Original Article

Beyond the Pandemic: End-of-Life Care Lessons From Latin America to Inform Future Health Emergencies

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Abstract

Context. The COVID-19 pandemic exposed critical weaknesses in end-of-life care (EOLC), particularly in Latin America, where fragmented health systems and inequities intensified suffering.

Objectives. To examine bereaved relatives' perceptions of EOLC during the pandemic in five Latin American countries, identify predictors of perceived adequacy, and assess alignment with the Core Outcome Set (COS) for best care for the dying person, a consensus-based set of patient-centered outcomes for end-of-life care.

Methods. A cross-sectional online survey of bereaved relatives was conducted in Argentina, Brazil, Chile, Colombia, and El Salvador (2021−2023) using an adapted iCODE questionnaire (Care of the Dying Evaluation). The primary outcome, perceived "adequate care" in the last 48 hours of life, was based on two iCODE items. Logistic regression identified associated factors.

Results. Among 1,125 respondents, 51% perceived care as adequate, varying from 45% in Argentina and Colombia to 81% in El Salvador ($P < 0.001$). Independent predictors included personal care support ($P < 0.001$), emotional support ($P < 0.001$), trust in professionals ($P < 0.001$), symptom relief ($P \leq 0.001$), effective communication ($P = 0.012$), and family involvement in decision-making ($P = 0.045$). COVID-19 restrictions were negatively associated with perceived adequacy. Alignment of our findings with the COS domains revealed persistent gaps in spiritual support, shared decision-making, and communication.

Conclusion. Perceptions of EOLC adequacy during the pandemic varied across Latin America. Relational, emotional, and physical aspects of care strongly influenced relatives' assessments. The COS offers a practical framework to identify and address care gaps. Its adoption could promote holistic, culturally sensitive EOLC, essential to improving care in the region. J Pain Symptom Manage 2026;71:280−289.

Key Words

End-of-life care, COVID-19, Latin America, bereavement, palliative care, core outcome set, quality of care

Key Message

Humanised, person-centred care, particularly symptom relief, trust in healthcare professionals, and family support, emerged as the strongest drivers of perceived EOLC quality, reported by relatives of deceased patients, during the COVID-19 pandemic in Latin America.

Mapping the findings to the Core Outcome Set (COS) for best care of the dying person provides a

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practical benchmark to identify care gaps and guide quality improvement efforts in the region.

The systematic integration of the COS into clinical practice and policy could promote resilient, equitable, and culturally responsive EOLC, essential for strengthening the provision of PC and improving health systems.

Introduction

Health emergencies cause significant suffering and can have both short-term psychological and social impacts, as well as long-lasting effects on affected populations.[1] The last pandemic influenced care practices for severely ill patients, with or without a COVID-19 infection, and may have influenced patients' and their relatives' experiences of dying in the physical, psychological, social, and spiritual domains.[2] The pandemic exposed profound vulnerabilities in health systems worldwide, creating unprecedented challenges for end-of-life care (EOLC). In Latin America, these challenges were further exacerbated by structural inequalities, fragmented health systems, and limited integration of palliative care (PC) services.[3–5] The pandemic magnified existing gaps in access to timely, culturally sensitive, and family-centred PC, while also introducing new barriers such as restricted visitation, reduced family participation in the dying process, and heightened emotional suffering among both patients and families.

Understanding how families perceived the quality of care provided to their loved ones during the pandemic is critical to assess the strengths and weaknesses of EOLC practices and inform the development of more resilient and adaptive care models for future health emergencies.[6,7] The impact of the pandemic on EOLC varied based on numerous aspects, including cultural values, patient characteristics, and the level of visitation restrictions. Previous research from other parts of the world emphasised the role of key care components such as symptom control, emotional support, communication, and relational aspects in shaping perceptions of quality at the end of life.[8,9,10] However, information on how Latin American bereaved relatives experienced these elements during the pandemic and how these experiences may inform broader improvements in care delivery and policy planning is limited.[11,12]

In recent years, there has been growing recognition of the need to standardise outcome measurement in EOLC to drive quality improvement, guide research, and inform health policies.[13] Although numerous tools have been developed to assess various aspects of PC, outcomes specifically relevant to the last days of life have historically been underrepresented, with a focus mainly on clinical perspectives. To address this gap, the international iLIVE "Live well, die well" project recently developed the Core Outcome Set for Best Care for the Dying Person (COS).[14,15] This 14-item set was created through a rigorous Delphi process involving clinicians, researchers, patients, and family caregivers from diverse cultural backgrounds. The COS evaluates patient-centred outcomes during end-of-life care, specifically during the last 48 hours of life, across physical, psychological, social, and relational dimensions.

Good EOLC is defined as dying in one's preferred place, free from pain, with dignity, and supported by quality care.[16] Given the lack of evidence from Latin America on family experiences of EOLC during the COVID-19 pandemic, this study aims to address this gap by exploring key factors associated with the perceived quality of care during end-of-life across five regional countries. In doing so, we also seek to reflect on how these findings align with the recently developed international COS for best care for the dying person, providing a framework to benchmark our results and inform quality improvement efforts in the region.

Methods

Study Design and Participants

In this cross-sectional observational study, an open online questionnaire was sent to assess the relative perception of the care provided to deceased family members who died during the COVID-19 pandemic in five Latin American countries (Argentina, Brazil, Colombia, Chile, and El Salvador). This study was part of a larger research project led by a research group from the Netherlands, which aimed to analyse EOLC experiences during the COVID-19 pandemic in different countries across Europe, Latin America, and Asia (the CO-LIVE Study).[17,18]

The questionnaire could be completed by adult individuals who had experienced the death of a family member or friend, regardless of the COVID-19 infectious status of the patient or the relative, and regardless of the place where the patient died. The surveys were completed between June 1, 2020, and July 31, 2021, during the first two waves of the pandemic. Originally, the survey was developed in Dutch and was translated into English, Spanish, Portuguese, and other languages for sharing purposes.[19] All Latin American countries used the same version in Spanish or Portuguese (Appendix 1, original English version). No further inclusion or exclusion criteria were used. The survey was generally distributed nationally through PC teams, networks, and professional associations. In most cases, healthcare providers or volunteers contacted bereaved relatives by phone or email, typically within the first week of survey launch. Those who agreed to participate received an information sheet and a consent form.

Measures

The survey included an abbreviated version of the international Care of the Dying Evaluation (iCODE) questionnaire an instrument that assesses the quality of care during the last two days of life and the bereavement period and asks about the characteristics of the care that was provided, respondents' appreciation of the care and communication with healthcare staff, and family support. This tool was validated into Spanish and Portuguese in a previous study.[20] Each item includes a statement describing an aspect of the care received and is answered using a 5-item Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree).

Additional self-developed questions about the impact of COVID-19-related restriction measures were asked. Options such as "don't know" or "not applicable" were included for respondents who were not allowed or unable to visit the dying person in the last days of life. Relatives were also asked to report the patient's and their demographic information and COVID-19 infection status. They were also asked to report on the place of death.

In this study, we used perceived *"adequate care"* as a proxy for overall quality of end-of-life care. *'Adequate care'* refers to the caregiver's perception that the medical and nursing care provided during the last days of life met the patient's essential needs. To assess this concept, we generated a new variable (*"adequate care received"*) using two items from the original iCODE questionnaire: perceived adequate nursing care and perceived adequate medical care. Each of the possible answers from the Likert scale was assigned a score ranging from one (strongly agree) to five (strongly disagree). The scores for the responses of the two original items were added, yielding a new score for the generated variable *"adequate care"* ranging from two to ten points. Cases in which the final scores ranged between two and three points were considered as having received *"adequate care"*. Those who scored four or higher in this newly generated variable were deemed not to have received *"adequate care"*. We used this high threshold to define the new variable, ensuring that the perception of receiving adequate care included cases that answered "agree" or "strongly agree" to both original questions. While inherently subjective, this concept encompasses both the sufficiency and appropriateness of care in areas such as personal attention, symptom management, emotional support, and communication. For simplicity, the term *"relatives"* refers throughout to bereaved family members who responded to the survey.

Statistical Analysis

Results are presented as mean ± standard deviation (SD) or per cent for categorical variables. First, a descriptive analysis of the variables included in the models was carried out.

In the univariate analysis, to simplify the report of the collected data, each one of the responses for iCODE items were dichotomised (0-1) and codified as one[1] when the answer was "strongly agree" or "agree": "Very easy" or "Fairly easy"; "Yes, in all"; "Yes, all the time"; "Yes, clearly". When similar questions were posed regarding doctors and nurses (confidence/trust, listening time, and attention to spiritual needs), new variables were generated using both items and coded as 1 when the answer was "strongly agree" or "agree" and "yes, in all of them" in both items. In questions about symptoms (shortness of breath, pain, and restlessness), the two questions (presence and relief) were merged into one variable to describe whether the symptom was relieved, as reported by the relative. These variables were coded as one when the response to the presence of the symptom was "no, s/he did not seem to suffer from it" or when the response to relief was "yes, all the time".

We then performed a bivariate analysis, comparing the proportion of the dichotomised iCODE variables with the newly generated variable *"adequate care"* to assess the association between this variable and each one of the variables describing the perceived quality of care during the last two days of life. Chi-square or mean (standard deviation) were used for this analysis, respectively, for categorical and numerical variables. Variables with $P < 0.05$ were used as possible predictors of *"adequate care"*.

A predictive multivariate model was built, with *"adequate care"* as the dependent variable, using Forward Stepwise Logistic Regression. This approach identifies the most significant predictors of perceived adequacy of care by sequentially adding variables that improve the model's explanatory power, while controlling for other relevant factors. Model discrimination was evaluated using the area under the curve (AUC), and model calibration was assessed using the goodness-of-fit test. In all cases, the significance level of the statistical tests was set at $P < 0.05$. Data was processed with Stata 16.0 software (StataCorp, TX, USA).

Finally, to contextualise our findings within an internationally recognised quality framework, we mapped the results of our study to the 14 domains of the COS for best care for the dying person.[15] This mapping was based on responses to specific iCODE questionnaire items, along with additional COVID-19-related questions. Domains that were directly assessed through validated items and included in the multivariable model are clearly indicated. For domains not directly evaluated, we included relevant inferences based on strongly associated constructs (e.g., emotional support and clinician communication contributing to reduced anxiety or fear of death). This approach enables us to identify where quality was perceived as present or lacking, and how the COS can inform improvements in future EOLC delivery and preparedness.

Ethical Considerations

Before accessing the survey, respondents expressed approval for their responses to be used in research. The study's data processing was entirely anonymous. No personally identifying information was gathered. Every nation and institution involved provided ethical consent, and local regulations, including lockdown restrictions, were adhered to during data collection.

Results

During the first year of the pandemic, we invited 1888 relatives to participate, of whom 1125 accepted and completed the questionnaire, equivalent to a 60% response rate. Baseline patient and relative characteristics, including COVID-19 infection status, are described in Table 1. Fifty-one per cent (n = 576) of the relatives considered that the care received during the last 48 hours of life was adequate, an indicator of the quality of care received. The proportion of relatives who reported that the care received was adequate varied significantly by country: Argentina (45%), Chile (62%), Colombia (45%), Brazil (57%), and El Salvador (81%), with $P < 0.001$. The perception of adequate care received was significantly associated with the relatives' country, cancer diagnosis, not having diabetes mellitus, and patients not having a COVID-19 infection. No differences in relative characteristics were identified between those who perceived that the patients received adequate care and those who did not.

Most relatives reported high level of agreement with each of the iCODE instrument items assessing relative's perception of the care received from nurses & doctors, with ranges between 63% for the variable *"the relative felt confidence/trust in the nurses who cared for the Patients"* and 85% for the variable *"the doctors had time to listen and discuss his/her condition with me"* (Table 2). Relatives who reported having received adequate care had a higher frequency of improved symptom control, including pain, breathlessness and restlessness.

Regarding the communicational aspects of care, relatives who reported a better perception of the care received also reported a higher frequency of adequacy regarding the way the information was delivered and a higher frequency of relatives' involvement in decisions about the patients' care and treatment (Table 3). Finally, relatives reporting that the care received was adequate had a higher frequency of discussions about limitations in treatments and a higher frequency of conversations about specific limitations, such as no resuscitation, no hospital admissions, or no admissions to other inpatient facilities. However, the overall frequency of conversations about limiting specific treatments was low, ranging between 7% (discussions about no admissions to other inpatient facilities) and 30% (discussions about no resuscitation). Relatives who reported that the care received was adequate

Table 1
Association Between Patient and Relative Characteristics, With the Perception of the Global Quality of Care Received

Items	Categories	Total (n = 1125)	Adequate Care		OR (95% CI)	P[a]
			Yes (n = 576)	No (n = 549)		
Patients' data						
Country	Argentina	489 (43)	220 (38)	269 (49)	——-	< 0.001
	Chile	267 (24)	167 (29)	100 (18)	0.49 (0.36−0.67)	
	Colombia	239 (21)	108 (19)	131 (24)	0.99 (0.72−1.37)	
	Brazil	99 (9)	56 (10)	43 (8)	0.63 (0.40−0.99)	
	El Salvador	31 (3)	25 (4)	6 (1)	0.20 (0.06−0.50)	
Mean age [SD][b]		74.3 ± 15.7 years				
Gender	Female	560 (50)	299 (52)	261 (48)	1.19 (0.93−1.52)	0.143
Health conditions	Cancer	466 (41)	258 (45)	208 (38)	1.33 (1.04−1.70)	0.018
	Cardiovascular	328 (29)	157 (27)	171 (31)	0.83 (0.63−1.08)	0.151
	Lung disease	166 (13)	85 (15)	81 (11)	1.00 (0.71−1.41)	0.999
	Diabetes mellitus	180 (16)	74 (13)	106 (19)	0.61 (0.44−0.86)	0.003
	Dementia	120 (11)	67 (12)	53 (10)	1.23 (0.83−1.84)	0.283
	Renal disease	63 (6)	31 (5)	32 (6)	0.92 (0.53−1.58)	0.745
	Neurological	71 (6)	32 (6)	39 (7)	0.77 (0.46−1.28)	0.286
	Another problem	133 (12)	71 (12)	62 (11)	1.10 (0.76−1.62)	0.592
	No other disease	164 (15)	77 (13)	87 (16)	0.82 (0.58−1.16)	0.239
Patient reported COVID−19 infection		259 (23)	102 (18)	157 (29)	0.54 (0.40−0.71)	0.000
Relatives' data						
Mean age (SD)		49.7 ± 13.4 years.				
Gender	Female	860 (76)	441 (78)	419 (76)	1.01 (0.76−1.35)	0.924
Relationship with the patient	Daughter/son	656 (58)	326 (57)	330 (60)	—	0.547
	Partner	160 (14)	88 (15)	72 (13)	0.81 (0.56−1.16)	
	Another family member	287 (26)	149 (26)	138 (25)	0.91 (0.69−1.22)	
	Other	22 (2)	13 (2)	9 (2)	0.68 (0.25−1.76)	
Relative reported COVID-19 infection		83 (7)	49 (9)	34 (6)	1.41 (0.87−2.29)	0.138

Categorical results are presented as n (%) or mean (SD) when described.
[a] P = P-value using chi-square test statistic.
[b] mean (standard deviation). ICU = intensive care unit.

Table 2
Association Between Perceived Quality of Care and Symptom Control (iCODE Items) and Relatives' Perception of Care Received

Items	Total (n = 1125)	Adequate Care		OR (95% CI)	P[a]
		Yes (n = 576)	No (n = 549)		
Care received from nurses & doctors					
Adequate help was available to meet the patient's personal care needs, such as washing, personal hygiene and toileting needs.	820 (73)	550 (95)	270 (49)	21.86 (14.13−34.84)	0.000
The bed area and the surrounding environment were comfortable for the patient	867 (77)	541 (94)	326 (59)	10.57 (7.15−15.94)	0.000
The bed area and the surrounding environment had adequate privacy for the patient.	868 (77)	532 (92)	345 (63)	7.15 (4.98−10.41)	0.000
The relative felt confident/trusted in the nurses who cared for the patients	706 (63)	483 (84)	223 (41)	7.59 (5.74−10.04)	0.000
The relative felt confident/trust in the doctors who cared for the patient?	856 (76)	537 (93)	283 (52)	12.94 (8.98−18.65)	0.000
The nurses had time to listen and discuss his/her condition with me.	728 (65)	488 (85)	240 (44)	7.14 (5.38−9.47)	0.000
The doctors had time to listen and discuss his/her condition with me.	947 (84)	556 (97)	391 (71)	11.23 (6.93−18.21)	0.000
The control of pain & other symptoms					
The patient did not experience shortness of breath, or clinicians adequately relieved it when present.	839 (75)	522 (91)	317 (58)	7.07 (5.10−9.81)	0.000
The patient did not experience pain, or clinicians adequately relieved it when present.	748 (66)	471 (82)	277 (50)	4.40 (3.36−5.77)	0.000
The patient did not experience restlessness, or clinicians adequately relieved it when present.	739 (66)	466 (81)	273 (50)	4.28 (3.28−5.59)	0.000

Results are presented as n(%).
[a]*P* = *P*-value using chi-square test statistic. ICU = intensive care unit.

reported a higher frequency of discussions about reasons for the limitations. These relatives were also less likely to report that the care provided was limited due to the Coronavirus crisis.

We also found that 50% or less of the relatives reported that their healthcare team provided emotional support or met the religious or spiritual needs of patients or relatives. Relatives who noted that the care received was adequate reported a higher frequency of perceived excellent emotional support from the healthcare team and that the religious or spiritual needs of patients and relatives were met (Table 3).

Table 3
Association Between Communication, Emotional and Spiritual Support (iCODE Items) and Relatives' Perception of Care Received

Items	Total (n = 1125)	Adequate Care		OR (95% CI)	P[a]
		Yes (n = 576)	No (n = 549)		
Communication with the healthcare team					
The healthcare team explained the patient's condition and/or treatment in a way you found easy to understand.	989 (88)	554 (96)	435 (79)	6.60 (4.11−10.59)	0.000
The relative was involved with the decisions about the patient's care and treatment.	1023 (91)	561 (97)	462 (84)	7.04 (4.02−12.35)	0.000
The team discussed limitations in treatments clearly.	591 (53)	352 (61)	239 (44)	2.04 (1.61−2.59)	0.000
The team discussed limitations of no resuscitation	336 (30)	195 (34)	141 (26)	1.48 (1.14−1.92)	0.003
The team discussed limitations about no ICU admission	234 (21)	120 (21)	114 (21)	1.00 (0.75−1.35)	0.977
The team discussed limitations about no hospital admission	136 (12)	91 (16)	45 (8)	2.10 (1.42−3.14)	0.000
The team discussed limitations about no admission to other inpatient care facilities	77 (7)	48 (8)	29 (5)	1.63 (0.99−2.72)	0.043
The team discussed other limitations.	169 (15)	80 (14)	89 (16)	0.83 (0.59−1.17)	0.276
The reason provided for the limitation was that the treatment was deemed futile due to the patient's condition.	376 (33)	214 (37)	162 (30)	1.41 (1.10−1.81)	0.007
The reason provided for the limitation was that the patient was too old	139 (12)	74 (13)	65 (12)	1.10 (0.76−1.59)	0.608
The reason provided for the limitation was that there were not adequate beds and equipment available	10 (1)	3 (1)	7 (1)	0.41 (0.67−1.79)	0.178
The reason provided for the limitation was not discussed	599 (53)	280 (49)	319 (58)	0.68 (0.54−0.87)	0.001
The care provided was limited due to the Coronavirus crisis	359 (32)	104 (18)	255 (46)	0.25 (0.19−0.33)	0.000
The emotional and spiritual support provided by the healthcare team					
Excellent emotional support to patients and relatives by the healthcare team	509 (45)	384 (67)	125 (23)	6.78 (5.21−8.84)	0.000
Overall, the healthcare team met his/her religious or spiritual needs.	558 (50)	376 (65)	182 (33)	3.79 (2.96−4.85)	0.000
Overall, my religious or spiritual needs were met by the healthcare team.	559 (50)	367 (64)	192 (35)	3.27 (2.56−4.17)	0.000

Results are presented as n (%).
[a]*P* = *P*-value using chi-square test statistic. ICU = intensive care unit.

Table 4
Association Between Items Describing the Circumstances Surrounding the Patient's Death and the Perception of the Care Received

Items	Total (n = 1125)	Adequate Care		OR (95% CI)	*P*
		Yes (n = 576)	No (n = 549)		
Circumstances of death					
Before the patient died, the relative was told that the patient was likely to die soon.	896 (80)	486 (84)	410 (75)	1.83 (1.36−2.46)	0.000
A member of the healthcare team talked to the relative about what to expect when the patient was dying	663 (59)	412 (72)	251 (46)	2.98 (2.33−3.82)	0.000
The patient died at home	390 (35)	241 (42)	149 (27)	1.93 (1.50−2.48)	0.000
The patient died in the right place	883 (78)	533 (93)	350 (64)	7.05 (4.94−10.06)	0.000
Visitors were allowed during the last two days of life without limitations.	353 (31)	233 (40)	120 (22)	2.43 (1.87−3.16)	0.000
I was given adequate help and support by the healthcare team at the actual time of his/her death.	790 (70)	510 (89)	280 (51)	7.42 (5.47−10.08)	0.000
After the patient had died, individuals from the healthcare team dealt with you sensitively	931 (83)	526 (91)	405 (74)	3.74 (2.64−5.29)	0.000
Considering the restrictions on infectious contact due to the pandemic, were family members allowed to assist with preparing the body?	337 (30)	230 (40)	107 (19)	2.75 (2.10−3.59)	0.000

Concerning the circumstances surrounding the patient's death, 35% of patients died at home, 31% of visitors were allowed to visit them during the last two days of life without limitations, and 30% of family members were allowed to prepare the body. We found that relatives who reported that the care received was adequate reported a higher frequency in all the items assessing quality of care during death, such as that the relative was told that the patient was likely to die soon, or that a member of the healthcare team talked about what to expect during the dying phase (Table 4).

A forward stepwise multivariate logistic regression analysis allowed us to identify variables that were independently associated with the perception of adequate care received (Table 5). Table 6 summarises the alignment between our findings and the 14 COS domains, highlighting that symptom control, emotional support, trust in professionals, and family involvement were the strongest predictors of perceived care adequacy during the pandemic.[15]

Discussion

This study presents the first multicountry regional analysis of bereaved family perceptions of EOLC during the COVID-19 pandemic in Latin America. Notably, approximately half of the surveyed relatives considered the care provided during the last days of life to be adequate. Personal care, symptom relief, emotional support, and trust in healthcare professionals emerged as the strongest predictors of this perceived

Table 5
Forward Stepwise Logistic Regression Multivariable Model With the Perception of Adequate Care Received as the Dependent Variable

Predictors	OR	95% CI	*P* Value
There was adequate help available to meet his/her personal care needs	7.71	4.55−13.06	0.000
Excellent emotional support to patients and relatives by the healthcare team	3.30	2.31−4.72	0.000
Confidence/trust in the nurses and doctors (Yes, in all of them)	3.19	2.22−4.59	0.000
S/he did not seem to suffer from shortness of breath, or all of the time, the doctors and nurses adequately relieved it.	2.15	1.36−3.39	0.001
Relative was involved in the decisions about his/her care and treatment.	2.14	1.02−4.51	0.045
The bed area and surrounding environment were comfortable (strongly agree or agree)	2.13	1.26−3.62	0.000
S/he did not seem to suffer from pain, or all of the time, the doctors and nurses adequately relieved it.	2.06	1.40−3.04	0.000
I was given adequate help and support by the healthcare team at the actual time of his/her death (strongly agree or agree)	1.85	1.21−2.82	0.004
Visitors were allowed without limit during the last two days of life	1.71	1.17−2.48	0.005
The nurses and doctors had time to listen and discuss his/her condition with me (strongly agree or agree)	1.66	1.12−2.45	0.012
Limitation of care due to the coronavirus crisis	0.60	0.41−0.87	0.008
Model discrimination: AUC 0.91. Model calibration: goodness of fit 0.97			

Table 6
Alignment of Study Findings With the Core Outcome Set (COS) for Best Care for the Dying Person

Core Outcome Set (COS)	Findings From the Latin American CO-LIVE Study
To address pain	Pain and symptom relief (Q19−Q20) were strong predictors of perceived care adequacy ($P < 0.000$).
To address anxiety	Emotional support (Q29) and clinician availability (Q15−Q16) contributed to anxiety reduction, but only half reported adequate support.
To address respiratory symptoms	Breathlessness relief (Q17−Q18) improved care perceptions ($P = 0.001$).
To reduce suffering	Emotional support (Q29) and spiritual support (Q30−Q31) were linked to positive perceptions. Among those who perceived care as inadequate, the reports of emotional support were notably low, indicating a significant gap.
To ensure family and friends have unrestricted access	Family presence at the bedside (Q36) and unrestricted access had a strong influence on perceived care ($P = 0.005$); however, unrestricted access was rare, revealing a pandemic-related gap.
To give the possibility to say goodbye	Visiting policies and body preparation (Q36−Q37) influenced perceptions; only 30% could participate, with restricted access linked to worse perceptions.
To address the fear of death	The fear of death was not directly assessed but could be inferred from responses to Q33−Q34. Better perceptions of care were associated with more adequate information delivery and greater involvement of relatives in care decisions.
To recognise and discuss the dying phase.	The patient's likely death and dying phase was communicated; a strong association was found between this communication and better care perception ($P = 0.012$). Adequate perceived care was associated with more discussions about reasons for care limitations and fewer reports of care being restricted due to the COVID-19 crisis (Q33−Q34).
To ensure dignity and respect.	Adequate personal care (Q11) and privacy (Q12) were strong predictors of positive perceptions ($P < 0.000$).
To ensure access to competent professionals and support	Most relatives expressed high agreement with items assessing perceptions of care, highlighting trust in nurses and the time doctors dedicated to listening and discussing the patient's condition (Q13−Q14). High confidence in healthcare professionals (Q9) and meeting basic care needs, both strong predictors in the regression model ($P < 0.000$).
To provide quality of death and dying	Although the proportion of individuals dying at home was low, the majority of relatives described that the patient died in the right place(Q35). Relatives perceiving care as adequate reported more frequent communication about impending death and what to expect during the dying phase(Q38), and were strongly valued by families
To provide compassionate care	The comfort of the environment (Q32) and postmortem sensitivity (Q38) contributed to the perceived compassion ($P = 0.000$).
To make patients and families feel heard and understood	Adequate help at the time of death (Q38) and clear communication about treatment limitations improved perceptions ($P = 0.004$).
To respect patients' autonomy, preferences, and wishes	Involvement in decisions (Q24) and discussions of limitations (Q25−Q27) supported the perception of autonomy, although clarity on the reasons for limitations was often lacking ($P = 0.045$).

care adequacy, aligning with the international COS for best care for the dying person. Despite the challenging circumstances, these findings reaffirm the centrality of humanised, family-centred care as a cornerstone of high-quality end-of-life care, even in health emergency contexts.[15]

The data also underscores the compounded suffering caused by pandemic-related restrictions, which limited family participation in the dying process, disrupted communication, and eroded trust. These findings echo prior studies from high-income countries, revealing distinct challenges in Latin America, including structural limitations in PC integration, resource scarcity, and cultural expectations of family proximity at the end-of-life.[2,5,18,21,22–24]

Another key finding from this study is the limited proportion of relatives who reported having clear discussions about the limitations of health services during the pandemic. Additionally, only 50% of the relatives reported that the reasons provided to support the limitations were not discussed, indicating challenges in clinicians' ability to engage in discussions about goals of care and treatment planning during the pandemic. Promoting communication training to enhance the ability to discuss care goals and establish treatment limitations is a relevant regional goal for the near future, which can be beneficial in both pandemic and nonpandemic contexts.

The data also show that clinicians give limited priority to emotional and spiritual support during the end-of-life. These two dimensions are essential components of EOLC and should be provided in a timely and sensitive manner to all patients who need or require them. Training for healthcare professionals to develop skills that support these two dimensions is needed, particularly for clinicians who commonly treat patients nearing the end of life. The inclusion of PC training in the undergraduate curriculum could be an essential strategy to address this gap.[25–27] Country-level analyses revealed significant contextual differences that shaped

EOLC experiences during the pandemic. In Argentina, an additional component of the CO-LIVE study explored healthcare teams' perspectives on communication during the crisis.[28,29] Findings highlighted tensions between ideal, real, and possible care, as well as the emotional burden borne by professionals. These insights point to the need to rethink care delivery through more collective, community-centred approaches.

In Colombia, the pandemic highlighted significant challenges for both families and healthcare providers, particularly in terms of communication and access to services.[30] The findings emphasised the need to strengthen the integration of PC into primary care, especially during public health emergencies. Chilean authors studied perceptions of dying with dignity across four countries.[31] Fewer than half of bereaved relatives felt that the death was dignified, with variations at the country level. Factors associated with dignified experiences included respectful nursing care and emotional support at the time of death. These country-specific insights underscore the diversity of pandemic experiences across Latin America and highlight the importance of culturally and structurally tailored approaches to PC preparedness and delivery.

The persistence and worsening of gaps in communication, spiritual support, and shared decision-making —highlighted through COS mapping—reveal structural vulnerabilities that necessitate urgent, systemic reforms to integrate relational, emotional, and spiritual components into routine and crisis-responsive EOLC models.[32] The COVID-19 pandemic presented an opportunity to incorporate quality planning, control, and assurance with improvement science to support sustainable, large-scale change.[5] Our study offers timely evidence to guide the development of resilient, community-centred PC strategies in Latin America, using the COS as a benchmark for assessing and improving EOLC. Systematic adoption of the COS in the region could drive quality improvement, inform policy, and ensure that holistic, culturally sensitive, and family-centred care is prioritised in routine services and preparedness for future health emergencies.

Limitations

This study has several limitations that warrant consideration. First, the cross-sectional design and retrospective data collection may introduce recall bias, particularly given the emotionally charged nature of bereavement experiences. Second, although the sample size is robust and geographically diverse, participation was voluntary and relied on convenience sampling, which may have introduced selection bias toward more engaged families or those connected to PC services. Third, although the iCODE questionnaire is validated and widely used, its reliance on self-reported perceptions may limit objectivity, and certain nuanced aspects of cultural and relational care may have been underexplored. The study focuses exclusively on family perceptions, without triangulating these perspectives with clinical or system-level data. Finally, the findings reflect experiences during the first and second pandemic waves and may not capture later evolutions in care practices. Nevertheless, the lessons drawn remain relevant and can inform preparedness strategies beyond the COVID-19 context.

Conclusion

This study highlights the experiences of bereaved families in five Latin American countries during the COVID-19 pandemic. The findings expose persistent deficits in communication, spiritual support, and family involvement, emphasising the relevance of the COS as a framework to guide improvements in EOLC. Embedding the COS into routine care planning and emergency preparedness may ensure dignified, culturally congruent end-of-life experiences across the region. This work contributes to the global effort to build resilient, community-based PC systems in resource-limited settings.

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Ethical Approval

Approved by local ethics committees in each participating country. Written informed consent was obtained from all participants.

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The authors used OpenAI's ChatGPT (version GPT-4) to support the revision and editing of English grammar, style, and clarity in the manuscript. The authors take full responsibility for the scientific content and final version of the text.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2025.10.016.

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