

Quality End-of-life for Inpatient Dying from COVID-19 in 2020: Opinions of Healthcare Providers

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Abstract

Context: Quality End of life during COVID 19 was challenge for health services.

Objectives: analyse quality end of life for inpatients dying from COVID-19 in 2020 in the first two waves. (1th March-May 31, and 1th September- 31th), compare both waves and compare opinions of the healthcare providers.

Methods: online questionnaire based on Rights of the Dying Charter was subjected to healthcare providers. Results: Seventy-two nurses and 19 physician answered for the first wave. Sixty-six 68 nurses and 16 physicians answered for the second wave. The opinions improved in the second wave about information patient condition (from 41.3% to 63.1% in the second, $p=0.0039$) and answers for patient questions (from 44.6% to 59.2%; $p=0.05$); in the second wave decreased the opinion concerning the proximity of loved ones patient (reduction from 95.7 to 84.5; $p=0.012$). Opinions between healthcare provider there are agreement (Cohen's kappa > 0.8) for proximity of loved ones, patient loneliness, environment, religious and psychological comfort, treatments and relief from physical symptoms.

Conclusions: the study based on the opinions of healthcare provider show a better end-of life quality in the second wave specially about the information and communication to patient. Treatment of physical symptoms was always a priority. This shows awareness of having implemented the most appropriate and available therapies to each patient. Psychological and spiritual needs were less primary issues.

Keymessage: This article describes the opinion healthcare providers about quality end-of-life their impatient dying from COVID-19 during first and second waves in 2020. The results indicate that in second wave was improve quality, treatment of physical symptoms was always the higher priority, instead psychological and spiritual needs were less primary issues.

Keywords: Quality, EOL, COVID-19, Pandemics, Palliative Care, Rights dying

Introduction

The Charter on the Rights of the Dying places end-of-life issues from the perspective of the dying person [1]. This point of view has been largely neglected by the scientific literature produced during the pandemic. Many articles indicate the difficulties in

providing palliative care during the pandemic. When implemented, the palliative care usually concern the clinical aspects of assistance, the treatment of physical symptoms, while they are not equivalent to the existential aspects [2].

Starting from the explained points in the Charter on the Rights of the Dying we investigated the quality of the end of life under the ethical point of view, using for this purpose the opinion of healthcare workers, as the restrictions dictated by the containment of the transmission of the virus prevented the family members from being close to their hospitalised loved ones [1, 3]. Therefore, in many situations operators have had to vine the role of caregivers in welcoming emotions, rituals, in proximity to patients at such a delicate moment of existence [4-6].

What is reported on clinical records and the data present in scientific literature are not exhaustive, nor they can be equivalent to the testimony of those who have lived moral distress and ethical dilemmas during the experience of the process of dying closely.

Focus your attention on important topics, such as advance directives and participatory care, enhancing emotional commitment and ethical discomfort, experienced by operators in this dramatic period, could allow to prepare intervention plans both organizationally and training, as well as to deal with any other emergency in the future [7, 8].

The purposes of the present study consist in analyzing the quality of the end of the life of patients hospitalised and deceased by Covid-19 in the period 1 March-May 31, 2020 and 1 September-31 December 2020, in comparing the results of the two sample periods, in comparing the answers given by the different professional figures.

With the outcome of the detection it will be possible to prepare training and organizational paths that allow to improve patient care, if it will be considered useful.

Methods

Doctors, nurses, patient care assistants (OSS) were recruited, still in service at San Martino Hospital, who directly assisted patients hospitalised and deceased by Covid-19 in San Martino Hospital in the periods 1 March-31 May, 2020 and 1 September-December

ber 31, 2020, as established by the Regional resolution No. 2429 of 30 December 2020 and No. 2007 of 4 November 2020.

After obtaining the approval by the Ethics Committee of the Liguria Region (Resolution No. 1425 of 07/21/2021) a notice was sent to the eligible personnel containing the instructions to access the LimeSurvey platform to be used for the compilation of a questionnaire, specifically designed for this survey, guaranteeing anonymity. A team of experts developed the questionnaire on the basis of the Charter on the Rights of the Dying. It demonstrated good reproducibility and agreement when analysed by Cohen's kappa coefficient (κ). The questionnaire was applied to the participants and presented as two different ones that contained 18 equal questions, but listed in different order for the purpose of allowing the identification of the period taken into consideration.

The detection was carried out in the period from 1 July to 30 September 2021.

Through the LimeSurvey platform, used to carry out online surveys, the staff could access two questionnaires and a demographic card (age, sex, profession, years of training service received on the end-of-life treatment of Covid-19 patients).

The compiler's responses were expressed on a five-level scale: "Not at all", "not very much", "enough", "a lot", "I don't know".

We used Epi info version 7 to descriptive analyze pooled data from all the questionnaires. In data processing the answers were divided into three types in order to simplify the analysis : "I don't know", "not at all and not very much", "enough and a lot". There were conducted using X2 for categorical variables a P-value of <0.05 was considered statistically significant. Cohen's Kappa was calculated to quantify the agreement of paired responses between healthcare providers.

Results

Table 1 describes the characteristics of the participants in the first period, between March 1st and May 31 2020, and in the second period, between September 1st and December 31 2020.

Table 1: Participant Characteristics

Participants	everyone		1st period		2nd period		1st and 2nd period	
	N	%	N	%	N	%	N	%
	99	100	92	92,3	84	84,4	75	75,8
Women	69	70	65	433,3	57	475,0	53	441,7
Men	29	29	26	173,3	26	216,7	23	191,7
Unanswered	1	1	1	6,7	1	8,3	1	8,3
Prefession								
Nurses	78	79	74	80,4	66	78,6	62	80,5
Doctors	19	19	16	17,4	16	19,0	13	16,9
Patient care assistants	2	2	2	2,2	2	2,4	2	2,6
training on end-of-life treatment of Covid-19 patients								
Yes	90	97.8	83	90,2	75	89,3	68	88,3
No	2	2.2	9	9.8	9	10,7	9	11,7
age								
Mean	43,2		43,4		42,3		42,3	

Standard deviation	10		10,8		10,7		10,7	
Min	25		25		25		25	
Max	63		63		62		62	
Median			46,5		45		45,5	
Service years								
Mean	15,8		16		14,6		14,6	
Standard deviation	11,6		11,7		10,9		10,95	
Min	1		1		1		1	
Max	40		40		39		39	
Median			15		12		12	

The questions and answers of all the operators have been compared and represented in Table 2, dividing the answers into three groups: "Not at all or not very much", "I don't know" and "enough or a lot" for the two periods analyzed.

Table 2: Comparison of 1st and 2nd period (Doctors and Nurses)

	1st period					pvalue	2nd period					pvalue	1st period					pvalue	2nd period					pvalue			
	NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%
	NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%	NOT ALL	AT ALL		NOT ALL	AT ALL	%
	VERY MUCH	VERY MUCH		VERY MUCH	VERY MUCH			VERY MUCH	VERY MUCH		VERY MUCH		VERY MUCH		VERY MUCH	VERY MUCH			VERY MUCH	VERY MUCH		VERY MUCH	VERY MUCH			VERY MUCH	VERY MUCH
Comparison of 1st and 2nd period operator response																											
Patient's will																											
The patient was informed of his condition	46	50,0%		29	34,5%	0,04		8	8,7%		2	2,4%	0,07		38	41,3%		53	63,1%					0			
The patient received truthful answers to his questions	42	45,7%		24	28,6%	0,07		9	9,8%		10	11,9%	0,65		41	44,6%		50	59,5%					0,05			
The patient was put able to participate in the decisions concerning him	54	58,7%		44	52,4%	0,4		6	6,5%		6	7,1%	0,87		32	34,8%		34	40,5%					0,44			
The patient was put able to carry out important acts in the imminence of death	71	78,0%		57	68,7%	0,16		15	16,5%		17	20,5%	0,49		5	5,5%		9	10,8%					0,19			
The patient obtained respect for his dignity up to death	33	35,9%		25	29,8%	0,39		1	1,1%		1	1,2%	0,94		58	63,0%		58	69,1%					0,4			
They were asked about their previously expressed will (oral / written)	55	59,8%		47	56,0%	0,6		21	22,8%		22	26,2%	0,6		16	17,4%		15	17,9%					0,93			
Abandonment and aggressive medical treatment																											
The patient was treated according to shared action lines among operators	14	15,2%		17	20,2%	0,38		5	5,4%		1	1,2%	0,04		73	79,4%		66	78,6%					0,89			
The patient obtained relief from physical symptoms	32	34,8%		20	23,8%	0,11		0	0%		2	2,4%	0,13		60	65,2%		62	73,8%					0,13			
The patient was assisted in the desired environment	64	69,6%		51	60,7%	0,21		7	7,6%		9	10,7%	0,47		21	22,8%		24	28,6%					0,38			
The patient died without interventions that prolonged the death process	35	38,0%		39	46,4%	0,26		16	17,4%		11	13,1%	0,43		41	44,6%		34	40,5%					0,58			
The patient obtained respect for his dignity to death	33	35,9%		25	29,8%	0,39		1	1,1%		1	1,2%	0,94		58	63,0%		58	69,1%					0,4			
The patient has achieved specialized end-of-life palliative cares	54	58,7%		40	47,6%	0,14		2	2,2%		1	1,2%	0,61		36	39,1%		43	51,2%					0,1			
More critical aspects due to the pandemic																											
The patient was put able to express his emotions	51	55,4%		42	50,0%	0,47		6	6,5%		6	7,1%	0,87		35	38,0%		36	42,9%					0,51			
The patient has achieved psychological help	80	87,0%		67	79,8%	0,2		5	5,4%		5	6,0%	0,88		7	7,6%		12	14,3%					0,14			
The patient has achieved spiritual comfort	79	85,9%		65	77,4%	0,14		7	7,6%		11	13,1%	0,23		6	6,5%		8	9,5%					0,46			
The patient has achieved religious comfort according to his faith	80	87,0%		68	81,0%	0,49		10	10,9%		12	14,3%	0,45		2	2,2%		4	4,8%					0,34			
The patient obtained some relief of his own loneliness	71	77,2%		57	67,9%	0,16		2	2,2%		3	3,6%	0,57		19	20,7%		24	28,6%					0,22			
The patient obtained the proximity of their loved ones	88	95,7%		71	84,5%	0,01		2	2,2%		2	2,4%	0,92		2	2,2%		11	13,1%					0,34			
The patient was made conscious of his imminent death	61	67,0%		53	63,9%	0,11		18	19,8%		12	14,5%	0,35		12	13,2%		18	21,7%					0,13			

The differences per qualification (doctors and nurses) found during the 1st and 2nd period are described in Table 3, where the percentage of concordance between the two periods is indicated as well as the differences of response statistics between the different qualifications, calculated with the Fisher test. The concor-

dance (Cohen Kappa) $k < 0$ is less than that random; $K = 0$ is the same as that random, k between 0.01 and 0.20 is poor, k between 0.21 and 0.40 is modest, k between 0.41 and 0.60 is moderate, k between 0.61 and 0.80 is substantial, $k > 0.8$ is almost perfect, $k = 1$ is perfect.

Table 3. Differences between 1st and 2nd Period per Qualification

QUESTION	NURSES				DOCTORS			
	agreement	Expected agreement	Kappa1	Prob>Z	agreement	expected agreement	Kappa1	Prob>Z
The patient obtained relief from physical symptoms	60.94%	48.61%	0.2399	0.0000	69.23%	53.25%	0.3418	0.0015
The patient was informed of his condition	65.63%	45.78%	0.3661	0.0002	92.31%	49.70%	0.8471	0.0010
The patient was put able to participate in the decisions concerning him	65.63%	44.36%	0.3822	0.0001	76.92%	47.34%	0.5618	0.0121
The patient was able to express his emotions	68.75%	43.80%	0.4440	0.0000	69.23%	45.56%	0.4348	0.0287
The patient died without interventions that prolonged the death process	70.31%	38.94%	0.5138	0.0000	100.00%	53.85%	1	0.0000

The patient received truthful answers to his questions	71.88%	40.82%	0.5248	0.0000	84.62%	56.21%	0.6486	0.0062
The patient was made conscious of his imminent death	73.02%	48.50%	0.4760	0.0000	84.62%	49.11%	0.6977	0.0004
The patient was assisted in the desired environment	78.13%	53.61%	0.5284	0.0000	92.31%	37.87%	0.8762	0.0000
The patient obtained respect for his dignity to death	79.69%	54.20%	0.5565	0.0000	92.31%	60.36%	0.8060	0.0015
The patient has achieved specialized end-of-life palliative cares	79.69%	48.75%	0.6036	0.0000	100.00%	52.66%	1	0.0002
They were asked about their previously expressed will (oral / written)	79.69%	42.02%	0.6497	0.0000	92.31%	48.52%	0.8506	0.0000
The patient obtained some relief of his own loneliness	82.81%	58.57%	0.5852	0.0000	100.00%	57.40%	1	0.0002
The patient obtained the proximity of their loved ones	84.38%	80.49%	0.1990	0.0015	84.62%	85.21%	-0.0400	0.6181
The patient was put able to carry out important acts in the imminence of death	85.71%	55.63%	0.6780	0.0000	92.31%	57.40%	0.8194	0.0001
The patient was treated according to shared action lines among operators	85.94%	62.89%	0.6211	0.0000	92.31%	92.31%	0.0000	0.5000
The patient has achieved religious comfort according to his own faith	90.63%	68.07%	0.7064	0.0000				
The patient has achieved psychological help	90.63%	69.97%	0.6878	0.0000	92.31%	79.29%	0.6286	0.0073
The patient has achieved spiritual comfort	93.75%	65.45%	0.8191	0.0000	84.62%	84.62%	0.0000	0.5000

1CONCORDANCE $k < 0$: is less than that random ; $k = 0$: is the same as that random , k between 0.01 and 0.20: is poor , k tra 0.21 e 0.40: is modest , k tra 0.41 e 0.60: is moderate, k tra 0.61 e 0.80: is substantial, $k > 0.8$: is almost perfect, $k = 1$: is perfect

Table 4 lists the questions that showed critical issues in both periods (the questions that have had a percentage greater than 60% of the answers "not at all or not very much") and the questions that showed a correct management of aspects evaluated

in the two periods (the questions that presented a percentage of more than 60% of the answers "enough or a lot" during the two periods).

Table 4: Adherence to Rights of the Dying Charter

Poor adherence1	Strong adherence2
-psychological help	-relief from physical symptoms
-religious and spiritual comfort	-respect for dignity up to death
-carrying out important acts before dying	
-loneliness	
-assisted in the desired environment	
-awareness of impending death	
11st and 2nd period "not at all/not very much" answers > 60%	21st and 2nd period "enough/a lot" answers > 60%

Discussion

The production of literature regarding the SARS-COV-2 virus is impressive. Despite this, articles concerning the rights of dying of Covid in hospital are not proved to be published. The study investigates, through the opinion of the health professionals who have treated patients deceased by Covid-19, the fundamental aspects described in the Charter on the Rights of the Dying, focusing on the period of the first wave (1 March-31 June) and of the second wave (1 September-31 December) [1]. It is advisable to keep in mind that Italy, after China, has been the country initially more affected by the sudden increase in the number of cases of Covid 19, and consequently the first, after China as well, to field containment aggressive measures, like Lockdown, and to draw up documents for managing the imposing number of patients who needed intensive care [3, 8].

For participation in the study, health professionals have been selected who have taken care of COVID-19 patients at the forefront, during the first and second established period. Only 9% (113 of 1201) of the professionals joined the study, despite the invitation through the presence registration system was repeated three times (5 July 2021, 5 August 2021, 5 September 2021) and also communicated through telephone interviews with ward managers. The reason of the scarce number of participants could lie in particularly heavy shift stress both from a physical and psychological point of view, in the reduced possibility of enjoying periods of holidays, as well as in depression related to the pandemic [9]. This takes on particular importance since they were personnel who took care of patients deceased by Covid-19, with a prevalence of secondary trauma stress of 47.5% according to the study of Orrù et al. [10]. Another possible reason for

the low participation in the study may consist, at what is always described in the study of Orrù et al., in the fact that the target population in the study period was still involved in the treatment of Covid patients during subsequent pandemic waves [10]. Despite the low participation, the percentage of participating doctors and nurses reflects the initial target population, ie 80% nurses and 20% doctors.

In comparing the second wave to the first, it is cleared in the responses of the professionals an increase in responses "enough or a lot" towards respect for the rights of dying of Covid-19. This improvement can be attributable to the increase and sharing of experiences, to greater understanding and knowledge of the disease and to implementation of new organizational models, with the transition from the first wave was full of uncertainties and lack of training to a situation better from an organisational point of view.

Comparison all Operators' Opinion Between the 1st and 2nd Period

The present study reveals differences regarding the aspects contained in the Charter on the Rights of the Dying[1] in the opinion of all health operators between the 1st and 2nd period. The variations deemed most significant are taken into consideration ($p < 0.05$). In particular to the question "they were informed of their conditions" the answers "enough or a lot" have increased in the second period of 21.8% (from 41.3% to 63.1%; $p = 0.0039$), while the answers "not at all or not very much" fell by 15.5% (from 50% to 34.5; $p = 0.038$). The question "they received truthful answers to their questions" has increased of 14.6% (from 44.6% to 59.2%; $p = 0.05$), probably attributable to the greater knowledge of the disease over time; While the answers "not at all or not very much" decreased in the second period of 17.1% (from 45.7% to 28.6%, $p = 0.000000$). For the question "they obtained the proximity of its loved ones" the answers "not at all or not very much" fell by 11.2% (from 95.7 to 84.5; $p = 0.012$).

The answers "I don't know" have increased in the second period, but in no case statistically significantly.

The most critical aspects (see table 4) recognized by this study are similar to what is reported in literature, due to the characteristics of the pandemic, to the measures adopted to fight it, to the unpredictability of the first cases and the evolution of the disease as well as to the organisational changes to face [2, 11-13]. During the two periods analyzed the aspects most adhering to the principles described in the Charter on the Rights of the Dying were the treatments according to lines of action agreed by all the operators, the relief of physical symptoms and respect for dignity until death [14-16].

Comparison of 1st and 2nd Period for Professional Profile

In both groups the answers "enough or a lot" have increased in the 2nd period compared to the first, probably attributable to a better organization. However, compared to the participation of patients in the decisions that concerned them, as highlighted in Table 3, for both professional profiles the concordance between the answers was modest or moderate. In the answers of the doctors and nurses there is an almost perfect concordance between the 1st and 2nd period for questions regarding the proximity of

their loved ones, the patient's loneliness, the environment, religious and psychological comfort, showing awareness of the of isolated-patient experience in pandemic. Moreover, there was also an almost perfect concordance for questions concerning treatments according to shared action lines and relief from physical symptoms, which shows the knowledge of having implemented the most appropriate therapies available to each patient.

Comparison between the Different Questions

In comparing the answers regarding the relief of physical symptoms and the provision of end-of-life specialist care, it is observed that despite both the answers "not at all or not very much" were decreased, the relief of physical symptoms was a very careful aspect of the rights of the dying in the two waves, while the palliative specialist care were less performed (see Table 2) [16]. This gap can find explanation in the fact that other aspects of end-of-life specialist palliatives, for the connotations of the pandemic, could not be equally taken care of [14].

Analyzing the question "respect for dignity to death" and comparing it with "were enabled to participate in the decisions that concerned them", "make important acts in the imminence of death", "information on their conditions", "they received truthful answers to their questions", an awareness of respect for dignity until death is evident; These aspects during the pandemic presented criticality [14].

The comparison between the questions "have been informed of their conditions", "were enabled to participate in the decisions that concerned them" and "were asked on their previously expressed will (oral / written)" (see Table 2), shows how, given the clinical conditions of extreme criticality of patients, it was not possible to manage these aspects in consistency with the provisions of the law 219/2017 "Rules on the subject of Informed Consent and Advance Directives on Treatment."

Study Limits

The analyzed sample is small, in particular with regard to the professional figures of doctors and healthcare professionals, so the possibility of comparing the different figures is very limited.

The sample's demand does not make it possible to discuss some aspects of the Charter on the Rights of the Dying such as specific implications of a specific professional profile.

Conclusion

The study confirms, despite the small sample size, that during the second phase of the pandemic it was possible to improve the management of the patient's end of life, in particular with regard to information and communication. In the first period the emergency took operators by surprise as well as the organizations, territorial and hospital, in the absence of dedicated organizational plans, of precise regional and ministerial indications, in the presence of shortcomings at different levels: training in the specific field, suitable structures, equipment and devices congruent with care requirements.

The experience of the first wave, the simultaneous arrangement of paths and replaced reorganisation have made it possible to change for the better in the second wave. Healthcare personnel gave little response to the questionnaires, probably due to fatigue

and stress not only physical and especially psychological, associated with the refusal to recall painful and stressful experiences. Further studies would be useful to better explore the analysis and any organisational actions to be promoted in order to achieve not only a better patient care when the therapeutic goal is to cure and heal, but even to implement paths of palliative care including all the aspects of the end of life such as physical symptoms, just as psychological and spiritual needs.

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