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Special article

Clinical and ethical recommendations for decision-making in nursing homes in the context of the COVID-19 crisis[☆]



Recomendaciones éticas y clínicas para la toma de decisiones en el entorno residencial en contexto de la crisis de COVID-19

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Introduction

The current SARS-CoV-2 (causing COVID-19) coronavirus pandemic has been particularly devastating for the elderly, a group that has accounted for more than 85% of deaths from this disease.¹ In this context, COVID-19 has severely disrupted nursing homes, where a large number of elderly people live (average age 87), with high multimorbidity (46% of people with dementia), complexity (51% of high-risk adjusted morbidity groups [AMG]), and a high prevalence of end-of-life situations (54%), with an overall annual mortality above 20%.^{2,3}

This fact, together with the clinical presentation peculiarities in this population group -which often manifests itself in atypical clinical presentations,⁴ the coexistence of multiple residents in restricted living spaces, the health care model in these centres and the shortage of human and other resources in the sector, have provided a perfect scenario that has impacted both on a systemic and individual level.⁵ On a systemic level, care responses in these facil-

ities have been heavily influenced by the impact of the pandemic on all other health and social system resources, which have been overwhelmed in their response capacity.⁶ On an individual level, the clinical complexity of these people and the epidemiological context have generated significant difficulties in decision-making, both for residents, their families, and the professionals in charge of their care.⁵

In the absence of definitive data, it is estimated that in developed countries more than half of all deaths from COVID-19 are concentrated in nursing homes - which in the case of Spain could rise to practically 2/3 (17,848 of the total of 26,920 deceased, as of 12th May).⁷ Taking into account that in Spain there are about 5,450 nursing-homes, with more than 270,000 residents,⁸ the need for specific measures, solid criteria and key ethical principles is evident in order to guide and support professionals and organizations in this very complex situation.^{9,10} To this end, the chairs of Palliative Care and Bioethics at the UVic-UCC, the Centre for Social and Health Studies (CESS) and the research group on chronicity in Central Catalonia (C3RG) have promoted a consensus with multiple organisations, which is outlined in this article.

Methodology

Given the lack of published evidence, as well as the need for a rapid consensus on recommendations, a flexible methodological proposal has been designed in 3 stages: 1) rapid literature review by editors, in a peer review process; 2) establishment of a author-

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¹ The professionals and organizations that have participated in the consensus recommendations are presented in [Appendix A](#).

Table 1
Professionals and entities participating in the consensus, in alphabetical order.

Authors	Jordi Amblàs-Novellas Xavier Gómez- Batiste	
Writing committee	Jordi Amblàs-Novellas Anna Casellas-Grau Xavier Costa Marina Geli	Xavier Gómez-Batiste Begoña Román Pepa Romero Núria Terribas
Review committee	Conxita Barbeta Montse Blasco Ester Busquets Cristina Casanovas Marta Chandre Alex Guarga	Angel Jover Montse Llopis Remedios Martín Miquel Angel Mas Sebastià Santaeugènia Antoni Sisó
Scientific societies and member organizations	SCIENTIFIC SOCIETIES Asociación Española de Enfermería en Cuidados Paliativos (AECPAL) Asociación Española de Planificación Compartida de la Atención (AEPCA) Associació d'Infermeria Familiar i Comunitària de Catalunya (AIFiCC) Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP) Societat Catalana de Geriatria i Gerontologia (SCGG) Societat Catalana de Medicina Familiar i Comunitària (CAMFIC) Societat Catalana de Metges Generals i de Família (SEMG Cat) Societat Catalano-Balear de Cures Pal·liatives (SCBCP) Sociedad Española de Cuidados Paliativos (SECPAL) Sociedad Española de Medicina Familiar y Comunitaria (SEMFYC) Sociedad Española de Geriatria y Gerontología (SEGG) Sociedad Española de Medicina Geriátrica (SEMEG)	OTHER ORGANIZATIONS Asociación de Bioética Fundamental y Clínica Associació Catalana de Recursos Assisencials (ACRA) Càtedra de Bioètica Universitat de Vic-UCC Càtedra de Cures Pal·liatives. Universitat de Vic-UCC Col·legi de Metges de Barcelona Col·legi Oficial d'Infermeres i Infermers de Barcelona (COIB) Col·legi Oficial de Psicologia de Catalunya Col·legi Oficial de Treball Social de Catalunya Consell de Col·legis de Metges de Catalunya Consorti de Salut i Social de Catalunya (CSSC) Fundació Salut i Envel·liment. Universitat Autònoma de Barcelona Grup de Recerca en Cronicitat de la Catalunya Central (C3RG) Institut Borja de Bioètica. Universitat Ramon Llull Institut Català de la Salut (ICS) Institut Català d'Oncologia La Unió (Associació d'Entitats Sanitàries i Socials) Marc Antoni Broggi (Presidente del Comitè de Bioètica de Catalunya) Pla d'atenció Integrada Social i Sanitària. Generalitat de Catalunya Begona Roman (Presidenta del Comitè de Ètica de los Servicios Sociales de Catalunya) Servei Català de la Salut

ing group and a review group, both made up of multidisciplinary professionals from different areas of the health and social system, and 3) consensus of the master document recommendations with scientific societies and other organizations (Table 1).

Results

Brief narrative synthesis of available literature and data

Firstly, a rapid non-systematic search was carried out, highlighting 5 articles on COVID-19 in the nursing home setting which were considered particularly relevant by the editors^{4,7–10} as well as 3 other articles related to palliative care and ethics in decision-making in this setting.^{11–13} In order to provide some context for the project, it was necessary to review the data related to the COVID-19 pandemic and the situation of nursing-homes in Spain.^{1–3,7,8}

Preparation of recommendations

On the basis of this evidence and the experience of the corresponding professionals, the writing group produced a first draft, which was subsequently assessed and improved by the review

group. In the preliminary document resulting from this process, and pending final contributions from scientific societies and other organisations, the following recommendations were agreed:

a) General recommendations

5 assessment and intervention steps were identified (person, family, team, territory resources and referral criteria), for which the following were described: 1) the steps (*what to do*); 2) the method (*how to do it*); 3) the expected outcome, and 4) a series of related practical recommendations (comments) (Fig. 1).

The assessment of the person included the diagnosis of the previous situation - which should go far beyond the chronological age of the person⁵ - as well as the identification of their values and preferences. In the section on the family, the need to examine their values, preferences and expectations was also highlighted; in the section on the team, the need to encourage their participation was identified, as well as their support in the assessment and decision making. In the analysis of territorial resources, the need to identify available external resources was highlighted, as well as the need for the intervention of support teams or admission criteria and intervention in the external resources.

GENERAL RECOMMENDATIONS				SPECIFIC RECOMMENDATIONS / Support Documents	
STEPS: WHAT TO DO?	METHOD: HOW TO DO IT?	WHAT OUTCOME WILL WE GET?	COMMENTS/RECOMMENDATIONS	IN CASE OF ADVANCED ILLNESS/TERMINAL SITUATION due to COVID-19 AND PALLIATIVE CARE DECISION IN THE CENTER TO CONSIDER:	FAMILY SUPPORT TO CONSIDER:
1 PERSON (patient) Perform the SITUATION DIAGNOSIS <i>When do we start from?</i> For example: • Baseline frailty • Complex Chronic Patient (CCP) • Advanced disease (ACM) (last months 1 year or TERMINAL last three months) Assess VALUES AND PREFERENCES • What values and preferences does the person have? • Does he/she have AHD* or SCP**? *AND: Advance Healthcare Directive **SCP: Advance Care Plan These two steps help us to situate the patient according to his progress, to identify his values and preferences, and allow us to prepare an initial PROPOSED LEVEL OF INTERVENTION before complications:	ADVANCED DISEASE or TERMINAL SURPRISE QUESTION: • "Would you be surprised if that person died within a year?" SHORT NECESSARY: • Needs palliative care? • Meets advanced criteria for the disease? • Has functional or nutritional impairment? • Has multimorbidity? • Has multiple emergency admissions? *A multidimensional assessment / Comprehensive Geriatric Assessment is recommended **In all cases it may be useful to know the degree of frailty (using the VIG frailty index or CF3). Short basic-SCP (person with the family if the person is not competent): • What worries you? • What are your expectations for the future? • What would you risk of us? • How do you see the current situation (COVID-19)? • In case of being COVID-19, where and how would you like to be treated?	IDENTIFICATION of people according to their situational diagnosis ENFERMEDAD PCC MACA GRADE FRAGILIDAD PCC MACA GRADE FRAGILIDAD PCC MACA OF EACH PERSON: • Values • Concerns • Priorities • Preferences *AND: Advance Healthcare Directive **SCP: Advance Care Plan	• Prognosis, chronological age (age in years) or the type of disorder should NOT be used as sole criteria. • It is recommended to review the person's medical records given the nursing home staff or that of primary care regarding the degree of frailty, multidimensional assessment, multimorbidity... • With great sensitivity • Explicitly (or implicitly if it can be inferred) • Evaluate possible impact • Commitment of support to the center (especially in terminal situation) • Privacy	REVIEW OBJECTIVES AND TREATMENT • Adaptation of all measures towards the objective of comfort MANAGEMENT: • Manual of symptom control in patients with terminal advanced cancer... 3rd edition • Guidelines on the symptomatic control of vertigo at patients suffering from COVID-19, avoiding palliative care EMOTIONAL AND SPIRITUAL SUPPORT • Manual of psychosocial and spiritual care for people with advanced diseases INDICATIONS OF SEDATION • The indications of sedation are specific, they follow a protocol (see manual cited in the previous point) and must be the result of a rigorous assessment • The most common causes are the persistence of refractory symptoms (dyspnea, hyperactive delirium...), severe existential distress or intense suffering • It is necessary to remember that the demand of the family is not a sedation indication REQUEST help from SUPPORT TEAMS in case of need • For managing complex situations, supporting the team or making decisions • Assess telephone support if face-to-face support is not feasible	DECISION MAKING IN PATIENTS WITH MODERATE/ADVANCED DEMENTIA or MENTAL RETARDATION TO CONSIDER: DECISION MAKING: • If there are no prior guidelines, carry out a procedure to review values and preferences with the family (legal representative or relatives) and the team • An online family meeting can be a good alternative in making decisions
2 FAMILY Assess the FAMILY <i>How does the family see/experience it?</i> • Expectations • Preferences • Demands	Short basic-SCP (family) • Inform about the situational and progression diagnosis already described • Report and share conversations with patients • Assess concerns, expectations and demands in relation to COVID-19 • Assess the response to predictable situations/scenarios	• Needs, expectations, priorities and demands • Support and counselling • Patient and information access	• Support and counselling on behaviours during isolation • Counselling on emotional support and accompanying • Ensure face-to-face (for telephone, remote...) information systems • Suggest accompanying formulas, especially in cases of worse prognosis • Prevent complicated bereavement.	DECISION MAKING IN PATIENTS WITH MODERATE/ADVANCED DEMENTIA or MENTAL RETARDATION TO CONSIDER: DECISION MAKING: • If there are no prior guidelines, carry out a procedure to review values and preferences with the family (legal representative or relatives) and the team • An online family meeting can be a good alternative in making decisions	IMPACT: The situation of uncertainty, of advanced disease and agony in solitude are experiences with high impact for users, their relatives, and their friendships in the nursing home environment. PRESENCE AND COMMUNICATIONS • Although isolation measures are necessary, the presence of a family representative is justifiable, and it should be facilitated... especially in end-of-life situations, with the necessary protection measures. • Additional alternative measures (video calls, telephone, etc.) must be proposed. • A regular system of information and support from the family must be established, especially by phone or any other online system. BEREAVEMENT: Identify the risk of complicated bereavement. Accompanying guidelines must be defined for the isolation process, as well as for the funeral protocol.
3 TEAM INVOLVE and give SUPPORT to the team <i>How does the team see/experience it?</i>	IT IS RECOMMENDED: • To share decision-making • To give support and counselling on health, emotional and spiritual care • To propose a reference professional for the patient / family	• Common goals • Consensual Therapeutic Plan • Consensual response level			TEAM SUPPORT TO CONSIDER: STRESS AND A FEELING OF GUILT • Sharing decision-making can be a preventive mechanism for stress, as it provides tools for prioritizing interventions. • In the context of high care pressure, uncertainty, risk of infection and limited resources, it is necessary to ensure that professionals experience the limitations of care quality and treatment of residents and families guilt-free. SUPPORT, COMPETENCE AND COMMITMENT • It is essential that professionals and nursing home teams have the support of institutional leaders. • Professionals (all) must be empowered to respond competently, with commitment and compassion to an ever-evolving crisis, emphasizing the outstanding value of their contribution.
4 RESOURCES ASSESS the situation of TERRITORIAL RESOURCES <i>What territorial resources may be available to respond to the needs of the person?</i>	IT requires an UPDATED MAPPING of: • support RESOURCES and degree of ACCESSIBILITY: Primary Care, Support teams, OSL, ... • Possible REFERRAL RESOURCES: • Emergency services, acute care hospitals, hospitals for intermediate/facial health care, hotels... • Assess TELEPHONE MONITORING with support resources. • Program PHARMACOLOGICAL REQUIREMENTS	• Degree of external access and resolution • Possibility of support of each resource • Realistic possibilities of using support technologies (ICU, ventilation...)	• Avoid using emergency services if objectives are not clear/think about alternatives • In case of basic support need (urgent intravenous medication, ...) assess the intermediate care resources or professional support systems • Carry out time planning and coordination with the objective of achieving 24x7 support • Use shared information systems • For particularly difficult ethical decisions, consider contacting the local ethics committees		
5 REFERRAL REFERRAL CRITERIA to other resources <i>When could a person benefit from being referred and where?</i>	• Depending on the previous SCP, diagnosis of the situation and therapeutic objectives, a CAREFUL TRANSFER INDICATION evaluation is necessary. • The possible benefits need to be weighed against the risks or impacts of the transfer to the hospital	• Decision to keep the patient at the Centre vs transfer • Clear referral or transfer criteria • External support options	• Establish direct access mechanisms in those territories with social healthcare/intermediate care resources with more technology (for example, oxygen) and support (medical, nursing, psychosocial) to care for patients with more complex needs. • Think of some alternatives (hotels) which could be useful in specific situations		

Fig. 1. Consensus Document: Clinical and ethical recommendations for decision-making in nursing homes in the context of the COVID-19 crisis.

This information should provide the identification of criteria that facilitate the decision-making process, including the preferred place of care (nursing home with internal resources or additional external support, or referral to another facility).

b) Specific recommendations

In this section, four worksheets were designed with a pragmatic approach, with the aim of responding to specific and prevalent situations: the first proposed palliative care measures in those cases where an advanced or terminal disease situation was identified without criteria for referral, and a proposal for care at the centre itself. The second worksheet outlined a series of recommendations for the support and assistance of the family, with criteria for support, presence, and bereavement support. They were complemented with recommendations for the care and decision-making of people with dementia, as well as measures to support the team for the prevention of stress, burnout, compassion fatigue or guilt (Fig. 1).

Consensus process with scientific societies and organizations

The preliminary document was submitted for review and acceptance by the 12 scientific societies, 5 bioethics entities or their chairmen, as well as 15 organizations -including professional associations, employers' associations, research and administration groups- (Table 1), who also made valuable contributions, finally obtaining a definitive consensus (Fig. 1).

Discussion

Faced with the current COVID-19 pandemic, ethical and clinical decisions in nursing-homes are the core element on which to build

quality, people-centred and equitable care. In this context, specific recommendations are essential to guide professionals in the difficult decision-making process, a fact that can ultimately help reduce collateral damage.^{5,14}

This document describes and organises a process that begins with the individualised assessment of the residents (and their needs and preferences), incorporating the family and the team as key players, as well as an evaluation of the territorial resources and their accessibility and referral criteria.

Despite the limitations derived from the scarce specific literature on decision-making in a nursing home environment in the current COVID-19 pandemic, as well as the numerous entities and professionals participating in this work, the methodological design in three stages has made it possible to develop a broad consensus in less than two weeks. There is no precedent in the published literature for a document of this nature, with such a broad consensus and with such a pragmatic and field-oriented approach. Most of the articles reviewed either focus on very specific aspects (epidemiology,⁷ clinical features,⁴ organizational aspects,⁷ palliative care,^{11,12} individual opinions,⁵ for example) or are published by working groups or isolated scientific societies.^{9,10}

Decisions made in this uncertain present will, in the short and medium term, have a significant impact on patients, families and care professionals, which can sometimes be as or more devastating than the disease itself.¹⁵ May these recommendations shed light to help build a future that will hopefully be better and more collaborative.

Conflict of interests

The authors declare no conflict of interest.

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We wish to thank all the people and entities that have participated in this consensus. Also, our gratitude to all the professionals who, in a context of crisis, with limited internal and external resources, are doing everything possible to offer quality care to the users.

Appendix A. Professionals and organizations that have participated in the consensus of recommendations (in alphabetical order)

Professionals: Conxita Barbeta, Montse Blasco, Marc Antoni Broggi, Ester Busquets, Cristina Casanovas, Anna Casellas-Grau, Marta Chandre, Xavier Costa, Marina Geli, Alex Guarga, Angel Jover, Montse Llopis, Remedios Martín, Miquel Àngel Mas, Begoña Román, Pepa Romero, Sebastià Santaeugènia, Antoni Sisó, Núria Terribas

Organizations: Asociación de Bioética Fundamental y Clínica, Asociación Española de Enfermería en Cuidados Paliativos (AEC-PAL), Asociación Española de Planificación Compartida de la Atención (AEPCA), Associació Catalana de Recursos Assisencials (ACRA), Associació d'Infermeria Familiar i Comunitària de Catalunya (AIFiCC), Càtedra de Bioètica Universitat de Vic-UCC, Càtedra de Cures Paliatives - Universitat de Vic-UCC, Col·legi de Metges de Barcelona, Col·legi Oficial d'Infermeres i Infermers de Barcelona (COIB), Col·legi Oficial de Psicologia de Catalunya, Col·legi Oficial de Treball Social de Catalunya, Consell de Col·legis de Metges de Catalunya, Consorci de Salut i Social de Catalunya (CSSC), Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP), Fundació Salut i Envelliment - Universitat Autònoma de Barcelona, Grup de Recerca en Cronicitat de la Catalunya Central (C3RG), Institut Borja de Bioètica, Universitat Ramon Llull, Institut Català de la Salut (ICS), Institut Català d'Oncologia, La Unió (Associació d'Entitats Sanitàries i Socials), Pla d'atenció Integrada Social i Sanitària (PAISS) - Generalitat de Catalunya, Servei Català de la Salut, Societat Catalana de Geriatria i Gerontologia (SCGG), Societat Catalana de Medicina Familiar i Comunitària (CAMFIC), Societat Catalana de Metges Generals i de Família (SEMG Cat), Societat Catalano-Balear de Cures Paliatives (SCBCP), Sociedad Española de Cuidados Paliativos (SECPAL), Sociedad Española de Medicina Familiar y Comunitaria (SEMFYC), Sociedad Española de Geriatria y Gerontología (SEGG), Sociedad Española de Medicina Geriátrica (SEMEG).

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