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Rodríguez Ruiz

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HUMANISATION IN INTENSIVE CARE. ETHICAL CONSIDERATIONS IN MANAGING CRITICALLY ILL PATIENTS: MODES OF DEATH, FAMILY PERCEPTIONS AND MORAL DISTRESS AMONG HEALTHCARE PROFESSIONALS

Santiago de Compostela, 2022

Doctoral Programme in Advances and New Strategies in Forensic Science

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TESE DE DOUTORAMENTO

HUMANISATION IN INTENSIVE CARE. ETHICAL CONSIDERATIONS IN MANAGING CRITICALLY ILL PATIENTS: MODES OF DEATH, FAMILY PERCEPTIONS AND MORAL DISTRESS AMONG HEALTHCARE PROFESSIONALS

Emilio Rodríguez Ruiz

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Emilio Rodríguez Ruiz has no conflict of interest to declare regarding this thesis.

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ETHICAL ASPECTS

This study was approved by the Institutional Review Boards of all participating institutions and all data collection and experiments were conducted in accordance with the guidelines for Good Clinical Practice and the Declaration of Helsinki. All alive participants provided written informed consent before enrolment. Informed consent was waived for dead patients before study initiation.

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- Los principios éticos de la Declaración de Helsinki vigente.
- Los Procedimientos Normalizados de Trabajo del CEIm-G de Galicia

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In Intensive Care, the most important thing is not technology.

In Intensive Care, the most important things are patients, families, and the ICU team.

– Maurizio Cecconi, 2022

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TABLE OF CONTENTS

RESUMO **27**

1 INTRODUCTION **37**

1.1 Intensive Care: some historical milestones **39**

1.2 Humanizing Intensive Care **40**

1.2.1 The Humanization of Intensive Care movement (Proyecto HU-CI) 41

1.2.2 End-of-life care 42

1.2.3 Communication, presence, and involvement of family members in the ICU 42

1.2.4 Caring for the healthcare professionals 43

2 HYPOTHESES AND OBJECTIVES **45**

3 MATERIAL AND METHODS **51**

4 RESULTS **55**

4.1 Modes of death in the Intensive Care Unit **57**

4.2 Empowerment and satisfaction of families in the Intensive Care Unit **73**

4.3 Moral distress among nurses and physicians working in Spanish ICUs **98**

4.4 Other studies conducted during the doctoral thesis period **173**

5 GENERAL DISCUSSION **179**

5.1 Modes of death in the Intensive Care Unit **181**

5.2 Empowerment and satisfaction of families in the Intensive Care Unit **184**

5.3 Moral distress among nurses and physicians working in Spanish ICUs **188**

5.4 Limitations **194**

6 GENERAL CONCLUSIONS **195**

7 FUTURE PERSPECTIVES BASED ON THIS RESEARCH **199**

8 INDICATIONS OF IMPACT OF THIS RESEARCH **203**

9 REFERENCES **207**

APPENDIX I: PERMISSIONS FOR REPRODUCTIONS **219**

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APPENDIX II: CO-AUTHORS' AUTHORISATIONS 223

APPENDIX III: JOURNALS' AUTHORISATIONS 233

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RESUMO

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A Medicina Intensiva é a especialidade médica encargada da atención aos doentes críticos, atendendo a persoas cuxa vida corre perigo inmediato, doentes con disfunción real ou potencialmente mortal dun ou varios órganos susceptibles de recuperación. Os Coidados Intensivos teñen como obxectivo restablecer o "equilibrio" dos órganos vitais defectuosos do doente antes de que poida ser trasladado a outro servizo. Existen varias figuras e acontecementos claves comunmente asociados á orixe da Medicina Intensiva e ao desenvolvemento das Unidades de Coidados Intensivos (UCI), aínda que moitos outros individuos non recoñecidos certamente contribuíron ao desenvolvemento deste campo. Dende a crearon das primeiras UCI, houbo grandes melloras en termos de avances tecnolóxicos, con ventiladores modernos que substituíron os voluminosos pulmóns de ferro do pasado, modernas máquinas de ultrasóns que proporcionan imaxes instantáneas á cabeceira dos doentes, modernos sistemas de monitorización que permiten unha avaliación non invasiva de múltiples variables, máquinas modernas para realizar terapias de substitución renal continua para apoiar o ril cando falla, e máquinas modernas para a osixenación con membrana extracorpórea (ECMO) para substituír temporalmente a función do corazón e dos pulmóns. Tamén houbo unha mellora na comprensión da fisiopatoloxía e a patoxénese dos procesos patolóxicos que afectan a doentes en estado crítico. Isto permitiu mellorar os resultados dos doentes que ingresan nas UCI.

Nas últimas décadas, a investigación en Coidados Intensivos levou a numerosos tratamentos novos, ao desenvolvemento profesional e a avances tecnolóxicos. Isto permitiu que a Medicina Intensiva moderna teña como obxectivo non só mellorar as taxas de supervivencia, senón tamén unha mellor calidade de vida despois do alta. Non obstante, os aspectos humanísticos da atención non foron abordados nin desenvolvidos coa mesma eficacia que os avances tecnolóxicos, afectando así a tres colectivos relevantes de individuos que forman parte do ámbito sanitario (doentes, familias e profesionais sanitarios). En certo sentido, en Coidados Intensivos, humanizar a tecnoloxía é un esforzo novo e obrigado. Mostrar bondade e preocupación por todos os implicados na atención sanitaria, apostando pola dignidade das persoas, é unha necesidade e mais o camiño para construír un excelente sistema sanitario. Humanizar significa "*todo o que hai que facer para promover e protexer a saúde, curar enfermidades e garantir un medio ambiente que favoreza unha vida saudable e harmónica a nivel físico, emocional, social e espiritual das persoas*". "*Falar de humanización reivindica a*

dignidade intrínseca de todo ser humano e os dereitos que dela se derivan, o que o converte nunha necesidade de vital importancia e transcendencia". Por iso, humanizar non só require cambios a nivel estrutural, senón que tamén implica individualizar os coidados, prestando especial atención ás necesidades dos doentes e as súas familias, así como aos aspectos éticos e dilemas que adoitan estar presentes. Ademais, por outra banda, humanizar é tamén comprender e aceptar que os profesionais teñen os seus propios valores morais, experiencias, sentimentos e poden ser falibles e/ou vulnerables; polo tanto, estes aspectos relevantes deben considerarse como pedras angulares para humanizar a atención sanitaria. En definitiva, a humanización dos Coidados Intensivos ten as súas raíces na ética e na calidade asistencial. A ética dos coidados é un concepto amplo que inclúe diversos aspectos sobre as accións morais dos pacientes, familiares e profesionais da saúde que xorden como consecuencia das relacións interpersoais clínicas dende o inicio ata o final da vida.

O movemento de Humanización dos Coidados Intensivos (Proxecto HU-CI) é un proxecto de investigación multicéntrico e internacional creado en España en 2014 que busca crear un cambio de paradigma na forma en que se prestan os Coidados Intensivos cara a un modelo máis amigable e centrado no ser humano. O principal obxectivo deste proxecto colaborativo é avaliar diferentes áreas e levar a cabo a posta en marcha das correspondentes accións de mellora. Estas áreas de mellora e investigación foron identificadas mediante a escoita activa e a reflexión compartida das opinións de miles de profesionais sanitarios. Esta iniciativa xerou un plan de Humanización da UCI que foi recoñecido como un cambio de paradigma no modelo asistencial e que sentou as bases do Manual de Boas Prácticas para a Humanización da UCI, que recolle 160 accións para transformar o modelo de xestión sanitaria divididas en oito áreas de mellora e investigación. Para ofrecer un modelo de Coidados Intensivos máis humanizado, recoñeceuse a necesidade de realizar esforzos de investigación centrados en aspectos tan importantes como o benestar e coidados dos doentes ao final da vida, a comunicación, a presenza e implicación dos familiares na UCI e na atención dos profesionais sanitarios.

Os doentes en estado crítico ingresan na UCI para recibir terapias potencialmente curativas e para restaurar a saúde do doente ao estado anterior ao ingreso. As intervencións médicas, as técnicas, os procedementos ou os medicamentos administrados a un paciente para atrasar a morte considéranse tratamentos que sosteñen a vida, independentemente de que se trate ou non da enfermidade subxacente ou do proceso biolóxico causante. Exemplos destas medidas son a ventilación mecánica, os fármacos vasoactivos ou a nutrición artificial, entre outros. O benestar do paciente debe ser un obxectivo tan importante como a súa curación, máis importante aínda se esta última non é posible. É imposible curar a tódolos enfermos, pero podemos mellorar a atención que se lles presta centrando os coidados na dignidade das persoas. Hai que modificar os coidados para reducir o sufrimento e ofrecer a mellor atención posible, especialmente ao final da vida do paciente. Nese momento, os coidados paliativos e os coidados intensivos deben coexistir ao longo do proceso de atención ao doente crítico. Nos últimos anos, cunha influencia crecente das consideracións éticas na UCI, obsérvase un cambio neste escenario, favorecido pola publicación de recomendacións e pautas internacionais sobre prácticas ao final da vida na UCI. A pesar destas directrices, hai unha heteroxeneidade significativa nos procesos de toma de decisións ao final da vida entre rexións, países, UCIs dentro do mesmo país e intensivistas individuais dentro dunha UCI.

A pesar da mellora dos resultados clínicos nas últimas décadas na UCI, a enfermidade crítica segue sendo un evento vital importante e estresante para os pacientes e as súas familias. Debido á gravidade da enfermidade, a toma de decisións estresantes adoita recaer nos membros da familia. Os familiares de doentes en estado crítico demandan cada vez máis participar na atención diaria dos pacientes e permanecer á beira da cama o maior tempo posible. Ademais, a participación dos familiares nos coidados dos doentes graves está asociada a mellores resultados. Isto reflicte a importancia dun enfoque centrado na familia para a atención e os procesos de toma de decisións compartidos para ofrecer unha atención de alta calidade aos doentes e ás súas familias, ao tempo que se recoñecen as necesidades e experiencias dos membros da familia. Ademais, as guías para a atención centrada na familia animan aos profesionais da saúde a comprometerse cos membros da familia para participar no proceso de toma de decisións sobre o tratamento e coidado do seu familiar. Unha maior presenza facilita o coñecemento de situacións clínicas e favorece unha maior implicación da familia no proceso do paciente. Para iso, cómpre transformar o concepto de "visitante" no de "colaborador nos coidados", devolvendo o papel de coidadores aos familiares e integrándoos, se así o desexan, na atención baixo a formación e supervisión dos profesionais sanitarios. Darlle á familia a oportunidade de participar no proceso de toma de decisións e axudar ao doente a recuperarse pode ter efectos positivos para o propio doente, a familia e os profesionais da saúde, xa que se reduce o estrés emocional e se facilita a comunicación e a proximidade de todas as partes implicadas, polo que aumenta a satisfacción da familia. En consecuencia, considérase que son necesarias intervencións e enfoques estruturados para apoiar aos familiares dos doentes críticos. É importante realizar actividades que permitan ás familias dos pacientes acceder á UCI e capacitalas para proporcionar información aos equipos da UCI. Tamén é fundamental habilitar elementos que axuden a ter unha comunicación adecuada e empática coas familias por parte de todos os membros do equipo para ter unha asistencia satisfactoria. Os resultados de satisfacción do doente e da familia son cada vez máis recoñecidos como un indicador de calidade no entorno dos Coidados Intensivos. En consecuencia, os resultados de satisfacción poderían proporcionar información valiosa para mellorar as prácticas da UCI, como a cultura de seguridade, a calidade da atención, a comunicación entre a familia e os equipos de UCI e a atención centrada no paciente.

As UCI son instalacións altamente especializadas nas que se presta atención médica avanzada, contando con tecnoloxía sofisticada. A pesar diso, o coidado dos doentes en estado crítico é un traballo estresante e emocionalmente esixente debido á alta morbilidade e mortalidade dos pacientes, aos enfrontamentos periódicos con desafíos éticos e a un ambiente tenso. Cando as cousas non van ben no traballo, o esgotamento emocional é importante entre os profesionais da saúde. Cando este esgotamento emocional aparece xunto coa falta de coidado da propia saúde e benestar, xorde a denominada "síndrome de Burnout". A síndrome de burnout é unha síndrome psicosocial caracterizada por tres aspectos básicos: esgotamento emocional, despersonalización e sentimentos de baixa autoestima profesional. Varios síndromes intermedios, como o desasosego moral, a percepción de proporcionar coidados inadecuados ou a fatiga compasiva, poden levar ao esgotamento profesional. O desasosego moral foi descrito como un desafío que xorde cando se sabe o que facer, médica ou eticamente, pero as limitacións institucionais e/ou externas fan case imposible seguir o curso de acción correcto. Especialmente

na UCI, o desasosego moral prodúcese cando os profesionais sanitarios están frecuentemente expostos a situacións de coidado dos pacientes e/ou ámbitos profesionais nos que cren que están a facer algo eticamente mal, pero non teñen a capacidade de cambiar a situación. Actualmente enténdese que este fenómeno é un grave problema que se pode xeneralizar a outras disciplinas hospitalarias, ameazando a integridade dos profesionais sanitarios e tamén dos sistemas de saúde. De feito, compromete a atención tanto a nivel persoal (como causa de burnout e abandono de postos de traballo) como a nivel do sistema (diminución da calidade asistencial). A sociedade e as organizacións teñen un deber moral, un imperativo ético e unha obriga legal de "coidar aos seus coidadores". É importante mellorar o coñecemento sobre o burnout profesional e o desasosego moral mediante ferramentas validadas e favorecendo a súa visibilidade. Para iso hai que marcar obxectivos prioritarios que nos orienten cara a accións preventivas e terapéuticas.

A humanización dos Coidados Intensivos é a vía para ofrecer unha mellor atención centrada en pacientes, familias e profesionais sanitarios. Tendo isto en conta, esta tese achega datos novos e importantes sobre varias áreas de mellora na humanización dos Coidados Intensivos. En primeiro lugar, preséntase un estudo observacional retrospectivo que avalía os modos de morte nos doentes falecidos nunha UCI terciaria española durante un período de 10 anos. Analiza e discute as tendencias cambiantes dos modos de morte ao longo do tempo e a epidemioloxía destes pacientes para comprender e mellorar a atención ao final da vida na UCI. En segundo lugar, ante a falta de instrumentos validados para medir as experiencias e satisfacción dos familiares no entorno dos Coidados Intensivos de adultos que abranguen todos os principios básicos da atención centrada na familia, esta tese ofrece unha nova ferramenta validada capaz de medir a satisfacción das familias cos coidados, o cuestionario EMPATHIC-F. Ademais, esta tese explora como as políticas restrinxidas de visitas á UCI durante a pandemia de COVID-19 afectaron a satisfacción dos familiares mediante o cuestionario EMPATHIC-F. Por último, esta tese presenta un estudo prospectivo transversal que mide o desasosego moral entre os profesionais sanitarios que traballan nas UCI en España utilizando o primeiro instrumento válido e fiable para medir o desasosego moral en español, o MMD-HP-SPA. Ademais, esta tese investiga como a pandemia de COVID-19 afectou o desasosego moral entre a enfermería e os médicos que traballan nas UCI españolas.

Centrándonos nos resultados do primeiro dos estudos recollidos nesta tese, un estudo observacional retrospectivo sobre os modos de morte nos 1553 doentes falecidos nunha UCI terciaria española durante un período de 10 anos, compre destacar que os ingresos na UCI aumentaron un 3,5% ao ano (IC 95%: 3,3%-3,7%; $p < 0,001$), e as mortes absolutas na UCI mantivéronse estables durante o período de estudo. Isto supón unha diminución da mortalidade (1,7%/ano, IC 95% 1,4%-2,0%; $p = 0,021$). Máis da metade dos pacientes (888, 57,2%) morreron a pesar do soporte máximo, 389 (25,0%) tras unha decisión compartida de limitar o tratamento de soporte vital e 276 (17,8%) debido á morte encefálica. A idade (OR 1,024; IC 95%: 1,013-1,037) e a enfermidade neurolóxica como causa de ingreso (OR 3,358 fronte a outra causa de ingreso; IC 95%: 2,492-4,524) asociáronse con maiores probabilidades de morrer despois da limitación do tratamento de soporte vital en comparación con morrer a pesar do soporte máximo. Pola contra, a morte durante a fin de semana (OR 0,793, IC 95%: 0,587-0,992) e a morte durante a quenda de noite (OR 0,630 *vs.* morte durante a quenda de mañá, IC 95%: 0,459-0,864) asociáronse con menores probabilidades de morrer despois da limitación do

tratamento de soporte vital en comparación coa morte a pesar do soporte máximo. Como era de esperar, a morte encefálica asociouse con enfermidades neurolóxicas e traumáticas como causas de ingreso. Os modos de morte cambiaron significativamente durante o período de estudo de 10 anos, cunha maior proporción de mortes despois da limitación do tratamento de soporte vital (15,1%/ano, IC do 95% 14,4% - 15,8%; p <0,001) e unha diminución en morte a pesar do soporte máximo ao final da vida (7,1%/ano, IC 95% 6,6% - 7,6%; p < 0,001). A proporción de pacientes diagnosticados de morte cerebral mantívose estable ao longo destes anos (p = 0,117). Estes achados supoñen que o equipo de UCI debe ser consciente dos cambios acontecidos nos últimos anos, así como dos problemas actuais nos coidados ao final da vida e da necesidade dun enfoque multidisciplinar centrado no paciente e a familia en tales circunstancias. Por iso, os profesionais sanitarios deben contar cos coñecementos, actitudes, habilidades e ferramentas necesarias para facer fronte a estas situacións e facer fronte aos posibles conflitos éticos.

No segundo dos estudos desta tese, un estudo transversal e prospectivo centrado nas experiencias e satisfacción dos familiares dos doentes ingresados na UCI, 262 coidadores primarios completaron o cuestionario EMPATHIC-F (taxa de resposta do 97%). O cuestionario EMPATHIC-F divídese en cinco dominios relacionados cos principios dos coidados centrados na familia. As respostas proporciónanse nunha escala ordinal Likert de 6 puntos, considerándose aceptable unha puntuación superior a 5. A estrutura empírica do cuestionario estableceuse mediante unha análise factorial confirmatoria, que confirmou 30 afirmacións dentro de cinco dominios teoricamente conceptualizados: información, coidados e tratamento, participación familiar, organización e actitude profesional. A nivel de ítem, dúas afirmacións obtiveron unha media inferior a 5,0: unha no ámbito de coidados e tratamento ("Todos os días sabiamos quen era o responsable do noso familiar, en canto ás enfermeiras"), e outra no dominio de implicación familiar ("Puidemos estar preto do noso familiar incluso durante os procedementos invasivos"). A consistencia interna dos cinco dominios, expresada como α de Cronbach, variou entre 0,64 (organización) e 0,75 (actitude profesional). A validez congruente foi adecuada entre os cinco dominios e catro ítem de satisfacción xeral (r's 0,26-0,54). A mediana das respostas do dominio variou de 5,7 na participación familiar ata 6,0 no dominio da actitude profesional. Estes achados demostran que o cuestionario EMPATHIC-F é un ferramenta fiable e válida para medir as percepcións dos membros da familia nas UCI de adultos.

Ademais, cando España se viu afectada pola pandemia de COVID-19 en marzo de 2020, as políticas de visitas nas UCI cambiaron cara a unha política máis restrinxida. Por iso, decidimos realizar o terceiro estudo desta tese, unha análise secundaria sobre o impacto das políticas de restrición de visitas antes e durante a COVID-19 na satisfacción das familias mediante o cuestionario EMPATHIC-F. Observamos que as políticas abertas de visita melloran a satisfacción das familias. Os familiares manifestaron unha maior satisfacción coa atención nunha UCI cunha política de visita aberta (p=0,010), especialmente nos ámbitos de organización (p=0,031) e coidado e tratamento (p=0,019). A pandemia de COVID-19 desafiou as prácticas de atención centrada na familia nas UCI. Durante as restricións de visitas na pandemia de COVID-19, as medianas no dominio da participación familiar foron máis baixas en ambas as UCI, e significativamente máis baixas na UCI cunha política previa de visitas abertas (5,83 *vs.* 5,67, p=0,016). Polo tanto, o persoal da UCI debe avaliar as súas propias prácticas de atención

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centrada na familia para garantir que os cambios temporais implementados durante a pandemia non menoscaben o papel que desempeñan as familias na recuperación do paciente.

Centrándonos nos resultados do cuarto dos estudos recollidos nesta tese, un estudo transversal e prospectivo deseñado para desenvolver e validar a versión española da Medida de Desasosego Moral para Profesionais Sanitarios (MMD-HP-SPA), compre sinalar que o MMD-HP-SPA demostrou ser un instrumento fiable (α= 0,97 de Cronbach) e válido para medir o desasosego moral xa que se confirmaron tres das catro hipóteses de validez. Unha vez validado o MMD-HP-SPA realizamos o quinto dos estudos desta tese, un estudo transversal e prospectivo deseñado para avaliar o desasosego moral entre os profesionais da saúde que traballan nas UCI españolas. Completaron o cuestionario un total de 1.065 profesionais sanitarios que traballan na UCI, 608 enfermeiros (57,1%) e 457 intensivistas (42,9%). O desasosego moral foi significativamente maior entre os médicos (80, IQR 40-135) que entre as enfermeiras (61, IQR 35-133, $p = 0,026$). En particular, entre aqueles médicos que estaban considerando deixar o seu posto de traballo (78, IQR 46-163 *vs*. 61, IQR 32-117; $p < 0,001$). A "*preocupación polo sufrimento dos pacientes pola falta de continuidade dos profesionais*" e "*ter que atender a máis pacientes dos que se pode atender con seguridade*" foron as cuestións que máis desasosego moral provocaron entre todos os participantes. Finalmente, neste estudo realizouse unha análise factorial exploratoria que revelou unha estrutura de catro factores do MMD-HP-SPA, que mostran os niveis de paciente, de equipo ou unidade e de sistema do desasosego moral. Tendo en conta todo o anterior, o MMD-HP-SPA constitúe un instrumento válido e fiable para avaliar as causas específicas do desasosego moral e pódese utilizar como ferramenta de diagnóstico para orientar as intervencións a nivel de unidades, equipos e profesionais.

A pandemia de COVID-19 provocou unha crise sanitaria mundial sen precedentes. Os profesionais sanitarios de primeira liña nas UCI traballaron baixo unha presión extrema e sufriron estrés no traballo e no fogar. Descoñécese o impacto da pandemia de COVID-19 no desasosego moral dos profesionais da saúde que traballan nas UCI. Para avaliar este impacto, realizouse un estudo transversal e prospectivo. Entre os resultados do sexto dos estudos desta tese compre destacar que durante a pandemia de COVID-19 os niveis de desasosego moral aumentaron, especialmente entre as enfermeiras da UCI, en comparación co período anterior á pandemia. Os intensivistas e as enfermeiras da UCI reportaron niveis similares de desasosego moral durante o período pandémico (81,0 [IQR, 39,0–138,5] *vs* 74,0 [IQR, 41,0–143,0]; $p = 0,837$). Durante a pandemia, os profesionais sanitarios máis novos e con menos experiencia, os que traballaban en áreas hospitalarias convertidas en UCI ou en UCI sen cubículos reportaron niveis máis altos de desasosego moral. Ademais, no período anterior á pandemia, as causas raíz a nivel do paciente foron as que máis desasosego moral causaban para as enfermeiras, mentres que os intensivistas reportaron maior desasosego moral para as causas raíz a nivel do sistema. Durante a pandemia, ambos os grupos informaron dun maior desasosego moral por causas raíz a nivel do sistema. Finalmente, durante a COVID-19, un número significativamente maior de profesionais sanitarios consideraron abandonar o seu traballo debido ao desasosego moral. Esta situación pode ter consecuencias negativas na calidade da atención ao paciente. Para previr e/ou mitigar a prevalencia do desasosego moral entre os profesionais sanitarios das UCI, son necesarias e deben implementarse estratexias como aumentar o persoal competente mediante a formación de todo o sistema, investimento en máis equipos, recursos e persoal adicional,

mellorar a colaboración entre médicos e enfermeiras para favorecer a continuidade asistencial e crear unha cultura laboral máis saudable.

Co fin de ofrecer un modelo de Coidados Intensivos máis humanizado para acadar unha maior calidade asistencial, o propósito desta tese foi estudar aspectos tan importantes como a atención ao final da vida, a comunicación, a presenza e implicación dos familiares na UCI e o benestar dos profesionais da saúde. A humanización dos Coidados Intensivos, centrada na dignidade das persoas, é o camiño para construír un excelente sistema de saúde. En definitiva, en Coidados Intensivos, o máis importante non é a tecnoloxía. En Coidados Intensivos o máis importante son os pacientes, as súas familias e os profesionais sanitarios da UCI.

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1.INTRODUCTION

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1! INTRODUCTION

1.1! INTENSIVE CARE: SOME HISTORICAL MILESTONES

Intensive Care is the medical specialty responsible for the care of critically ill patients, it supports persons whose lives are in immediate danger, patients with an actual or potential life-threatening dysfunction of one or more organs that are amenable to recovery. Intensive care aims to reset the "balance" of the patient's defective vital organs before the patient can be transferred to another service[1,2].

There are several key figures and events commonly associated with the origin of Intensive Care and development of Intensive Care Units (ICUs)[3], although many other unrecognized individuals have certainly contributed to the development of this field[4]. During the Crimean War in the 1850s, Florence Nightingale organized a separate area near the nursing station in the Selimiye Military Barracks to care the for critically injured British soldiers from the battlefront requiring the most intensive nursing, so that they could be watched more closely[5], creating an early focus on the importance of a separate geographical area for critically ill patients[4]. In 1923, Johns Hopkins Hospital in Baltimore (MD, USA) created a special three-bed unit for the more critically ill postoperative neurosurgical patients. This unit was staffed by specially trained nurses to help monitor and manage them[4,5]. During World War II, specialized shock units were created to care for the severely wounded soldiers and postoperative patients to provide efficient resuscitation. All marked the implementation of particular attention given to critically ill patients[6].

Modern Intensive Care began with the development of new technology, specifically a very large negative pressure ventilator (the iron lung) designed at Boston Children's Hospital in the 1950s to treat children with polio[5,6]. When the poliomyelitis epidemic hit Copenhagen in 1952, with patients developing respiratory muscle paralysis and/or bulbar palsy, with subsequent respiratory failure and pooling of secretions, hospitals became overwhelmed[7]. At the height of the epidemic, over 300 patients were admitted per week, 30–50 per day, with approximately 10% either 'suffocating or drowning in their own secretions'[8]. Professor Lassen and Dr Bjorn Ibsen, from Blegdam Hospital, hoped that positive pressure ventilation might be a solution[8]. As a result, patients were hand ventilated by teams of medical students via tracheostomy tubes[5,7]. By using such a strategy, mortality from polio in Copenhagen decreased from over 80% to approximately 40%[7]. Subsequently, Dr Bjorn Ibsen had the idea of caring for all such patients in a dedicated ward, where each patient could have their own nurse. Thus, by December 1953, the first ICU was set up to care for polio patients[7,9].

Among the first modern ICUs opened in 1958 and 1959 were those at the University of Southern California and the University of Pittsburgh, both staffed by specially trained intensive care physicians around the clock[6]. These units were opened to improve the recognition and

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treatment of serious complications in critically ill patients[4]. Over the next decade, ICUs began to be created in hospitals across Europe, North America, Australia, and Asia[4].

Since the first ICUs were developed, huge improvements have been made in terms of technological advancements, with modern ventilators replacing the bulky iron lungs of the past, modern ultrasound machines providing instant imaging at the bedside, modern monitoring systems enabling non-invasive assessment of multiple variables, modern machines for continuous renal replacement therapy to support the kidney when it has failed, and modern extracorporeal membrane oxygenation (ECMO) machines to temporally replace the function of the heart and lungs. Improvements have also been made in the understanding of the pathophysiology and pathogenesis of the disease processes that affect critically ill patients[4]. This has led to better outcomes for ICU patients.

Another relevant improvement in modern Intensive Care is the concept of Intensive Care to facilitate organ donation[10]. Currently, Intensive Care to facilitate organ donation is a reality in many countries around us[11,12]. In Spain, its practice is formally recommended by the SEMICYUC[13], is widely practised in ICUs in Spain[14] and accounts for 24% of all organ donors, with 2.3 organs per million donors per year. Consequently, the rate of donors per million population has improved substantially in recent years in our country[10].

1.2! HUMANIZING INTENSIVE CARE

Over the past few decades, research in Intensive Care have resulted in numerous treatments, professional development, and technological advancements. This has enabled modern Intensive Care Medicine to target not only better survival rates but also a better quality of life after discharge[15]. However, humanistic aspects of care have not addressed and developed as effectively as technological advancements, thereby affecting three relevant groups of individuals that are part of the healthcare environment (patients, families, and healthcare professionals)[16]. In some sense, in Intensive Care humanizing the technology is a new and mandatory endeavour.

Early ICUs were somewhat isolated, slightly mysterious, and rather frightening places[4]. In many places, the organizational and architectural characteristics of the ICUs created hostile environments for all[16]. Staff and visitors (when allowed) were often wearing personal protective equipment, patients were often heavily sedated, and visiting hours and contacts with patients and professionals were highly restricted[4]. Displaying kindness and concern for all those involved in healthcare, focusing on the dignity of people, is a necessity and the path toward building an excellent healthcare system[16].

Humanizing means, "*everything that has to be done to promote and protect health, cure diseases and guarantee an environment that favours a healthy and harmonious life on a physical, emotional, social and spiritual level in people*"[17]. "*Talking about humanization demands the intrinsic dignity of every human being and the rights that derive from it, and this makes it a necessity of vital importance and transcendence*"[17]. Thus, humanizing does not only require structural changes, but it also involves individualizing care by paying attention to what patients and relatives need as well as the ethical aspects and dilemmas that use to be present. Moreover, on the other side, humanizing is also understanding and accepting that professionals have their own moral values, experiences, feelings and may be fallible and/or vulnerable;

therefore, we need to be contemplated such relevant aspects as cornerstones to humanize healthcare[16].

Ultimately, humanizing Intensive Care has roots in the ethics and quality-of-care. The ethics of care is a broad concept that includes several aspects about the moral actions of patients, families, and healthcare professionals that arise as result of clinical interpersonal relationships from the beginning to the end-of-life[18-21].

1.2.1! The Humanization of Intensive Care movement (Proyecto HU-CI)

The Humanization of Intensive Care movement (Proyecto HU-CI) is a multicentre and international research project created in Spain in 2014 that seeks to create a paradigm shift in the way Intensive Care is delivered toward a more friendly and human-centred model[22,23]. The main aim of this collaborative project is to evaluate different areas and carry out the implementation of the corresponding improvement actions. These areas of improvement and research were identified through active listening and shared reflections on the opinions of thousands of healthcare professionals[22]. This initiative generated an ICU Humanization plan[24] that was recognized as a paradigm shift in the healthcare model and has laid the foundations for the ICU Manual of Good Practices in Humanization[25], including 160 actions to transform the healthcare management model divided into eight areas of improvement and research (**Figure 1**)[26].

Figure 1. The ICU and the human care bundle. Published in NEJM Catalyst (under Massachusetts Medical Society license and reproduced with their editorial permission)[26]

In order to offer a more humanized Intensive Care model, it has been acknowledged that research efforts are needed to focus on such important aspects as patient well-being and end-of-life care, communication, presence, and involvement of family members in the ICU and the care of healthcare professionals.

1.2.2! End-of-life care

Critically ill patients are admitted to the ICU to receive potentially curative therapies and to restore the patient's health to pre-admission status. Medical interventions, techniques, procedures, or medications administered to a patient to delay death are considered a life-sustaining treatment, whether they are directed at the underlying disease or the causal biological process or not. Examples of these measures are mechanical ventilation, vasoactive drugs, or artificial nutrition, among others.

Patient well-being should be just as an important goal as curing them, even more important if the latter is not possible[25]. It is impossible to cure every patient, but we can improve the care that it is provided by focusing on the dignity of people[16]. Care must be dynamically modified to reduce suffering and offer the best possible care, especially at the end of a patient's life. At that point, palliative and intensive care should coexist throughout the critical patient care process[25,27]. Over the last few years, with a growing influence of ethical considerations in ICU, a change in this scenario has been observed favoured by the publication of international recommendations and guidelines regarding end-of-life practices in ICU[28-34]. Despite these guidelines, there is substantial heterogeneity in end-of-life decision-making processes between regions, countries, individual ICUs within a country, and individual intensivists within one ICU[35-37].

1.2.3! Communication, presence, and involvement of family members in the ICU

Despite the improvement in clinical outcomes over the past few decades in the ICU, critical illness remains an important and stressful life event for patients and their families. Due to patients' illness severity, stressful decision-making often falls to family members[38]. Relatives of critically ill patients increasingly demand to be involved in patients' daily care and to stay at the bedside as much as possible. Moreover, engaging relatives in the care of seriously ill patients is associated with better outcomes[39,40]. This reflects the importance of a family-centred care approach and shared decision processes to deliver high-quality care to the patient and family while recognizing the needs and experiences of the family members[41]. Furthermore, guidelines for family-centred care encourage healthcare professionals to engage with family members to participate in the decision-making process about treatment and care of their relative[42].

A higher presence facilitates the awareness of clinical situations and favours higher family involvement in the patient's process. This requires transforming the concept from "visitor" to that of "partner in care," restoring the role of caregivers to family members and integrating them, if they wish, into the care under the training and supervision of healthcare professionals[25]. Giving the family the chance to be involved in the decision-making process and help towards patient recovery can have positive effects for the patient, family and healthcare professionals, as emotional stress is reduced and communication and proximity by all involved parties is

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enabled, therefore increasing family satisfaction[16]. Accordingly, it is considered that structured interventions and approaches to support family members of critically ill patients are needed.

It is important to carry out activities that enable the patient's family to access the ICU and empower them to provide feedback to ICU teams. It is also essential to enable elements that help to have suitable and empathetic communication with families by all team members to have satisfactory assistance, as well as access to information[25]. Patient and family satisfaction outcomes are increasingly recognized as a quality performance indicator in Intensive Care settings[43-46]. Consequently, satisfaction outcomes might provide valuable information to improve ICU practices such as safety culture, quality of care, communication between family and ICU teams, and family-centred care.

1.2.4! Caring for the healthcare professionals

ICUs are highly specialized facilities where advanced and technologically sophisticated medical care is provided. Despite that, caring for critically ill patients is a stressful and emotionally demanding job due to high patient morbidity and mortality, regular confrontations with ethical challenges, and a tension-charged atmosphere[47-50].

When things do not go well at work, emotional drain is significant among healthcare professionals. When this emotional drain appears alongside not looking after their own health and well-being, the so-called "Burnout Syndrome" emerges. Burnout syndrome is a psychosocial syndrome characterised by three basic aspects: emotional drain, depersonalisation, and feelings of low professional self-esteem[25]. Several intermediate syndromes such as moral distress, the perception of offering inappropriate care or compassion fatigue, can lead to occupational burnout[25]. Moral distress has been described as a challenge that arises when one knows the right thing to do, medically or ethically, but institutional and/or external constraints make it nearly impossible to pursue the right course of action[51]. Particularly in ICU, moral distress occurs when healthcare professionals have frequent exposure to patient care situations and/or to professional environments where they believe they are doing something ethically wrong, but they lack the ability to change the situation[49,50,52,53]. This phenomenon is now understood to be a serious problem generalizable to other disciplines at hospitals, threatening the integrity of healthcare professionals and healthcare systems as well[49,50,52,54]. In fact, it compromises care both at a personal (as a root cause of burnout and employee attrition) and at a system (decreased quality of care) level[55].

Society and organisations have a moral duty, an ethical imperative and a legal obligation to "take care of their carers". It is important to improve knowledge on occupational burnout and moral distress by using validated tools and favouring its visibility. Accordingly, priority objectives should be set to guide us towards preventative and therapeutic actions[25].

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2. HYPOTHESES AND OBJECTIVES

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2! HYPOTHESES AND OBJECTIVES

Although humanisation in Intensive Care is a very broad field of knowledge with many different areas of improvement and research, there are areas that deserve specific attention (patients, families, and healthcare professionals). Following, the hypotheses and objectives behind the works developed along the next sections of this thesis are described.

Section **4.1. MODES OF DEATH IN THE INTENSIVE CARE UNIT** presents an observational retrospective study which evaluates the modes of death in all patients who died in a Spanish tertiary ICU over a 10-year period. Modes of death were classified as death despite maximal support, brain death, and death following life-sustaining treatment limitation.

Although mortality is an important outcome in Intensive Care and has therefore been thoroughly studied, the way critically ill patients die in the ICU has been poorly reported. The death of a patient in the ICU can happen in different ways, classically despite maximal support or when brain death is declared. However, in most developed countries, death following life-sustaining treatment limitation has become the most frequent way patients die in ICU[35-37]. In fact, following current recommendations regarding end-of-life care in ICU, there should be a specific register for the limitation of life-sustaining treatment[25].

Hypothesis

An analysis of the modes of death, the circumstances surrounding it, and the characteristics of patients who died in the ICU, as well as temporal trends regarding death, will help us to better understand and improve end-of-life care in the ICU today.

Objectives

To describe the modes of death of patients who died in a general ICU.
To identify possible changes in the modes of death over the last ten years.
To describe the epidemiology of patients who died in a general ICU.

Section **4.2. EMPOWERMENT AND SATISFACTION OF FAMILIES IN THE INTENSIVE CARE UNIT** presents a cross-sectional prospective study designed to construct a valid and reliable instrument to measure the experiences and satisfaction with care of patients' primary support persons in the ICU.

A. The EMpowerment of PAtients in THe Intensive Care-Family (EMPATHIC-F) questionnaire

Critical illness remains an important and stressful life event for patients and their families. The effective incorporation of the family as a member of the ICU team can reduce anxiety and stress,

improving satisfaction, and decreasing post-intensive care syndrome[25]. Satisfaction outcomes might provide valuable information to improve ICU practices such as safety culture, quality-of-care, communication between family and ICU teams, and family-centred care. Accordingly, validated satisfaction measurement tools are essential to evaluate health care professionals' performance from the patients' and relatives' points of view. Besides, these tools can be used to detect best practices and areas of care to improve[56]. None of the previously validated instruments in adult ICUs cover all the core principles of family-centred care. Satisfaction with care is at the heart of a framework comprised of the respect for the needs of family members, adequate information, participation in decision-making, emotional and physical support, and coordination of care.

Hypothesis

We hypothesized that the EMpowerment of PArents in The Intensive Care (EMPATHIC-30) questionnaire could be adapted and used in adult critical care settings as a standardized measure of family members' experience and satisfaction of the Intensive Care process.

Objectives

To adapt and validate the Spanish EMPATHIC-30 questionnaire in adult intensive care settings.

To construct and psychometrically test the EMPATHIC-F questionnaire to measure family satisfaction.

To explore relatives' experiences and satisfaction with family-centred care domains in the ICU.

B. Impact of different visiting policies on family satisfaction before and during COVID-19

When Spain was hit by COVID-19 pandemic in March 2020, visiting policies in ICUs changed towards a more restricted policy. These restrictions have left family members unable to visit their loved ones[57,58].

Hypothesis

Although strategies have been implemented to improve communication with relatives of ICU patients during COVID-19 pandemic[59], we hypothesized that under current circumstances family satisfaction outcomes, measured by the EMPATHIC-F questionnaire, have worsened compared to before the pandemic.

Objectives

To analyse the impact of restricted visiting policies during COVID-19 on family satisfaction measured by the validated EMPATHIC-F questionnaire.

Section **4.3. MORAL DISTRESS AMONG NURSES AND PHYSICIANS WORKING IN SPANISH ICUs** presents a cross-sectional prospective study designed to construct the first valid and reliable instrument in Spanish to measure moral distress among healthcare professionals.

A. Moral distress in ICUs, the DEMOUCI project

In ICUs, the natural stressors of patient care are augment by the suffering and death, fear, and uncertainty of the patients. Sometimes, healthcare professionals may feel helpless, unable to provide care according to their own belief system, and therefore prone to develop moral distress[48,50,51]. Moral distress is the psychological consequence that occurs when healthcare professionals cannot carry on what they believe is the ethically correct action[51]. This serious problem threats the integrity not only of healthcare professionals but of healthcare organizations as well. Moral distress has been associated with risk of burnout, employee attrition, propensity to leave a position and decreased quality of care[49,53-55,60].

Valid and reliable instruments to measure moral distress are needed to explore its impact in order to develop effective interventions[61,62]. Furthermore, conditions and factors that contribute to increase moral distress should be studied at local level as socio-demographic and health system characteristics are heterogeneous between countries.

To our knowledge, no prior instruments to measure moral distress has been validated in Spanish and no prior studies have evaluated moral distress among Spanish-speaking healthcare professionals.

Hypothesis

We hypothesized that the Spanish version of the Measure of Moral Distress for Healthcare Professionals (MMD-HP-SPA) could be culturally adapted, translated, and validated as a standardized tool to measure moral distress among Spanish healthcare professionals.

Objectives

To develop and validate the Spanish version of the Measure of Moral Distress for Healthcare Professionals (MMD-HP-SPA).

To measure moral distress levels in Spanish ICU healthcare professionals.

To explore the potential relationship between moral distress, demographic factors, and ICU ethical climate.

B. Impact of COVID-19 pandemic on moral distress among healthcare professionals in Spanish ICUs

COVID-19 pandemic has resulted in an unprecedented global healthcare crisis[63]. The management of critically ill patients during the pandemic has been one of the greatest challenges faced by healthcare professionals and healthcare systems[64]. Throughout 2020, globally, frontline healthcare professionals in ICUs worked under extreme pressure and have suffered from several occupational and domestic stressors[65]. Thus, during the COVID-19 pandemic, healthcare professionals in ICUs may be at particularly high risk of moral distress[66,67]. It is unknown how COVID-19 pandemic has impacted on moral distress among healthcare professionals working in ICU.

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Hypothesis

We hypothesized that COVID-19 pandemic has increased the frequency and intensity of moral distress among Spanish ICU healthcare professionals.

Objectives

To measure moral distress levels in Spanish ICU healthcare professionals during the second wave of the pandemic.

To compare these levels with those before the COVID-19 surge.

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3. MATERIAL AND METHODS

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3! MATERIAL AND METHODS

Material and methods are described in detail in the articles presented in the next sections.

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4. RESULTS

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4! RESULTS

4.1! MODES OF DEATH IN THE INTENSIVE CARE UNIT

Article 001 *- Title:* ***Shifting trends in modes of death in the Intensive Care Unit***.

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Montserrat Mansilla Rodríguez, Beatriz Elena Lence Massa, Ana Estany-Gestal, Andrés Blanco Hortas, Raquel Cruz-Guerrero, Cristobal Galbán Rodríguez, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Journal of Critical Care****.*
ISSN: 0883-9441.
Publisher: Elsevier.
Indexed in Web of Science – JCR 2021 impact factor: ***4.298 – Q1****, Critical Care Medicine.*
Indexed in Scopus – SJR 2021 impact factor: 1.149 – Q1, Critical Care and Intensive Care Medicine.

Rodriguez-Ruiz E, Campelo-Izquierdo M, Mansilla Rodríguez M, Lence Massa BE, Estany-Gestal A, Blanco Hortas A, et al. Shifting trends in modes of death in the Intensive Care Unit. J Crit Care. 202;64:131-138. https://doi.org/10.1016/j.jcrc.2021.04.003

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4.2! EMPOWERMENT AND SATISFACTION OF FAMILIES IN THE INTENSIVE CARE UNIT

Article 002 - *Title:* ***Measuring family-centred care practices in adult intensive care units: The EMPATHIC-F questionnaire***.

Article 003 - *Title:* ***Impact of different visiting policies on family satisfaction in two Spanish ICUs before and during COVID-19***.

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Article 002 - *Title:* ***Measuring family-centred care practices in adult intensive care units: The EMPATHIC-F questionnaire***.

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Montserrat Mansilla Rodríguez, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez, Jos M. Latour.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Nursing in Critical Care****.*
ISSN: 1478-5153.
Publisher: Wiley Online Library.
Indexed in Web of Science – JCR 2021 impact factor: ***2.897 – D1****, Nursing.*
Indexed in Scopus – SJR 2021 impact factor: 0.689 – D1, Critical Care Nursing.

Rodríguez-Ruiz E, Campelo-Izquierdo M, Mansilla Rodríguez M, Estany-Gestal A, Blanco Hortas A, Rodríguez-Calvo MS, et al. Measuring family-centred care practices in adult intensive care units: The EMPATHIC-F questionnaire. Nurs Crit Care. 2022;27(3):375-383. https://doi.org/10.1111/nicc.12670

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Article 003 *– (letter) Title:* ***Impact of different visiting policies on family satisfaction in two Spanish ICUs before and during COVID-19****.*

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Ana Estany-Gestal, Antonio Rodríguez-Núñez, Jos M. Latour.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Intensive Care Medicine****.*
ISSN: 0342-4642.
Publisher: Springer.
Indexed in Web of Science – JCR 2021 impact factor: ***41.787 – D1****, Critical Care Medicine.*
Indexed in Scopus – SJR 2021 impact factor: 3.658 – D1, Critical Care and Intensive Care Medicine.

Rodriguez-Ruiz E, Campelo-Izquierdo M, Estany-Gestal A, Rodríguez-Núñez A, Latour JM. Impact of different visiting policies on family satisfaction in two Spanish ICUs before and during COVID-19. Intensive Care Med. 2021;47(10):1165-1166. https://doi.org/10.1007/s00134-021-06485-0

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4.3! MORAL DISTRESS AMONG NURSES AND PHYSICIANS WORKING IN SPANISH ICUS

Article 004 - *Title:* ***Validation and psychometric properties of the Spanish version of the Measure of Moral Distress for Health Care Professionals (MMD-HP-SPA)***.

Article 005 - *Title:* ***Moral distress among healthcare professionals working in intensive care units in Spain***.

Article 006 - *Title:* ***Impact of the COVID-19 Pandemic on Moral Distress among Nurses and Physicians in Spanish ICUs***.

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Article 004 *– (letter) Title:* ***Validation and psychometric properties of the Spanish version of the Measure of Moral Distress for Health Care Professionals (MMD-HP-SPA)****.*

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Medicina Intensiva (Engl Ed)****.*
ISSN: 0210-5691.
Publisher: Elsevier.
Indexed in Web of Science – JCR 2021 impact factor: ***2.799 – Q2****, Critical Care Medicine.*
Indexed in Scopus – SJR 2021 impact factor: 0.336 – Q2, Critical Care and Intensive Care Medicine.

Rodriguez-Ruiz E, Campelo-Izquierdo M, Estany-Gestal A, Hortas AB, Rodríguez-Calvo MS, Rodríguez-Núñez A. Validation and psychometric properties of the Spanish version of the Measure of Moral Distress for Health Care Professionals (MMD-HP-SPA). Med Intensiva (Engl Ed). 2022;46(3):169-170. https://doi.org/10.1016/j.medine.2022.02.001

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Article 005 *- Title:* ***Moral distress among healthcare professionals working in intensive care units in Spain****.*

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Paula Boga Veiras, Montserrat Mansilla Rodríguez, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Medicina Intensiva (Engl Ed)****.*
ISSN: 0210-5691.
Publisher: Elsevier.
Indexed in Web of Science – JCR 2021 impact factor: ***2.799 – Q2****, Critical Care Medicine.*
Indexed in Scopus – SJR 2021 impact factor: 0.336 – Q2, Critical Care and Intensive Care Medicine.

Rodriguez-Ruiz E, Campelo-Izquierdo M, Veiras PB, Rodríguez MM, Estany-Gestal A, Hortas AB, et al. Moral distress among healthcare professionals working in intensive care units in Spain. Med Intensiva (Engl Ed). 2022;46(7):383-391. https://doi.org/10.1016/j.medin.2021.06.004

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Article 006 *- Title:* ***Impact of the COVID-19 Pandemic on Moral Distress among Nurses and Physicians in Spanish ICUs****.*

Authors: ***Emilio Rodriguez-Ruiz****, Maitane Campelo-Izquierdo, Paula Boga Veiras, Montserrat Mansilla Rodríguez, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez.*

Specific contribution of the PhD candidate to the article: Conception and design of the study, analysis, and interpretation of data, drafting of the manuscript and revision after peer-review.

Journal: ***Critical Care Medicine****.*
ISSN: 0090-3493.
Publisher: Wolters Kluwer.
Indexed in Web of Science – JCR 2021 impact factor: ***9.296 – D1****, Critical Care Medicine.*
Indexed in Scopus – SJR 2021 impact factor: 3.002 – D1, Critical Care and Intensive Care Medicine.

Rodriguez-Ruiz E, Campelo-Izquierdo M, Boga Veiras P, Mansilla Rodríguez M, Estany-Gestal A, Blanco Hortas A, Rodríguez-Calvo MS, Rodríguez-Núñez A. Impact of the COVID-19 Pandemic on Moral Distress among Nurses and Physicians in Spanish ICUs. Crit Care Med. 2022;50(5):e487-e497. https://doi.org/10.1097/CCM.0000000000005434

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4.4! OTHER STUDIES CONDUCTED DURING THE DOCTORAL THESIS PERIOD

In addition to the specific results derived from the main research projects, the following research studies were also conducted during the doctoral thesis period, framed within the fields of Simulation, Life Support, Intensive Care, Sepsis Biomarkers, and Clinical Ethics. Following, these contributions are presented in chronological order:

1. **Original Research Article**: Cruz R, Almeida SD, Heredia ML, Quintela I, Ceballos FC, Pita G, Lorenzo-Salazar JM, González-Montelongo R, Gago-Domínguez M, Porras MS, Castaño JAT, Nevado J, Aguado JM, Aguilar C, Aguilera-Albesa S, Almadana V, Almoguera B, Alvarez N, Andreu-Bernabeu Á, Arana-Arri E, Arango C, Arranz MJ, Artiga MJ, Baptista-Rosas RC, Barreda-Sánchez M, Belhassen-Garcia M, Bezerra JF, Bezerra MAC, Boix-Palop L, Brion M, Brugada R, Bustos M, Calderón EJ, Carbonell C, Castano L, Castelao JE, Conde-Vicente R, Cordero-Lorenzana ML, Cortes-Sanchez JL, Corton M, Darnaude MT, De Martino-Rodríguez A, Campo-Pérez V, Bustamante AD, Domínguez-Garrido E, Luchessi AD, Eirós R, Sanabria GME, Fariñas MC, Fernández-Robelo U, Fernández-Rodríguez A, Fernández-Villa T, Gil-Fournier B, Gómez-Arrue J, Álvarez BG, Quirós FGB, González-Peñas J, Gutiérrez-Bautista JF, Herrero MJ, Herrero-Gonzalez A, Jimenez-Sousa MA, Lattig MC, Borja AL, Lopez-Rodriguez R, Mancebo E, Martín-López C, Martín V, Martinez-Nieto O, Martinez-Lopez I, Martinez-Resendez MF, Martinez-Perez Á, Mazzeu JA, Macías EM, Minguez P, Cuerda VM, Silbiger VN, Oliveira SF, Ortega-Paino E, Parellada M, Paz-Artal E, Santos NPC, Pérez-Matute P, Perez P, Pérez-Tomás ME, Perucho T, Pinsach-Abuin ML, Pompa-Mera EN, Porras-Hurtado GL, Pujol A, León SR, Resino S, Fernandes MR, ***Rodríguez-Ruiz E***, Rodriguez-Artalejo F, Rodriguez-Garcia JA, Ruiz-Cabello F, Ruiz-Hornillos J, Ryan P, Soria JM, Souto JC, Tamayo E, Tamayo-Velasco A, Taracido-Fernandez JC, Teper A, Torres-Tobar L, Urioste M, Valencia-Ramos J, Yáñez Z, Zarate R, Nakanishi T, Pigazzini S, Degenhardt F, Butler-Laporte G, Maya-Miles D, Bujanda L, Bouysran Y, Palom A, Ellinghaus D, Martínez-Bueno M, Rolker S, Amitrano S, Roade L, Fava F, Spinner CD, Prati D, Bernardo D, Garcia F, Darcis G, Fernández-Cadenas I, Holter JC, Banales JM, Frithiof R, Duga S, Asselta R, Pereira AC, Romero-Gómez M, Nafría-Jiménez B, Hov JR, Migeotte I, Renieri A, Planas AM, Ludwig KU, Buti M, Rahmouni S, Alarcón-Riquelme ME, Schulte EC, Franke A, Karlsen TH, Valenti L, Zeberg H, Richards B, Ganna A, Boada M, Rojas I, Ruiz A, Sánchez P, Real LM; SCOURGE Cohort Group; HOSTAGE Cohort Group; GRA@CE Cohort Group, Guillen-Navarro E, Ayuso C, González-Neira A, Riancho JA, Rojas-Martinez A, Flores C, Lapunzina P, Carracedo Á. **Novel genes and sex differences in COVID-19 severity**. **Hum Mol Genet**. 2022, ddac132. https://doi.org/10.1093/hmg/ddac132.

2. **Letter to the Editor**: Carballo-Fazanes A, Abelairas-Gómez C, ***Rodríguez-Ruiz E***, Barcala-Furelos R, Rodríguez-Núñez A. **Anti-choking suction devices use. A pilot simulated study with parents and kindergarten teachers**. ***Resuscitation***. 2022, S0300-9572(22)00567-6. https://doi.org/10.1016/j.resuscitation.2022.06.005.

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3. **Original Research Article**: Greco M, De Corte T, Ercole A, Antonelli M, Azoulay E, Citerio G, Morris AC, De Pascale G, Duska F, Elbers P, Einav S, Forni L, Galarza L, Girbes ARJ, Grasselli G, Gusarov V, Jubb A, Kesecioglu J, Lavinio A, Delgado MCM, Mellinghoff J, Myatra SN, Ostermann M, Pellegrini M, Povoa P, Schaller SJ, Teboul JL, Wong A, De Waele JJ, Cecconi M, **ESICM UNITE-COVID investigators**. **Clinical and organizational factors associated with mortality during the peak of first COVID-19 wave: the global UNITE-COVID study**. ***Intensive Care Med***. 2022, 1-16. https://doi.org/10.1007/s00134-022-06705-1.

4. **Letter to the Editor**: Riera J, Alcántara S, Bonilla C, Fortuna P, Ortiz AB, Vaz A, Albacete C, Millán P, Ricart P, Boado MV, de Gopegui PR, Santa Teresa P, Sandoval E, Pérez-Chomón H, González-Pérez A, Duerto J, Gimeno R, Colomina J, Gómez V, Renedo G, Naranjo J, García MA, ***Rodríguez-Ruiz E***, Silva PE, Pérez D, Veganzones J, Voces R, Martínez S, Blanco-Schweizer P, García M, Villanueva-Fernández H, Fuset MP, Luna SM, Martínez-Martínez M, Argudo E, Chiscano L, Roncon-Albuquerque Jr R. **Risk factors for mortality in patients with COVID-19 needing extracorporeal respiratory support**. ***Eur Respir J***. 2022, 59(2):2102463. https://doi.org/10.1183/13993003.02463-2021.

5. **Letter to the Editor**: Riera J, Roncon-Albuquerque Jr R, Fuset MP, Alcántara S, Blanco-Schweizer P, Bonilla C, Vaz A, Luna SM, Fortuna P, Silva PE, Albacete CL, Pérez D, García M, Millán P, Veganzones J, Ricart P, Martínez S, Boado MV, Voces R, Villanueva-Fernández H, Blandino A, Santa-Teresa P, Sandoval E, de Gopegui PR, González-Pérez A, Duerto J, Gimeno R, Colomina J, Gómez V, Pérez-Chomón H, Renedo G, García MA, Naranjo JR, ***Rodríguez-Ruiz E***. **Increased mortality in patients with COVID-19 receiving extracorporeal respiratory support during the second wave of the pandemic**. ***Intensive Care Med***. 2021 9;1-4. https://doi.org/10.1007/s00134-021-06517-9.

6. **Letter to the Editor**: ***Rodriguez-Ruiz E***[#], Estany-Gestal A, Hoyme DB, Nadkarni VM, Rodríguez-Núñez A. **Evidence-based defibrillation dosage for children: Is it feasible to power a reliable pediatric clinical trial or it is mission impossible?** ***Resuscitation***. 2021;162:266-267. https://doi.org/10.1016/j.resuscitation.2021.03.026.

7. **Original Research Article**: Almengló C, ***Rodriguez-Ruiz E***[#], Alvarez E, López-Lago A, González-Juanatey JR, Garcia-Allut JL. **Minimal invasive fluorescence methods to quantify advanced glycation end products (AGEs) in skin and plasma of humans**. ***Methods***. 2022;203:103-107. https://doi.org/10.1016/j.ymeth.2020.12.003.

8. **Letter to the Editor**: ***Rodriguez-Ruiz E***[#], Abelairas-Gómez C, Barcala-Furelos R, Rodríguez-Núñez A. **Foreign body airway obstruction and anti-choking suction devices. Time to step forward**. ***Resuscitation***. 2020;157:133-134. https://doi.org/10.1016/j.resuscitation.2020.09.038.

9. **Original Research Article**: Agra-Tuñas C, ***Rodriguez-Ruiz E***[#], Rodríguez Merino E, MOMUCIP-2 study group of the SECIP. **How Do Children Die in PICUs Nowadays? A Multicenter Study from Spain.** ***Pediatr Crit Care Med***. 2020;21(9):e610-e616. https://doi.org/10.1097/PCC.0000000000002359.

10. **Original Research Article**: ***Rodriguez-Ruiz E***[#], Lopez-Lago A, Hernandez-Vaquero R, Granja-Gomez I, Estany-Gestal A, Alvarez E, Garcia-Gonzalez M, Garcia-Allut JL. **First-Days Reduction of Plasma and Skin Advanced Glycation End Products is Related to Outcome in Septic Patients**. ***Shock***. 2020;53(4):400-406. https://doi.org/10.1097/SHK.0000000000001396.

11. **Original Research Article**: González-Salvado V, ***Rodríguez-Ruiz E***, Abelairas-Gómez C, Ruano-Raviña A, Peña-Gil C, González-Juanatey JR, Rodríguez-Núñez A. **Training adult laypeople in basic life support. A systematic review.** ***Rev Esp Cardiol (Engl Ed)***. 2020;73(1):53-68. https://doi.org/10.1016/j.rec.2018.11.013.

12. **Case Report**: ***Rodriguez-Ruiz E***[#], Barral-Segade P, Fernández-González AL, Prim JMG, Galbán Rodríguez C. **Venovenous extracorporeal membrane oxygenation as a bridge to traumatic bronchial fistula closure**. ***Rev Esp Anestesiol Reanim (Engl Ed)***. 2019;66(10):533-536. https://doi.org/10.1016/j.redar.2019.02.008.

13. **Original Research Article**: ***Rodriguez-Ruiz E***[#], Martínez-Puga A, Carballo-Fazanes A, Abelairas-Gómez C, Rodríguez-Nuñez A. **Two new chest compression methods might challenge the standard in a simulated infant model**. ***Eur J Pediatr***. 2019;178(10):1529-1535. https://doi.org/10.1007/s00431-019-03452-2.

14. **Case Report**: ***Rodriguez-Ruiz E***[#], López-Lago A, Barredo MA. **Mobile thrombus in right atrium during cannulation of veno-venous extracorporeal membrane oxygenation**. ***Med Intensiva (Engl Ed)***. 2019;43(6):390-391. https://doi.org/10.1016/j.medin.2018.10.003.

15. **Letter to the Editor**: ***Rodriguez-Ruiz E***[#], Rodríguez-Nuñez A. **In reply to "The thumbs angle used in the novel infant chest compression technique (nTTT) can influence the quality parameters of resuscitation".** ***Med Intensiva (Engl Ed)***. 2019;43(6):388. https://doi.org/10.1016/j.medin.2018.10.004.

16. **Original Research Article**: ***Rodriguez-Ruiz E***[#], Martín VG, Abelairas-Gómez C, Vidal FS, González CG, Barcala-Furelos R, Rodríguez-Nuñez A. **A new chest compression technique in infants.** ***Med Intensiva (Engl Ed)***. 2019;43(6):346-351. https://doi.org/10.1016/j.medin.2018.04.010.

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17. **Original Research Article**: Abelairas-Gómez C, Rey E, González-Salvado V, Mecías-Calvo M, ***Rodríguez-Ruiz E***, Rodríguez-Núñez A. **Acute muscle fatigue and CPR quality assisted by visual feedback devices: A randomized-crossover simulation trial**. ***PLoS One***. 2018;13(9):e0203576. https://doi.org/10.1371/journal.pone.0203576.

    [#]*Corresponding author*.

In addition, the following research have been presented at different national and international scientific congresses:

1. **Poster presentation**: Saito C, Gonzales-Fernandez L, Trastoy-Quintela J, ***Rodriguez-Ruiz E***, Rodriguez-Nuñez A. **Preliminary experience with a new management protocol for diabetic ketoacidosis based on isotonic fuids and continuous subcutaneous glucose monitoring.** ***Intensive Care Medicine Experimental***. 2021, 9(1): 000458.

2. **Poster presentation**: Martinez-Martinez M, Carmona SA, Mateo-Sidron JAR, Álvarez JD, Sánchez-Girón GR, Núñez JM, Gómez V, Naranjo JR, ***Rodríguez-Ruiz E***, García MG, Moura A, Ibars CP, Bonilla C, Barrera RR, Fructuoso OV, Girón P, Riera J, ECMOVIBER Study Group. **Complications and causes of death of patients with COVID-19 requiring extracorporeal respiratory support. A subanalysis of the ECMOVIBER study**. ***Perfusion***. 2021;36(1_supl):4-81. https://doi.org/10.1177/02676591211007763.

3. **Poster presentation**: ***Rodriguez-Ruiz E***, Pardo MR, López CM, Moreira LS, Segade PB, Antelo MCD, Pedreira AV, Freire AIS, Castiñeiras GB, Sedes PR. **Are surveillance cultures useful for predicting multi-drug resistant bacterial infections?** ESICM LIVES 2019. ***Intensive Care Medicine Experimental***. 2019; 7(Suppl 3):000643. https://doi.org/10.1186/s40635-019-0265-y.

4. **Poster presentation**: ***Rodríguez-Ruiz E***, Sayagués Moreira L, Domínguez Antelo C, Barral Segade P, Robelo Pardo M, Suárez Freire A, Virgós Pedreira A y Rascado Sedes P. **Morbimortalidad asociada a colonización/infección por Klebsiella productora de carbapenemasas**. ***Med Intensiva***. 2019; 43 Supl Congr:91-185.

5. **Poster presentation**: Domínguez Antelo C, Martín López C, Sayagués Moreira L, Barral Segade P, Robelo Pardo M, ***Rodríguez-Ruiz E***, Barbeito Castiñeiras G, Virgós Pedreira A, Suárez Freire A, Rascado Sedes P. **¿Es necesario realizar cultivos de vigilancia a todos los pacientes que ingresan en UCI?.** ***Med Intensiva***. 2019;43 Supl Congr:1-91.

6. **Poster presentation**: Villanueva JRF, Garda RF, Vaquero RH, Gómez IG, ***Rodriguez-Ruiz E,*** Rodríguez CG, Pérez EV. **Elderly Donor and Gender Impact on Cumulative**

Survival Rates of Liver Graft Recipient in 20 Years of Experience in Santiago de Compostela, Spain. ***Intensive Care Medicine Experimental***. 2018;6(Suppl 2):0828.

7. **Poster presentation**: ***Rodriguez-Ruiz E***, Hernández-Vaquero R, Gómez IG, Allut JLG, Lago AL, Gestal AE, González MAG. **Advanced Glycation End Products and New-Onset Atrial Fibrillation in Sepsis.** ***Intensive Care Medicine Experimental***. 2018, 6(Suppl 2):1207.

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5. GENERAL DISCUSSION

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5! GENERAL DISCUSSION

Intensive Care is the medical specialty responsible for the care of critically ill patients. It aims to support patients whose lives are in immediate danger, patients with an actual or potential life-threatening dysfunction of one or more organs that are amenable to recovery[1,2]. Despite the evolution and improvements in Intensive care over the past few decades, there are many non-technological aspects to explore in the care of critically ill patients. The ICU Manual of Good Practices in Humanization[25] includes 160 actions divided into eight strategic lines (**Figure 1**)[26] to deliver a more friendly and human-centred Intensive Care model. Humanizing Intensive Care is the way to deliver a better care focused on patients, families, and healthcare professionals. Taking this in mind, this thesis provides new important data regarding several areas of improvement in the humanisation of Intensive Care:

First, this thesis presents an observational retrospective study which evaluates the modes of death in 1553 patients who died in a Spanish tertiary ICU over a 10-year period. It analyses and discusses shifting trends in modes of death overtime and epidemiology these patients to better understand and improve end-of-life care practices in ICU.

Second, because of the lack of validated instruments to measure the experiences and satisfaction of relatives in adult Intensive Care settings covering all the core principles of family-centred care, this thesis affords a new validated tool able to measure the satisfaction with care of relatives, the EMPATHIC-F questionnaire. Besides, this thesis explores how restricted ICU visiting policies during COVID-19 pandemic impacted on family satisfaction using the EMPATHIC-F questionnaire.

Lastly, this thesis presents a cross-sectional prospective study which measures moral distress among healthcare professionals working in ICUs in Spain by using the first valid and reliable instrument to measure moral distress in Spanish, the MMD-HP-SPA. Moreover, this thesis investigates how the COVID-19 pandemic impacted on moral distress among nurses and physicians working in Spanish ICUs.

5.1! MODES OF DEATH IN THE INTENSIVE CARE UNIT

This thesis reports on the clinical characteristics and modes of death of 1553 patients who died in a Spanish tertiary ICU over a 10-year period. Mortality in ICU patients is an essential outcome; thus, it has been broadly analysed. However, there are few studies on circumstances surrounding death and specifically how critically ill patients finally die are limited and focused on selected populations[68-70].

Advancements in Intensive Care have led to an improvement in ICU survival over the past decades. As it is described in our study, we have observed a significant yearly reduction in mortality over the last ten years, with a similar mortality rate to those reported worldwide, currently around 15%[15,71]. Modern high-quality Intensive Care has provided ICU teams the

ability to extend life, even of the sickest patients[36]. This may have led to an increase in ICU admissions[37,72]. In this sense, we have observed a yearly increase of 3.5% in ICU admissions. Furthermore, Angus et al.[73] detected an extensive ICU utilization at the end-of-life, with an estimated one in five deaths in the U.S. happened to be within an ICU. In accordance, approximately 30% of adults older than 65 years are treated in an ICU during the last month of life[74].

Unfortunately, development of interventions to improve patient and family-centred care have not been as effective as technological advancements[16,24,42]. The availability of more sophisticated and invasive resuscitation and life support techniques in Intensive Care have further complicated decision-making processes at the end-of-life[75]. Healthcare workers attending severely ill patients near the end of their lives in the ICU should be able to provide quality and humanized end-of-life care. This is a foundational aspect of modern Intensive Care and nowadays a professional challenge for all the ICU team[76]. Quality end-of-life care involves a multidisciplinary palliative care plan reaching the physical, psychosocial, ethical, and spiritual needs of patients and relatives[77]. Thus, palliative care should be integrated into ICUs, and it must coexist with Intensive Care throughout the critical care process[16,78,79]. This integration decreases the use of nonbeneficial (futile) life-prolonging treatments[80], allowing patients to die with dignity and without pain[29].

In the last few years, clinicians have increased their knowledge in end-of-life care[28-34]. Nevertheless, despite current recommendations, there is still a significant variability in end-of-life decision-making processes[35-37]. Different cultural[30], legal[81], political, socioeconomic[82], religious[35,81,83], and ethical preconditions may play an important role in such decisions and must be considered. More specifically, there is significant variability in modes of death of patients dying in ICU. Studies from diverse international settings reported that death following life-sustaining treatment limitation occurs in 14–88% of deaths, consistent with our findings of 25%[35-37,84,85]. On the other hand, death despite maximal support was observed in 57.2% of the decedents in our cohort, ranging in recent literature from 6.2% to 47%[35-37]. In our study, death following life-sustaining treatment limitation was associated with patient age, pre-existing comorbidity, and hospital stay. Previous studies reported that this mode of death was also associated with geographical and religious factors[35,37]. As was to be expected, brain death was associated with neurological and trauma disease as causes of admission. The proportion of patients diagnosed with brain death in our study (17.8%) was among the highest in current literature[35,37], and has remained stable over time. Our finding could be related to multiple factors such as the better outcomes in trauma patients[86] or the greater focus on identification and support of potential organ donors because of the National Transplant Organization (Organización Nacional de Trasplantes, ONT) initiatives[10].

During the period of our study, new European laws[87], recommendations[34], guidelines[32,33], consensus statements by Scientific Societies[31,42,88], and research regarding end-of-life practices have been developed. Consequently, the mode how critically ill patients die seems to be changing. In the past, critically ill patients were more likely to die receiving maximal support. On the contrary, recent developments may explain the increase in limiting life-prolonging treatment and the decrease in death despite maximal support, with death following life-sustaining treatment limitation as the predominant mode of death within the ICU nowadays.

Despite limited contemporary data on temporal trends, most recent end-of-life practice comparison studies are consistent to our results. McLean et al.[89] compared the mode of death between 1988 and 1993 in two Canadian ICUs and found 23% and 34% increases in the withdrawal of life-sustaining treatments in both ICUs. Between 2012 and 2016 Lesieur et al.[85] demonstrated a 36% decrease in death despite maximal support and a 16% increase in death following life-sustaining treatment limitation in a French single-centre study. The ETHICUS-2 study reported the changes in end-of-life practices between 1999 and 2016 in 22 European ICUs and found an increase of withholding (9%) and withdrawing (14%) life-sustaining therapies, whereas death despite maximal support decreased (−16%)[37]. Our study found, from 2009 to 2018, an increase of death following life-sustaining treatment limitation (25%) and a reduction in patients receiving maximal support at end-of-life (−23.1%).

Increasing rates of death following life-sustaining treatment limitation and declining rates of death despite maximal support may signify an improvement in end-of-life care in ICU. Death is just another part of life and the day that this is understood, the day that we approach the process of dying realising that the objective is to die well, the day when death is no longer seen as a failure, we will have taken a very important step forward in the humanisation of the health system. Even though our figures of death following life-sustaining treatment limitation are far from the latest reports in Southern Europe (84.2%)[37], regional differences may be decreasing due to a change towards more humanistic aspects of care in ICU[16]. Life-sustaining treatment limitation implies a shared decision-making process between patients, families, and healthcare team. Although limited, our study highlight that ICU team must be aware of the changes that happened in last years as well as the current end-of-life issues and the need for a multidisciplinary patient and family-centred approach in such circumstances. In this sense, it is essential to adequately train Intensive Care residents and fellows in life-sustaining treatment limitation processes; also, seniors should be updated in such processes. They should be able to offer the best possible quality end-of-life care in the ICU. Therefore, healthcare professionals should have the necessary knowledge, attitudes, skills, and tools to deal with these situations and to face potential ethical conflicts.

One of the potential limitations of our study is that it is based on a single-centre experience and may not be generalizable. However, our study includes a large number of patients, a long study period, the same healthcare professionals being responsible for end-of-life decisions and data collection, and the evaluation of changes in the study ICU in relation to modes of death.

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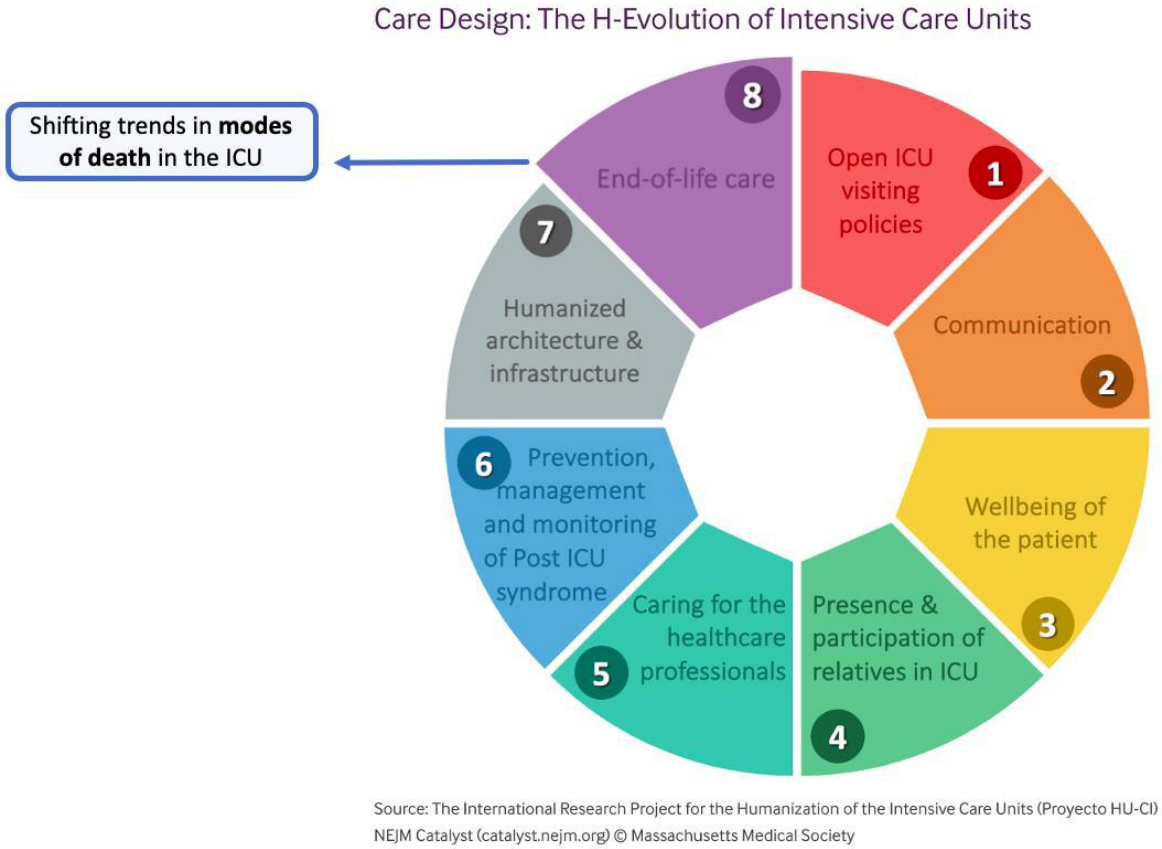

Figure 2. End-of-life care: shifting trends in modes of death in the Intensive Care Unit. Adapted from: The ICU and the human care bundle. Published in NEJM Catalyst (under Massachusetts Medical Society license and reproduced with their editorial permission)[26]

5.2! EMPOWERMENT AND SATISFACTION OF FAMILIES IN THE INTENSIVE CARE UNIT

Family-centred care has been defined as an approach to healthcare that is respectful of and responsive to individual families' needs and values[42]. It requires that the patient's family participates and collaborates with healthcare professionals as partners in care[16]. Individualized care by paying attention to what patients and family members need must be part of humanizing Intensive Care[16]. The effective incorporation of the family as a member of the ICU team can reduce anxiety and stress, improving satisfaction, and decreasing post-intensive care syndrome[16]. Thus, the implementation of family-centred care should further improve ICU care. Current efforts to explore family needs and satisfaction serve as a quality performance indicator in Intensive Care setting[43,46]. In this sense, the ICU Manual of Good Practices in Humanization recommend in its second strategic line[25] to enable elements that help to have suitable and empathetic communication with families by all team members to have satisfactory assistance, as well as access to information. The availability of a valid family-reported outcome measure would enable benchmarking and might contribute to identifying interventions to improve quality of care in the ICU (**Figure 3**).

Unfortunately, in recent years, only a few ICU family satisfaction instruments have been developed and tested. Despite the Family Satisfaction in the Intensive Care Unit questionnaire (FS-ICU) being the most widely validated measure of family experience in adult ICU[90,91], it did not specifically originate from a family-centred care perspective but from frameworks of patient satisfaction, decision-making, and quality of end-of-life care[92]. Moreover, the FS-ICU only measures family satisfaction in two domains: satisfaction with care and satisfaction with medical decision-making[93,94]. In contrast, the EMPATHIC-30 questionnaire, which was broadly studied in paediatric ICU settings[95-99], covers five family-centred care domains: information, organization, care and treatment, professional attitude, and parent participation[100]. The 30 statements of this questionnaire have been shown to provide a comprehensive conceptualization of parent satisfaction in paediatric ICUs. This instrument fits in the concept of continuous quality of care measurements, empowerment of parents and international benchmarking strategies. In view of the above, we conducted study to adapt the EMPATHIC-30 into the EMPATHIC-F questionnaire for adult Intensive Care settings, and to subsequently validate it.

Our study showed that, with slight adaptations, the utility of the EMPATHIC-30 may be extended to adult Intensive Care settings. The EMPATHIC-F questionnaire performed adequately when tested for reliability and validity in a Spanish adult Intensive Care setting. Cronbach α was used to assess the reliability of the questionnaire. The overall Cronbach α at domain level was homogenous, ranging between 0.64 (Organization) and 0.75 (Professional attitude). A questionable internal was observed in the organization and the family participation domains with a value less than 0.7. We observed that the mean values of all the statements in both domains were above 5, and there was not a specific statement that could increase the Cronbach's α value. These results could be explained by the low number of participants (n = 262). When testing the overall reliability of an instrument with many domains and a limited number of items, it has been recommended to do it with more than 300 responses[101]. Taking this into account, further studies with larger sample sizes are suggested and should be performed. On the other side, we found an adequate congruent validity assessing the correlation between the five EMPATHIC-F domains scores and four overall satisfaction indicators (Would recommend ICU to others, would come back again if needed, overall satisfaction with physicians, overall satisfaction with nurses). In addition, we evaluated the validity of EMPATHIC-F to confirm that it meant the same for subgroups of patients' primary support persons (relatives or primary caregivers) such as gender, whether the patient's admission was medical or surgical, and whether the patient needed mechanical ventilation during ICU stay. Each domain of the instrument really measures what it is expected for each of the subgroups since there were no significant differences in responses between these groups.

In Latour's original study[100] the questionnaires were mailed 2-3 weeks after discharge of the child from the paediatric ICU. In contrast, we handed the questionnaires over to the patients' primary support persons face-to-face at ICU discharge. Our strategy resulted in a response rate up to 97%, higher than in the previous paediatric studies[100,102]. Therefore, the EMPATHIC-F questionnaire seems to be easy to complete and feasible to use. Additionally, we wonder if the experience in ICU could be reported differently if expressed immediately compared to weeks after discharge.

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Despite overall and domain-specific family satisfaction items measured with the EMPATHIC-F questionnaire received excellent scores in our study, potential for improvement was identified. Two statements showed a mean value less than or equal to 5.0: one in the care and treatment domain ("*Every day we knew who was responsible for our relative, regarding the nurses*"), and one in the familiar participation domain ("*We were able to be close to our relative even during invasive procedures*"). Both statements are important aspects of family-centred care. As regards the first statement, the relationship between the responsible staff and the family members might be less effective if there is not one single person in charge for the daily talks. In the ICUs in which the study was conducted nurses are not present in daily information meetings with the families. This fact might explain the low score in the statement of knowing the responsible nurse of the patient. Besides, patients are assigned to the responsibility of the same intensivist from admission to discharge in both ICUs, while they do not have an assigned nurse. Nurses use to oversee more than one patient each shift. For the second statement, during invasive procedures no general rule exists about the presence of family members, so decisions are individually made by the ICU staff at any case scenario. During the study period, most intensivists and nurses in both ICUs did not allow family members to stay near their relative during invasive procedures. Patients in these situations are usually scared and need to feel supported from their loved ones. Despite that current guideline recommend more presence of family members at the bedside[42], including during invasive procedures, this is not yet happening in our ICUs and hence there is scope for improvement.

The "*not applicable*" response type was more frequent in two statements than in the others. The response of "*not applicable*" to "*The ICU could easily be reached by telephone*" may be explained because family members did not need to phone the ICU to know the status of their relative. They were daily informed by the responsible intensivist of their relative. Besides, intensivists could easily reach the families on their private mobile phones. The response of "*not applicable*" to "*Even during invasive procedures, we could always stay close to our relative*" may reflect that intensivists and nurses do not allow family members in the ICU while invasive procedures are being undertaken. However, this could also mean that patients' primary support persons did not expect to be close to their family member during invasive procedures. Therefore, the results of the EMPATHIC-F should be carefully assessed and compared to the wider principles of family-centred care[42] to identify interventions to improve these practices.

5.2.1! Impact of different visiting policies on family satisfaction before and during COVID19

Critical illness remains an important and stressful life event for patients and their families. Involving relatives in the care of severely ill patients is associated with better outcomes. This reflects the importance of family-centred care to deliver high-quality Intensive Care in ICUs. When Spain was hit by COVID-19 pandemic in March 2020, visiting policies in ICUs changed towards a more restricted policy. These restrictions have left family members unable to visit their loved ones[57,58].

Using the EMPATHIC-F questionnaire covering five family-centred care domains (information, organization, care and treatment, professional attitude, and parent participation), we observed that open visiting policies enhance family satisfaction. According to previous reports, COVID-19 pandemic has challenged family-centred care

practices in ICUs[59]. We have demonstrated that this has impacted on family satisfaction in an ICU with open visiting and where family members actively participate in patients' care.

Although strategies have been implemented to improve communication with relatives of ICU patients[59], we believe that under current circumstances (better knowledge of the disease, availability of resources, and increasing vaccination rates), ICUs should be open or re-opened to families. Family satisfaction outcomes can support strategies to promptly return to family-centred care and open visiting. This would be in line with what is recommended in the first strategic line of the ICU Manual of Good Practices in Humanization[25]. In addition, activities to enable the patient's family access the ICU and to be involve in their relative's care should be carried out. The sample size of our study was small, limiting the generalisability. Therefore, ICU staff need to assess their own family-centred care practices to ensure that temporary changes implemented during the pandemic do not undermine the role that families play in patient recovery.

Together with the aspects already discussed, one of the potential limitations of our study is that it was conducted in only two ICUs in one hospital located in northwest Spain. However, the EMATHIC-F was based on the family-centred care principles and its current validation outcomes might justify its applicability to other ICUs. This offers an opportunity to invite several ICUs from different Spanish regions and perhaps including family satisfaction data in a continuously open national ICU registry for benchmarking.

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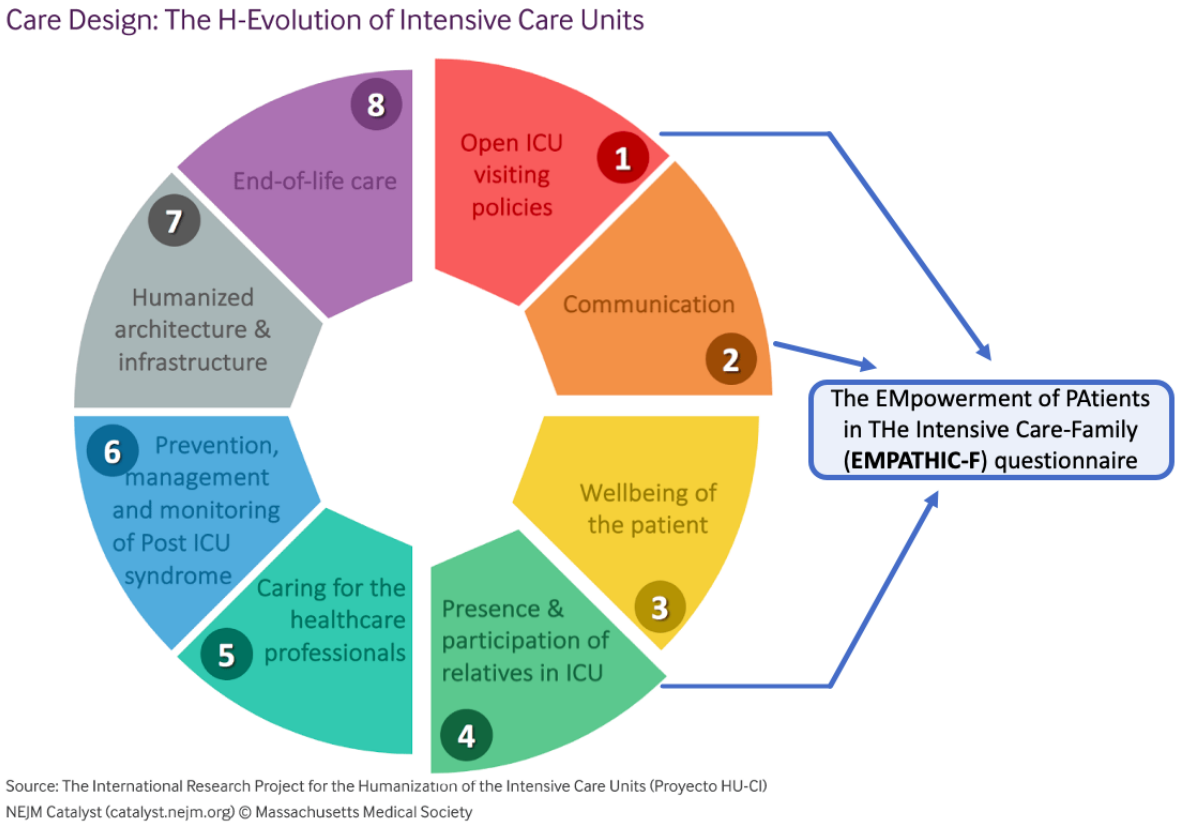

Figure 3. Communication, presence, and involvement of family members in the Intensive Care Unit: The EMpowerment of PAtients in THe Intensive Care-Family (EMPATHIC-F) questionnaire. Adapted from: The ICU and the human care bundle. Published in NEJM Catalyst (under Massachusetts Medical Society license and reproduced with their editorial permission)[26]

5.3! MORAL DISTRESS AMONG NURSES AND PHYSICIANS WORKING IN SPANISH ICUS

Improvements in ICU survival have been achieved due to numerous treatments and technological advancements during the past decades. However, interventions to improve patient and family-centred care have not kept pace[16,24,42]. In addition, these advancements have sometimes led to futile aggressive treatments. The feeling of inappropriateness about some aspects of Intensive Care can further development of moral distress among the ICU team[55]. Previous studies in different health sectors found that this feeling has negative consequences for healthcare professionals, teams, and health systems[49,54,103].

Bearing in mind all the above, it becomes essential to have valid and reliable instruments to explore the causes of moral distress among healthcare professionals to design effective interventions[61]. The Moral Distress Scale (MDS) was the first available measure of moral distress[104,105]. Afterwards, the MDS was shortened and revised to be applicable to all healthcare professionals, the MDS-Revised (MDS-R)[50,55,106-108]. Recent studies have revealed additional root causes of moral distress not captured by the MDS-R[54,61,109]. In this sense, after a comprehensive review, Epstein et al.[110] developed the newest instrument for measuring moral

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distress. The Measure of Moral Distress for Healthcare Professionals (MMD-HP) captures the five key components of moral distress: complicity in wrongdoing, lack of voice, wrongdoing associated with professional (not personal) values, repeated experiences, and three levels of root causes (patient, unit, system). In order to use this tool to assess moral distress among healthcare professionals working in ICU in Spain, we translated and validated the Spanish version of the Measure of Moral Distress for Healthcare Professionals (MMD-HP-SPA). Our findings show that the MMD-HP-SPA is a valid and reliable instrument to measure moral distress among Spanish Intensive Care staff. Consequently, we consider that this instrument can be used in future studies on moral distress to be performed both in Spanish and Latin-American ICUs.

In our study, moral distress was present in all healthcare professionals' groups (median MMD-HP-SPA score of 68). Although previously MMD-HP scores were expressed in means and the comparison between means and medians is not advisable, our MMD-HP-SPA scores are relatively lower than those reported in the previous studies that used the MMD-HP questionnaire, both conducted in North America[60,110]. This difference may reflect the specifics of ICU environment, the hospitals organization, or the type of healthcare system. In Spain most ICUs are part of public hospitals, many of them affiliated to universities, with complex and hierarchical structures.

Our results are somewhat inconsistent with previously reported data when assessing the differences between nurses and intensivists. We have observed that moral distress was higher for physicians than nurses. On the contrary, most of the previous studies, using the MDS-R[50,55,107] and the MMD-HP[110], reported higher levels of moral distress in nurses than physicians. This phenomenon has been thought to be due to nurses' consistent presence at the bedside, where many patient-level root causes occur[50,52,55,61,111]. In our study, when looking at the responses to the MMD-HP-SPA items, we noted an interesting pattern emerging. Our results indicate that system-level root causes, particularly those related to patient's suffering due to lack of provider continuity and to be required to care for more patients than one can safely care for, are among the most morally distressing for all healthcare professionals, especially intensivists. In addition, three of the top-ranked root causes, excessive documentation, lack of resources, and lack of administrative action, were newly added to the MMD-HP[110] and are related also to system-level problems. Epstein et al.[110] already noted a smaller difference in moral distress levels than was expected using the new MMD-HP. They suggested that with the addition of new items related to system-level root causes this questionnaire may apply more broadly to all healthcare professionals, not only those at the bedside. Accordingly, our findings highlight the substantial contribution of system-level root causes to moral distress. Thus, they must be considered when designing specific interventions to different professional groups.

Among all the potential negative consequences moral distress can have, one of the most studied is the association between moral distress and the propensity to leave a job position. It is relevant that nearly half of intensivists (40.7%) and nurses (48.4%) considered to leave or left their job in the past because of moral distress. Additionally, almost 40% of participants are currently thinking about leaving their position. Our results are slightly higher than those from recent studies in Intensive Care settings from the US[110] and Canada[60], where 20% and 13.8% of participants were currently considering leaving their position, respectively. Also, Druwé et al.[54], in a study with emergency medicine physicians from 24 different countries, found that 33.8%

of participants were thinking of leaving their position due to moral distress. To abandon a position when working in ICU is a matter of great concern, since working experience in the ICU is crucial to manage both standard and complex patients. Moral distress may accelerate the staff turnover and may be associated with suboptimal quality-of-care[52,61,112]. Despite the significant difference in moral distress levels between intensivists and nurses in our study, it should be noted that the prevalence of intention to leave a position is quite similar between groups. This fact could be attributed to the differences in specialization in Intensive Care between nurses and intensivists. In Spain, Intensive Care Medicine is a primary specialty for physicians, whereas Critical Care Nursing is not recognized yet as a nursing specialty. This situation allows nurses to find other alternative jobs easily.

In our study, it was noted that both extremes in age (young and senior healthcare professionals) report higher moral distress levels. Concomitant with our results, some previous studies have reported higher moral distress levels with increasing years of experience[50]. On the contrary, Austin et al.[113] did not correlate the number of years working in health care to higher moral distress. They suggested that it may be due to conditioning to the workplace environment over time or feeling more content the closer one gets to retirement. We consider that moral distress in junior staff might be related to lack of experience and, in some cases, to premature burnout. In the case of mean age healthcare professionals, those with moral distress could be more prone to quit their job and therefore this age category become less represented in moral distress surveys.

In line with other authors, we consider that there is a clear need to design and implement strategies to reduce and prevent moral distress and other contributors to burnout[103,113,114]. As the ICU Manual of Good Practices in Humanization recommend in its fourth strategic line[25], the first step should be to acknowledge the problem and measure its impact using validated tools [60,110], this is still a pending task in Spain (**Figure 4**). Targeting high-risk areas or groups may yield substantial benefit. Units and teams may differ in which root causes are most problematic[110,115]. Some authors have proposed to counteract moral distress and its burnout consequences by enhancing the ethical climate in ICUs[116]. It was suggested that this could avoid disrupting the continuity of care due to increased absenteeism[55]. In this sense, a good ethical climate may be essential[106,117]. In our study, scores from the Hospital Ethical Climate Survey (HECS) scores were inversely correlated with MMD-HP-SPA scores, which supports the validity of the Spanish version of the MMD-HP.

5.3.1! Impact of COVID-19 pandemic on moral distress among healthcare professionals in Spanish ICUs

The COVID-19 global crisis has left ICU frontline healthcare professionals with their backs against the wall since they were exposed to several stressors[64]. The fear to get infected and to infect their loved ones, national lockdown policies, constant bad or alarming news in the media[118], and the absence of family members at the bedside, among others, have resulted in an overburdening of ICU healthcare professionals[119,120].

Ours is the first national, cross-sectional study focused on moral distress in ICU healthcare professionals comparing prepandemic and pandemic periods. Our findings confirm that moral distress levels have increased among Spanish ICU healthcare

professionals during COVID-19 pandemic, particularly among ICU nurses, when compared with the immediate prepandemic situation. Although, before COVID-19, we noted that Spanish intensivists reported significantly higher levels of moral distress than ICU nurses, we have observed that these differences have decreased during the pandemic period. Although in most studies conducted before the pandemic nurses reported higher moral distress levels than physicians[50,55,107,110], our results are consistent with the most recently published data where both groups of healthcare professionals had similar moral distress levels[121,122].

As it has been previously mentioned, moral distress has negative consequences not only for healthcare professionals, but also for teams and healthcare systems[49,54,103]. Moral distress negatively impacts on physical and emotional well-being of healthcare professionals affecting their ability to assume expected job responsibilities and decreasing the amount of time spent with patients and their families[112]. As a result, patient satisfaction, outcomes, and mortality rates are worsened[123]. Thus, this increase in moral distress levels during COVID-19 pandemic may ultimately lead to a deterioration of quality-of-care and patient safety[120].

Our study points out a change in the profile of healthcare professionals and the working conditions in ICUs during COVID-19 surge that could have influenced on increased moral distress levels. Due to the scarcity of medical, structural, and human resources, healthcare professionals and institutions had to allocate those resources fairly[124-128]. Under these circumstances, younger and less experienced healthcare professionals, sometimes even with a little or no qualification to deliver quality Intensive Care, were called to work in Spanish ICUs during the pandemic. In this study, such healthcare professionals reported higher levels of moral distress than older and more experienced healthcare professionals. Furthermore, the lack of ICU bed capacity led Intensive Care departments to open additional ICU beds in other hospital areas that used to lack the most adequate characteristics for full Intensive Care. In line with previous studies[49], our results have shown that working in unfamiliar working environments proved to be a source of moral distress. In addition, participants reported that the structural organization of the ICUs also influenced in the moral distress they experienced.

As it was already mentioned, the MMD-HP-SPA is an instrument that measures moral distress at three different levels of root causes (Patient, Unit, and System)[110]. Item-level analysis of moral distress root causes allows for a more accurate study into the situations that are morally distressing for ICU healthcare professionals. Our findings underscore that system-level root causes became more morally distressing during the pandemic period. Six system-level root causes were ranked in the top 10. Particularly, caring for too many patients was the situation in which healthcare professionals experienced moral distress the most. In line with a recent Dutch study conducted among ICU healthcare professionals[122], other two situations became substantially more morally distressing in the pandemic period: compromised patient care due to scarcity of resources and having to work with colleagues believed not to be competent enough. Due to the high volume of patients and the scarcity of resources, patient-to-professionals ratios, and

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the need for less-qualified colleagues to deliver Intensive Care were greatly increased[120,124,129]. These conditions have contributed to a constant dilemma between safe working conditions and high quality-of-care during COVID-19 pandemic[120].

It is assumed that COVID-19 pandemic has jeopardized frontline healthcare professionals' mental health. Recent published data evidenced that the overwhelming situation experienced by ICU healthcare professionals has resulted in an overall surge of new cases of depression and anxiety[119,120,130]. In this sense, we have observed that healthcare professionals who were off work due to this psychologic burden reported the highest levels of moral distress among all participants.

Another important issue to consider is that current shortage of ICU healthcare professionals worldwide, particularly ICU nurses, has been exacerbated during the pandemic[131]. As previously demonstrated, moral distress is associated with the propensity to leave one's job[60,103,110,116]. In our study, it is relevant that nearly one-third of ICU healthcare professionals (27.0%) were thinking about leaving their position due to moral distress. It should be noted that in the pandemic period, the number of healthcare professionals thinking of leaving their job was significantly higher than the prepandemic period[60,110]. In addition to the negative effects on quality-of-care caused by healthcare professionals with working experience in the ICU leaving their job due to moral distress[52,61,112], the cost of replacing high-qualified ICU healthcare professionals is greater than the cost of retaining them. Consequently, moral distress can increase healthcare costs and decrease productivity[132]. Our results have shown that the association between moral distress and the propensity to abandon one's position has been compounded during the COVID-19 pandemic. Healthcare professionals considering leaving their job reported higher levels of moral distress during the pandemic than that in the prepandemic period, particularly intensivists (128.0 [54.5–207.0]).

In the context of COVID-19 pandemic, there is a clear need to design and implement strategies to reduce and prevent moral distress. Once the most morally distressing situations have been assessed, targeting high-risk areas or teams to design specific interventions to different healthcare professional groups may yield substantial benefits on patient safety and quality-of-care. Different interventions have been proposed to alleviate moral distress[48,61,133]. Since caring for too many patients and the scarcity of resources were two of the most morally distressing situations reported by healthcare professionals, increase the number of high-qualified ICU healthcare professionals through system wide training, and an adequate investment in the material and human resources required would reduce the likelihood of moral distress. Besides, improving the collaboration between intensivists and ICU nurses to aid in continuity of care and building a healthier working culture where healthcare professionals could freely speak out or seek advice could assist in mitigating the prevalence of moral distress among healthcare professionals. Furthermore, studies are needed to ascertain whether these strategies and interventions may achieve a reduction in moral distress levels and how is quality of patient care impacted.

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Together with the aspects already discussed, one of the potential limitations of our study is that, using a similar methodology to previous studies, an online survey, we have no information about the exact number of healthcare professionals who received the questionnaire to calculate the response rates across centres or societies, so the findings may be biased and difficult to generalize. However, with more than 1,000 participants in each study period, this is the largest study assessing moral distress among ICU healthcare professionals to date. In addition, a selection bias should be considered. If the most morally distressed healthcare professionals return less surveys, the "healthy worker effect" may have occurred or vice versa. Another potential limitation to be considered is that interregional differences of moral distress levels were not considered. Although we surveyed broadly using the mailing lists of our adult and paediatric Intensive Care national societies (SEMICYUC, SEEIUC, and SECIP), we cannot exclude the potential effect of different pandemic pressures on the regional healthcare. Finally, moral distress among Spanish ICU healthcare professionals during COVID-19 pandemic may differ from that in other countries. Studies assessing moral distress in relation with the pandemic in other countries are warranted.

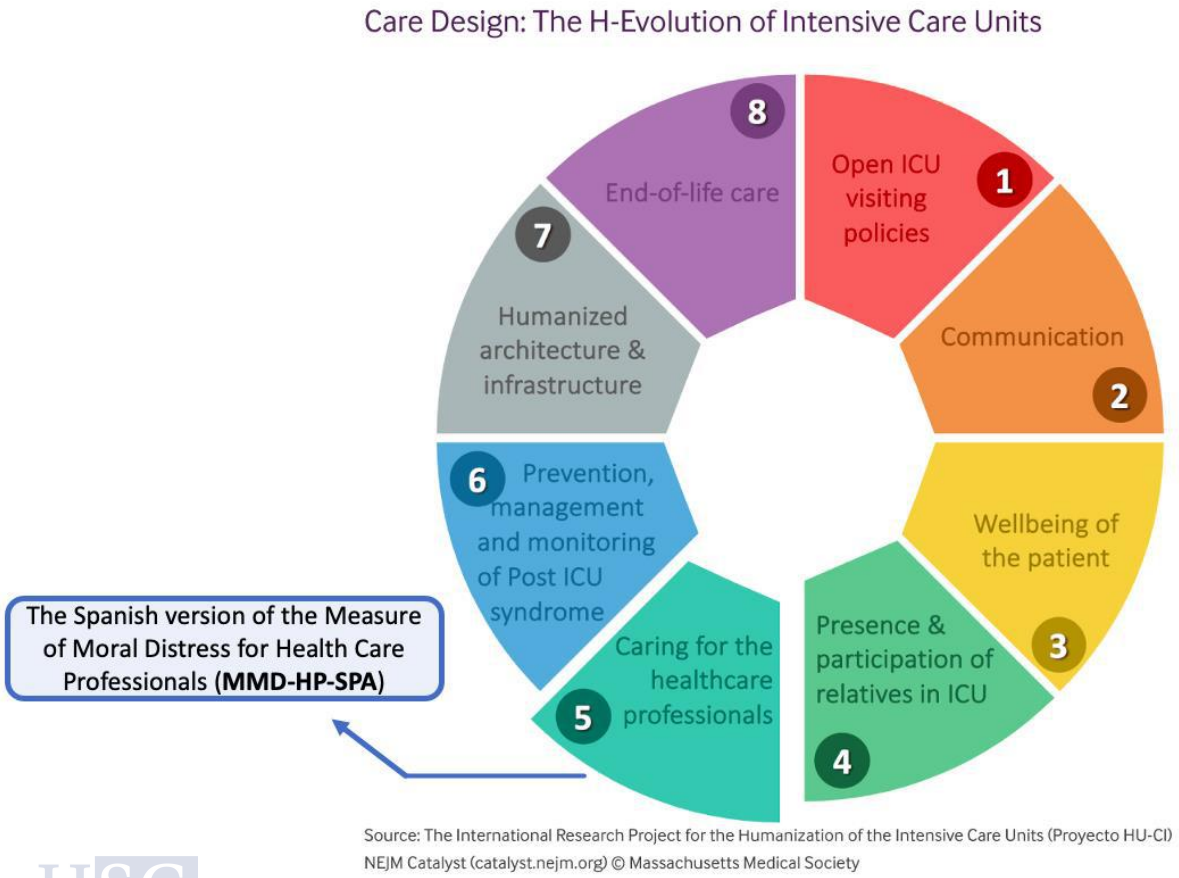

Figure 4. Caring for the healthcare professionals: the Spanish version of the Measure of Moral Distress for Health Care Professionals (MMD-HP-SPA). Adapted from: The ICU and the human care bundle. Published in NEJM Catalyst (under Massachusetts Medical Society license and reproduced with their editorial permission)[26]

5.4! LIMITATIONS

Limitations have been pointed out in all the articles that make up this thesis. In addition, main limitations of the studies have been described in each specific section of the general discussion.

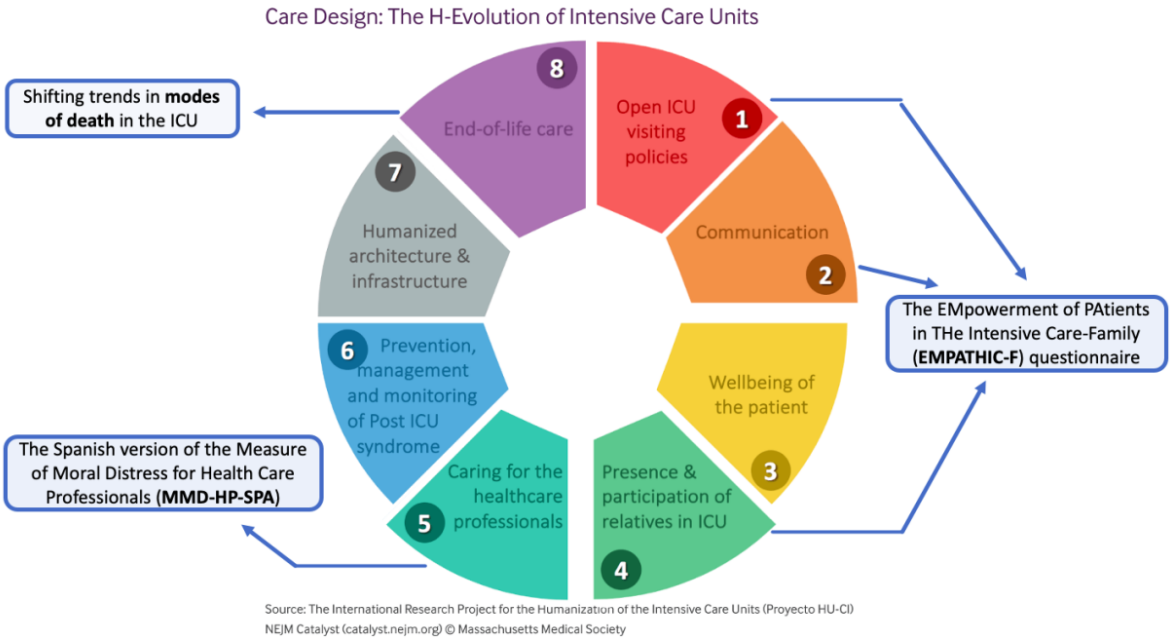

Figure 5. Contribution of this thesis to the humanisation in Intensive Care. Adapted from: The ICU and the human care bundle. Published in NEJM Catalyst (under Massachusetts Medical Society license and reproduced with their editorial permission)[26]

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6. GENERAL CONCLUSIONS

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6! GENERAL CONCLUSIONS

1. Modes of death in our ICU have significantly changed. Death following life-sustaining treatment limitation has steadily increased, whereas death despite maximal support occurred substantially less frequently. These findings suggest a shift in end-of-life practices in Intensive Care. Thus, healthcare professionals who treat critically ill patients should be adequately trained in ethical and humanistic end-of-life practices to achieve the necessary knowledge, attitudes, skills, and tools with the aim of offering the best possible quality end-of-life care.

2. The EMPATHIC-F questionnaire has been proven to be a reliable and valid instrument to measure family satisfaction in adult Intensive Care settings in Spain. Therefore, the EMPATHIC-F questionnaire should contribute to the empowerment of relatives to work along with ICU nurses and intensivists focusing on high-quality family-centred care issues.

3. The MMD-HP-SPA is a valid and reliable instrument to assess specific moral distress root causes that can be used as a diagnostic tool to target interventions for units, teams, and professionals.
4. The COVID-19 pandemic has led to an increase in the levels of moral distress among ICU healthcare professionals in Spain compared with the prepandemic period. Both ICU nurses and intensivists reported similar levels of moral distress, reporting higher moral distress on system-level root causes This situation may have negative consequences on quality of patients' care.
5. Strategies such increasing competent staff through systemwide training; investing in more equipment, resources, and supplemental staff; improving the collaboration between physicians and nurses to aid in continuity of care; and building a healthier working culture are needed and should be implemented to prevent and/or mitigate the prevalence of moral distress among ICU healthcare professionals.

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7. FUTURE PERSPECTIVES BASED ON THIS RESEARCH

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7! FUTURE PERSPECTIVES BASED ON THIS RESEARCH

The future areas of research will focus on the following points.

- To improve end-of-life care it is essential to continue to know and analyse the circumstances of how patients die in the ICU. Thus, it is necessary to conduct a prospective observational study on modes of death in all the patients who die in the ICU. This will allow us to know better the types of life-sustaining treatment limitation performed in these patients and to compare them with those of previous years. In addition, it will be possible to check how the limitation of life-sustaining treatments is carried out and recorded. This information will enable us to improve and provide better end-of-life care.

- The validation of the EMPATHIC-F questionnaire offers an opportunity to invite several ICUs from different Spanish regions and perhaps to start an open national registry on family satisfaction in ICU for benchmarking. Also, if adapted and tested in other languages, could allow benchmarking the quality of family-centre care between ICUs and between countries.

- As we have ranked the situations that caused the highest moral distress among healthcare professionals during COVID-19 pandemic, strategies to prevent and mitigate moral distress should be design and implement. After implementing such strategies moral distress levels should be measure with the MMD-HP-SPA for benchmarking.

- Also, it would be important to assess long-term consequences of increases in moral distress on ICU healthcare professionals and their families, the patients, and the healthcare systems. A collaborative initiative could be promoted at national level through the main scientific societies involved in the care of critically ill patients (SEMICYUC, SEEIUC, SECIP).

- Finally, during the pandemic interregional differences of moral distress levels were not considered. However, due to the different pandemic pressures on the regional healthcare there could have been significant interregional differences of moral distress levels. Thus, as we surveyed broadly using the mailing lists of the adult and paediatric Intensive Care national societies, we could look for interregional differences of moral distress levels analysing our data.

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8. INDICATIONS OF IMPACT OF THIS RESEARCH

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8! INDICATIONS OF IMPACT OF THIS RESEARCH

(Until July 2022)

Article 002 - Title: ***Measuring family-centred care practices in adult intensive care units: The EMPATHIC-F questionnaire***.

Citations:

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Article 003 - Title*: **Impact of different visiting policies on family satisfaction in two Spanish ICUs before and during COVID-19***.

Citations:

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Citations:

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Article 005 - *Title:* ***Moral distress among healthcare professionals working in intensive care units in Spain***.

Citations:

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Article 006 - *Title:* ***Impact of the COVID-19 Pandemic on Moral Distress among Nurses and Physicians in Spanish ICUs***.

Citations:

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9. REFERENCES

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APPENDIX I: PERMISSIONS FOR REPRODUCTIONS

Written permission to use the Measure of Moral Distress for Healthcare Professionals (MMD-HP).

Gmail — Emilio Rodriguez-Ruiz <r.ruizemilio@gmail.com>

Written permission to use MDS-R

Ann Hamric <abhamric@vcu.edu> 27 de agosto de 2019, 1:34
Para: Emilio Rodriguez-Ruiz <r.ruizemilio@gmail.com>

Dear Dr. Rodriguez-Ruiz,

Thank you for writing and for your interest in moral distress. We have completed a significant revision of the Moral Distress Scale-Revised (MDS-R) and are no longer recommending this older scale. The new instrument, the Measure of Moral Distress for Healthcare Professionals (MMD-HP), has been validated and our results just published in the following citation:

Epstein, E.G., Whitehead, P.B., Prompahakul, C., Thacker, L.R., & Hamric, A.B. (2019). Enhancing understanding of moral distress: the measure of moral distress for healthcare professionals. AJOB Empirical Bioethics. DOI: 10.1080/23294515.2019.1586008.

I have attached a copy of the article for your review. There are three Supplemental Tables available at the Taylor and Francis website; NOTE the first Table is the full MMD-HP, including guidelines for scoring and interpretation. This article also contains our most recent thinking on the definition and key attributes of moral distress.

You are free to use the MMD-HP so long as you cite the full article in any use. Please read the article and carefully review the MMD-HP to ensure that it is appropriate for your research or planned project.

Best wishes,

Ann Hamric

****

Ann B. Hamric, PhD, RN, FAAN
Professor Emeritus, School of Nursing
Virginia Commonwealth University
Richmond, VA

****

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Written permission to use the Hospital Ethical Climate Survey (HECS) and or the shortened version (HECS-s).

August 22, 2019

Emilio Rodriguez-Ruiz, MD
Intensive Care Medicine and Intensive Care Medicine Research Group
University Clinical Hospital of Santiago de Compostela
Travesia Choupana s/n
15706 Santiago de Compostela
Spain

Dear Dr. Rodriguez-Ruiz:

I am writing to grant you permission to use the tool, the Hospital Ethical Climate Survey (HECS) and or the shortened version , HECS-s, in your research on nurses' and physicians' perceptions of the ethical climate in Spanish ICU and levels of moral distress. You will also translate the tool into Spanish.

I would appreciate your keeping me informed of your progress, and also of sharing your results when you have completed your research. This sounds like an exciting study.

Thank you for your interest in the Hospital Ethical Climate Survey.

Sincerely,

Linda L. Olson

Linda L. Olson, PhD, RN, NEA-BC, FAAN

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Written permission to use the EMpowerment of PArents in The Intensive Care (EMPATHIC-30) questionnaire.

De: Jos Latour [mailto:jos.latour@plymouth.ac.uk]
Enviado el: miércoles, 04 de septiembre de 2019 10:00
Para: FCO. JAVIER PILAR ORIVE
Asunto: RE: Permission

Dear Javier,

I am very pleased to provide permission to use the translated and validated EMPATHIC-30 instrument.

I hope this email confirmation is sufficient to proceed.

Looking forward to the results of the study

Best wishes

Jos

Prof. Dr. Jos M. Latour - Professor in Clinical Nursing & Associate Head of School - Research

School of Nursing and Midwifery | Faculty of Health and Human Sciences | University of Plymouth | 8-11 Kirkby Place| Room 205 | Drake Circus, Plymouth PL4 8AA | UK

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APPENDIX II: CO-AUTHORS' AUTHORISATIONS

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AUTORIZACIÓN COAUTOR/A DOUTOR/A

D./Dna.: **María Sol Rodríguez Calvo**

Email: **msol.rodriguez@usc.es**

MANIFESTO QUE:

Como coautor/a DOUTOR/A dos artigos/publicacións integrados na tese **"Humanisation in Intensive Care. Ethical considerations in managing critically ill patients: modes of death, family perceptions and moral distress among healthcare professionals"** que presenta o doutorando/a **Emilio Rodríguez Ruiz**:

1. Quedo informado/a de que ten solicitada autorización da CAPD da USC para a presentación do exemplar:

   (seleccionar so unha das opcións)

   ☐ Tese monográfica na que se reproduza total ou parcialmente unha ou máis publicacións das que formo parte como coautor/a.

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3. Declaro que as contribucións que achegan contidos á tese son orixinais e propias do doutorando/a.

En **Santiago de Compostela, 5 de Marzo de 2022**

RODRIGUEZ CALVO MARIA SOL - 32451244S

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Sinatura electrónica

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MANIFESTO QUE:

Como coautor/a DOUTOR/A dos artigos/publicacións integrados na tese **"Humanisation in Intensive Care. Ethical considerations in managing critically ill patients: modes of death, family perceptions and moral distress among healthcare professionals"** que presenta o doutorando/a **Emilio Rodríguez Ruiz**:

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En **Santiago de Compostela, 04 de Marzo de 2022**

Firmado por RODRIGUEZ NUÑEZ ANTONIO - 35551538R el día 04/03/2022 con un certificado emitido por AC FNMT Usuarios

Sinatura electrónica

AUTORIZACIÓN COAUTOR/A DOUTOR/A

D./Dna.: **Ana Estany-Gestal**

Email: **Ana.Estany.Gestal@sergas.es**

MANIFESTO QUE:

Como coautor/a DOUTOR/A dos artigos/publicacións integrados na tese **"Humanisation in Intensive Care. Ethical considerations in managing critically ill patients: modes of death, family perceptions and moral distress among healthcare professionals"** que presenta o doutorando/a **Emilio Rodríguez Ruiz**:

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En **Santiago de Compostela**, **07 de Marzo de 2022**

ESTANY GESTAL ANA - 46896853Z

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Author: Emilio Rodríguez-Ruiz, Maitane Campelo-Izquierdo, Montserrat Mansilla Rodríguez, et al
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Validation and psychometric properties of the Spanish version of the Measure of Moral Distress for Health Care Professionals (MMD-HP-SPA)

Autor(es)

Emilio Rodriguez-Ruiz, Maitane Campelo-Izquierdo, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez

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Título del artículo

Moral distress among healthcare professionals working in intensive care units in Spain

Autor(es)

Emilio Rodriguez-Ruiz, Maitane Campelo-Izquierdo, Paula Boga Veiras, Montserrat Mansilla Rodríguez, Ana Estany-Gestal, Andrés Blanco Hortas, María Sol Rodríguez-Calvo, Antonio Rodríguez-Núñez

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Author: Emilio Rodriguez-Ruiz, Maitane Campelo-Izquierdo, Paula Boga Veiras, et al
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