

Caregiving during the COVID-19 pandemic: The new challenge in oncology assistance?

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Abstract. *Background and aim:* The coronavirus disease 2019 (COVID-19) pandemic led to significant restrictions regarding cancer patients, who are considered vulnerable. The aim of our study is to evaluate COVID-19's impact on oncological caregiving. *Methods:* Between February and April 2021, we submitted a survey to caregivers of patients who were undergoing active treatment regarding their perception of patient safety and continuity of care in 6 Oncology Departments (OD) in the Marche region. We also conducted Zarit Burden Interview (ZBI) to evaluate the burden placed on caregivers. *Results:* 112 caregivers responded to our survey and the majority of which declared to have increased assistance time. Furthermore, caregivers over 45 years of age did not experience statistically significant worse economic effects ($p=0.04$). All caregivers asserted that OD complied with safety recommendations to limit virus spread. Although 86 (76.8%) confirmed that hospital accesses had been restricted, only 10 (8.9%) perceived these precautions to be too restrictive. Approximately all respondents declared they had effective communication with healthcare providers and more than half perceived that quality of care had not been affected by the pandemic. According to ZBI scores, 46 caregivers (41.1%) had a mild to moderate burden level. *Conclusions:* Our survey underlined the negative effect of COVID-19 on cancer patients' caregivers, although cancer care was not perceived to have worsened owing to the pandemic, contrary to previous literature. (www.actabiomedica.it)

Key words: COVID-19, caregivers, cancer patients, Zarit Burden Interview, survey

Introduction

The coronavirus disease 2019 (COVID-19) has spread globally since February 2020, becoming a pandemic and has required an immediate and extensive re-organization of medical assistance (1). Advancing age, male gender and comorbidities, such as cardiovascular diseases, diabetes and cancer, seem to increase

COVID-19 infection risk and related mortality rate (2). Cancer patients have been reported to be more vulnerable owing to the frailty of their immune system caused by treatment, cancer and comorbidities (3,4). Oncology Departments (OD) extensively reorganized assistance in order to reduce hospital accesses, to manage therapy-induced adverse events and to guarantee the continuity of care, further aided by the use of

digitalization (5). Caregivers usually provide physical and psychological assistance to cancer patients, playing a key role in their care and treatment compliance (6). Moreover, caregivers' support to cancer patients improves outcomes through better management and adherence to active oncological treatments, especially if administered orally (7). During the COVID-19 pandemic, caregiver hospital admission has been prohibited in favour of social distancing to strategically protect cancer patients (8). This difficult scenario may cause cancer patients both physical and emotional distress as well as representing a risk factor for caregivers and impacting on the burden placed on them (9). Therefore, telemedicine (telephonic interviews, video conference) was improved as a communication tool for cancer patients' care between health-care professionals and caregivers (10,11). In this setting, the aim of our study was to investigate and quantify the impact of the COVID-19 pandemic on oncology caregiving.

Patient and methods

Study design and setting

We conducted a cross-sectional study about informal caregivers of cancer patients undergoing active treatments in six OD in the Marche region: Ancona, Macerata, Urbino, San Severino Marche, Fermo and Jesi during the COVID-19 epidemic in Italy, from February 9 to April 2, 2021.

Caregivers' recruitment

An anonymous paper questionnaire written in Italian language was submitted to all caregivers, when they accompanied their relatives at OD waiting room. Caregivers, provided with information about the survey, voluntarily filled in the questionnaire, after they had given their consent to participate. We excluded incomplete and/or not decipherable surveys from the analysis. This study was conducted in accordance with principles embodied in the Declaration of Helsinki. According to Italian law (resolution March 1, 2012, Gazzetta Ufficiale n.72 of March 26, 2012), ethics approval was not required for the current study.

Variables analysed

The survey consisted of 26 multiple choice questions, including 5 demographic questions, about age, gender, relationship to cancer patients, Oncological Department and type of cancer, 4 regarding cancer patients' care and 17 about the impact of the COVID-19 pandemic on cancer patients' care. In particular, we asked the time in hours dedicated to cancer patients and if this time has been changed due to pandemic, the necessity or not to accompany patients at any access to Oncological Departments, the impact on caregivers' daily activities and the impact on financial circumstances made by cancer patients' assistance and if it has been worsened due to pandemic. We then investigated the experience of COVID-19 infection in family, the caregivers' perception about the healthcare professional's adherence to safety measures limiting the spread of the pandemic (daily temperature measurement, wearing individual safety devices, limited access to hospital departments) and the caregivers' perception about cancer treatment and cancer quality care during pandemic. The majority of the questions had a binary answer (yes or no) or a multiple answer (no, little, enough, highly). The questions have been freely conceived based on validated burden scale such as Caregiver Burden Inventory (CBI), in order to evidence the COVID-19 impact on caregiving of cancer patients. The complete questionnaire of our survey is reported in Supplementary Materials as Figure S1. In addition to the above survey, we administered the "Caregiver Burden Self-assessment questionnaire", known as the Zarit Burden Interview (ZBI), to assess the burden of care on informal caregivers (12). The 22 questions investigate major areas such as caregiver's health, psychological status, economic and social aspects of assistance, together with the patient-caregiver relationship (12). The magnitude of the scale reflects two important aspects of caregiving: how stressful the experience is (personal strain), and stress induced by role conflict or overload (role strain) (13). Responses to each item were scored on a five-point Likert scale, ranging from "never" associated to 0 to "nearly always" associated to 4. Total scores of the 22 items ranged from 0 to 88. A higher score was associated with a higher informal caregiver burden and consequent distress. Scores ranging from

21 to 40 indicate a mild to moderate caregiver burden, while scores from 41 to 60 demonstrate a moderate to severe burden and scores from 61 to 88 indicate a severe caregiver burden.

Statistical analysis

Demographic characteristics and answers were reported using relative frequency distribution. The association between age, considering 45 years old the cut-off point according to the median age of the sample, gender and answers was estimated by Chi square analysis. A level of 0.05 was chosen to assess the statistical significance. The ZBI, used as a burden assessment tool, has been used and validated in many previous studies, with a Cronbach's α of 0.92 in the original scale (12,13). At the same time, we used a Cronbach's α of 0.92 in our analysis.

Ethical consideration

This study was conducted in accordance with principles embodied in the Declaration of Helsinki. According to Italian law (resolution March 1, 2012, Gazzetta Ufficiale n.72 of March 26, 2012), ethics approval was not required for the current study.

Results

Demographic questions and the impact of the COVID-19 pandemic on oncology care

A total of 112 informal caregivers were enrolled in this study. Most of the participants were female (57.1%) and nearly a half (46.4%) were of age 46 to 65 years old. With regards to relationships with cancer patients, 29.5% were the patient's husband or wife and gastro-intestinal was the most frequent type of tumour (40.2%). All social and demographic characteristics of caregivers are summarized in Table 1.

In terms of daily time spent with the patient, 40.2% declared that they dedicated more than 6 hours/day to patient care as showed in Figure 1; in addition, only forty-nine caregivers (43.7%) confirmed that they spent more time supporting their cancer relatives during the COVID-19 pandemic.

Table 1. Social and demographic characteristics of caregivers.

Caregiver Characteristics	Survey Participants N= 112 (%)
Age-Years	
<35	8 (7.2%)
36-45	24 (21.4%)
46-65	52 (46.4%)
>65	28 (25.0%)
Gender	
Female	64 (57.1%)
Male	48 (42.9%)
Relationship with Cancer Patient	
Husband/wife	33 (29.5%)
Brother/sister	4 (3.6%)
Father/mother	25 (22.3%)
Other	50 (44.6%)
Patient's Cancer Diagnosis	
Gastro-intestinal cancer	45 (40.2%)
Breast cancer	29 (25.9%)
Lung cancer	13 (11.6%)
Uro-gynaecological cancer	16 (14.3%)
Central nervous system cancer	4 (3.6%)
Rare cancer	5 (4.4%)

Ninety-four (83.9%) caregivers stated the need to accompany cancer patients to each hospital admission and fifty-seven (50.9%) respondents reported that providing assistance to cancer patients has changed their usual daily activities. 73.2% of the caregivers declared little or no impact on their financial circumstances, conversely twenty participants (17.9%) declared worsening economic difficulties during the pandemic. Thirty-six (32.1%) reported a COVID-19 infection among their family members, while 76 (67.9%) did not report any cases. Almost all caregivers (99.1%) affirmed that the Oncology Departments had complied with the safety recommendations to limit the spread of the virus and, similarly, 98.2% declared health care professionals had been equipped with the recommended safety devices. Eighty-six caregivers (76.8%) confirmed that hospital access for caregivers had been restricted due to the pandemic and only 10 participants (8.9%) perceived these precautions to

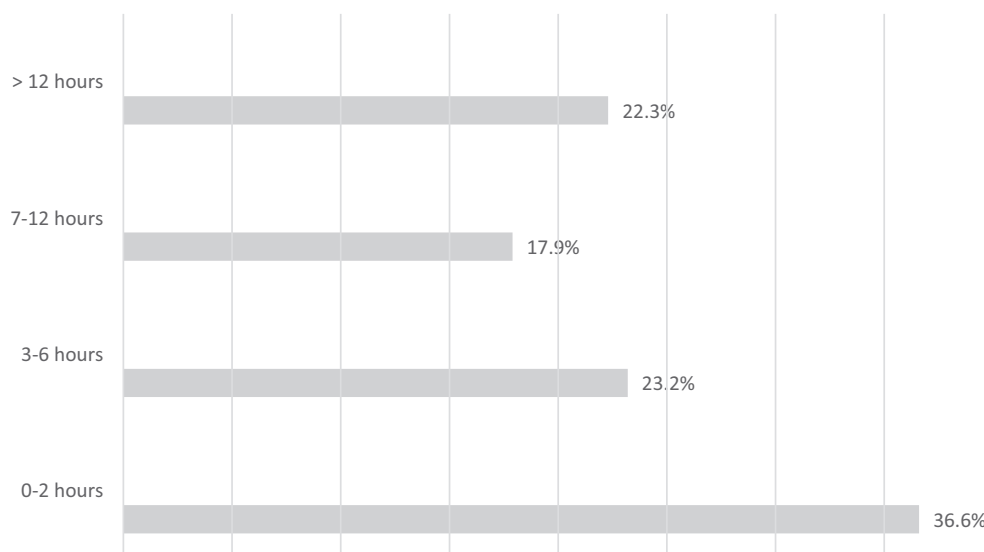


Figure 1. Distribution in hours of caregivers' time dedicated to patient care.

be too restrictive, while 87.5% of all respondents considered them effective. Approximately all respondents (106) declared that, if needed, they had the chance to speak to healthcare providers and 101 participants (90.2%) confirmed that they could access the OD, if needed. In particular, ninety-four (83.9%) caregivers declared they had to fill in a COVID-19 questionnaire and almost all of them (90.2%) confirmed they had to measure their temperature before each hospital visit. Almost all caregivers (97.3%) confirmed that safety distances were respected in waiting rooms and fifty-six participants (50.0%) did not perceive an increased risk of infection when accessing Oncology Departments. Despite restricted access to caregivers, 66.1% of them did not perceive the family member to have been abandoned during hospitalization. However, forty-nine (43.7%) expressed anxiety due to the impossibility of assisting patients and almost half (49.1%) perceived the quality of oncological care to have been affected by the pandemic. The distribution of survey's answers is summarized in Tables 2 and 3.

Chi square analysis did not reveal any significant association between time dedicated to the care of patients and their gender ($p=0.46$) or age ($p=0.96$),

including time to accompany relatives to the hospital ($p=0.35$ and $p=0.81$, respectively); moreover, no significant association was found between an increase in the time spent by relatives supporting cancer patients and gender ($p=0.70$) or age ($p=0.21$), similarly according to modification of daily activities ($p=0.39$ and $p=0.82$, respectively). Regarding the economic impact of the pandemic, there was no statistically significant association between age ($p=0.36$) and gender ($p=0.82$). Similarly, caregivers over 45 years of age did not experience statistically significant worse economic effects ($p=0.04$). There was no association between COVID-19 cases among family members and age ($p=0.10$) or gender ($p=0.86$), similarly with use of safety equipment ($p=0.37$ for age and $p=0.10$ for gender) and respect of safety recommendations ($p=0.53$ for age and $p=0.25$ for gender). Hospital access restriction was not significantly correlated to age ($p=0.83$) or gender ($p=0.70$); moreover, no significant association was found between perception of restrictive precautions and age ($p=0.12$) and gender ($p=0.39$), similarly with perception of effective precautions used ($p=0.70$ and $p=0.54$, respectively). Furthermore, no statistically significant association was found between age or

Table 2. Distribution of caregivers' answers at binary (YES/NO) questions included in the survey.

Question	Answer	
	YES n (%)	NO n (%)
Need to accompany cancer patient to hospital	94 (83.9%)	18 (16.1%)
Increase of care time during pandemic	49 (43.7%)	63 (56.3%)
COVID-19 family cases	76 (67.9%)	36 (32.1%)
Use of safety equipment by healthcare professionals	110 (98.2%)	2 (1.8%)
Respect of safety recommendations	111 (99.1%)	1 (0.9%)
Hospital access restriction	86 (76.8%)	26 (23.2%)
Perception of restrictive precautions	10 (8.9%)	102 (91.1%)
Respect of safety distance in waiting rooms	109 (97.3%)	3 (2.7%)
Possibility of hospital access	101 (90.2%)	11 (9.8%)
Possibility to speak to healthcare providers	106 (94.6%)	6 (5.4%)
Request of COVID-19 questionnaire before access	94 (83.9%)	18 (16.1%)
Temperature measurement before access	101 (90.2%)	11 (9.8%)

Table 3. Distribution of caregivers' answers at multiple choice questions included in the survey.

Question	Answer			
	No	Little	Enough	Highly
Modification of daily activities	16 (14.3%)	39 (34.8%)	47 (42.0%)	10 (8.9%)
Economic impact	56 (50.0%)	26 (23.2%)	26 (23.2%)	4 (3.6%)
Economic situation worsening due to pandemic	62 (55.4%)	30 (26.7%)	16 (14.3%)	4 (3.6%)
Perception of effective precautions	5 (4.5%)	9 (8.0%)	64 (57.1%)	34 (30.4%)
Perception of infectious risk	56 (50.0%)	37 (33.0%)	18 (16.1%)	1 (0.9%)
Anxiety perception	35 (31.3%)	28 (25.0%)	38 (33.9%)	11 (9.8%)
Abandonment perception	74 (66.1%)	23 (20.5%)	10 (8.9%)	5 (4.5%)
Modification of quality of oncologic care	57 (50.9%)	14 (12.5%)	36 (32.1%)	5 (4.5%)

gender with measures to limit virus spreading, for example, respect of safety distances ($p=0.85$ and $p=0.74$, respectively) and perception of infectious risk ($p=0.77$ for age and $p=0.41$ for gender). Regarding hospital accesses, no correlation was shown between gender ($p=0.41$) and age ($p=0.55$); similarly, according to the possibility to speak to healthcare providers ($p=0.72$ for gender and $p=0.79$ for age). No significant correlation was found between neither anxiety nor abandonment feelings with gender ($p=0.33$ and $p=0.29$, respectively) and age ($p=0.21$ and $p=0.69$, respectively). Finally,

quality of oncologic care was not statistically significant correlated to age ($p=0.08$) or gender ($p=0.65$). All chi square results are summarized in Table 4.

Zarit Burden Interview Results

Based on the ZBI Scale scores, 41.1% of caregivers (46) had a mild to moderate burden, 13.4% (15) had a moderate to severe burden, and 11.6% (13) of the respondents had a severe burden. The mean caregiver burden was 32.5 ± 14.9 (ranging from 0 to 65).

Table 4. Chi square analysis between age, gender and caregivers' answers to survey.

Questions	Gender (p value)	Age (p value)
Time dedicated to cancer patient's care	0.46	0.96
Time to accompany cancer patient to hospital	0.35	0.81
Increase of care time during pandemic	0.70	0.21
Modification of daily activities	0.39	0.82
Economic impact	0.82	0.36
Economic situation worsening	0.73	0.04
COVID19 family cases	0.86	0.10
Use of safety equipment by healthcare professionals	0.10	0.37
Respect of safety recommendations	0.25	0.53
Hospital access restriction	0.70	0.83
Perception of restrictive precautions	0.39	0.12
Perception of effective precautions	0.54	0.70
Respect of safety distance in waiting rooms	0.74	0.85
Perception of infectious risk	0.41	0.77
Hospital access	0.41	0.55
Possibility to speak to healthcare providers	0.72	0.79
Anxiety perception	0.33	0.21
Abandonment perception	0.29	0.69
Quality of oncologic care perception	0.65	0.08

Table 5. "Caregiver Burden Self-assessment questionnaire", the Zarit Burden Interview.

Scores	Meaning	Survey Participants No. (%)
< 20	No burden	38 (33.9%)
21-40	Mild to moderate burden	46 (41.1%)
41-60	Moderate to severe	15 (13.4%)
61-88	Severe burden	13 (11.6%)

Results are listed in Table 5. Chi square analysis did not evidence a significant association between ZBI scores and gender ($p=0.20$) or age ($p=0.25$).

Conclusions

Caregivers represent a cornerstone in the provision of physical and psychological care for cancer patients. Our cross-sectional study focuses on the impact

of the COVID-19 pandemic on caregiving, presenting a picture of the assistance to cancer patients compared with pre-pandemic habits. In particular, the survey shows that caregivers are mostly middle-aged women, as already seen in previous trials that demonstrated women are particularly empathetic and dedicated to assisting others and to providing more intensive and complex care (14). Caregivers spend a lot of time assisting patients, and this time has increased during the pandemic probably because of the increase of practical (buying food, finding drugs) and psychological needs (feelings of anxiety, loneliness, fear) caused by social restrictions during periods of lockdown. Almost all caregivers confirmed OD's adherence to the contagion containment measures and resulting feelings of safety. Although, 8.9% of caregivers defined hospital rules as too restrictive and experienced feelings of isolation and distress and at least 33.9% of caregivers were forced to stay outside the OD during patients' treatments. It is likely that these emotions were perceived and shared by patients. The ZBI Scale shows that 41.1% of the

participants had experienced a mild to moderate level of burden, meaning that they have already faced the caregiving role's difficulties with intermittent moments of stress, remaining below their threshold limit. Akkus et al. showed a similar caregiver burden level (mean ZBI score: 21.06 ± 14.64), stressing the role of spirituality to reduce caregivers' anxiety (15). Our survey showed a negative impact of the COVID-19 pandemic on cancer patients' caregivers, with similar data being reported in literature worldwide. A recent study conducted in Singapore among 408 caregivers showed that 72.8% of them reported a high level of fear caused by COVID-19, in particular about patients dying alone in hospital (16). Also, Rajovic et al., when analysing 798 informal caregivers in Serbia, evidenced that 71.9% experienced a burden and 27.1% had symptoms of depression, stressing the caregivers' need for psychosocial support in a pandemic setting (17). Fisher et al. underlined pandemic effects on caregivers, such as the increase of distress and isolation, the reduction of in-person care opportunities and the change in family communication (18). This is consistent with our results where almost all caregivers (94.6%) reported effective communication with medical staff, although in different ways than in the pre-pandemic period, such as via phone and smartphone-enabled telehealth as suggested by Wu et al. (19). Interestingly, our results showed that caregivers over 45 years of age did not experience an increase in economic difficulties in assisting cancer patients with statistical significance ($p=0.04$). This could be explained by a more probable economic stability after the age of 45 years old and by the fact that retired subjects fall into this category. Amaniera et al. confirmed the financial stress and food insecurity as determining factors of mental health impact, reported by 70% of caregivers interviewed, due to the COVID-19 pandemic (9). Caregiving is important in every phase of the oncologic disease and the greatest commitment is during the end of life phase, when physical presence is essential for both patient and caregiver (20), and certainly the pandemic scenario has had a profound impact on this milestone of care since face to face contact was hindered (21). Similarly, the COVID-19 pandemic has affected the role of caregivers in every chronic disease, such as neurological dementia and neuro-degenerative illnesses. A survey

conducted on 204 caregivers in Greece reported an increased psychological and physical burden during this period, due to the limitation of access to support sources (22). Moreover, dementia caregivers with high resilience showed a more significant increase in anxiety levels during periods of lockdown than caregivers with low resilience (23). Giusiano et al. analysing 59 amyotrophic lateral sclerosis caregivers, confirmed that the caregiver burden significantly increased, primarily because of restrictions imposed by the pandemic which limited help from family members, reflecting the central role of social support in the management of this neuro-degenerative disease (24). Finally, in our survey, more than half of caregivers surveyed (51.9%) perceived that the quality of oncologic care had not been affected by the pandemic. This evidence disagrees with previous studies, which underlined delays in cancer screening, treatment and care during the COVID-19 pandemic according to the perception of patients and caregivers (25). The relatively small number of caregivers interviewed represents the biggest limit of our study. Furthermore, we did not include in the survey the question regarding stage of disease because the questionnaire was anonymous and it was submitted to informal caregivers, who may not be aware of this information. Despite that, our positive results could be important evidence of OD's adaptability and/or caregivers' resilience, during a worldwide emergency such as COVID-19 pandemic. In conclusion, our survey focuses on and gives information about the impact of COVID-19 on cancer patients' caregivers, whose role has remained crucial and become even more demanding during the pandemic. We are optimistic that our results will be useful to better understand the needs of caregivers and to give them the right support in order to reduce the burden placed upon them.

Ethic Committee: This study was conducted in accordance with principles embodied in the Declaration of Helsinki. According to Italian law (resolution March 1, 2012, *Gazzetta Ufficiale* n.72 of March 26, 2012), ethics approval was not required for the current study.

Statement of Conflicts of Interest: Rossana Berardi has served as a consultant/advisory board member for Astrazeneca, Boehringer Ingelheim, Novartis, MSD, Otsuka Pharmaceutical, Eli Lilly and

Roche. The other authors declare that they have no commercial associations that might pose a conflict of interest in connection with the submitted article.

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Appendix – Supplementary files

Figure S1. The complete questionnaire of our survey

- 1) Indicate your age range:
 - <25 years;
 - 26-35 years;
 - 36-45 years;
 - 46-65 years;
 - >65 years.
- 2) Indicate your gender:
 - Male;
 - female.
- 3) Indicate your relationship with cancer patient:
 - husband/wife;
 - brother/sister;
 - father/mother;
 - other.
- 4) Indicate Oncological Department where your relative is being treated:
 - Ancona;
 - Macerata;
 - Urbino;
 - San Severino Marche;
 - Fermo;
 - Jesi.

- 5) Indicate patient's cancer diagnosis:
 - Gastro-intestinal cancer;
 - Breast cancer;
 - Lung cancer;
 - Uro-gynaecological cancer;
 - Central nervous system cancer;
 - Rare cancer.
- 6) How much daily time do you dedicate to patient's care?
 - 0-2 hours;
 - 3-6 hours;
 - 7-12 hours;
 - >12 hours.
- 7) Did the time spent caring for your family member with cancer increase during the COVID19 pandemic?
 - No;
 - Yes.
- 8) Did your family member with cancer need to be accompanied to any access to the Day Hospital/ Oncology Departments?
 - No;
 - Yes.
- 9) Do the care of your family member with cancer condition the course of your daily activities?
 - No;
 - Little;
 - Enough;
 - Highly.
- 10) Did the assistance of your family member have impact on your financial circumstances?
 - No;
 - Little;
 - Enough;
 - Highly.
- 11) Has this situation worsened following the COVID19 pandemic?
 - No;
 - Little;
 - Enough;
 - Highly.
- 12) Have you or one of your family members ever been diagnosed with COVID19?
 - No;
 - Yes.

- 13) Since the start of the COVID19 pandemic, do you think that the cancer center where your family member is being treated has complied with the rules of security and recommendations to limit the spread of the virus?
 - No;
 - Yes.
- 14) In your opinion, did healthcare professionals have available all the personal protective equipment recommended during pandemic?
 - No;
 - Yes.
- 15) Have caregivers' access to Oncological Departments been restricted following the pandemic?
 - No;
 - Yes.
- 16) Do you think that these precautions have been too restrictive?
 - No;
 - Yes.
- 17) Do you think that these precautions have been effective to limit virus spreading?
 - No;
 - Little;
 - Enough;
 - Highly.
- 18) Did you have the chance to speak to healthcare providers, if you need?
 - No;
 - Yes.
- 19) Could you access the Oncological Departments if needed?
 - No;
 - Yes.
- 20) In this case, did you have to fill in a questionnaire about your COVID19 situation?
 - No;
 - Yes.
- 21) In this case, has your temperature been measured?
 - No;
 - Yes.
- 22) In the Oncological Departments, is there a waiting room that allows compliance with the recommended safety distances?
 - No;
 - Yes.
- 23) Do you perceive a greater risk of exposure / contagion accompanying your family member to the hospital?
 - No;
 - Little;
 - Enough;
 - Highly.

- 24) Do you think your family member with cancer felt abandoned during Oncology access, without the caregivers?
- No;
 - Little;
 - Enough;
 - Highly.
- 25) Do you feel anxious about not being able to assist your family member with cancer in hospital?
- No;
 - Little;
 - Enough;
 - Highly.
- 26) Do you think the quality of your family member's cancer care has been affected by the pandemic?
- No;
 - Little;
 - Enough;
 - Highly.