy) would have broadened the picture of the patients' experiences.

## 5. Conclusion

During the COVID-19 pandemic, patients with cancer felt supported by integrative medicine and cancer nursing consultations. A holistic personalized approach with more

time resources for the patients was supported through the restructuring of the Comprehensive Cancer Center of Zurich in preparation for a potential COVID-19 emergency. After the pandemic, we still need a strong supportive cancer care in Swiss hospitals with secured resources. Only then, will we be able to address the needs of patients with cancer for holistic, personalised cancer treatment.

## Data Availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## Ethical Approval

Approval was obtained from the corresponding Swiss Ethics Committee *Commission cantonale d'éthique de la recherche sur l'être humain*, Vaud (CER-VD). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

## Consent

Written informed consent was obtained from all individual participants included in this study.

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

## Authors' Contributions

Claudia M. Witt, Manuela Eicher, Karin Ribi, and Sara Colomer-Lahiguera contributed to the study conception and design. Claudia Canella and Matthias Naegele conducted the interviews. The Zurich study site-specific data analysis was performed by Claudia Canella, Matthias Naegele, Karin Ribi, Stelio Giacomini, and Kim Lê Van. Claudia Canella, Matthias Naegele, and Claudia M. Witt wrote the first draft of the manuscript. All authors contributed to the interpretation of the results and approved the final version of the manuscript.

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## Supplementary Materials

Appendix: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist. (*Supplementary Materials*)

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