The emotional impact of the COVID-19 outbreak on cancer outpatients and their caregivers: results of a survey conducted in the midst of the Italian pandemic

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Abstract
Introduction The study investigates the emotional discomfort of cancer patients and their caregivers, who need to access the oncology day hospital to receive treatment during the COVID-19 pandemic in Italy.

Methods This is a single-institution, prospective, cross-sectional study. From May to June 2020, the points of view of both patients and caregivers were compared through 2 different multiple-choice questionnaires, enquiring demographic characteristics, changes in emotional status, interpersonal relationships with health professionals (HCPs) and self-perception of treatment outcomes.

Results Six hundred twenty-five patients and 254 caregivers were enrolled. Females were prevalent and patients were generally older than caregivers. Forty percent of patients and 25.6% of caregivers thought they were at a greater risk of contagion because lived together with a cancer patient or accessed the hospital. Both patients (86.3%) and caregivers (85.4%) considered containment measures a valid support to avoid the spread of infection. People with a lower education level were less worried about being infected with SARS-COV-2. Waiting and performing visits/treatments without caregivers had no impact on the emotional status of patients (64.4%), but generated in caregivers greater anxiety (58.8%) and fear (19.8%) of not properly managing patients at home. The majority of patients (54%) and caregivers (39.4%) thought the pandemic does not influence treatment outcomes. The relationship with HCPs was not negatively impacted for majority of patients and caregivers.

Conclusions Starting from these data, we can better understand the current psychological distress of patients and their families in order to develop potential strategies to support them in this strenuous period of crisis.

Keywords COVID-19 · Survey · Cancer patients · Caregivers · Emotional distress
Introduction

In February 2020, the coronavirus disease 2019 (COVID-19) outbreak swept Italy. To prevent the spread of the SARS-CoV-2 infection, starting from March 9th, the Italian Government progressively introduced mitigation measures that drastically limited social interactions [1].

The “lockdown” led to substantial changes in people’s lifestyles with a consequent negative impact on their psychological well-being. The limitations in daily activities, the social isolation combined with the fear of contracting the infection and the uncertainties related to this new and unexpected condition have generated insecurity, anxiety and emotional distress [2]. Healthcare professionals (HCPs), who were on the frontline fighting the pandemic, have been one of the most physically and emotionally involved category [3]. Furthermore, the COVID-19 pandemic led to a reorganization of the Healthcare System, in particular for those people who needed to continue “life-saving” treatments, as in the case of cancer patients.

An important goal for the oncologist is to guarantee the continuum of care for cancer patients, even during a period of sanitary crisis, despite the potential risk of COVID-19 infection. Delaying treatment of metastatic cancer patients can lead to disease progression, performance status deterioration and worsening of symptoms. On the other hand, the omission or delay of adjuvant therapies can increase mortality. The main International Societies of Oncology have issued recommendations aimed to mitigate the negative effects of COVID-19 pandemic on diagnosis and treatment of cancer patients [4–8].

First of all, they recommended making a correct patient selection, categorising them into high, medium or low priority, in order to minimize hospital access for those patients who could continue the treatment/surveillance while staying at home through online medical counselling (telemedicine) or home drug delivery. For outpatients who needed to access the hospital, it was crucial to adopt all procedures aimed to reduce the risk of potential contagion, through a correct triage at the entrance of the day hospital and clinic, the use of individual protection devices and a reorganization of spaces in order to maintain social distancing [9]. The implementation of these procedures led to the unavoidable consequence that patients accessed the hospital without caregivers, who could not stay with them in the waiting room and during the visit. All the activities (visits and therapy administration) took place in a new and unusual way, which could destabilize the already fragile emotional balance of patients but also of their caregivers. During the pandemic, because of the strict social isolation and the travel limitation (including the use of public means of transport), caregivers could no longer share the burden of taking care of patients with others (friends or support groups) and this situation had enhanced the psychological, economic and practical burden of caregivers. Some surveys on patients’ insights were conducted but to date, just very few data are available about a direct comparison of patients and caregivers’ opinions on these topics [10].

The aim of our study is to evaluate how the COVID-19 pandemic impacted on the emotional approach to therapeutic path of cancer outpatients and their caregivers and to compare the points of view of both patients and caregivers about this topic. Investigating these aspects is important in order to understand the difficulties that cancer patients and their families are facing during this health crisis, and to develop adequate strategies to deal with them.

Materials and methods

This is a single-institution, prospective, cross-sectional study of the Department of Oncology at Luigi Sacco Hospital, one of the Italian hospitals which was mostly involved in the COVID-19 pandemic. The survey was conducted on outpatients who were receiving active cancer treatment and their caregivers. Data collection was performed from 5 May to 5 June 2020. We devised two different multiple-choice questionnaires (15 questions for patients and 17 for caregivers) enquiring about demographic characteristics, changes in emotional status, interpersonal relationships with health professionals (HCPs) and self-perception of treatment outcomes. The answers could be “Yes”, “No”, “I don’t know” and “Enough” (Enough = the responder partially agrees with the statement formulated in the question).

Statistical methods

The answers were categorized into two groups: “Yes” and “Enough” versus “No”. If the proportion of subjects answering “I don’t know” was higher than 5% in patients’ questionnaires and 10% in caregivers’ questionnaires, the impact of the demographic characteristics on the answer “I don’t know” was investigated. Differences in the answers to questions in both patients and caregivers questionnaires were investigated by chi-squared test. Details on the matching of questions in the two questionnaires are provided in Table 1.

We also evaluated the impact of demographic characteristics on the answers to each question, which was investigated by univariable and multivariable logistic regression models. Results were expressed in terms of odds ratios (ORs) and their 95% confidence intervals (95%CI).

A p-value < 0.05 was considered statistically significant. Analyses were carried out using SAS statistical software (version 9.4).
|                           | Patient questionnaire                                                                 | Caregiver questionnaire                                                                 |
|---------------------------|---------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| Triage utility            | Do you think that the triage (questionnaire and temperature measurement) performed at the entrance and the safety standards applied during the stay are useful to reduce the risk of contagion of COVID-19? | Do you think that the triage (questionnaire and temperature measurement) performed at the entrance and the safety standards applied during the stay are useful to reduce the risk of contagion of COVID-19? |
| Expenditure of time for triage | Do you believe that the application of such procedures involves an excessive expenditure of time? | Do you believe that the application of these procedures involves an excessive expenditure of time? |
| Risk in the patient accompanying | Do you think that your caregiver/cohabiting people are more exposed to COVID-19 infection in relation to your hospital access? | Do you think that accompanying the patient to the hospital entails a greater risk of contagion for you than the healthy population? |
| Risk in the patient cohabiting | Do you think that your caregiver/cohabiting people are more exposed to COVID-19 infection in relation to your hospital access? | Do you think that cohabiting with the patient entails a greater risk of contagion for you than the healthy population? |
| Changes in personal emotional status | Do you think that the application of safety procedures has changed the way you deal emotionally with the path of care? | Do you feel that not sharing the wait and not attending the visit has a negative impact on your emotional state? |
| Type of changes            | If you answered yes to the previous question, how?                                     | If you answered yes to the previous question, how?                                       |
| Changes in patient emotional status | Do you think that the application of safety procedures has changed the way you deal emotionally with the path of care? | Do you feel that not sharing the wait and not attending the visit has a negative impact on the emotional state of the patient? |
| Negative impact of pandemic on patient treatment | Do you think the pandemic could have a negative effect on your treatment? | Do you believe that the pandemic can have a negative effect on the patient’s treatment path? |
| Attention of doctors on COVID-19 | Do you think that currently the attention of doctors is more focused on COVID-19 than on cancer treatment? | Do you think that currently the attention of doctors is more focused on COVID-19 than on cancer treatment? |
| Balance of restrictions and the reduction of the risk of contagion | Overall, do you believe that the negative aspects of the restrictions imposed are balanced by the reduction of the risk of contagion? | Overall, do you believe that the negative aspects of the restrictions imposed are balanced by the reduction of the risk of contagion? |
**Results**

Six hundred twenty-five consecutive patients and 254 caregivers were enrolled. The whole population was mainly made up of females: 407 (65.1%) patients and 143 (56.3%) caregivers were females. Patients were generally older than caregivers: 436 (69.8%) were >60 years while the majority of caregivers were 41–60 years old (128, 50.4%) ($p<0.001$). Moreover, 315 (50.5%) patients had a low education level (primary and secondary school) while 170 (67.5%) caregivers had a higher degree (high school or greater) ($p<0.001$). All the demographic characteristics of patients and caregivers are reported in Table 2.

About half of the patients (330, 52.8%) reached the hospital with their own caregivers, who were usually a son/daughter (104, 40.9%) or the partner (97, 38.2%), and frequently lived together (148, 58.3%). The answers of patients' and caregivers' questionnaires are reported in Tables 3 and 4, respectively.

### Table 2  Demographic characteristics of patients and caregivers

|                          | Patients | Caregivers | $p$-value |
|--------------------------|----------|------------|-----------|
| **Age**                  |          |            |           |
| 18–40 years              | 26 (4.2) | 13 (5.1)   | <0.001    |
| 41–60 years              | 163 (26.1)| 128 (50.4)|           |
| > 60 years               | 436 (69.8)| 113 (44.5)|           |
| **Sex**                  |          |            | 0.014     |
| Female                   | 407 (65.1)| 143 (56.3)|           |
| Male                     | 218 (34.9)| 111 (43.7)|           |
| **Educational qualification** |          |            | <0.001    |
| Primary school           | 100 (16.0)| 13 (5.2)  |           |
| Lower secondary school   | 215 (34.5)| 69 (27.4) |           |
| Upper secondary school   | 230 (36.9)| 125 (49.6)|           |
| Higher education         | 79 (12.7)| 45 (17.9) |           |
| Missing                  | 1        | 2          |           |
| **Reason for patient being in hospital** |          |            |           |
| Therapy                  | 174 (27.8)| 67 (26.4)|           |
| Visit                    | 451 (72.2)| 187 (73.6)|           |
| **Accompanied by a relative/friend/caregiver** |          |            |           |
| No                       | 295 (47.2)|           |           |
| Yes                      | 330 (52.8)|           |           |
| **Relationship with the patient** |          |            |           |
| Spouse                   | 97 (38.2)|           |           |
| Son/daughter             | 104 (40.9)|           |           |
| Parent                   | 11 (4.3) |           |           |
| Other                    | 42 (16.5)|           |           |
| **Do you cohabit with the patient?** |          |            |           |
| No                       | 106 (41.7)|           |           |
| Yes                      | 148 (58.3)|           |           |

**Comparison between patients and caregivers**

Table 5 reports the comparison between patients and caregivers’ answers (see Table 1 for details on matching questions).

About half of the cancer patients felt more vulnerable to COVID-19 compared to their caregivers (question P1: 250, 52.5%). Patients were more worried than caregivers about the risk of exposing cohabiting people to the COVID-19 infection because of their frequent access to the hospital (question P4 and question C2: yes/enough 117 [25.1%] vs. 32 [14.7%], $p=0.002$).

Both patients and caregivers considered the containment measures (triage at the entrance, social distancing, personal protective equipment) a valid support to avoid the spread of infection (question P2 and C3: 538 [92.0%] vs 217 [88.9%] respectively, $p=0.163$).

Both patients and caregivers believed that the containment measures did not involve an excessive expenditure of time, with a major prevalence of positive judgments in caregivers compared to patients (questions P3 and C4: 489 [85.9%] vs. 225 [91.5%] $p=0.028$).

A personal emotional change caused by waiting and performing visits and treatments without caregivers was reported more by caregivers (158, 66.1%) than by patients (195, 32.7%) (questions P6 and C6, $p<0.001$). Specifically, 77 (58.8%) caregivers reported greater anxiety and 26 (19.8%) had a fear of not managing the patients properly at home (question C7). Moreover, caregivers thought that the pandemic caused a negative impact on the emotional state of the patients more than what the patients themselves stated (questions P6 and C5: 195 [32.7%] vs 155 [66.5%], $p<0.001$).

The majority of patients (336, 73.2%) and caregivers (100, 62.1%) thought that the pandemic did not influence treatment outcomes, with a higher prevalence of positive answers in patients (questions P8 and C9, $p=0.008$). The relationship with HCPs was not negatively affected for both patients (question P5: 457, 79.6%) and caregivers (question C8: 167, 94.9%), but about a quarter of patients and caregivers thought that the attention of HCPs was more focused on COVID-19 than on cancer treatment (questions P9 and C10: 119 [25.0%] vs. 45 [29.2%], $p=0.300$).

**Impact of patients’ characteristics on answers**

The results of logistic regression analyses on patients’ questionnaires are summarized in Table 6a, b, and c in the supplementary file.

No statistically significant associations were found between age and sex and the answers to questions, although males were more likely to answer “I don’t know” to the questions concerning the time spent for the triage and application of safety standards (question P3: adjusted OR [aOR] 1.78,
| Question                                                                 | No       | Enough  | Yes     | I don’t know | Missing |
|-------------------------------------------------------------------------|----------|---------|---------|--------------|---------|
| Do you think you are at greater risk of contagion than the healthy population? | 226 (36.2) | 76 (12.2) | 174 (27.9) | 148 (23.7) | 1       |
| Do you think that the triage (questionnaire and temperature measurement) performed at the entrance and the safety standards applied in the waiting room are useful to reduce the risk of contagion of COVID-19? | 47 (7.5) | 54 (8.7) | 484 (77.6) | 39 (6.3) | 1       |
| Do you believe that the application of such procedures involves an excessive expenditure of time? | 489 (78.2) | 32 (5.1) | 48 (7.7) | 56 (9.0) | 1       |
| Do you think that your caregiver/cohabiting people are more exposed to COVID-19 infection in relation to your hospital access? | 349 (55.9) | 64 (10.3) | 53 (8.5) | 158 (25.3) | 1       |
| Do you believe that the application of safety procedures has changed the relationship with health care professionals? | 457 (73.1) | 46 (7.4) | 71 (11.4) | 51 (8.2) | 1       |
| Do you think that the application of safety procedures has changed the way you deal emotionally with the path of care? | 401 (64.4) | 20 (3.2) | 175 (28.1) | 27 (4.3) | 2       |
| If you answered yes to the previous question, how?                      | 86 (53.4) | 41 (25.5) | 15 (9.3) | 17 (10.6) | 2       |
| Do you think the pandemic could have a negative effect on your treatment? | 336 (53.9) | 60 (9.6) | 63 (10.1) | 164 (26.3) | 2       |
95%CI 1.01–3.15, \( p = 0.047 \), online table S1). Compared to patients with a lower education level, those with an upper secondary school degree were more likely to think that cohabiting people were more exposed to COVID-19 infection due to their frequent access to the hospital (question P4: aOR 2.18, 95%CI 1.08–4.41, \( p = 0.030 \)) and to declare a possible negative effect of the pandemic on their treatment (question P8: aOR 2.35, 95%CI 1.11–4.99, \( p = 0.025 \)). Moreover, patients with an upper secondary school degree were more likely to think that the attention of doctors was more focused on COVID-19 than on cancer treatment (question P9: aOR 2.60, 95%CI 1.28–5.28, \( p = 0.009 \)). In regards to the possibility of receiving “I don’t know” as an answer, patients with a primary school degree had more difficulty in answering several questions (online table S1).

Moreover, patients who accessed the hospital for a visit were less likely to think they had a higher risk of contagion compared to patients who accessed it for the therapy (question P1: aOR 0.45, 95%CI 0.30–0.69, \( p < 0.001 \)) and they were more likely to answer “I don’t know” to the same question (aOR 2.12, 95%CI 1.32–3.40, \( p = 0.002 \)); more frequently, they thought that the application of safety procedures had changed the relationship with HCPs and that the attention of doctors was more focused on COVID-19 (question P5: aOR 1.86, 95%CI 1.12–3.09, \( p = 0.016 \); question P9: aOR 1.96, 95%CI 1.17–3.25, \( p = 0.010 \) respectively). Finally, they were more likely to answer “I don’t know” to this last question (question P9: aOR 1.76, 95%CI 1.12–2.77, \( p = 0.015 \)).

Impact of caregivers’ characteristics on answers

The results of logistic regression analyses on caregivers’ questionnaires are summarized in Table 7a, b, and c in the supplementary file.

No statistically significant associations were found between the answers and the demographic characteristics, except for sex and education level. Compared to female caregivers, males were less likely to believe in a negative effect of the pandemic on patients’ treatment (question C9: aOR 0.48, 95%CI 0.24–0.96, \( p = 0.039 \)).

Compared to caregivers with a low education level, caregivers with a higher education level were more likely to think they were at a greater risk of contagion because they were accompanying (question C1: caregivers with upper secondary school degree: aOR 2.56, 95%CI 1.12–5.86, \( p = 0.026 \); caregivers with higher school degree: aOR 3.11, 95%CI 1.17–8.26, \( p = 0.023 \)) or cohabiting with the patients (question C2: caregivers with upper secondary school degree: aOR 4.48, 95%CI 1.24–16.2, \( p = 0.022 \); caregivers with higher school degree: aOR 4.54, 95%CI 1.06–19.5, \( p = 0.042 \)).

As for patients, some caregivers had difficulty in answering the questions and checked the “I don’t know” option. More details are available in online Table S2.

Discussion

This is the first Italian survey aimed to investigate the emotional approach to the care of cancer outpatients and their caregivers, who needed to access the day hospital and clinic of the Department of Oncology during the pandemic. With this study, we wanted to collect the points of view of both the “players” to compare them and evaluate differences and points of agreement, in order to identify the most suitable strategies to support patients and their families in this strenuous period of crisis.

We enrolled a large number of patients in only 1 month and these data reflect the attention of our cancer centre to the continuum of care and the participants’ involvement in this topic. Enrolled patients were mostly female, aged > 60 years old and with a low education level, while caregivers were usually younger, female and with a higher education level.
## Table 4  Caregivers’ questionnaire

| Question                                                                 | No          | Enough     | Yes         | I don’t know | Total |
|-------------------------------------------------------------------------|-------------|------------|-------------|--------------|-------|
| Do you think that accompanying the patient to the hospital entails a greater risk of contagion for you than the healthy population? | 147 (57.9)  | 35 (13.8)  | 30 (11.8)   | 42 (16.5)    | 254   |
| Do you think that cohabiting with the patient entails a greater risk of contagion for you than the healthy population?       | 186 (73.2)  | 12 (4.7)   | 20 (7.9)    | 36 (14.2)    |       |
| Do you think that the triage (questionnaire and temperature measurement) performed at the entrance and the safety standards applied during the stay are useful to reduce the risk of contagion of COVID-19? | 27 (10.6)   | 18 (7.1)   | 199 (78.3)  | 10 (3.9)     |       |
| Do you believe that the application of these procedures involves an excessive expenditure of time?                          | 225 (88.6)  | 9 (3.5)    | 12 (4.7)    | 8 (3.1)      |       |
| Do you feel that not sharing the wait and not attending the visit has a negative impact on the emotional state of the patient? | 78 (30.7)   | 39 (15.4)  | 116 (45.7)  | 21 (8.3)     |       |
| Do you feel that not sharing the wait and not attending the visit has a negative impact on your emotional state?          | 81 (32.3)   | 30 (12.0)  | 128 (51.0)  | 12 (4.8)     |       |
| If you answered yes to the previous question, how?                      | Increased anxiety | 76 (76.0)  | 11 (11.0)   | 11 (11.0)    | 2 (2.0) |
|                                                                        | Fear of the disease | 11 (11.0) |           |             | 28     |
| In this complex situation, do you think you can still interface with doctors properly?                                   | 9 (3.6)     | 30 (12.0)  | 137 (54.6)  | 75 (29.9)    |       |
| Do you believe that the pandemic can have a negative effect on the patient’s treatment path?                             | 100 (39.4)  | 22 (8.7)   | 39 (15.4)   | 9 (3.6)      |       |
About half of the patients reached the hospital with their own caregivers; however, the number of questionnaires filled in by caregivers was lower (77% of caregivers who accompanied patients to the hospital), probably because a part of them delivered patients to the hospital without accessing the cancer centre to avoid the potential risk of contagion.

What emerges from our survey is that the majority of patients felt more vulnerable to the SARS-CoV-2 infection compared to caregivers; this perception is coherent with the news reported by mass media, drawn from the scientific literature. The first data about COVID-19 in cancer patients were published by Liang and colleagues in March 2020: in their cohort of 1590 COVID-19 positive Chinese patients, 18 had a history of cancer. The authors found that cancer patients had a higher risk of contracting COVID-19 because of their systemic immunosuppression and had a poorer prognosis than those without cancer [11]. Zang et al. retrospectively studied the clinical features of 28 COVID-19-positive cancer patients from three hospitals in Wuhan: they observed that 15 (53.6%) patients developed severe events with a mortality rate of 28.6%, confirming that cancer patients presented a poor outcome with a high occurrence of clinically severe events and a high mortality [12]. The TERAVolt study also confirmed the high mortality rate (33%) and low admission rate to intensive care units in patients with thoracic cancer [13].

Differently from patients, caregivers did not feel more exposed to infection although they were involved in taking care of someone who was undergoing active cancer treatment. This occurred even if they lived together with patients and needed to access the hospital for the patients’ treatment. Probably, caregivers did not feel more exposed to COVID-19 because they were generally in good general condition, with no significant comorbidity and on average younger than the patient.

Beyond this difference, we found that the education level influenced the perception of the risk of contagion: a higher education level probably led the person to gather more information about the pandemic and to a greater awareness of the severity of the health crisis, causing greater apprehension for their own safety. On the other hand, both patients and caregivers with a low education level were more likely to answer “I don’t know” to the question investigating this setting. These data are consistent with a previous survey aimed to analyse the different levels of risk perception in various populations during a health crisis, and the relative factors that influenced them [14, 15].

Regardless of the perceived risk of contagion, study participants appreciated the application of general risk prevention and mitigation measures, as reported in literature [16].

Caregivers were particularly worried about the psychological well-being of their relatives: they believed that the patients’ concern about the pandemic and the feelings of loneliness during the visit/therapy might add up to the apprehension for the disease and the effort to deal with a complex therapeutic plan. Moreover, since the access of the caregivers to the hospital was limited, patients were alone during the visit and could not share information with the GCs. This situation resulted in the concern of caregivers of not managing the patients properly at home. The most interesting finding of this study was that patients thought that the COVID-19 pandemic would not negatively impact the course of their treatment, the outcome of the therapy and the relationship with HCPs, despite the physical and mental load of their disease. This is probably due to the trust that a patient with a chronic disease has in the people who take care of him [17].

In a subgroup of survey participants, the fear of a “distraction effect” emerged. In fact, in our study we found that patients with a higher education level or patients...
Table 5  Comparison between patients' and caregivers' answers to questionnaire

|                                     | Patients | Caregivers | o-value | Patients | Caregivers | o-value |
|-------------------------------------|----------|------------|---------|----------|------------|---------|
| **Triage utility**                  |          |            |         |          |            |         |
| No                                  | 47 (7.5) | 27 (10.6)  | 0.227   | 47 (8.0) | 27 (11.1)  | 0.163   |
| Enough                              | 54 (8.7) | 18 (7.1)   |         | 538 (92.0)| 217 (88.9) |         |
| Yes                                 | 484 (77.6)| 199 (78.3)|         |          |            |         |
| I don't know                        | 39 (6.3) | 10 (3.9)   |         |          |            |         |
| Missing                             | 1        | 0          |         |          |            |         |
| **Expenditure of time for triage**  |          |            | 0.003   |          |            | 0.028   |
| No                                  | 489 (78.2)| 225 (88.6)|         | 489 (85.9)| 225 (91.5) |         |
| Enough                              | 32 (5.1) | 9 (3.5)    |         | 80 (14.1) | 21 (8.5)   |         |
| Yes                                 | 48 (7.7) | 12 (4.7)   |         |          |            |         |
| I don't know                        | 56 (9.0) | 8 (3.1)    |         |          |            |         |
| **Risk in the patient accompanying**|         |            | 0.016   |          |            | 0.130   |
| No                                  | 349 (55.9)| 147 (57.9)|         | 349 (74.9)| 147 (69.3)|         |
| Enough                              | 64 (10.3)| 35 (13.8) |         | 117 (25.1)| 65 (30.7) |         |
| Yes                                 | 53 (8.5) | 30 (11.8)  |         |          |            |         |
| I don't know                        | 158 (25.3)| 42 (16.5)|         |          |            |         |
| Missing                             | 1        | 0          |         |          |            |         |
| **Risk in the patient cohabiting**  |          |            | <0.001  |          |            | 0.002   |
| No                                  | 349 (55.9)| 186 (73.2)|         | 349 (74.9)| 186 (85.3)|         |
| Enough                              | 64 (10.3)| 12 (4.7)   |         | 117 (25.1)| 32 (14.7) |         |
| Yes                                 | 53 (8.5) | 20 (7.9)   |         |          |            |         |
| I don't know                        | 158 (25.3)| 36 (14.2)|         |          |            |         |
| Missing                             | 1        | 0          |         |          |            |         |
| **Changes in personal emotional status** |       |          | <0.001  |          |            | <0.001  |
| No                                  | 401 (64.4)| 81 (32.3)|         | 401 (67.3)| 81 (33.9) |         |
| Enough                              | 20 (3.2) | 30 (12.0)  |         | 195 (32.7)| 158 (66.1)|         |
| Yes                                 | 175 (28.1)| 128 (51.0)|         |          |            |         |
| I don’t know                        | 27 (4.3) | 12 (4.8)   |         |          |            |         |
| Missing                             | 2        | 3          |         |          |            |         |
| **Type of changes**                 |          |            |         |          |            |         |
| Increased anxiety                   | 90 (52.3)| 77 (58.8)  |         |          |            |         |
| Fear of the disease                 | 43 (25.0)| 13 (9.9)   |         |          |            |         |
| Sense of solitude                   | 18 (10.5)| 12 (9.2)   |         |          |            |         |
| Difficulty in managing the behaviour of the patient at home due to no shared communication with the doctor or the nurse | 0 (0.0) | 26 (19.8) |         |          |            |         |
| Fear of not remembering what the doctor said during the visit | 18 (10.5) | 0 (0.0) |         |          |            |         |
| Other                               | 3 (1.7)  | 3 (2.3)    |         |          |            |         |
| Missing                             | 453      | 123        |         |          |            |         |
| **Changes in patient emotional status** |       |          | <0.001  |          |            | <0.001  |
| No                                  | 401 (64.4)| 78 (30.7)|         | 401 (67.3)| 78 (33.5) |         |
| Enough                              | 20 (3.2) | 39 (15.4)  |         | 195 (32.7)| 155 (66.5)|         |
| Yes                                 | 175 (28.1)| 116 (45.7)|         |          |            |         |
| I don’t know                        | 27 (4.3) | 21 (8.3)   |         |          |            |         |
| Missing                             | 2        | 0          |         |          |            |         |
| **Negative impact of pandemic on patient treatment** |       |          | <0.001  |          |            | 0.008   |
| No                                  | 336 (53.9)| 100 (39.4)|         | 336 (73.2)| 100 (62.1)|         |
who accessed the oncology department only occasionally (for example for a visit every 6 months) were concerned because they thought that COVID-19 captured all the HCP’s attention, overshadowing cancer treatment and prevention (https://www.nytimes.com/2020/04/20/health/treatment-delays-coronavirus.html, https://www.rcseng.ac.uk/news-and-events/blog/cancer-patients-the-forgotten-victims-of-the-covid-19-global-pandemic/, https://www.fightcancer.org/releases/survey-covid-19-affecting-patients%E2%80%99-access-cancer-care) [18].

All the information acquired through this survey allowed us to better understand the emotional changes which occurred in cancer patients and their caregivers during the COVID-19 pandemic. Starting from these data, we can develop potential strategies to help them cope better with the current psychological distress. Some suggestions could be for example to enhance online medical counselling (telemedicine) in order to minimize patients’ exposure to COVID-19; to reorganise internal spaces and adopt protective measures also for caregivers to allow them to have access to the visit with the patients in order to gain the necessary information about the patients’ care; to spend time with people who have a lower education level in order to better explain the consequences of the pandemic and the behaviours to adopt to avoid contagion; and to reassure patients and caregivers that the priority of oncologists is cancer care, which is their mission [19–22].

This study also has limitations. First of all, some selection bias exists due to the voluntary nature of participation. Moreover, even if the number of enrolled subjects is significant for a monocentric study, we have to consider that a number of data has been lost because of the inability of some patients to answer questionnaires (due to performance status, physical or cultural limitations) or the refusal to join the survey both of patients and caregivers. Finally, there is a percentage of particularly apprehensive patients who have postponed visits/therapies and caregivers who prefer not to access in the day hospital for fear of contagion: in these cases, submit the questionnaire was not possible.

To take care of a cancer patient does not only mean to administer therapy but to take care of a whole person, without disregarding the family environment and psychological well-being. Patient-centred care remains the best approach for a successful outcome, even more so during this devastating global pandemic.

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**Table 5** (continued)

| Answers categorized as No, Enough, Yes, I don’t know | Patients | N=625 | Caregivers | N=254 | o-value | Patients | N=625 | Caregivers | N=254 | o-value |
|---|---|---|---|---|---|---|---|---|---|---|
| Enough | 60 (9.6) | 22 (8.7) | 123 (26.8) | 61 (37.9) |
| Yes | 63 (10.1) | 39 (15.4) | |
| I don’t know | 164 (26.3) | 93 (36.6) | |
| Missing | 2 | 0 | |
| Attention of doctors on COVID-19 | <0.001 | 0.300 |
| No | 357 (57.1) | 109 (43.1) | 357 (75.0) | 109 (70.8) |
| Enough | 45 (7.2) | 19 (7.5) | 119 (25.0) | 45 (29.2) |
| Yes | 74 (11.8) | 26 (10.3) | |
| I don’t know | 149 (23.8) | 99 (39.1) | |
| Missing | 0 | 1 | |
| Balance of restrictions and the reduction of the risk of contagion | 0.003* | 0.114 |
| No | 91 (14.6) | 22 (8.7) | 91 (20.3) | 22 (14.5) |
| Enough | 60 (9.6) | 21 (8.3) | 358 (79.7) | 130 (85.5) |
| Yes | 298 (47.7) | 109 (43.1) | |
| I don’t know | 176 (28.2) | 101 (39.9) | |
| Missing | 0 | 1 | |
All authors contributed to manuscript revision and have read and approved the submitted version.

Availability of data and material All data are available in the manuscript and in the supplementary files.

Code availability Not applicable.

Declarations

Ethics approval Ethical approval was gained from the internal Ethical Committee of the Luigi Sacco Hospital in Milan (Prot. nr. 34675/2020). Participants gave informed consent before filling the questionnaires. The information sheet included details on data anonymity and procedures for stopping participation.

Consent to participate All participants signed informed consent before filling the questionnaires.

Consent for publication Not applicable.

Competing interests Dr. N. La Verde reports: grants from EISAI, speaker bureau, travel expenses for conference from ROCHE, GENITILI, advisory role from NOVARTIS and CELGENE, advisor role, travel expenses for conference from PFIZER, advisory board from MSD. Dr D. Dalu reports: speaker bureau, travel expenses for conference from ROCHE, GENITILI. The other authors declare no competing interest.

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