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 (pts) and their caregivers (CGs), 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 the “players” 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 625 pts and 254 CGs were enrolled. Female were prevalent and pts were generally older than CGs. 40% pts and 25.6% CGs thought they were at a greater risk of contagion because lived together with a cancer pts or accessed the hospital. Both pts (86.3%) and CGs (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 CGs had no impact on the emotional status of pts (64.4%), but generated in CGs greater anxiety (58.8%) and fear (19.8%) of not properly managing pts at home . The majority of pts (54%) and CGs (39.4%) thought the pandemic doesn’t influence treatment outcomes. The relationship with HCPs was not negatively impacted for majority of pts and CGs.

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

1: 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]. 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 (pts).

An important goal for the Oncologist is to guarantee the *continuum of care* for cancer pts, even during a period of sanitary crisis, despite the potential risk of COVID-19 infection. Delaying treatment of metastatic cancer pts 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 pts. [3–7]

First of all, they recommended making a correct patient selection, categorising them into high, medium, or low priority, in order to minimise hospital access for those pts 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. The implementation of these procedures led to the unavoidable consequence that patients accessed the hospital without caregivers (CGs), 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 pts and their CGs.

Several surveys on pts' insights are ongoing but to date no study has been published regarding CGs' perceptions, and nobody has analysed their opinion on these topics to see if they are in agreement or not.

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

2: 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 CGs. Data collection was performed from 5th May to 5th June 2020. We devised two different multiple-choice questionnaires (15 questions for pts and 17 for CGs) 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", "Enough", "No" and "I don't know".

2.1: 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 pts' questionnaires and 10% in CGs' questionnaires, the impact of the demographic characteristics on the answer "I don't know" was investigated. Differences in the answers to questions in both pts and CGs questionnaires were investigated by chi-squared test. Details on the matching of questions in the two questionnaires are provided in Table 1.

Table 1
Matching of patients' and caregivers' questionnaires

	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?

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).

3: Results

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

About half of the pts (330, 52.8%) reached the hospital with their own CGs, 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 CGs' questionnaires are reported in table 3 and 4, respectively.

	Patients N=625	Caregivers N=254	P-value
Age			**<0.001***
18-40 years	26 (4.2)	13 (5.1)	
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)	

Table 2. Demographic characteristics of patients and caregivers.

	Patients N=625
Do you think you are at greater risk of contagion than the healthy population?	
No	226 (36.2)
Enough	76 (12.2)
Yes	174 (27.9)
I don't know	148 (23.7)
Missing	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?	
No	47 (7.5)
Enough	54 (8.7)
Yes	484 (77.6)
I don't know	39 (6.3)
Missing	1
Do you believe that the application of such procedures involves an excessive expenditure of time?	
No	489 (78.2)
Enough	32 (5.1)
Yes	48 (7.7)
I don't know	56 (9.0)
Do you think that your caregiver/cohabiting people are more exposed to COVID-19 infection in relation to your hospital access?	
No	349 (55.9)
Enough	64 (10.3)
Yes	53 (8.5)
I don't know	158 (25.3)
Missing	1
Do you believe that the application of safety procedures has changed the relationship with health care professionals?	
No	457 (73.1)

	Patients N=625
Enough	46 (7.4)
Yes	71 (11.4)
I don't know	51 (8.2)
Do you think that the application of safety procedures has changed the way you deal emotionally with the path of care?	
No	401 (64.4)
Enough	20 (3.2)
Yes	175 (28.1)
I don't know	27 (4.3)
Missing	2
If you answered yes to the previous question, how?	
Increased anxiety	86 (53.4)
Fear of the disease	41 (25.5)
Sense of solitude	15 (9.3)
Fear of not remembering what the doctor said during the visit	17 (10.6)
Other	2 (1.2)
Missing	14
Do you think the pandemic could have a negative effect on your treatment?	
No	336 (53.9)
Enough	60 (9.6)
Yes	63 (10.1)
I don't know	164 (26.3)
Missing	2
Do you think that currently the attention of doctors is more focused on COVID-19 than on cancer treatment?	
No	357 (57.1)
Enough	45 (7.2)
Yes	74 (11.8)

	Patients N=625
I don't know	149 (23.8)
Overall, do you believe that the negative aspects of the restrictions imposed are balanced by the reduction of the risk of contagion?	
No	91 (14.6)
Enough	60 (9.6)
Yes	298 (47.7)
I don't know	176 (28.2)

Table 3. Patients' questionnaire.

	Caregivers N=254
Do you think that accompanying the patient to the hospital entails a greater risk of contagion for you than the healthy population?	
No	147 (57.9)
Enough	35 (13.8)
Yes	30 (11.8)
I don't know	42 (16.5)
Do you think that cohabiting with the patient entails a greater risk of contagion for you than the healthy population?	
No	186 (73.2)
Enough	12 (4.7)
Yes	20 (7.9)
I don't know	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?	
No	27 (10.6)
Enough	18 (7.1)
Yes	199 (78.3)
I don't know	10 (3.9)
Do you believe that the application of these procedures involves an excessive expenditure of time?	
No	225 (88.6)
Enough	9 (3.5)
Yes	12 (4.7)
I don't know	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?	
No	78 (30.7)
Enough	39 (15.4)
Yes	116 (45.7)
I don't know	21 (8.3)

	Caregivers N=254
Do you feel that not sharing the wait and not attending the visit has a negative impact on your emotional state?	
No	81 (32.3)
Enough	30 (12.0)
Yes	128 (51.0)
I don't know	12 (4.8)
Missing	3
If you answered yes to the previous question, how?	
Increased anxiety	76 (76.0)
Fear of the disease	11 (11.0)
Sense of solitude	11 (11.0)
Other	2 (2.0)
Missing	28
In this complex situation, do you think you can still interface with doctors properly?	
No	9 (3.6)
Enough	30 (12.0)
Yes	137 (54.6)
I don't know	75 (29.9)
Missing	3
Do you believe that the pandemic can have a negative effect on the patient’s treatment path?	
No	100 (39.4)
Enough	22 (8.7)
Yes	39 (15.4)
I don't know	93 (36.6)
Do you think that currently the attention of doctors is more focused on COVID-19 than on cancer treatment?	
No	109 (43.1)
Enough	19 (7.5)

	Caregivers N=254
Yes	26 (10.3)
I don't know	99 (39.1)
Missing	1
Overall, do you believe that the negative aspects of the restrictions imposed are balanced by the reduction of the risk of contagion?	
No	22 (8.7)
Enough	21 (8.3)
Yes	109 (43.1)
I don't know	101 (39.9)
Missing	1

Table 4. Caregivers' questionnaire.

3.1: Comparison between pts and CGs

Table 5 reports the comparison between pts and CGs answers (see Table 1 for details on matching questions).

Table 5
Comparison between patients' and caregivers' answers to questionnaire.

	Answers categorized as No, Enough, Yes, I don't know			**Answers categorized as No, Enough/Yes**		
	Patients N = 625	**Caregivers N = 254**	**P-value**	**Patients N = 625**	**Caregivers N = 254**	**P-value**
Triage utility			0.227			0.163
No	47 (7.5)	27 (10.6)		47 (8.0)	27 (11.1)	
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)	

	Answers categorized as No, Enough, Yes, I don't know			Answers categorized as No, Enough/Yes		
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)	

	Answers categorized as No, Enough, Yes, I don't know			Answers categorized as No, Enough/Yes		
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)	
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)				

	Answers categorized as No, Enough, Yes, I don't know		Answers categorized as No, Enough/Yes
I don't know	176 (28.2)	101 (39.9)	
Missing	0	1	

About half of the cancer pts felt more vulnerable to COVID-19 compared to the general population (question P1: 250, 52.5%). Pts 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 pts and CGs 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 pts and CGs believed that the containment measures did not involve an excessive expenditure of time, with a major prevalence of positive judgments in CGs compared to pts (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 CGs was reported more by CGs (158, 66.1%) than by pts (195, 32.7%) (questions P6 and C6, p < 0.001). Specifically, 77 (58.8%) CGs reported greater anxiety and 26 (19.8%) had a fear of not managing the patients properly at home (question C7). Moreover, CGs thought that the pandemic caused a negative impact on the emotional state of the pts more than what the pts themselves stated (questions P6 and C5: 195 [32.7%] vs 155 [66.5%], p < 0.001).

The majority of pts (336, 73.2%) and CGs (100, 62.1%) thought that the pandemic did not influence treatment outcomes, with a higher prevalence of positive answers in pts (questions P8 and C9, p = 0.008). The relationship with HCPs was not negatively affected for both pts (question P5: 457, 79.6%) and CGs (question C8:167, 94.9%), but about a quarter of pts and CGs 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).

3.2: Impact of pts' characteristics on answers

The results of logistic regression analyses on pts' questionnaires are summarized in Tables 6a,b,c (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, 95%CI 1.01–3.15, p = 0.047, online table S1). Compared to pts 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, these pts 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, pts with a primary school degree had more difficulty in answering several questions (online table S1).

Moreover, pts who accessed the hospital for a visit were less likely to think they had a higher risk of contagion compared to pts 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).

3.3: Impact of CGs’ characteristics on answers

The results of logistic regression analyses on CGs’ questionnaires are summarized in Tables 7a,b,c (supplementary file).

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

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

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

4: Discussion

This is the first Italian survey aimed to investigate the emotional approach to the care of cancer outpatients and their CGs, 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 pts and their families in this strenuous period of crisis.

We enrolled a large number of pts in only one month and these data reflect the attention of our cancer centre to the *continuum of care* and the participants' involvement in this topic. Enrolled pts were mostly female, aged > 60 years old and with a low education level, while CGs were usually younger, female and with a higher education level. About half of the pts reached the hospital with their own CGs, however the number of questionnaires filled in by CGs was lower (77% of CGs who accompanied pts to the hospital), probably because a part of them delivered pts 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 pts felt more vulnerable to the SARS-CoV-2 infection compared to healthy people; this perception is coherent with the news reported by mass-media, drawn from the scientific literature. The first data about COVID-19 in cancer pts were published by Liang and colleagues in March 2020: in their cohort of 1590 COVID-19 positive Chinese pts, 18 had a history of cancer. The authors found that cancer pts had a higher risk of contracting COVID-19 because of their systemic immunosuppression and had a poorer prognosis than those without cancer [8]. Zang et al retrospectively studied the clinical features of 28 COVID-19 positive cancer pts from three hospitals in Wuhan: they observed that 15 (53.6%) pts developed severe events with a mortality rate of 28.6%, confirming that cancer pts presented a poor outcome with a high occurrence of clinically severe events and a high mortality [9]. The TERAVOLT study also confirmed the high mortality rate (33%) and low admission rate to intensive care units in pts with thoracic cancer [10].

Differently from pts, CGs 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 pts and needed to access the hospital for the pts' treatment.

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 pts and CGs 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 [11–12].

Regardless of the perceived risk of contagion, study participants appreciated the application of general risk prevention and mitigation measures, as reported in literature [13].

CGs were particularly worried about the psychological well-being of their relatives: they believed that the pts' 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 CGs to the hospital was limited, pts were alone during the visit and could not share information with the GCs. This situation resulted in the concern of CGs of not managing the patients properly at home. The most interesting finding of this study was that pts 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 [14].

In a subgroup of survey participants, the fear of a “distraction effect” emerged. In fact, in our study we found that pts with a higher education level or pts who accessed the oncology department only occasionally (for example for a visit every six months) were concerned because they thought that COVID-19 captured all the HCP’s attention, overshadowing cancer treatment and prevention [15–18].

All the information acquired through this survey allowed us to better understand the emotional changes which occurred in cancer pts and their CGs 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 minimise pts’ exposure to COVID-19; to reorganise internal spaces and adopt protective measures also for CGs to allow them to have access to the visit with the pts in order to gain the necessary information about the pts' 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; to reassure pts and CGs 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 pts to answer questionnaires (due to performance status, physical or cultural limitations) or the refusal to join the survey both of pts and CGs. Finally, there is a percentage of particularly apprehensive pts who have postponed visits/therapies and CGs 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 pts does not only mean to administer therapy but to take care of a whole person, without disregarding the family environment and psychological well-being. A patient-centred care remains the best approach for a successful outcome, even more so during this devastating global pandemic.

Declarations

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All the authors have no conflicts of interest to declare that are relevant to the content of this article.

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AUTHORS' CONTRIBUTIONS:

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All authors contributed to manuscript revision, read and approved the submitted version.

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

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