ORIGINAL ARTICLE

Health care professionals and end-of-life care during the COVID-19 pandemic

Esther Angélica Luiz Ferreira[1]* ⬤, Cristina Ortiz Sobrinho Valete[1] ⬤,
André Filipe Junqueira dos Santos[2] ⬤, Juliana Nalin de Souza Passarini[3] ⬤,
Alexandre Ernesto Silva[4] ⬤, Michelle Uchida Miwa[5] ⬤

SUMMARY

OBJECTIVE: The aim of this study was to estimate self-perception of anguish and low quality of life among health care professionals who cared for the dying patients during the COVID-19 pandemic and to determine the characteristics of health care professionals and patients and end-of-life care.

METHODS: An online survey that included health care professionals who cared for the dying patient from July 1 to October 31, 2020 was conducted. Low quality of life, anguish, characteristics of patients and health care professionals, and end-of-life care were recorded. Poisson regression was performed to assess the predictors of anguish and low quality of life.

RESULTS: A total of 102 health care professionals, including 14 males (13.7%), with a median age of 37 years, composed of 41 physicians (40.2%), 36 physiotherapists (35.3%), and 25 nurses (24.5%) were included in this study. Self-perception of anguish occurred in 69.6% and was associated with physicians and disagreement with end-of-life care offered. Low quality of life was reported in 64.7% and was associated with not having time to talk to patients' relatives. The agreement that medical care was enough reduced self-perception of low quality of life.

CONCLUSION: Self-reported anguish was more frequent in physicians and when the disagreement about end-of-life care occurred. Low quality of life was more frequent when health care professionals did not have time to talk to patients' relatives and was less frequent when health care professionals agreed that medical care was enough. Strategies should be done by health services to reduce the impact of the pandemic on health care professionals.

KEYWORDS: COVID-19. COVID-19 pandemic. Palliative care. End-of-life care. Assisted death. Grief.

INTRODUCTION

The COVID-19 pandemic represents a severe threat to public health. Aiming at reducing the infection rate, social distancing and isolation measures have been adopted. Nevertheless, they led to social and behavioral changes that considerably altered the human relationship with the environment[1].

For patients and their relatives, the coronavirus crisis has caused fear and anxiety exacerbated by the lack of information about this new disease. If the health system capacity is exhausted, these hardships may increase due to the unavailability of medical services and equipment to provide them support[2].

[1]Universidade Federal de São Carlos, Medicine Department – São Carlos (SP), Brazil.
[2]Oncological Institute of Ribeirão Preto, Oncoclínicas Group, Palliative Care Service – Riberão Preto (SP), Brazil
[3]Universidade Estadual de Campinas, Faculty of Medical Sciences, Department of Clinical Medicine – Campinas (SP), Brazil.
[4]Universidade Federal de São João del-Rei, Medical and Nursing Course – São João del Rei (MG), Brazil.
[5]Hospital de Amor de Barretos, Department of Palliative Care – Barretos (SP), Brazil.
*Corresponding author: estherferreira@ufscar.br

In these circumstances, essential principles that orient the medical support of the ill patients, such as the attention to the needs and preferences of the ill person and their families, may be compromised. Emotional, cognitive, physical, and behavioral responses following the demise are common elements of uncomplicated grief[3]. The usual grief experiences during the COVID-19 pandemic were often interrupted, and thus it is imperative to reconsider the standard approaches and find new solutions. For many hospitalized patients, for example, visits were limited or even prohibited, regardless of having received a diagnosis of COVID-19 or not. For the grieving relatives, funerals and burials were postponed or ensued at a distance, often without the presence and warmth of their loved ones[4].

Overwhelmed hospitals demanded the transfer of patients to other health care units. These experiences can be traumatic, just as passing away in a ward or other facilities dedicated to the treatment of patients with COVID-19, which may also lead to a psychological stigma. It is known that family members of those who died at a hospital or an intensive therapy unit represent a larger risk for extended grief and depression[5]. The impossibility of a "farewell" between the family and the deceased is associated with complicated grief. Studies demonstrate that severe symptoms of anticipatory grief, lower levels of social support, lack of preparation and planning for death, and guilt are risk factors for complicated grief and depression after bereavement. These factors are relevant to the COVID-19 pandemic context[6-9].

In Brazil, the pandemic stressed the health system, which already operated at its limit in normal situations, leading to the collapse of medical groups[10]. Health care professionals handled an overwhelming flow of severely ill patients, the ailment of their medical colleagues, and the moral suffering due to their inability to provide basic care that they considered humane and necessary. Along with their workload, they also had to manage a preoccupation with their own health and that of their families[11].

In light of these data, this study aimed to estimate self-perception of anguish and low quality of life among health care professionals who cared for the dying patients during the COVID-19 pandemic. Also, it intended to determine the characteristics of health care professionals and patients and end-of-life care associated with self-perception of anguish and low quality of life.

METHODS

In this online survey, we enrolled 102 health care professionals who cared for the dying patients in their last days of life, from July 1 to October 31, 2020. This article writing followed the STROBE form for the cross-sectional studies[12].

The survey form was a short version from the international form "Care of the Dying Evaluation" (iCODE) that focused on the last 2 days of life and the grief period, asked about the quality of patient care and family support[13], and included questions about COVID-19. The translation, adaptation, and use of form were approved. The protocol proposed by Kulis et al. was used[14].

Inclusion criteria: health care professionals who took care of a patient in their last 2 days of life.

Exclusion criteria: incomplete forms.

Quality of life was registered on a scale from 1–7 and defined by the World Health Organization as "the individual perception about his life position, according to cultural context and values systems in which he lives and in relation to his objectives, expectations, patterns, and concerns"[15].

Health care professional characteristics (i.e., age, sex, and professional category) and patient characteristics (e.g., age, sex, SARS-CoV-2 infection, and if he/she felt pain always or sometimes) were registered. End-of-life care offered for the last 2 days (agreement with end-of-life care offered, a shared decision regarding limited life care support, have time to talk to patients' relatives, the agreement that medical care was enough, if visits were allowed, if emotional and spiritual support was offered to patients' relatives, the place where care was offered, and if death occurred in a COVID-19 division) was investigated.

Outcome variables were self-perception of low quality of life (≤4) and anguish (yes/no) of health care professionals. The following three hierarchical blocks of variables were analyzed: health care professional characteristics (distal variables), patient characteristics (intermediate variables), and end-of-life care (proximal variables).

Statistical analysis: All statistical analyses were done using Stata software, version 13 (https://www.stata.com/). To test if the variables were normally distributed, the Kolmogorov–Smirnov test was performed. For continuous variables, data were presented as the median and interquartile range (IQR). Categorical variables were presented as number values, percentage, and 95% confidence interval (95%CI). To determine the predictors of low quality of life and anguish, a Poisson regression (robust estimation and log link function) was used to estimate crude prevalence ratios. The variables with a significance of $p<0.20$ were included in blocks in the hierarchical multivariate analysis. The multivariate hierarchical model estimated adjusted prevalence ratios. A $p<0.05$ was considered statistically significant.

This study was approved by the São Carlos Federal University Research Ethics Committee (CAAE 31896820.1.0000.5504). Informed consent was obtained from all participants.

RESULTS

The number of health care professionals included was 102; 14 of them (13.7%) were males, with a median age of 37 years (IQR 33–42). Among health care professionals, 41 (40.2%) were physicians, 25 (24.5%) were nurses, and 36 (35.3%) were physiotherapists.

Patients' median age was 60 years (IQR 40–73), and 65 (63.7%) of them were males. Patients were taken care in 14 states, allocated in the 5 Brazilian regions. São Paulo state represented 63.8%, followed by Minas Gerais (6.9%), Bahia (5.9%), and Rio de Janeiro (5.9%). Ninety-four (92.1%) patients were taken care of in a hospital, where 52 of them (55.3%) died at a COVID-19 intensive care unit, 20 (21.2%) of them died at a COVID-19 infirmary, 16 (17.0%) of them died at a general infirmary, and 7 (7.4%) of them died at a general intensive care unit.

There was a shared decision regarding the limited life support in 59 (57.9%) patients. The most frequent decision was do-not-resuscitate in 43 of them (72.9%) followed by do-not-admit at the intensive care unit in 11 cases (18.6%). The most frequent reason to limit the life support was the clinical condition in 46 patients (77.9%). Figure 1 shows the other end-of-life care.

Self-perception of anguish was referred by 71 (69.6%) health care professionals. The predictors of anguish were identified using univariate and multivariate Poisson regression analysis as shown in Table 1. Physicians were associated with 37% more anguish (p=0.02) and disagree with end-of-life care was associated with 42% more anguish (p=0.006).

Low quality of life (≤4) was reported by 66 (64.7%) health care professionals. The predictors of low quality of life were identified using univariate and multivariate Poisson regression analysis as shown in Table 2. Low quality of life was more frequently reported in 46% where health care professionals did not have time to talk to patients' relatives (p=0.02) and 30% less frequent where health care professionals agreed that medical care was enough (p=0.01).

DISCUSSION

This study analyzed the psychosocial impact of the COVID-19 pandemic in health care professionals, exploring communication, symptom control, support, and comfort offered to relatives of end-of-life patients.

Self-perception of anguish was referred by 69.6% of health care professionals and was associated with physicians and disagreement with end-of-life care. As anguish is a condition related to negative feelings and suffering[16], we hypothesized that physicians had more anguish probably because of some factors such as the impotence feeling, as many patients died in a short time, regardless of all procedures and the responsibility of certifying death. In a multidisciplinary team, physicians usually assume a team-leader position and must take hard decisions that are extremely stressful. The high prevalence of anguish reflects moral suffering, is concerning, and may reflect harm to the work environment[16,17]. Reinforcing compassion could
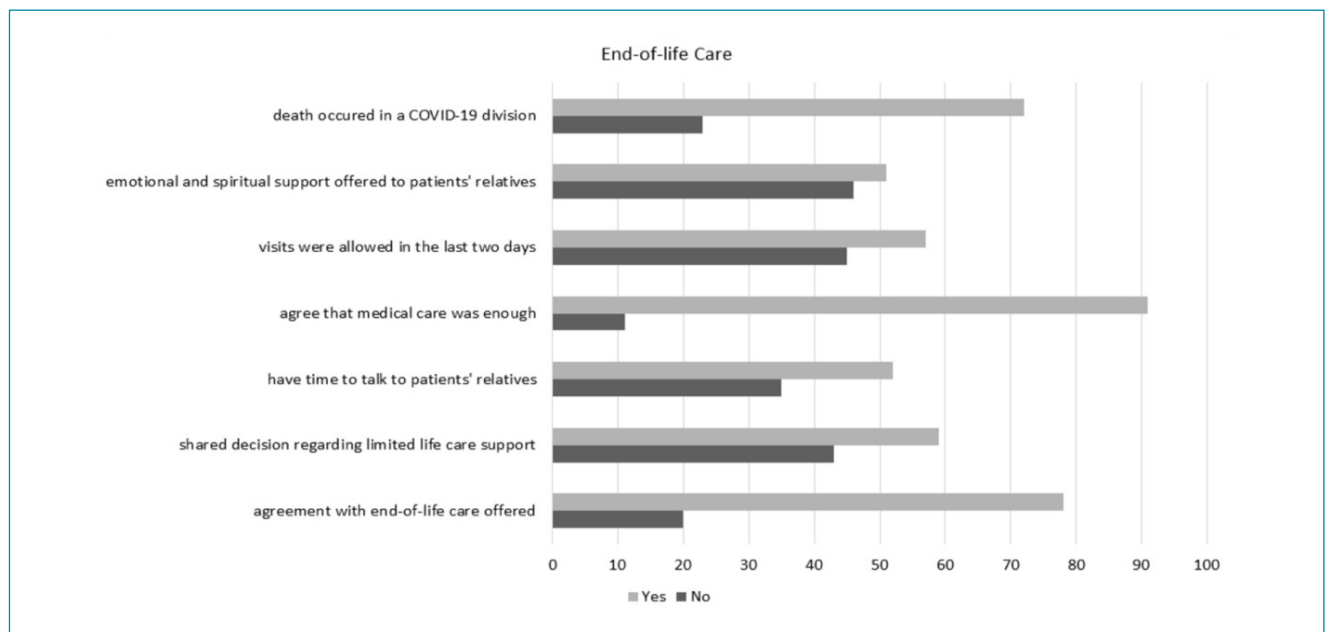

Figure 1. Health professionals and patients' characteristics and end of life care.

Table 1. Univariate and multivariate hierarchical Poisson regression for the predictors of self-perception of anguish in health care professionals.

	Anguish (%)	CPR	p-value*	APR	95%CI	p-value*
Health care professionals						
Age (years)						
>37	70.0	1.01	0,93	Not included		
≤37	69.2	1				
Sex						
Male	50.0	0.68	0.17	Not included		
Female	72.7	1				
Professional category						
Physician	78.0	1.24	0.09	1.37	1.05–1.79	0.02
Others	63.9	1				
Patients						
Age (years)						
>60	72.0	1.06	0.60	Not included		
≤60	67.3	1				
Sex						
Male	70.0	1.01	0.89	Not included		
Female	69.4	1				
SARS-CoV-2 infection						
Confirmed or probable	67.5	0.95	0.76	Not included		
No	70.8	1				
Felt pain all the time or sometimes						
Yes	64.4	0.87	0.32	Not included		
No	73.6	1				
End-of-life care						
Agreement with end-of-life care offered						
No	85.0	1.32	0.02	1.42	1.10–1.83	0.006
Others	64.1	1				
Shared decision regarding limited life care support						
Yes	71.0	1.05	0.68	Not included		
Others	67.0	1				
Have time to talk to patients' relatives						
No	80.0	1.09	0.45	Not included		
Others	73.0	1				
Agree that medical care was enough						
Yes	67.0	0.73	0.01	Not included		
Others	90.0	1				
Visits were allowed in the last 2 days						
Yes	63.1	1	0.10	Not included		
No	77.7	1.23				
Emotional and spiritual support offered to patients' relatives						
No/probably no	73.0	1	0.56	Not included		
Yes	68.0	0.92				
Place where care was offered						
Hospital	69.1	0.92	0.70	Not included		
Others	75.0	1				
Death occurred in a COVID-19 division						
Yes	69.4	0.93	0.55	Not included		
No	73.9	1				

95%CI: 95% confidence interval; CPR: crude prevalence rate for univariate analysis; APR: adjusted prevalence rate for multivariate analysis. *p-value associated with Poisson regression.

Table 2. Univariate and multivariate hierarchical Poisson regression for the predictors of self-perception of quality of life in health care professionals.

	Quality of life≤4(%)	CPR	p-value*	APR	95%CI	p-value*
Health care professionals						
Age (years)						
>37	54.0	0.72	0.03	Adjusting variable		
≤37	75.0	1				
Sex						
Male	50.0	0.74	0.29	Not included		
Female	67.0	1				
Professional category						
Physician	68.2	1.09	0.53	Not included		
Others	62.3	1				
Patients						
Age (years)						
>60	60.0	0.86	0.33	Not included		
≤60	69.2	1				
Sex						
Male	64.6	1.01	0.94	Not included		
Female	63.8	1				
SARS-CoV-2 infection						
Confirmed or probable	67.5	1.35	0.17	Not included		
No	50.0	1				
Felt pain all the time or sometimes						
Yes	66.6	1.05	0.71	Not included		
No	63.1	1				
End-of-life care						
Agreement with end-of-life care offered						
No	70.0	1.13	0.45	Not included		
Others	61.5	1				
Shared decision regarding limited life care support						
Yes	64.4	0.98	0.94	Not included		
Others	65.1	1				
Have time to talk to patients' relatives						
No	80.0	1.54	0.007	1.43	1.04–1.98	0.02
Others	51.9					
Agree that medical care was enough						
Yes	61.5	0.67	0.002	0.70	0.52–0.94	0.01
Others	90.9	1				
Visits were allowed in the last 2 days						
Yes	66.6	1	0.64	Not included		
No	62.2	0.93				
Emotional and spiritual support offered to patients' relatives						
No/probably no	68.6	1.16	0.31	Not included		
Yes	58.6	1				
Place where care was offered						
Hospital	68.0	2.72	0.10	Not included		
Others	25.0	1				
Death occurred in a COVID-19 division						
Yes	69.4	1.06	0.71	Not included		
No	65.2	1				

95%CI: 95% confidence interval; CPR: crude prevalence rate for univariate analysis; APR: adjusted prevalence rate for multivariate analysis. *p-value associated with Poisson regression.

help health care professionals overcome anguish[18]. The disagreement with end-of-life care may reflect communication difficulties during the COVID-19 pandemic.

Low quality of life was referred by 64.7% of health care professionals and was associated with not having time to talk to patients' relatives. Effective verbal and non-verbal communication are the cornerstones of health care, provide possibilities in decision-making to the patients' relatives, and may reduce stress and disagreements with the health care team and between relatives[19]. In contrast, literature has shown that bereaved relatives who did not receive effective communication during the death and dying process of their relative demonstrate a bad understanding of the clinical aspects of the disease, resulting in wrong decisions, hassles, fear, guilt, and frustration[19]. Low quality of life was less frequent when health care professionals agreed that medical care was enough. This also reflects the importance of an adequate work environment, with the necessary resources, where physical and mental aspects are articulated[16].

In this study, shared decisions regarding limiting life support were frequent, and this was surprising as we considered that the availability of palliative care teams was estimated to be present in less than 5% of all hospitals with less than 50 beds in Brazil[20]. The most frequent decision was do-not-resuscitate. Forte et al. also reported that do-not-resuscitate was the limiting support most frequently reported by physicians who attended at an intensive care unit[21]. The decision to withdraw life support in end-of-life patients requires medical education and the recognition of unnecessary procedures[22]. This issue has been addressed in graduation courses.

Half of the health care professionals referred that visits were allowed and emotional and spiritual support to patients' relatives were offered. These attitudes contribute to prevent relatives' depression and enhance satisfaction with end-of-life care[23].

This study has some limitations. First, it was a cross-sectional study and temporal relations were not assessed. The online survey design may include selection bias. Other studies are needed to confirm our results.

CONCLUSIONS

Based on our study findings, health care professionals' self-perception of anguish and low quality of life was high. Anguish was more frequent in physicians and when the disagreement about end-of-life care occurred. Low quality of life was more frequent when health care professionals did not have time to talk to patients' relatives and was less frequent when health care professionals agreed that medical care was enough. Strategies should be developed by health services to reduce the impact of the pandemic on health care professionals.

ACKNOWLEDGMENT

AUTHORS' CONTRIBUTIONS

Ealf: Conceptualization, Data curation, Formal Analysis, Writing – review & editing. **COSV:** Data curation, Formal Analysis, Writing – review & editing. **AFJS**: Conceptualization, Writing – original draft. **JNSP:** Conceptualization, Writing – review & editing. **AES:** Conceptualization, Writing – review & editing. **MUM:** Conceptualization, Writing – review & editing.

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