

Journal Pre-proof



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

Vilma A. Tripodoro , Pedro Pérez-Cruz , Marina Khoury , Martha Ximena León , José Mario López Saca , Verónica Veloso , Ángela Acero , Sebastián Soto-Guerrero , Marco Rodríguez , Michelle Uchida , Ida Korfage , Agnes van der Heide , on behalf of the CO-LIVE Latin America research group

PII: S0885-3924(25)00907-8
DOI: <https://doi.org/10.1016/j.jpainsymman.2025.10.016>
Reference: JPS 12120

To appear in: *Journal of Pain and Symptom Management*

Accepted date: 17 October 2025

Please cite this article as: Vilma A. Tripodoro , Pedro Pérez-Cruz , Marina Khoury , Martha Ximena León , José Mario López Saca , Verónica Veloso , Ángela Acero , Sebastián Soto-Guerrero , Marco Rodríguez , Michelle Uchida , Ida Korfage , Agnes van der Heide , on behalf of the CO-LIVE Latin America research group, Beyond the Pandemic: End-of-Life Care Lessons from Latin America to Inform Future Health Emergencies, *Journal of Pain and Symptom Management* (2025), doi: <https://doi.org/10.1016/j.jpainsymman.2025.10.016>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

© 2025 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

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

Vilma A. Tripodoro^{1,2}, Pedro Pérez-Cruz^{3,4}, Marina Khoury⁵, Martha Ximena León⁶, José Mario López Saca⁷, Verónica Veloso⁵, Ángela Acero⁶, Sebastián Soto-Guerrero³, Marco Rodríguez⁷, Michelle Uchida⁸, Ida Korfage⁹, Agnes van der Heide⁹ on behalf of the CO-LIVE Latin America research group.

Affiliations

¹ RED-InPal Pallium Latinoamérica, Buenos Aires, Argentina.

² ATLANTES, Global Observatory of Palliative Care, Institute of Culture and Society, University of Navarra, Spain

³ Medicina Paliativa, Facultad de Medicina, Pontificia Universidad Católica de Chile, Santiago de Chile, Chile

⁴ Centro para la Prevención y el Control del Cáncer, CECAN, Santiago, Chile

⁵ Instituto de Investigaciones Médicas Alfredo Lanari, Universidad de Buenos Aires, Argentina

⁶ Universidad de La Sabana, Bogotá, Colombia

⁷ Hospice La Cima, El Salvador

⁸ Barretos Cancer Hospital, Brazil

⁹ Erasmus Medical Centre, Rotterdam, The Netherlands

Corresponding author: Vilma A. Tripodoro vtripodoro@unav.es

Universidad de Navarra Campus Universitario s/n (31009) Pamplona, Navarra, Spain

Figures: 0

Tables: 6

Supplementary: 1

Word count: 3339

References 32

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.

Keywords:

End-of-life care, COVID-19, Latin America, bereavement, palliative care, Core Outcome Set, quality of care.

Running title: Family Perceptions of EOLC in Latin America**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 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 end-of-life care 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 end-of-life care 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 1 (strongly agree) to 5 (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 \pm 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 (1) 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 t-test statistics 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, Texas, 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 end-of-life care 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.

Insert Table 1

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.

Insert Table 2

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 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.

Insert Table 3

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).

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).

Insert 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).

Insert Table 5

Insert Table 6

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 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 non-pandemic 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.

Acknowledgment

We are deeply grateful to all the bereaved families who, despite their grief, generously shared their experiences for this study. We also thank the healthcare teams and volunteers who conducted the surveys across all participating countries under the challenging conditions of the pandemic and strict lockdown measures.

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

Conflict of Interest: nothing to disclose

Disclaimer on Language Editing: 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.

Funding: This study received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. Foundations for Change in Mental Health in the Americas - a series of webinars [Internet]. [cited 2024 Jun 25]. Available from: <https://www.paho.org/en-foundations-change-mental-health-americas-series-webinars>
2. Becqué YN, van der Geugten W, van der Heide A, Korfage IJ, Pasman HRW, Onwuteaka-Philipsen BD, et al. Dignity reflections based on experiences of end-of-life care during the first wave of the COVID-19 pandemic: A qualitative inquiry among bereaved relatives in the Netherlands (the CO-LIVE study). *Scand J Caring Sci.* 2022 Sep;36(3):769–81.
3. Knaul FM, Arreola-Ornelas H, Kwete XJ, Bhadelia A, Rosa WE, Touchton M, et al. The evolution of serious health-related suffering from 1990 to 2021: an update to The Lancet Commission on global access to palliative care and pain relief. *Lancet Glob Health.* 2025 Mar;13(3):e422–36.
4. Hennis AJM, Coates A, Del Pino S, Ghidinelli M, Gomez Ponce de Leon R, Bolastig E, et al. COVID-19 and inequities in the Americas: lessons learned and implications for essential health services. *Rev Panam Salud Publica.* 2021 Dec 28;45:e130.
5. Garcia Elorrio E, Arrieta J, Arce H, Delgado P, Malik AM, Orrego Villagran C, et al. The COVID-19 pandemic: A call to action for health systems in Latin America to strengthen quality of care. *Int J Qual Health Care* [Internet]. 2021 Mar 5;33(1). Available from: <http://dx.doi.org/10.1093/intqhc/mzaa062>
6. Health emergencies [Internet]. [cited 2024 Jun 24]. Available from: <https://www.who.int/our-work/health-emergencies>
7. Morris SE, Moment A, Thomas JD. Caring for Bereaved Family Members During the COVID-19 Pandemic: Before and After the Death of a Patient. *J Pain Symptom Manage.* 2020 Aug;60(2):e70–4.
8. Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, et al. Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic. *Palliat Med.* 2021 May;35(5):852–61.
9. Yildiz B, Korfage IJ, Witkamp EF, Goossensen A, van Lent LG, Pasman HR, et al. Dying in times of COVID-19: Experiences in different care settings - An online questionnaire study among bereaved relatives (the CO-LIVE study). *Palliat Med.* 2022 Apr;36(4):751–61.
10. Schloesser K, Simon ST, Pauli B, Voltz R, Jung N, Leisse C, et al. Saying goodbye all alone with no close support was difficult"- Dying during the COVID-19 pandemic: an online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. *BMC Health Services Research.* 2021;21(1).
11. Benítez MA, Velasco C, Sequeira AR, Henríquez J, Menezes FM, Paolucci F. Responses to COVID-19 in five Latin American countries. *Health Policy Technol.* 2020 Dec;9(4):525–59.

12. Impact of COVID-19 on human resources for health and policy response: the case of Plurinational State of Bolivia, Chile, Colombia, Ecuador and Peru. Overview of findings from five Latin American countries. World Health Organization; 2021. 54 p.
13. Zambrano SC, Haugen DF, van der Heide A, Tripodoro VA, Ellershaw J, Fürst CJ, et al. Development of an international Core Outcome Set (COS) for best care for the dying person: study protocol. *BMC Palliat Care*. 2020 Nov 30;19(1):184.
14. Yildiz B, Allan S, Bakan M, Barnestein-Fonseca P, Berger M, Boughey M, et al. Live well, die well – an international cohort study on experiences, concerns and preferences of patients in the last phase of life: the research protocol of the iLIVE study. *BMJ Open*. 2022 Aug 1;12(8):e057229.
15. Zambrano SC, Egloff M, Gonzalez-Jaramillo V, Christen-Cevallos Rosero A, Allan S, Barnestein-Fonseca P, et al. A core outcome set for best care for the dying person: Results of an international Delphi study and consensus meeting. *Palliat Med [Internet]*. 2024 Dec 4; Available from: <https://pubmed.ncbi.nlm.nih.gov/39629728/>
16. McGlinchey T, Early R, Mason S, Johan-Fürst C, van Zuylen L, Wilkinson S, et al. Updating international consensus on best practice in care of the dying: A Delphi study. *Palliat Med*. 2023 Mar;37(3):329–42.
17. Onwuteaka-Philipsen BD, Pasman HRW, Korfage IJ, Witkamp E, Zee M, van Lent LG, et al. Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study). *Palliat Med*. 2021 May;35(5):830–42.
18. Zee MS, Pasman HR, Witkamp E, Goossensen A, Korfage IJ, Becqué YN, et al. How end-of-life care was limited during the first 18 months of the COVID-19 pandemic: a longitudinal survey study among healthcare providers (the CO-LIVE study). *BMC Palliat Care*. 2024 Jul 26;23(1):187.
19. Koller M, Aaronson NK, Blazeby J, Bottomley A, Dewolf L, Fayers P, et al. Translation procedures for standardised quality of life questionnaires: The European Organisation for Research and Treatment of Cancer (EORTC) approach. *Eur J Cancer*. 2007 Aug;43(12):1810–20.
20. Mayland CR, Gerlach C, Sigurdardottir K, Hansen MIT, Leppert W, Stachowiak A, et al. Assessing quality of care for the dying from the bereaved relatives' perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure. *Palliat Med*. 2019 Mar;33(3):357–68.
21. Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. *Palliat Med*. 2021 Sep;35(8):1480–91.
22. MacArtney JI, Eccles A, Fleming J, Grimley C, Mayland CR, Mitchell S, et al. Pandemic narratives in stories about hospice palliative care: The impact of Covid-19 upon ideals of timely, holistic care and quality of life. *SSM Qual Res Health*. 2024 Jun;5(100447):100447.
23. Selman LE, Farnell DJJ, Longo M, Goss S, Torrens-Burton A, Seddon K, et al. Factors

associated with higher levels of grief and support needs among people bereaved during the pandemic: Results from a national online survey. *Omega (Westport)*. 2025 Jun;91(2):904-31.

24. Chang BKW, Matthews P. How is COVID-19 changing the ways doctors make end-of-life decisions? *J Med Ethics*. 2022 Jul 25: medethics-2022-108268. doi: 10.1136/medethics-2022-108268. Epub ahead of print. PMID: 35879103.
25. Carrasco JM, Lynch TJ, Garralda E, Woitha K, Elsner F, Filbet M, Ellershaw JE, Clark D, Centeno C. Palliative Care Medical Education in European Universities: A Descriptive Study and Numerical Scoring System Proposal for Assessing Educational Development. *J Pain Symptom Manage*. 2015 Oct;50(4):516-23.e2. doi: 10.1016/j.jpainsympman.2015.04.019. Epub 2015 May 27. PMID: 26025273.
26. Tripodoro VA, Specos M, Mutto E, De Vito EL, De Simone GG. Consenso Delphi sobre la formación de grado en medicina paliativa (EDUPAL-Ar). *Educ médica*. 2024 May;25(3):100903.
27. Noguera A, Mosoiu D, Payne C, Paal P. "this project helped me to grow": Experiences of teaching Palliative Care using the EDUPALL project medical undergraduate curriculum. *J Palliat Med*. 2022 Jul;25(7):1072-8.
28. Carballo B, Montilla S, Orellana S, Veloso V, Castro S, Florit G. Lo ideal, lo posible, lo real y lo común de la comunicación durante la pandemia de. *Argumentos. Revista de Crítica Social* (2022) Available from: <https://publicaciones.sociales.uba.ar/index.php/argumentos/article/view/7963/6670>
29. Iturri A, Veloso V, De las Heras JI, Steren Z, Tripodoro VA. Cuidados al final de la vida y despedidas durante la pandemia: relatos sobre experiencias de familiares en duelo. *Rev. M. (Rio J.)* [Internet]. 5º de janeiro de 2024 [cited 11th August de 2025];9(17). Available from: <https://seer.unirio.br/revistam/article/view/12649>
30. Gonzalez A, Delgado L. Cuidados De Fin De Vida Durante La Pandemia: Similitudes Y Diferencias En Latinoamerica (Colive Proyect). 2022. Poster Available from: <https://pure.unisabana.edu.co/es/publications/cuidados-de-fin-de-vida-durante-la-pandemia-similitudes-y-diferen>
31. Soto-Guerrero S, Pérez-Cruz P, León MX, Ferreira EL, Veloso V, Tripodoro VA. Morir con dignidad durante la pandemia de. Poster available from https://www.researchgate.net/publication/374919143_Morir_con_dignidad_durante_la_pandemia_de_COVID-19_desde_la_perspectiva_de_familiares_en_duelo_de_cuatro_paises_de_Latinoamerica#fullTextContent
32. Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: a WHO guide. Geneva: World Health Organization. 2018. Available from: <https://www.who.int/publications/i/item/9789241514460>

Table 1. Association between patient and relative characteristics, with the perception of the global quality of care received.

			Adequate care			
Items	Categories	Total (n=1125)	Yes (n=576)	No (n=549)	OR (95%CI)	p
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]		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. *p = p-value using chi-square test statistic. ICU: Intensive Care Unit. #=t-test statistic to compare means.

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*
		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(%). *p = p-value using chi-square test statistic. ICU: Intensive Care Unit

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
		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 & 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 (%). *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	Adequate care				
	Total (n=1125)	Yes (n=576)	No (n=549)	OR (95%CI)	p
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	337 (30)	230 (40)	107 (19)	2.75 (2.10-3.59)	0.000

members allowed to assist with preparing the body?					
--	--	--	--	--	--

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 post-mortem 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 ($p = 0.045$).



Questionnaire on relatives' experiences of end-of-life care

Dear Sir or Madam

This is a questionnaire about end-of-life care. You can fill in this questionnaire if you have recently experienced the death of a close relative, family or friend. This must be difficult for you, especially in the complex situation we are all facing due to the Corona epidemic. We would like to express our sincere condolences for your loss.

The reason for asking people to fill in this questionnaire now, is that we, as healthcare professionals, aim at providing the best care possible, also in this stressful time. We would like to learn from your experiences and those of other people. It would be very helpful if you could inform us about your experiences concerning the care that was provided during the last phase of life of your relative. By filling in this questionnaire you can let us know how you appreciated this care and where it could have gone better.

Filling in the questionnaire will take you 15-20 minutes. Please note that we are interested in your views and experiences. There are no “right” or “wrong” answers. The questions may evoke emotions. If you feel upset or distressed, you can stop answering questions at any time. If you prefer not to answer a question, you can move on to the next question. If you feel a need for personal support after filling in the questionnaire, you can contact

At the end of the questionnaire you can provide additional comments and thoughts. If you have questions about this research or the questionnaire you can contact the research team.

We appreciate your contribution very much and wish you all the best.

Kind regards

Contact details research team:

Do you agree with the use of your answers to the questions in this questionnaire for the research purpose described above?

I agree with the use of my answers for the research purpose described above

What happens to your data?

To protect your privacy, your personal data is not saved. We only save the answers you have given to the questions in the questionnaire. We guarantee that these answers can never be traced back to you, your deceased patient or someone who was involved in caring for this patient.

Please let us know on what day you completed the questionnaire:

Informed consent

Do you agree with the use of your answers to the questions in this questionnaire for the research purpose described above?

I agree with the use of my answers for the research purpose described above

What happens to your data?

To protect your privacy, your personal data is not saved. We only save the answers you have given to the questions in the questionnaire. We guarantee that these answers can never be traced back to you, your deceased patient or someone who was involved in caring for this patient.

Please let us know on what day you completed the questionnaire:

Date completed: [Day/Month /Year]

Part 1: Your relative

In this part, we ask you some general questions about your deceased relative.

1. What was the age of your relative?	_____ years
2. Was your relative a man or a woman?	<input type="checkbox"/> Man <input type="checkbox"/> Women <input type="checkbox"/> Other
3. Where did your relative live?	4. ... 5. Etc.
6. When did your relative die? <i>Please fill in the date.</i>	7. .. /.. /2020
8. How were you related to your relative?	9. S/he was my parent 10. S/he was my partner 11. S/he was another family member, namely: 12. _____ 13. S/he was a friend 14. Other relationship, namely: 15. S/he was my _____
16. Was your relative infected with the new Coronavirus?	<input type="checkbox"/> Yes, certainly <input type="checkbox"/> Yes, probably <input type="checkbox"/> No, probably not <input type="checkbox"/> No, certainly not <input type="checkbox"/> Don't know
17. Did your relative have (other) health problems? <i>(more than one answer possible)</i>	<input type="checkbox"/> Cancer <input type="checkbox"/> Heart disease <input type="checkbox"/> Lung disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Dementia <input type="checkbox"/> Other disease, namely: _____ <input type="checkbox"/> No, my relative had no (other) disease

Part 2: Care for your relative

Please look at the following statements and cross the answer box that corresponds best with your opinion.

The care received from the nurses & doctors

*These questions are concerned with the general care your relative received from the doctors and nurses and, where appropriate, the environment in which this care was delivered. The questions apply to the last **two days** of his/her life and relate to the doctors and nurses (including healthcare assistants and / or care agency staff) who were most involved with his/her care during this time.*

18. There was enough medical care, from the general practitioner or another doctor.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> I don't know
19. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> I don't know
20. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> I don't know
21. The bed area and surrounding environment was comfortable for him/her.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> I don't know
22. The bed area and surrounding environment had adequate privacy for my relative.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> I don't know

23. Did you have confidence and trust in the nurses who were caring for him/her?	<input type="checkbox"/> Yes, in all of them <input type="checkbox"/> Yes, in some of them <input type="checkbox"/> No, not in any of the nurses <input type="checkbox"/> Not applicable, there were no nurses caring for my relative
24. Did you have confidence and trust in the doctors who were caring for him/her?	<input type="checkbox"/> Yes, in all of them <input type="checkbox"/> Yes, in some of them <input type="checkbox"/> No, not in any of the doctors <input type="checkbox"/> Not applicable, there were no doctors caring for my relative
25. The nurses had time to listen and discuss his/her condition with me.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Not applicable, I have had no contact with nurses
26. The doctors had time to listen and discuss his/her condition with me.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Not applicable, I have had no contact with doctors
The control of pain & other symptoms	
<i>These questions are concerned with the symptoms s/he had and the care s/he received during the last two days of his/her life.</i>	
27. In your opinion, during the last two days, did s/he appear to suffer from shortness of breath?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, s/he did not seem to suffer from shortness of breath
28. In your view, did the doctors and nurses do enough to help relieve the shortness of breath?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, not at all <input type="checkbox"/> Not applicable, s/he did not seem to suffer from shortness of breath
29. In your opinion, during the last two days, did s/he appear to be in pain?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, s/he did not appear to be in pain
30. In your view, did the doctors and nurses do enough to help relieve the pain?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, not at all

	<input type="checkbox"/> Not applicable, s/he was not in pain <input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, s/he did not appear to be restless
31. In your opinion, during the last two days, did s/he appear to be restless?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, not at all <input type="checkbox"/> Not applicable, s/he was not restless
32. In your view, did the doctors and nurses do enough to help relieve the restlessness?	<input type="checkbox"/> Yes, all of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> No, not at all <input type="checkbox"/> Not applicable, s/he was not restless
Communication with the healthcare team	
<p><i>The following questions are about the communication that you, your family members and friends received from the healthcare team who were most involved with his/her care in the last two days of his/her life. By 'healthcare team', we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.</i></p>	
33. Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?	<input type="checkbox"/> Very easy <input type="checkbox"/> Fairly easy <input type="checkbox"/> Fairly difficult <input type="checkbox"/> Very difficult <input type="checkbox"/> They did not explain his/her condition or treatment to me
34. How involved were you with the decisions about his/her care and treatment?	<input type="checkbox"/> Very involved <input type="checkbox"/> Fairly involved <input type="checkbox"/> Not involved
35. Did the healthcare team discuss any limitations in his/her treatment or care?	<input type="checkbox"/> Yes, clearly <input type="checkbox"/> Yes, but not very clearly <input type="checkbox"/> No, not that I know of → go to question 28 <input type="checkbox"/> Don't know → go to question 28
36. Which limitations were discussed? (more than one answer possible)	<input type="checkbox"/> No resuscitation <input type="checkbox"/> No ICU admission <input type="checkbox"/> No hospital admission <input type="checkbox"/> No admission to other inpatient care facility <input type="checkbox"/> Other limitation, namely: _____
37. Did the healthcare team discuss the reason for limiting his/her treatment or care?	<input type="checkbox"/> Yes, namely: ○ Full treatment was futile because of his/her medical condition

(more than one answer possible)	<ul style="list-style-type: none"> <input type="radio"/> It was my relative's choice <input type="radio"/> My relative was too old <input type="radio"/> There were not enough beds available <input type="radio"/> There was not enough healthcare staff available <input type="radio"/> Other reason, namely: _____ <p><input type="checkbox"/> No, the reason was not discussed</p>
38. Do you think that the treatment or care of your relative was limited due to the Corona crisis?	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p>
If you wish, you can explain your answer:	

The emotional & spiritual support provided by the healthcare team

The following questions are about the emotional and spiritual support that was provided to you and your family member or friend by the healthcare team in the last two days of his/her life. By 'spiritual support', we mean support relating to important personal beliefs. These beliefs may be connected with a specific religion but may also be personal beliefs about what life means, what provided you or your family member / friend with hope and helped you cope.

39. How would you assess the overall level of emotional support given to you by the healthcare team?	<p><input type="checkbox"/> Excellent</p> <p><input type="checkbox"/> Good</p> <p><input type="checkbox"/> Fair</p> <p><input type="checkbox"/> Poor</p>
40. Overall, his/her religious or spiritual needs were met by the healthcare team.	<p><input type="checkbox"/> Strongly agree</p> <p><input type="checkbox"/> Agree</p> <p><input type="checkbox"/> Neither agree nor disagree</p> <p><input type="checkbox"/> Disagree</p> <p><input type="checkbox"/> Strongly disagree</p>
41. Overall, my religious or spiritual needs were met by the healthcare team.	<p><input type="checkbox"/> Strongly agree</p> <p><input type="checkbox"/> Agree</p> <p><input type="checkbox"/> Neither agree nor disagree</p> <p><input type="checkbox"/> Disagree</p> <p><input type="checkbox"/> Strongly disagree</p>

The circumstances surrounding his/her death

The following questions are about the circumstances surrounding his/her death, and your feelings about the way in which the healthcare team treated you and your family member at this time. By 'healthcare team', we mean the doctors, the nurses and any

<p><i>other member of staff who may have been involved in his/her care such as a social worker or a chaplain.</i></p>	
42. Before s/he died, were you told s/he was likely to die soon?	<input type="checkbox"/> Yes <input type="checkbox"/> No
43. Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g. symptoms that may arise)?	<input type="checkbox"/> Yes → go to question 35 <input type="checkbox"/> No
44. Would a discussion about what to expect when s/he was dying have been helpful?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable, we had these types of discussions
45. Where did s/he die?	<input type="checkbox"/> At home <input type="checkbox"/> In a hospital: <input type="checkbox"/> At an ICU <input type="checkbox"/> At a ward for Corona patients <input type="checkbox"/> At another ward <input type="checkbox"/> In a care home / nursing home <input type="checkbox"/> At a ward for Corona patients <input type="checkbox"/> At another ward <input type="checkbox"/> In an institution for Corona patients <input type="checkbox"/> In a hospice (not specifically for Corona patients) <input type="checkbox"/> Other (please specify) : _____
46. Were visitors allowed during the last two days of his/her life? <small>(more than one answer possible)</small>	<input type="checkbox"/> Yes, without limitation <input type="checkbox"/> Yes, with limitations: <small>ximum number of visitors per day:</small> <hr/> <input type="checkbox"/> Yes, with limitations: <small>ximum amount of time per visit:</small> <hr/> <small>_____ minutes</small> <input type="checkbox"/> No visitors were allowed
47. In your opinion did s/he die in the right place?	<input type="checkbox"/> Yes, it was the right place <input type="checkbox"/> No, it was not the right place <input type="checkbox"/> Not sure <input type="checkbox"/> Don't know
48. I was given enough help and support by the healthcare team at the actual time of his/her death.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree

	<input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree
49. After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable, I didn't have any contact with the healthcare team
50. Was it allowed for relatives to assist in laying out his/her body?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> We did not ask for this <input type="checkbox"/> Don't know

Part 3: Your own situation and health

In order to better understand your experience, it is important that we have some understanding of your own situation. Can you please answer the following questions?

33. Thinking about yourself, please indicate to what extent you feel this way today	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Interested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Excited	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guilty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hostile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enthusiastic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Proud	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alert	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ashamed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Inspired	<input type="checkbox"/>				
Nervous	<input type="checkbox"/>				
Determined	<input type="checkbox"/>				
Attentive	<input type="checkbox"/>				
Jittery	<input type="checkbox"/>				
Active	<input type="checkbox"/>				
Afraid	<input type="checkbox"/>				

34. Are you infected with the Corona virus?	<input type="checkbox"/> Yes, certainly <input type="checkbox"/> Yes, probably <input type="checkbox"/> No, probably not <input type="checkbox"/> No, certainly not <input type="checkbox"/> Don't know			
Support from others				
35. In the two days before the death of your relative, how often did you experience any of the following?				
	Never	Rarely	Sometimes	Often
I lacked companionship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt close to people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There were people I could turn to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt that people really understood me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. In the days after the death of your relative, how often did you experience any of the following?				
	Never	Rarely	Sometimes	Often
I lacked companionship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt close to people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There were people I could turn to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt that people really understood me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. What is your age?	<input type="text"/> years			
38. Are you a man or a woman?	<input type="checkbox"/> Man <input type="checkbox"/> Women <input type="checkbox"/> Other			

End of questionnaire

**Any additional comments on any of the topics in this questionnaire are welcome:
what went well, what went less well, what could have gone better?**

**Thank you for completing this questionnaire. You can now submit the
questionnaire.**

Contact details research team: