El deseo de adelantar la muerte en pacientes con procesos avanzados de enfermedad

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EL DESEO DE ADELANTAR LA MUERTE EN PACIENTES CON PROCESOS AVANZADOS DE ENFERMEDAD

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Dr. Albert Balaguer Santamaría

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A mi familia,

por su apoyo incondicional y

su comprensión durante estos años

por todo el tiempo que les he robado.

A mi padre,

que muy probablemente

estará sintiéndose orgulloso de sus hijas.

Con todo mi cariño

Si puedes conservar la cabeza cuando a tu alrededor
todos la pierden y te echan la culpa;
si puedes confiar en ti mismo cuando los demás dudan de ti,
pero al mismo tiempo tienes en cuenta su duda;
si puedes esperar y no cansarte de la espera,
o siendo engañado por los que te rodean, no pagar con mentiras,
o siendo odiado no dar cabida al odio,
y no obstante no parecer demasiado bueno, ni hablar con demasiada sabiduría...
Si puedes soñar y no dejar que los sueños te dominen;
si puedes pensar y no hacer de los pensamientos tu objetivo;
si puedes encontrarte con el triunfo y el fracaso (desastre)
y tratar a estos dos impostores de la misma manera;
si puedes soportar el escuchar la verdad que has dicho:
tergiversada por bribones para hacer una trampa para los necios,
o contemplar destrozadas las cosas a las que habías dedicado tu vida
y agacharte y reconstruirlas con las herramientas desgastadas...
Si puedes hacer un hato con todos tus triunfos
y arriesgarlo todo de una vez a una sola carta,
y perder, y comenzar de nuevo por el principio
y no dejar de escapar nunca una palabra sobre tu pérdida;
y si puedes obligar a tu corazón, a tus nervios y a tus músculos
a servirte en tu camino mucho después de que hayan perdido su fuerza,
excepto La Voluntad que les dice "¡Continuad!".
Si puedes hablar con la multitud y perseverar en la virtud
o caminar entre Reyes y no cambiar tu manera de ser;
si ni los enemigos ni los buenos amigos pueden dañarte,
si todos los hombres cuentan contigo pero ninguno demasiado;
si puedes emplear el inexorable minuto
recorriendo una distancia que valga los sesenta segundos
tuya es la Tierra y todo lo que hay en ella,
y lo que es más, serás un hombre, hijo mío.

Rudyard Kipling

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RESUMEN

RESUMEN

El deseo de adelantar la muerte (DAM) puede aparecer en determinados momentos de la vida sin formar parte, necesariamente, de un proceso depresivo. Este deseo parece darse con mayor frecuencia e intensidad en pacientes con enfermedades crónicas o en fases avanzadas de la enfermedad y se acompaña de compromiso psicológico y afectación negativa de la calidad de vida. Aunque el estudio del DAM resulta un campo de indudable interés para clínicos y teóricos, lo cierto es que en la práctica, su investigación presenta considerables dificultades.

Bajo la denominación de DAM se han englobado fenómenos heterogéneos y poco delimitados, dando lugar a estudios en los que las diferencias conceptuales y metodológicas limitan la comprensión y comparación de sus conclusiones. Asimismo, el DAM se ha relacionado con otros constructos psicológicos, como el Sentido de la Vida (SV).

Las hipótesis que se plantean en este estudio son que el DAM puede aparecer en pacientes con patología crónica o proceso avanzado de enfermedad; el DAM es un fenómeno diferente de las peticiones de eutanasia y suicidio médicamente asistido; se desconoce el verdadero significado del DAM en los pacientes con procesos avanzados de enfermedad; asimismo, el DAM está condicionado por instancias psicológicas ligadas al sufrimiento, no suficientemente exploradas hasta el momento. Particularmente, una de estas dimensiones fundamentales sería el SV, según la perspectiva de Frankl, para cuya evaluación se ha estudiado y validado al español el instrumento de medida SMiLE.

Los objetivos de este estudio fueron realizar una síntesis del conocimiento actual sobre el DAM en personas con procesos crónicos o fases avanzadas de enfermedad desde una perspectiva clínica y a la luz de los estudios publicados, profundizando en su conceptualización y conociendo su relación con otros fenómenos; explorar el significado del DAM desde la perspectiva del propio paciente, realizando una revisión sistemática cualitativa y, por último, obtener un instrumento cuantificador del SV para uso en nuestro entorno.

Los hallazgos obtenidos concluyen que el DAM es un fenómeno multifactorial con múltiples significados que no implican necesariamente la acción literal de querer morir. La síntesis de estudios cualitativos realizada ha aportado un modelo explicativo del fenómeno del DAM, cuyo objetivo no es en sí mismo morir, sino más bien una respuesta a un sufrimiento extremo, una solicitud de ayuda y a su vez un mecanismo de control y autodeterminación. Las propiedades métricas de la versión española de la escala SMiLE le avalan para considerarlo un instrumento adecuado de evaluación del SV. El estudio del SV en pacientes en cuidados paliativos no ha sido abordado en el entorno español.

En conclusión, el fenómeno del DAM es una realidad compleja en nuestra sociedad. Conocerlo es requisito imprescindible para poder abordarlo. Podemos concluir que es necesario un esfuerzo multidisciplinar para mejorar el acompañamiento y cuidados de nuestros enfermos cercanos al final de su vida. El correcto abordaje del DAM desde visiones antropológicas y clínicas integrales, de la mano de las unidades de cuidados paliativos, debería ser un objetivo prioritario en esta tarea. Futuros estudios deberían contemplar el estudio del DAM en otros contextos como las patologías neurodegenerativas y las patologías crónicas evolucionadas.

ABREVIATURAS

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- CINAHL: Cumulative Index to Nursing and Allied Health Literature

- DAI-R: Death Anxiety Inventory—Revised

- DAM: Deseo de adelantar la muerte

- DT: Desviación Típica

- IoS: Index of Satisfaction

- IoW: Index of Weighting

- IoWS: Index of Weighted-Satisfaction or Total SMiLE Index

- KUAS: Kuwait University Anxiety Scale

- MD: Mental Dimension

- MiL: Meaning in Life

- PAS: Physician Assisted Suicide

- PD: Physical Dimension

- PsychINFO: Base de Datos de American Psychology Association

- RSES: Rosenberg Self-esteem Scale

- SADH: Schedule of Attitudes toward Hastened Death

- SD: Standard Deviation

- SDFV: Síndrome de desesperanza al final de la vida

- SDS: Self-Rating Depression Scale

- SEIQoL-DW: Schedule for the Evaluation of Individual Quality of Life – Direct Weighting

- SF-12 Health Survey: Short Form-12 Health Survey

- SMA: Suicidio médicamente asistido

- SMiLE: Schedule Meaning in Life Evaluation

- SPSS: Statistical Package Social Science

- SV: Sentido de la vida

- WTHD: Wish to hasten death

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1. INTRODUCCIÓN

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Los procesos avanzados de enfermedad, ya sean de origen oncológico, procesos neurodegenerativos lentamente progresivos, incluso procesos secundarios a patologías crónicas, generan en los enfermos una serie de signos y síntomas invalidantes y molestos que pueden provocar gran malestar psicológico, tanto en el paciente como en su familia y/o cuidadores [1,2]. En este contexto, incluso a pesar de un aceptable control sintomatológico, algunos pacientes pueden experimentar deseo de adelantar la muerte (DAM), estimándose este porcentaje entre un 8-10% de los pacientes oncológicos en situación de final de la vida, muchas veces asociado a un pronóstico inferior a seis meses de vida [3]. Esta situación es de gran complejidad y de difícil manejo tanto para la familia, como para los profesionales del equipo asistencial que deben atender a estos pacientes. No obstante, los datos sobre la incidencia del DAM son discrepantes y varían según los estudios revisados y la metodología utilizada en los mismos [4].

En la sociedad occidental se ha reactivado la discusión sobre la legitimidad de facilitar el suicidio asistido o la eutanasia. El punto de arranque del debate suelen ser casos concretos, situaciones difíciles en personas con patología con grave pronóstico, que ven la muerte como la única salida posible a su situación. La experiencia en los lugares donde se dispone de alguna regulación favorable no está exenta de controversia [5,6]. ¿El suicidio asistido y la eutanasia son soluciones o, al menos, salidas adecuadas para determinadas situaciones? ¿Se beneficia al individuo y a la sociedad arbitrando una normativa abierta a su regulación? En el afrontamiento de este debate a menudo se olvida el origen de la problemática. ¿Qué se sabe sobre el deseo de adelantar la muerte en pacientes con enfermedades graves?, ¿ocurre muy a menudo?, ¿cuál es el cortejo de motivos que desencadena un fenómeno tan complejo? Este estudio pretende aportar información para intentar dar respuesta a alguna de estas preguntas.

Tradicionalmente, la cultura occidental ha contemplado la idea de desear la muerte como algo negativo e incluso patológico [7,8]. Sin embargo, su aparición transitoria o genérica como resultado de un especial estado anímico, intelectual o espiritual, puede carecer de esta connotación. En algunos casos parece constituirse en una opción vital no necesariamente ligada a un proceso de sufrimiento, sino a la manifestación de que se está preparado para morir [1,9,10], o bien del deseo de

otra vida mejor. Éste podría ser el caso expuesto con tanta belleza por algunos místicos españoles, como Teresa de Ávila o San Juan de la Cruz. Sin embargo, el deseo de morir mantenido y reiterado en el tiempo, especialmente cuando acompaña la enfermedad, suele valorarse como manifestación de patología o de sufrimiento extremo [11,12].

A principios de los años setenta, comienza a aparecer en la literatura clínica la satisfacción del DAM como una solución racional al sufrimiento insoportable de pacientes con enfermedades crónicas o procesos avanzados de enfermedad [13]. Si bien el significado profundo de este deseo no se esclarece [4,14], algunos autores reconocen en el DAM y su consecución, decisiones legítimas bajo los principios éticos de autonomía y beneficencia, y no consecuencia de un estado de sufrimiento o de psicopatología [15-17].

En las últimas décadas ha emergido un creciente interés entre clínicos e investigadores por analizar el DAM en el contexto de la enfermedad grave o incurable. Este fenómeno parece afectar a un número no despreciable de pacientes, especialmente en fases finales de su vida [18-20]. Los avances médicos y tecnológicos en países desarrollados son una evidencia que se expresa en un incremento constante y progresivo de la esperanza de vida. Actualmente en España la EV es de 81.1 años, (84.3 años en mujeres y 78.2 años en varones) [21]. La presencia de una población que envejece paulatinamente en una sociedad en la que la muerte se puede retrasar cada vez más, permite pronosticar un incremento progresivo de la incidencia y prevalencia de enfermedades degenerativas e incapacitantes. Todo ello, junto a otros fenómenos sociales ligados al desarrollo, hace pensar que la realidad del DAM, lejos de disminuir, pueda incrementarse [22-25]. Esta circunstancia nos alienta, de alguna manera, a avanzar en el conocimiento del DAM, ya que en palabras de Callahan [26]: *Hemos cambiado una vida corta y una muerte rápida por una vida larga y una muerte lenta*; y nuestros pacientes siguen necesitando atención y cuidados en este acto tan humano como es la realidad de morir.

Recientemente ha aumentado el interés por analizar el DAM en el contexto clínico [27,28], en especial en el ámbito de cuidados paliativos (CP) [20,29,30], siendo abordado desde diferentes perspectivas y disciplinas [31,32]. Se han estudiado las actitudes de la población general y de los profesionales de la salud ante las

decisiones de los pacientes de adelantar la muerte [33-35]. También se han explorado diversos factores relacionados con el DAM, como la depresión, la desesperanza, el sentimiento de carga, de pérdida de autonomía [36-38], aunque algunos de estos estudios presentan limitaciones relacionadas con su diseño y con la obtención de datos a través de fuentes indirectas [39-41]. En respuesta a estas limitaciones, otros autores han explorado el DAM de manera prospectiva desde la perspectiva de los pacientes [41,42], aunque, la gran mayoría, restringen el fenómeno del DAM a unas pocas variables de estudio, seleccionadas y valoradas de manera algo reduccionista. Recientemente, se han desarrollado estudios cualitativos con el objetivo de comprender mejor el verdadero significado del deseo de adelantar la muerte en su globalidad desde el propio escenario natural donde sucede [43,44-47]. Sin embargo, puesto que tanto los contextos como las características de los participantes son diferentes en cada caso, los hallazgos han de ser interpretados con cierta cautela.

En el ámbito español existen estudios clínicos que analizan el sufrimiento [48,49], el dolor [50], la ansiedad ante la muerte [51], pero no el DAM propiamente, ni los posibles factores relacionados con él. No obstante, ante la posibilidad de que se amplíe su frecuencia debido a factores anteriormente comentados, es previsible un incremento del interés por este fenómeno en el contexto de las ciencias de la salud.

Los estudios que han tratado de identificar factores causales o favorecedores del DAM apuntan hacia un fenómeno de naturaleza compleja y multifactorial, donde intervienen variables de muy diversa índole. Los principales factores que se han relacionado con el DAM, podrían agruparse en las siguientes áreas: A) sintomatología física en forma de dolor, sufrimiento físico, malestar, fatiga, etc.; B) afectación psicológica (desesperanza, miedo —a sufrir, al dolor, a la evolución de la enfermedad, a la soledad—, depresión y afines); C) factores 'sociales', como el sentimiento de ser una carga para los demás, tanto física como económica y la percepción de falta de apoyo social. Por último, se vislumbran una amplia gama de elementos englobados bajo la etiqueta de 'sufrimiento psico-existencial', entre los que encontraríamos la pérdida de autonomía, la pérdida de rol social, el deseo de control del modo y momento de la muerte y la pérdida de sentido de la vida, este último, poco explorado y conceptualizado en la literatura.

En la sociedad occidental, el concepto de significado o sentido de la vida (SV) fue introducido, en el ámbito de la psicología clínica, por Víctor Frankl, en gran medida como consecuencia de sus experiencias vitales como prisionero en los campos de concentración de Auschwitz y Dachau durante la II Guerra Mundial. Para Frankl [52], la búsqueda del sentido constituye la fuerza primaria capaz de dar respuesta a las cuestiones que la existencia nos plantea; el SV puede ser buscado y descubierto aún en las circunstancias más extremas de la vida, favoreciendo la adaptación y la superación de los acontecimientos. En el ámbito de los cuidados paliativos, el concepto de SV, está cobrando relevancia a partir de algunos estudios que han puesto de manifiesto que, en estos pacientes, la falta de percepción de 'sentido' se asocia a distrés psicológico [53] y podría relacionarse con el deseo de morir. Asimismo, el SV difiere de una persona a otra e incluso, en una misma persona, puede variar con el tiempo y las circunstancias [52].

Diversos autores, inspirados en parte por esta idea, han abordado el estudio de la importancia del SV en el devenir vital de la persona [54-56] y su papel en el bienestar psicológico [57], cobrando una mayor relevancia en el terreno clínico-asistencial, especialmente en pacientes con enfermedades graves o que afrontan el periodo final de su vida [58,59]. En este ámbito, se ha encontrado una relación directa entre la pérdida de SV y un aumento del distrés psicológico [53,54]; de manera similar, se ha relacionado el incremento de la percepción del SV con mayor bienestar psicológico [54,60], e incluso con menor mortalidad, según un estudio realizado en pacientes oncológicos [61].

Aunque se han realizado tentativas para el desarrollo y evaluación de intervenciones dirigidas a mejorar el SV [57,60,62], estos estudios presentan algunas limitaciones metodológicas que dificultan su adecuada valoración. Una de ellas es la relativa a la propia precisión del concepto de SV usado. Lee et al. [63], realizaron una revisión sistemática para clarificar el concepto de "sentido" utilizado en distintos estudios sobre el afrontamiento del cáncer. Esta revisión concluyó destacando la heterogeneidad en las definiciones conceptuales utilizadas en los diferentes trabajos. La falta de instrumentos diseñados específicamente para su cuantificación, es otro elemento que complica la profundización en su estudio.

Recientemente, Fegg et al. [58], partiendo del concepto de SV de Frankl [52], han diseñado y validado una escala para la evaluación del SV, considerando que, dada la

naturaleza del constructo a medir -personal e individual-, el instrumento de medida más adecuado debería ser de naturaleza ideográfica. De esta manera, dichos autores, inspirándose en la metodología de la escala sobre calidad de vida desarrollada por O'Boyle en la 'Schedule for the Evaluation of Individual Quality of life – Direct Weighting' (SEIQoL-DW) [64], han desarrollado el 'Schedule for Meaning in Life Evaluation' (SMiLE) [58], cuya originalidad radica en que permite cuantificar el SV y a la vez efectuar el análisis cualitativo de este concepto genérico de manera individualizada, ya que es la persona evaluada quien debe indicar aquellas áreas que dan sentido a su vida [58,65]. Además, la SMiLE permite calcular tres tipos de índices: SMiLE total (IoWS), Índice de satisfacción (IoS) e Índice importancia (IoW), útiles para cuantificar variaciones en el tiempo de un mismo sujeto e incluso para comparar entre diferentes personas y grupos [58].

Los autores de la SMiLE la desarrollaron simultáneamente en alemán y en inglés [58], utilizando sendas muestras de estudiantes universitarios. Posteriormente se llevó a cabo la validación de la forma francesa [59], en este caso en una muestra de pacientes de cuidados paliativos.

Uno de los objetivos de este estudio es efectuar la adaptación española de la escala SMiLE y estudiar sus propiedades métricas, aportando de este modo, evidencias de validez y fiabilidad. Disponer de un instrumento de estas características en español permitiría, en futuros estudios, evaluar el sentido de la vida en distintos grupos de personas, particularmente en personas con patología crónica o degenerativa y fases avanzadas de su enfermedad.

Asimismo, en este trabajo se efectúa una síntesis del conocimiento actual sobre el DAM en personas en fases avanzadas de enfermedad, desde una perspectiva clínica y a la luz de los estudios clínicos publicados.

Por otro lado, es necesario un abordaje metodológico que permita profundizar y conocer el verdadero significado del DAM, que ayude a precisar sus límites conceptuales y a comprender la posible manifestación del DAM en pacientes con patología crónica o procesos avanzados de enfermedad. Para ello, la perspectiva del paciente parece ser esencial. La metodología de la investigación cualitativa es la adecuada para entender las experiencias subjetivas al centrarse en describir e interpretar el significado del fenómeno de estudio, permitiendo explorarlo en

profundidad al aprehender su naturaleza y esencia misma [66]. El conocimiento que puede adquirirse desde las experiencias vividas por los pacientes que presentan DAM y de lo que es significativo en este deseo, podría guiar intervenciones futuras para atender las necesidades de los pacientes en esta situación y mejorarían en su conjunto la percepción de calidad de vida de estos pacientes mientras conviven con una enfermedad incurable. La ausencia de estudios sobre el DAM en nuestro entorno desde la perspectiva clínica-asistencial, motiva a la realización de un estudio cualitativo en la geografía española, ya que, como en otros países, el DAM está presente en nuestros pacientes en la realidad asistencial diaria, y se desconoce la mejor manera de abordarlo. Desde esta perspectiva, se inició un estudio piloto en mayo de 2007, que consistió en la realización de un grupo focal con cinco participantes, profesionales de la salud con experiencia en la atención de pacientes al final de la vida, tres entrevistas semi-estructuradas a profesionales de la salud, un psicólogo especialista en oncología, una trabajadora social y una enfermera de un equipo del Programa de Atención Domiciliaria y Equipos de soporte (PADES) de Barcelona y una entrevista en profundidad a un paciente con patología neuro-degenerativa que manifestaba DAM.

El grupo focal se llevó a cabo en un aula de la Universitat Internacional de Catalunya y tuvo una duración de 96 minutos. Todos los participantes firmaron el consentimiento informado y el equipo investigador garantizó la confidencialidad a todos los participantes. La participación fue libre y voluntaria. Los criterios de selección de la muestra fueron: ser profesionales en activo en equipos de atención sanitaria, tanto atención primaria como hospitalaria y domiciliaria y haber trabajado al menos dos años en unidades donde es frecuente asistir en el acompañamiento al final de la vida tanto del paciente como de la familia. El muestreo fue de conveniencia. En la tabla 1 se recogen las características de los participantes. Junto a la moderadora del grupo focal asistieron dos observadores que recogieron los aspectos no verbales, que fueron analizados junto a los datos que se recogieron mediante grabación de audio. La discusión fue libre y abierta entre los participantes. La primera pregunta que se planteó al grupo focal fue la siguiente: 'Entre los pacientes con diagnóstico de patología grave o proceso avanzado de enfermedad, hay algunos que presentan deseo de adelantar su muerte, ¿cómo es este deseo?, ¿por qué creéis que presentan DAM?' Posteriormente, los datos obtenidos fueron transcritos por la investigadora principal. Se realizó un análisis de

contenido del grupo focal; los datos fueron inicialmente codificados, apareciendo 54 códigos; posteriormente se agruparon en 20 subcategorías y finalmente emergieron 5 categorías. Estas categorías finales permitieron elaborar un guión de entrevista semi-estructurada que se utilizó posteriormente en las entrevistas a los profesionales de la salud. Los resultados finales forman parte de un estudio activo en la actualidad, cuyo objetivo es comprender el significado del DAM desde la propia perspectiva del paciente que lo presenta, en presencia de patología crónica o proceso avanzado de enfermedad, en la comunidad autónoma de Catalunya.

Recientemente, en la literatura destaca el interés de los estudios que mediante una perspectiva cualitativa analizan el deseo de morir desde la propia voz del paciente que lo manifiesta [29,43,45-47,67]. Realizar una revisión sistemática cualitativa de la literatura y una síntesis interpretativa de los estudios cualitativos primarios sobre el deseo de adelantar la muerte desde la perspectiva del propio paciente que lo presenta, es otro de los objetivos que se plantea este estudio.

TABLA 1| CARACTERÍSTICAS DE LOS PARTICIPANTES DEL GRUPO FOCAL DE LA PRUEBA PILOTO

PARTICIPANTE	LUGAR DE TRABAJO	AÑOS DE EXPERIENCIA PROFESIONAL	OTRAS CARACTERÍSTICAS
Enfermera	Unidad de hospitalización de oncología	5 años	
Enfermera	Centro de día de oncología	3 años	Haber padecido un Linfoma tipo Hodking
Enfermero	Servicio de urgencias hospitalarias	3 años	
Psicóloga clínica y enfermera	Unidad de hospitalización de oncología y hospital de día oncológico	10 años como enfermera en oncología	7 años como psicóloga clínica
Médico	Neonatólogo	20 años	Experto en comunicar malas noticias

2. HIPÓTESIS Y OBJETIVOS

HIPÓTESIS

1) El Deseo de Adelantar la Muerte (DAM) es un fenómeno que puede aparecer en pacientes con patología crónica o procesos avanzados de enfermedad.

2) El DAM, en estos pacientes, es una entidad diferente de las peticiones de eutanasia y suicidio médicamente asistido.

3) El DAM está condicionado por instancias psicológicas ligadas al sufrimiento, no suficientemente exploradas hasta el momento.

OBJETIVOS

Generales:

1- Profundizar en el conocimiento del fenómeno del DAM en las personas con procesos crónicos o fases avanzadas de enfermedad, en su conceptualización y en su relación con otros fenómenos.

2- Explorar el significado del DAM desde la perspectiva de los mismos pacientes que lo manifiestan.

Específicos:

1- Realizar una síntesis del conocimiento global sobre el DAM en estos pacientes, desde una perspectiva clínica a la luz de los estudios publicados.

2- Diseñar una estrategia de búsqueda sensible y eficaz de todos los estudios cualitativos primarios que analicen el DAM desde la perspectiva del paciente

3- Efectuar una revisión sistemática de los estudios cualitativos sobre el DAM desde la perspectiva del paciente y una síntesis interpretativa de los mismos.

4- Explorar la posible relación entre DAM y el Sentido de la Vida, desde la bibliografía clínica.

5- Efectuar la adaptación española de la escala SMiLE (Schedule for Meaning in Life Evaluation) y estudiar sus propiedades métricas, aportando evidencias de validez y fiabilidad.

3. METODOLOGÍA

METODOLOGÍA

En esta tesis se presentan 3 artículos, dos de ellos publicados y otro en revisión. En el primer estudio titulado "The wish to hasten death: a review of clinical studies", se ha efectuado una revisión amplia de la literatura sobre el fenómeno del DAM, presentando una clasificación de los estudios sobre el deseo de morir, según los países donde se ha llevado a cabo el estudio y la metodología utilizada; asimismo, se ha realizado una distinción conceptual del DAM, versus otros conceptos relacionados, a la luz de la literatura clínica. En el segundo artículo titulado "The wish to hasten death in patients with advanced diseases: a systematic review of qualitative research", se hace una revisión sistemática de la literatura sobre estudios cualitativos primarios que analizan el DAM desde la perspectiva del paciente con patología crónica o proceso avanzado de enfermedad y, por último, en el tercero, titulado "Psychometric properties of the Spanish form of the schedule for meaning in life evaluation", se ha efectuado la adaptación transcultural y validación al español de la Escala de evaluación del sentido de la vida (SMiLE) de Fegg et al. [58].

1er Artículo: The wish to hasten death: a review of clinical studies

En este estudio se procedió a una revisión en profundidad de la literatura científica sobre el concepto del *deseo de adelantar la muerte* y otros conceptos relacionados, como suicidio médicamente asistido (SMA), eutanasia, deseo de morir, querer morir, etc. La estrategia de búsqueda se efectuó en MEDLINE (bajo la interfaz de PubMed), PsychINFO, CINAHL, Web of Science y CUIDEN. El marco temporal usado para la búsqueda fue desde el inicio de la base de datos hasta enero de 2010. No se aplicaron límites o restricciones de ningún tipo en la búsqueda.

Inicialmente se encontraron 1.239 referencias entre todas las bases de datos que fueron clasificadas mediante el gestor bibliográfico EndNote versión 9.0. Tras la extracción de los duplicados, fueron 1.133 las referencias identificadas para su análisis. La lectura de títulos y resúmenes permitió seleccionar 226 artículos que se consideraron de probable interés para el objetivo de esta revisión. La revisión de las

referencias citadas por dichos estudios, junto a la consulta a expertos, permitió localizar finalmente 282 estudios de relevancia para la revisión.

Tras la lectura de los artículos, se procedió a clasificar los estudios según los países en los que habían sido realizados. Por otro lado, se analizó la metodología utilizada en cada estudio y se delimitó el concepto de DAM. Se examinó su epidemiología, se clasificaron los instrumentos de medida utilizados para cuantificarlo y, finalmente, se analizaron los factores relacionados con el DAM, así como los que lo originan y/o pueden predecirlo.

2º Artículo: The wish to hasten death in patients with advanced diseases: a systematic review of qualitative research (Under Review)

El segundo trabajo comprende la realización de una revisión sistemática cualitativa y análisis interpretativo de los datos mediante el método Metaetnográfico de Noblit y Hare [68], método analítico usado para la síntesis interpretativa de resultados cualitativos primarios. Los hallazgos de los diversos estudios cualitativos primarios son nuevamente analizados y sintetizados con el objetivo de aumentar el conocimiento y proveer una mayor comprensión del fenómeno de estudio.

Los criterios de inclusión para la selección de los estudios fueron los siguientes: artículos cualitativos primarios que describieran o analizaran el DAM en pacientes con diagnóstico de enfermedad crónica o proceso avanzado de enfermedad desde la propia perspectiva del paciente que lo presenta y/o manifiesta. No se aplicaron límites de idioma de los estudios ni restricciones en el diseño metodológico cualitativo empleado por el estudio primario; al igual que otros autores [69], el objetivo de selección de los estudios primarios se centró en el tema de estudio más que en la metodología utilizada. También fueron posibles candidatos de inclusión en la revisión, los estudios que utilizaron diseños mixtos, cualitativos-cuantitativos, siempre y cuando quedaran patentes los resultados obtenidos mediante la metodología cualitativa.

Diseño de la estrategia de búsqueda y selección de los estudios:

En primer lugar, los estudios fueron identificados a través de una búsqueda sistemática en diferentes bases de datos. Se diseñó una estrategia de búsqueda mediante términos MeSH (Medical Subject Headings) y texto libre. Los términos MeSH utilizados fueron: 'suicide, assisted'; 'euthanasia' y 'qualitative research'. El texto libre utilizado fue: advanced disease; advanced cancer; advanced illness; chronic illness; chronic disease; desire to hasten death; wish to hasten death; end of life decisions. Estos términos fueron combinados hasta hallar la estrategia más adecuada. Asimismo, con el objetivo de aumentar la sensibilidad en la estrategia de búsqueda y disminuir las pérdidas por falta de especificidad de estudios cualitativos, se utilizó, junto a la estrategia diseñada, el filtro cualitativo de la Universidad de Rochester, adaptado a MEDLINE por Nesbit [70], y desarrollado posteriormente por McKibbon [71] y otros investigadores [72,73]. Esta estrategia fue adaptada a cada base de datos utilizada. Las búsquedas se realizaron en MEDLINE (bajo la interfaz de PubMed), PsycINFO, CINAHL, Web of Science y Cochrane Register of Controlled Trials. El marco temporal cubierto fue desde el inicio de las bases de datos hasta Octubre de 2009. También se realizó una búsqueda manual en las publicaciones Qualitative Health Research y Qualitative Research, desde 1995 hasta octubre de 2009. Se revisaron las referencias bibliográficas de los estudios incluidos. Este proceso se complementó con la consulta a expertos en la materia.

Las citas halladas inicialmente fueron evaluadas en tres estadios, al igual que las revisiones sistemáticas cuantitativas. Primero se revisaron las 191 citas halladas por título, en segundo lugar por el resumen y finalmente por el texto completo. Se excluyeron los estudios que no cumplían criterios de inclusión. Los desacuerdos se resolvieron mediante consenso entre los investigadores y por referencia al texto completo. Finalmente se consensuaron 7 estudios (n=7) que habían de ser incluidos en la síntesis.

Se excluyeron los estudios que no se centraban suficientemente en el tema de estudio, los que no habían recogido los datos desde la perspectiva del paciente (uno de los estudios que se incluyó, además de analizar la perspectiva de los pacientes, consideraba a su vez la perspectiva de los cuidadores). También se excluyeron los estudios que, aunque hubieran utilizado métodos de recogida de datos cualitativos, no hubieran realizado un análisis cualitativo.

Evaluación de la calidad:

No existen guías estandarizadas para evaluar la calidad de los estudios [74,75]. A pesar de haberse usado un amplio elenco de herramientas de evaluación de la calidad de los estudios cualitativos [75-78], ninguno de ellos se ha constituido como estándar de referencia. Se decidió aplicar el Critical Appraisal Skills Programme (CASP) [79] para estudios cualitativos, por su amplio uso entre los investigadores [80,81].

Por diferentes razones no se excluyeron estudios en base a la calidad. Edwards et al. [82] sugieren incluir todos los estudios y no sólo los de cierta calidad metodológica, puesto que, en caso contrario, las revisiones podrían infravalorar la evidencia publicada en estudios de supuesta baja calidad; otros investigadores afirman que los estudios de baja calidad tienden a contribuir menos a la síntesis y, por lo tanto, la síntesis se pondera y equilibra entre estudios de mejor calidad con los de peor calidad [83,84]. De este modo se evita eliminar estudios que, bajo el argumento de baja calidad, podrían aportar hallazgos pertinentes para la revisión [85]. No existe consenso entre investigadores sobre la función de los criterios de calidad y cómo éstos deben aplicarse [86]. El objetivo de esta evaluación de la calidad no tenía como objetivo la exclusión de estudios, sino la evaluación de la claridad y exhaustividad de la información.

Este estudio no precisó la aprobación de un comité de ética de la investigación al tratarse de un estudio de análisis de datos secundario. Todos los estudios incluidos en la revisión fueron aprobados por sus respectivos comités de ética de la investigación.

Síntesis:

Los siete estudios fueron analizados y sintetizados con el método de Noblit y Hare [68]. El método consiste en realizar, mediante un proceso inductivo, una combinación de resultados de forma interpretativa en vez de agregativa, constituyendo una forma de comparación sistemática. La aplicación de la meta-etnografía sigue siete fases. La primera fase busca identificar un tema de interés para el cual la investigación cualitativa puede ser de utilidad. Durante esta primera

fase el equipo investigador se planteó la siguiente pregunta de investigación, ¿por qué algunos pacientes desean adelantar la muerte en el contexto de patología crónica o proceso avanzado de enfermedad?, ¿qué significado otorgan los pacientes que presentan DAM a este deseo? La segunda fase consiste en la búsqueda de las referencias bibliográficas de interés para documentar el fenómeno a estudiar y selección final de los estudios a incluir en la revisión. Al finalizar esta fase se habían identificado los 7 estudios a incluir en la revisión. Durante la tercera fase, tras la lectura y relectura de los siete estudios, se identificaron las categorías o temas principales en cada uno de ellos. Los apartados de resultados de cada uno de los estudios se dividieron en unidades de análisis que fueron codificados por palabras, frases o párrafos, de acuerdo a su contenido. Posteriormente los códigos se agruparon en categorías que definían las características o dimensiones del fenómeno de estudio. En la cuarta fase se buscó determinar cómo se relacionan los estudios entre sí. Para ello se creó una lista de metáforas clave, frases o conceptos utilizados para cada estudio, y se organizaron de forma que se facilitara la comparación entre ellos. Al final de esta fase se pudo comenzar a analizar la relación existente entre los siete estudios. El método de Noblit y Hare [68] plantea la posibilidad de encontrar tres formas diferentes de relación entre los estudios: a) Estudios directamente comparables, en los que se pueden hacer traducciones recíprocas; b) relatos en contraposición, en los que se distinguen las diferentes categorías o temas por refutación; c) estudios que, al ser combinados entre ellos, logran representar una línea de argumentación, al valorar diferentes aspectos del fenómeno. Al final de esta fase se pudo decidir que los estudios eran directamente comparables por traducción recíproca. Este método permite comparar hallazgos similares y a la vez mantener la singularidad de alguno de los temas cuando es específico de alguno de los estudios. La traducción recíproca se utiliza de forma adecuada cuando los temas de estudio son esencialmente similares. En la quinta fase se aplica el proceso de traducción entre los estudios. La traducción de los estudios se refiere al proceso de examen de los conceptos clave en relación a otros conceptos dentro de cada estudio y entre los estudios entre sí. Se realiza de forma similar al método de comparación constante. Una vez se identificaron los temas principales en cada artículo, se hizo una búsqueda exhaustiva de cada concepto en cada uno de los 7 estudios. La síntesis comenzó por el estudio de Lavery et al [43], el primero en publicarse, y se continuó la comparación entre los estudios por orden

cronológico de publicación. El proceso de comparación comenzó con las categorías identificadas en el primer estudio, y continuó con las categorías del siguiente, que aún sin ser idénticas, se referían a un mismo concepto clave; a medida que otras categorías iban emergiendo, se fueron incorporando a la lista de categorías a comparar entre los estudios. No se trató únicamente de hacer analogías, sino de profundizar en los conceptos sin perder de vista la perspectiva de lo particular. Tras la traducción recíproca entre los estudios se pudieron entrelazar las categorías que emergieron con la síntesis interpretativa, junto a las categorías de los diferentes estudios y los verbatims explicativos de las diferentes categorías en cada uno de ellos.

El objetivo de la sexta fase fue sintetizar las traducciones. Para ello fue preciso valorar la existencia de conceptos que podían abarcar más de un estudio. Este proceso es similar al que se realiza en el análisis de estudios cualitativos primarios, en los que se desea llevar a cabo un segundo nivel de análisis.

Finalmente, la séptima fase consiste en expresar y redactar la síntesis en un producto final. Al llegar a esta etapa final de resultado de la síntesis, se analizó la síntesis obtenida mediante las traducciones recíprocas. Este proceso implicó nuevas relecturas de los estudios originales y comparaciones con las categorías finales obtenidas. Esta nueva comparación dio lugar a lo que Noblit y Hare [68] expresan como *línea de argumentación*. En esta fase fue posible realizar una nueva reconceptualización de los hallazgos, generando una nueva interpretación del fenómeno de estudio que los datos aportaban, obteniendo una síntesis que representa más que la suma de las partes y, a la vez, preserva la integridad individual de cada uno de los estudios. Tras la aplicación de la línea de argumentación de Noblit y Hare [68], la síntesis dio lugar a un modelo explicativo del DAM en pacientes con patología crónico o proceso avanzado de enfermedad.

3er Artículo: Psychometric properties of the Spanish form of the schedule for meaning in life evaluation.

En el tercer estudio se realizó la adaptación y validación de la forma española de la escala de evaluación del sentido de la vida (Schedule for Meaning in Life Evaluation, SMiLE) [58]. Para la validación de la escala SMiLE se reclutó una muestra incidental de 250 estudiantes universitarios de enfermería y odontología de 2 universidades españolas. Finalmente, entregaron los cuestionarios debidamente cumplimentados 213 estudiantes, 59 hombres y 154 mujeres. Los alumnos que no lo entregaron o lo entregaron en blanco se excluyeron del estudio. La edad media en los hombres fue de 24,7 (*DT* = 7,0) años y de 24,01 (*DT*=6,2) en las mujeres. El 63,4% eran estudiantes de enfermería de los tres cursos de la diplomatura y el 36,6% estudiantes de odontología de 3er y 4º curso.

Para determinar la validez convergente y discriminante, se administró la escala juntamente con medidas de depresión, ansiedad general, ansiedad ante la muerte, calidad de vida y autoestima, al considerar que la falta de sentido de la vida se manifiesta por un estado de tedio, desesperanza, percepción de falta de control sobre la propia vida y ausencia de metas vitales, mientras que el logro del sentido se asocia a la percepción positiva de la vida, del futuro y de sí mismo, así como a una autorrealización satisfactoria [87].

Los estudiantes respondieron un cuestionario anónimo y auto administrado que, además de datos sobre sexo y edad, contenía los siguientes instrumentos:

- La versión española de la escala SMiLE de Fegg et al. [58]. Este cuestionario consta de tres estadios. En el primero la persona evaluada debe indicar entre tres y siete áreas que dan sentido a su vida, generando así una lista de áreas individual para cada persona. En el segundo estadio la persona debe indicar el grado de satisfacción o insatisfacción que tiene en ese momento en cada área contestada en el estadio anterior, con un rango que va desde -3 muy insatisfecho a +3, muy satisfecho. El tercer estadio de la escala interroga sobre la importancia que tiene cada área en el significado global de su vida, con un rango que va de 0 -nada importante-, a 7 -extremadamente importante-. Una vez cumplimentados los tres estadios, se puede calcular el IoS o índice de satisfacción, que nos indica la satisfacción media de las áreas expresadas. El rango del IoS fluctúa entre 0 -nada

satisfecho- y 100 -totalmente satisfecho-, y se calcula mediante la fórmula siguiente:

$$IoS = \frac{\sum_{i=1}^{n} s'_i}{n}$$

Asimismo, se puede calcular el IoW o índice de importancia, que expresa la importancia media otorgada a las áreas definidas. Las puntuaciones del IoW tienen un rango entre 20 (algo importante) y 100 (muy importante). A continuación figura la fórmula que se utiliza para calcular dicho índice.

$$IoW = \tfrac{100}{7} \circ \frac{w_{ges}}{n};$$

$$w_{ges} = \sum_{i=1}^{n} w_i$$

Por último, se realiza el cálculo del IoWS o índice SMiLE total, que combina las puntuaciones de satisfacción e importancia en un único valor. Este índice ofrece una estimación conjunta del sentido, agrupando las medidas de satisfacción e importancia. El IoWS puede calcularse mediante la siguiente fórmula:

$$IoWS = \sum_{i=1}^{n} \left(\frac{w_i}{w_{ges}} \circ s'_i \right)$$

- La versión española de la escala de Autoestima de Rosenberg (Rosenberg Self-esteem Scale = RSES) [88]. Este cuestionario consta de 10 preguntas con un formato de respuesta tipo Likert de 4 puntos, desde total desacuerdo a total

acuerdo. Las posibles puntuaciones totales presentan un rango de 10 a 40, siendo la puntuación 10 la de más baja autoestima.

- La escala Auto aplicada de Depresión de Zung (Self-Rating Depression Scale = SDS) [89] en su versión española [90]. La SDS es una escala auto aplicada formada por 20 frases relacionadas con la depresión, formuladas la mitad en términos positivos y la otra mitad en términos negativos, utilizando una escala de Likert de 4 puntos, desde 1 (raramente o nunca) hasta 4 (casi todo el tiempo o siempre).

- La forma española del Inventario Revisado de Ansiedad ante la Muerte (Death Anxiety Inventory Revised = DAI-R) [91,92]. El DAI-R consta de 17 ítems con formato de respuesta tipo Likert de cinco puntos, desde 1 para total desacuerdo hasta 5 para total acuerdo, de manera que las posibles puntuaciones totales fluctúan entre 17 y 85, correspondiendo las puntuaciones más altas a superiores niveles de ansiedad ante la muerte.

- La escala de Ansiedad de la Universidad de Kuwait (Kuwait University Anxiety Scale = KUAS) [93], en su adaptación española [94]. La KUAS contiene 20 ítems con formato de respuesta tipo Likert de cuatro puntos, de 1 hasta 4, con un rango de posibles puntuaciones totales entre 20 y 80, correspondiendo las puntuaciones más altas a mayores niveles de ansiedad.

- La adaptación española del Cuestionario de Salud SF-12, realizada para España por Alonso et al. [95] del SF-12 Health Survey [96]. El SF-12 es una versión reducida del Cuestionario de Salud SF-36 [97]. Este instrumento proporciona un perfil del estado de salud y es aplicable en la población general con una edad mínima de 14 años. Se trata de un cuestionario auto-administrado que consta de 12 ítems provenientes de las 8 dimensiones del SF-36, función física, función social, rol físico, rol emocional, salud mental, vitalidad, dolor corporal y salud general. La versión utilizada fue desarrollada en EEUU en 2002 y permite obtener puntuaciones de medida física y mental.

Procedimiento. Todos los sujetos que respondieron al cuestionario participaron de forma libre y voluntaria y fueron informados del compromiso de los investigadores de mantener el anonimato y confidencialidad de los datos. Se solicitó permiso a los autores de las escalas originales para su autorización de uso en el estudio. Para la

obtención de la versión española de la escala SMiLE, se siguió la metodología de traducción y retrotraducción -back translation- recomendada por la *Scientific Advisory Comitte of the Medical Outcomes Trust* [98]. Partiendo de la versión inglesa validada por el propio autor de SMiLE [58], cuatro traductores de origen español realizaron traducciones independientes que se consensuaron posteriormente en una única versión. Esta versión española fue retrotraducida al inglés por un traductor bilingüe, de origen inglés, que desconocía la versión inglesa original. Finalmente se comparó la versión original con la retrotraducción, clasificando la equivalencia conceptual y semántica y realizando los ajustes necesarios para mejorar la equivalencia de la traducción. Para la obtención de la versión española final, se realizó una prueba piloto en la que se administró la escala a 20 personas de ámbitos socio-culturales diversos, profesores, estudiantes y personal no docente de la universidad; tras la prueba piloto se verificó no necesitar modificaciones en la versión.

Para valorar la estabilidad temporal de la escala, ésta se volvió a administrar a una submuestra aleatoria de 58 estudiantes de ambas universidades, con un intervalo de un mes entre el test y el re-test. Finalmente se obtuvieron 52 respuestas válidas. Se realizó un análisis cualitativo sobre las categorías o áreas contestadas en el primer ítem la primera vez que se pasaron los cuestionarios y las contestadas en el retest. Asimismo, se realizó un análisis estadístico de correlación entre el número de categorías contestadas en el primer tiempo y las contestadas transcurrido el tiempo previsto en el retest. Se procedió de igual modo con los índices de importancia, de satisfacción y SMiLE total.

Todos los datos fueron tabulados y analizados mediante el paquete estadístico SPSS versión 16.0. Se utilizaron métodos de análisis estadísticos descriptivos e inferenciales. Para valorar la consistencia interna de los índices se realizó un análisis del coeficiente alfa de Cronbach. Como la distribución de los datos no cumplía criterios de normalidad, se utilizaron para el análisis las pruebas no paramétricas *U* de Mann Whitney y coeficiente de correlación *Rho* de Spearman.

4. ARTÍCULOS PUBLICADOS

4.1 The wish to hasten death: A review of clinical studies

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Review

The wish to hasten death: a review of clinical studies

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Abstract

It is common for patients who are faced with physical or psychological suffering, particularly those in the advanced stages of a disease, to have some kind of wish to hasten death (WTHD). This paper reviews and summarises the current state of knowledge about the WTHD among people with end-stage disease, doing so from a clinical perspective and on the basis of published clinical research. Studies were identified through a search strategy applied to the main scientific databases.

Clinical studies show that the WTHD has a multi-factor aetiology. The literature review suggests—perhaps in line with better management of physical pain—that psychological and spiritual aspects, including social factors, are the most important cause of such a wish. One of the difficulties facing clinical research is the lack of terminological and conceptual precision in defining the construct. Indeed, studies frequently blur the distinction between a generic wish to die, a WTDH (whether sporadic or persistent over time), the explicit expression of a wish to die, and a request for euthanasia or physician-assisted suicide.

A notable contribution to knowledge in this field has been made by scales designed to evaluate the WTHD, although the problems of conceptual definition may once again limit the conclusions, which can be drawn from the results. Studies using qualitative methodology have also provided new information that can help in understanding such wishes.

Further clinical research is needed to provide a complete understanding of this phenomenon and to foster the development of suitable care plans.

Keywords: palliative care; wish to hasten death; cancer; oncology; literature review

Introduction

Western societies are once again debating the advisability of allowing assisted suicide or euthanasia. This debate usually arises from specific cases involving people with a severe disease prognosis and who regard death as the only way out of their situation. The controversy itself extends to those places where the law is currently in favour of some form of assisted suicide [1,2], and the questions being posed include the following: Can physician-assisted suicide (PAS) and euthanasia be regarded as solutions, or at least as appropriate responses to certain situations? Would a law on assisted suicide and euthanasia benefit both the individual and society at large? At all events, it is worth noting that when engaging with this debate it is easy to lose sight of other questions that lie at the heart of the problem: How much do we actually know about the wish to hasten death (WTHD) in terminally ill people? Does it occur very often? What are the various motives that might lie behind such a complex phenomenon?

Recently, there has been a growing interest in analysing the WTHD in the clinical context [3,4], especially in the area of palliative care [5–7], and this has been approached from different perspectives and disciplines [8,9]. Some studies have considered the attitudes of the general public and health professionals towards the wish of patients to hasten their death [10–12]. Other research has explored various factors related with the WTHD [13–15], although some of these studies have limitations in terms of their design and the way in which data were obtained via indirect sources [16–18]. In response to these limitations, other authors have explored the WTHD prospectively from the patient's perspective [16,19], although the majority of them limit the WTHD phenomenon to a few study variables that are selected and assessed in a rather reductionist way. More recently, qualitative research has been conducted with the aim of understanding better the real meaning of the WTHD in all its aspects and in a naturalistic context [20–23]. However, given the wide variety in both contexts and participants, the findings must be interpreted with caution.

This paper provides a review of published clinical studies in order to summarise current knowledge about the WTHD among people with end-stage disease.

Methods

The first step involved a detailed review of the international scientific literature regarding the WTHD and related concepts. Studies were identified primarily through conventional systematic searches of relevant electronic databases using medical subject heading terms and text words. The search strategy was conducted in MEDLINE (PubMed), PsycINFO, CINAHL, the Web of Science and CUIDEN. The timeframe covered for the databases used in the search was from their inception to January 2010. No restrictions were imposed. Table 1 lists the search strategy used.

Table 1. Bibliographic search strategy

♯1	'*Wish to hasten death*' [Text Word]
♯2	'*Desire to hasten death*' [Text Word]
♯3	'*Desire for death*' [Text Word]
♯4	'*Desire for early death*' [Text Word]
♯5	'*Euthanasia*' OR '*physician assisted suicide*' [MeSH]
♯6	♯1 OR ♯2 OR ♯3 OR ♯4 OR ♯5
♯7	'*Advanced cancer patients*' [Text Word]
♯8	'*Advanced illness*' [Text Word]
♯9	'*Chronic disease*' [MeSH]
♯10	'*Chronic illness*' [MeSH]
♯11	'*Terminal illness*' [Text Word]
♯12	♯7 OR ♯8 OR ♯9 OR ♯10 OR ♯11
♯13	♯6 AND ♯12
♯14	♯13 NOT child*

We did not restrict the search strategy to a particular type of research design. Figure 1 illustrates the search process followed.

Of the 1239 references initially retrieved, 1133 potentially relevant citations were then identified. Analysis of their titles and abstracts reduced the pool to 226 articles of potential interest to this review. Reading these articles and reviewing their reference lists, as well as consulting with experts in the field, produced a final sample comprising 282 relevant studies.

The lead researcher (CM) carried out the literature search, which was then verified by another researcher (AB). First, CM was responsible for reviewing the 1133 citations, and the results of this search were then fed back to the other researchers. Disagreements were resolved by

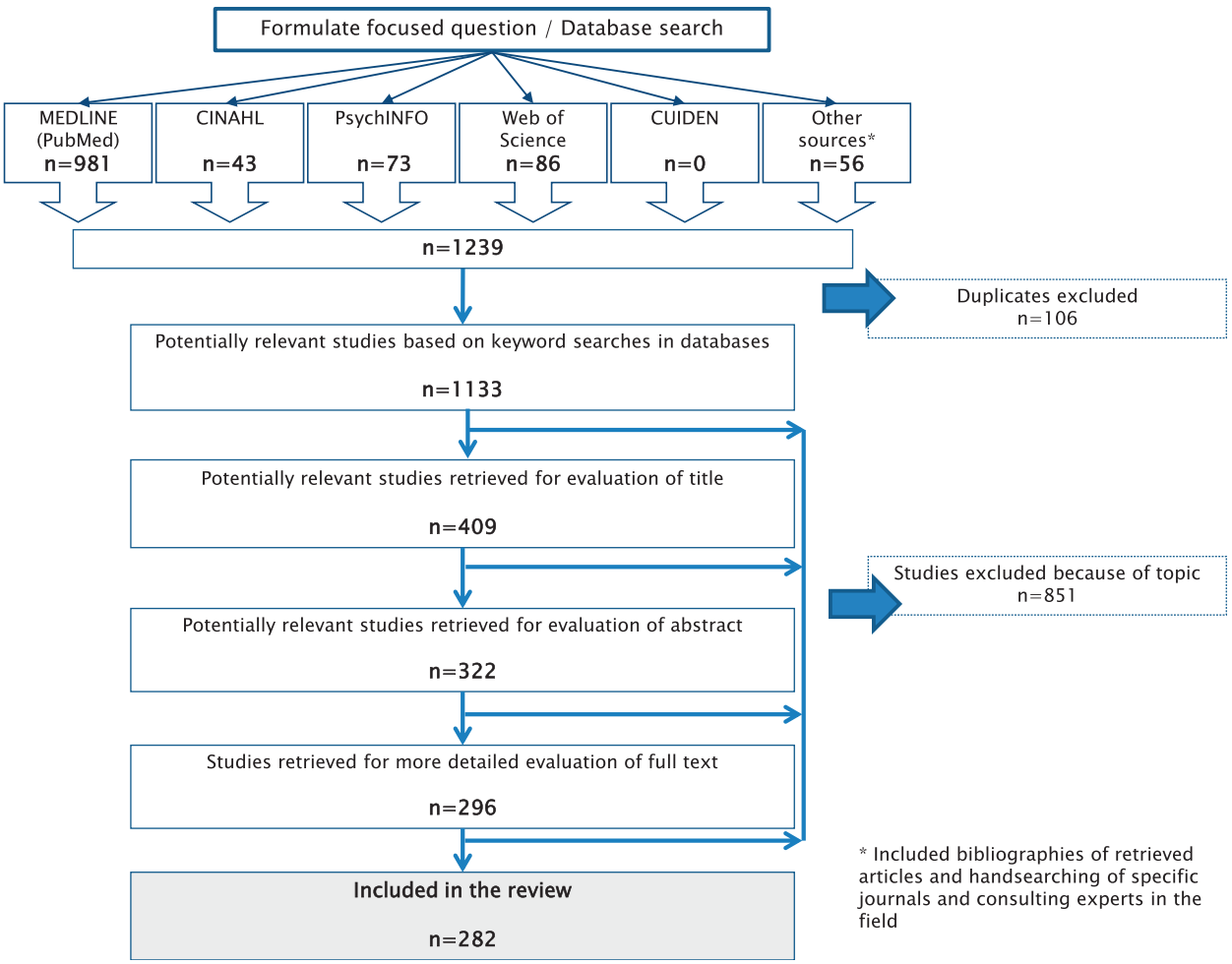

Figure 1. Flowchart of search results

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discussion between the reviewers and reference to the full article. Finally, the research team reached an agreement on the final studies ($n = 282$) that should be included in the review, which was conducted using a narrative synthesis approach. The main findings that emerged from the review have been summarised under four headings: conceptualisation of the WTHD; aetiology of the WTHD; temporal stability of the WTHD; and epidemiology of the WTHD and instruments for measuring it.

Results

The studies were categorised by research design or focus topic (Table 2). In terms of the different types of articles identified, the analysis showed there to be similar proportions of clinical studies focussed directly on the WTHD, studies that analyse attitudes toward the WTHD, case report and case series and more theoretical or discussion papers. It should be noted that among the clinical studies that directly analysed the WTHD, only 14 obtained their data from patients themselves.

The breakdown of the MEDLINE (PubMed) search by publication date shows the growing interest in this topic over the last few decades (Table 3).

With regard to the geographical distribution of articles, around 50% of them (146) originated from the United States; they were distributed across almost all this country's states, although 25 referred to research conducted in Oregon. Europe was the next most common source of articles on this topic ($n = 80$). More than half of these came from Belgium ($n = 16$) and the Netherlands ($n = 26$). The remaining studies were distributed among Spain ($n = 9$), the United Kingdom ($n = 6$) and other European countries ($n = 12$). Australia was another country that conducted a considerable number of studies ($n = 21$), followed by Canada ($n = 17$) and Japan ($n = 10$). Finally, four studies were conducted in Israel, two in China, one in India and one in Mexico.

The main sector of the population in which the WTHD has been explored comprises palliative care and cancer patients (Table 4).

Table 2. Categorisation of articles selected by design or focus topic

Kind of study	Data sources	Number of studies	%
Clinical studies focussing directly on the WTHD[a]		83	29
Quantitative (57 studies)			
Health professionals		20	
Palliative-care patients/patients in palliative care		14	
Family members		12	
Other patients[b]		6	
Retrospective study with official euthanasia and/or PAS data		5	
Qualitative (26 studies)			
Health professionals or family members		15	
Patients in palliative care		11	
Studies that analyse attitudes towards the WTHD		75	26
Health professionals		40	
Family members		14	
Patients		10	
General population		8	
University students		2	
Comments/Reflections: non-empirical studies		73	25
Case report and/or case-series		17	6
Health professionals' role with respect to the WTHD		12	4
Clinical practice guidelines		12	4
Reviews		10	3

[a]Evaluating clinical aspects of the WTHD: epidemiology, aetiology, etc.
[b]Patients in the early stage of the disease or with life expectancy of more than six months.

Table 3. Results of the search strategy by year of publication

Years	Number of articles
< 1970	1
1970–1979	35
1980–1989	144
1990–1999	373
2000–2009	428

Performed in MEDLINE (PubMed) on 1/2/2010.

Table 4. Type of population studied

Main illness (when specified)	Number of studies
Cancer patients[a]/hospice patients	42
AIDS	18
Amyotrophic lateral sclerosis	7
Chronic kidney failure	4
Elderly population	3
Chronic respiratory and cardiac failure	1

[a]Cancer patients in all stages of the illness and not necessarily in palliative care.

Discussion

Conceptualisation of the WTHD

Noteworthy among the first clinical studies of the WTHD were those conducted by Kraus [24,25], who took an epidemiological perspective. This research was based on a number of surveys that gathered opinions about the WTHD among the general public and health professionals in Ontario. In these pioneering studies, the concept of the *wish to die* was used in a somewhat imprecise way, such that it could encapsulate both a generic or occasional desire and a more specific and persistent WTHD.

The growing interest in these topics led to numerous studies being conducted in the field, although their terminological, conceptual and methodological differences made it difficult to compare the results [4,26,27]. For example, these studies did not distinguish clearly between a

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general wish to die, the WTHD and requests for euthanasia or PAS. Thus, one finds the indistinct use of terms such as '*wish to die*' [28], '*want to die*' [29] or '*desire to die*' [30,31], as well as '*wish to hasten death*' [6,22], '*desire for early death*' [32] and other related expressions for requests for euthanasia or assisted suicide, such as '*death-hastening request*' [33], '*request to die*' [34], '*request for euthanasia*' [35] and '*request for physician-assisted suicide*' [36]. Table 5 shows the number of studies identified that use each of these terms.

However, in these concepts one could, at least in theory, differentiate between *thoughts, wishes* and *intentions*, which would imply progressively greater proximity to actual death. Thus, a distinction should be made between: (a) a generic wish to die; (b) a WTHD (sporadic or persistent over time); (c) the explicit manifestation of a WTHD and (d) the final stage in this process, i.e. the request for PAS or euthanasia. The concept of the WTHD would, therefore, appear around the midpoint of this process, it being more specific than a simple wish to die but coming prior to and being distinct from a request for euthanasia or PAS.

In response to these difficulties, a number of more recent clinical studies have sought to bring greater conceptual accuracy to the field [4,30,37,38]. Key authors such as Breitbart *et al.* [4] and Rosenfeld [39] have also recognised the need for this. However, these authors, who coined the term '*desire for hastened death* (*DHD*)', use it as a 'catch-all' term covering everything from a generic wish to die to requests for euthanasia and PAS.

Faced with the lack of methods for quantifying patients' wish to die, and in an attempt to standardise the criteria used when studying the WTHD, Rosenfeld *et al.* [38] developed the Schedule of Attitudes Toward Hastened Death (SAHD) [40]. This instrument contemplates a wide range of concepts, from general ideas about hastening death to requests for euthanasia and PAS. However, although the SAHD does distinguish between different notions, the fact that its final results are presented in numerical form means that, in practice, it does not really bring the conceptual accuracy it sets out to do. Nevertheless, the instrument has enabled researchers to compare this phenomenon in different populations and under different circumstances [4,7,13,37,41,42].

Table 5. Terms used in studies focussed directly on the WTHD

Terms used	Studies
'Desire to die' or 'desire to hasten death' or 'desire for early death'	18
'Wish to hasten death' or 'wish to die'	12
'Consider hasten death' or 'consider hastening death'	9
'Want to die'	5

The paper by Schroepfer [43] was the first clinical study to clearly highlight these conceptual differences. Using qualitative methodology, the author studied 96 patients (elderly people with fewer than six months to live) in order to examine the factors that motivated them to consider hastening their death. The findings led to the development of a conceptual framework that clearly distinguished between six stages or 'mind frames', which did not necessarily correlate with one another. The first referred to those elders who were neither ready for nor accepted death. The second concerned elders who were not ready for but did accept death. The third group comprised elders who were both ready and accepting. The fourth included elders who were ready, accepting and wishing that death would come. The fifth stage referred to elders who were considering a hastened death but who had no specific plan. And finally, the sixth mind frame was that of elders who already had a specific plan to hasten their death. According to Schroepfer [43], these six stages can be dichotomised according to whether or not there is a WTHD, and thus the last two stages would be grouped separately from the first four. Although there are no other studies that corroborate these findings, the paper is of considerable interest in that it offers a conceptual framework based on clinical data, which would seem to be essential from a theoretical point of view.

Aetiology of the WTHD

In recent years, there have been several published studies that have sought to identify, from a clinical perspective, the factors that might cause or foster the WTHD. Overall, these studies suggest a multi-factor basis for the WTHD [6,44], one that includes pain, physical suffering, psychiatric disorders, and psychological or existential distress. In general, there is a broad consensus regarding the need for a greater understanding of the factors that might influence the WTHD, especially those which could potentially be modified through clinical or social interventions [14,45].

Morita *et al.* [31] analysed the multi-factor nature of the WTHD by interviewing the families of patients who had died in a palliative care unit. They found that in 30% of patients who had wished to die the main reason for this was not the physical symptomatology but the existential suffering. Among the multiple causal factors behind this existential suffering the authors introduced the concept of a lack or loss of meaning to life.

In the most recent retrospective studies, the key factors behind the WTHD are reported to be of a psychosocial nature, especially the reduced ability to take part in pleasurable activities, the fear of pain or unmanageable symptoms as the disease progresses, the loss of autonomy, the feeling of

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being a burden, a perceived loss of dignity, the loss of meaning in life, a loss of control over bodily functions and over when and how one might die, and a loss of control in general [46–49]. None of these studies analysed the presence of depression as a causal factor in the WTHD, and only two of them found evidence that pain motivated such a wish [46,49].

However, depression is one of the most widely analysed factors among probable causes of the WTHD [50]. The study by Breitbart *et al.* [4] found that patients who expressed a WTHD were around four times more likely to be depressed than were patients who did not wish to die or may not have considered it. Two studies conducted in Canada and the United States quantified the prevalence of depression in cancer patients who wished to hasten their death as being between 8.5 and 17% [4,30].

Another factor that has been studied in relation to the WTHD is hopelessness, which is defined in this context as a cognitive state of pessimism [51]. Hopelessness is reported in 44% of cases, as a state prior to depression [4]. In the same line, a study conducted by Ganzini *et al.* [52] in Oregon reported that hopelessness is associated with a greater interest in PAS. In another study, the same authors [53] found that hopelessness was a predictive factor for the WTHD.

Pain, understood as physical suffering, has for many decades been regarded as one of the primary causes of the WTHD [54]. However, since the end of the 1990s most studies have identified pain as an isolated factor that does not play a key role in fostering the WTHD [4,31]. As an alternative, some authors have introduced the concept of 'overall physical distress', which includes other physical signs and symptoms and whose presence is significantly associated with the emergence of a WTHD [36]. Another factor that has been analysed as a potential cause of the WTHD is inadequate symptom control, behind which would lie not just pain but the whole range of physical symptomatology [3,55,56].

The feeling of being a burden to others is another causal aspect that has been studied recently [57]. This feeling, which is closely related to dependence and a lack of autonomy, is defined as the patient's perception that his/her dependence on others has a detrimental effect on their personal or social development. Studies conducted in the United States and Japan found, respectively, that this feeling was present in 58% [57] and 98% [31] of patients who expressed a WTHD.

In summary, the main factors that have been related to the WTHD can be grouped into the following areas: (a) physical symptoms in the form of pain, physical suffering, distress, fatigue, dyspnoea, etc.; (b) psychological distress (hopelessness, the fear of pain, of advancing disease and physical deterioration, of a loss of autonomy, of aloneness) or psychiatric disorders (such as depression or related symptoms); (c) social factors, such as feeling like a burden to others, both physically and financially, and the perceived lack of social support; and finally (d) a wide range of factors that come under the label of 'psycho-existential suffering', such as the loss of autonomy, the loss of a social role, the wish to control how and when one dies, and the loss of meaning to life, the latter having received scant attention and conceptualisation in the literature.

Temporal stability of the WTHD

It should be clear from the above that patients with a chronic disease or those in the advanced stages of an acute illness often report some sort of WTHD, even when they are receiving palliative care [30,31,58]. Although many factors have been identified as contributing to the WTHD, it has also been shown to be a fluctuating and unstable feeling in patients with advanced disease [17,30].

Moreover, research has also found that the request to hasten death is not always accompanied by a genuine desire to die. In this context a systematic review by Alcázar-Olán *et al.* [59], the aim of which was to examine the medical and psychological criteria used to assess patients who requested a hastened death, concluded that the majority of such requests were, paradoxically, a request for help with living. One year later, a phenomenological study conducted by Coyle *et al.* [22] in a palliative care unit in New York reached similar conclusions. The authors noted the dual meaning of each expression of the WTHD, in the sense that it can reflect both a genuine desire to end one's life and a wish to live, it being a request for help in the face of a life that has become difficult, complicated, and painful [22].

Similarly, a qualitative study carried out in Belgium [7] found that some patients admitted to a palliative care unit and who had expressed a wish to hasten their death changed their minds after feeling that their plight had been heard. The authors of this study concluded that on many occasions the cause or the factor that triggers the initial decision is a feeling of social isolation or lack of support, which in this case was addressed through the nursing care given. Other researchers have argued the need to explore each individual request, as well as the possible reasons behind each expression of a WTHD [8,60,61]. Emanuel [62] proposed a set of clinical guidelines for working with patients who express a wish to die, the aim being to ensure that each patient is correctly assessed and to rule out the presence of a potentially treatable cause.

Another phenomenological study conducted in Hong Kong [20] analysed the experience and expression of the WTHD in six palliative care

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patients. The authors concluded that behind each decision and request for euthanasia lay 'hidden existential yearnings for connectedness, care, and respect'. Other similar studies [3,63,64] conducted in Canada and the United States have found that the WTHD becomes less strong when the patient perceives a degree of hope in the treatment and care being received.

Epidemiology of the WTHD and instruments for measuring it

Determining the epidemiology of the WTHD is not an easy task, due, above all, to the very nature of the phenomenon, its variability and dependency on external factors, and the problem of its conceptualisation. In addition, it is difficult to compare the results of clinical studies conducted using different methodologies.

A sizeable majority of the research published on this topic corresponds to retrospective studies which analyse data collected from indirect sources: health professionals or informal caregivers and relatives of patients who have expressed a WTHD [65,66]. With regard to prospective studies, they can be classified according to one of two methodological approaches. The first concerns those studies that analyse the responses of patients with a terminal illness to questions about potential future scenarios involving pain or unbearable suffering, discomfort, etc., where the patients must answer according to what they would do in such a situation [53,67,68]. Clearly, however, these responses are based on preconceived attitudes and may not necessarily reflect a person's actual behaviour or decisions in real situations [69].

The second category of prospective research concerns those studies that use various questionnaires or scales that have been designed to quantify the WTHD. Studies of this kind first appeared during the 1990s. For example, Chochinov *et al.* [30] designed a study in which, in addition to sociodemographic variables and other possible factors related to the wish to die, they added a question about the wish to die soon. In the event that subjects responded affirmatively to this question they were then asked a further three questions in order to assess their degree of conviction. These questions constituted the first instrument developed to evaluate the wish to die, namely the Desire for Death Rating Scale (DDRS). The authors then used this scale with a sample of 200 palliative care patients and found a prevalence rate of 8.5% for a real and persistent wish to die.

O'Mahony *et al.* [70] used the same scale to analyse the desire for death in a sample of 64 cancer patients who presented both pain and depression. These patients were treated for their pain, and the authors took pre- and post-intervention measures. The former showed that a third of patients expressed a WTHD, whereas after pain relief only a quarter of the sample expressed such a wish, as measured by the DDRS. However, the researchers themselves suggest that the instrument may lack sensitivity in terms of detecting small changes in the quantification of the WTHD.

The DDRS has recently been modified by Kelly *et al.* [71] with the aim of producing an instrument that is capable of assessing both the intensity of the desire for death and potentially related factors. The modified version of the scale (the WTHD scale) comprises six items that are scored on a five-point Likert scale. In the study by Kelly *et al.* [71], the scale was administered to a sample of 256 terminally ill patients in Australia and showed adequate validity and reliability. Prevalence data showed that 14% of patients reported a strong WTHD [71].

Rosenfeld *et al.* [38], in an attempt to overcome the limitations of the scale developed by Chochinov *et al.* [30], designed the already-mentioned Schedule of Attitudes Towards Hastened Death (SAHD), which aims to evaluate the WTHD among terminally ill patients. The SAHD is a self-report scale comprising 20 true/false items, and it was initially validated in a sample of 195 AIDS patients. Analysis of its psychometric properties showed that the scale has adequate validity and reliability [37,38]. In this original patient sample, the mean number of items endorsed was 3.05 (SD = 3.80). The scale was subsequently validated in a sample of 92 terminally ill cancer patients [37], who endorsed an average of 4.76 items (SD = 4.3). Three categories can be distinguished according to the number of scale items endorsed: $\leqslant 3$, between 4 and 9, and >10, which correspond, respectively, to low, moderate, and high levels of desire to hasten death. However, this terminology may be somewhat schematic and the authors themselves acknowledge that scores below 10 could reflect states of mind in which people accept their own death [4,39].

Since its publication the SAHD has been used by numerous authors to evaluate the WTHD. For example, Jones *et al.* [41] studied 224 cancer patients and found a strong WTHD among 2% of them. Ransom *et al.* [42] applied the same scale to 60 late-stage cancer patients being cared for at home and found high values for the WTHD in 3.3% of them. A recent study by Rodin *et al.* [7] analysed the WTHD in 326 ambulatory patients with either gastrointestinal cancer (all stages) or pre-terminal lung cancer, and reported high levels in 2% of patients. The study by Pessin *et al.* [13] analysed the WTHD in a sample of 109 patients in the advanced stage of AIDS, the mean score for the WTHD being 2.8 (SD = 3.0). Furthermore, 17% of this sample endorsed between four and seven scale items, while 10% endorsed more than seven. It should also be noted that the maximum score obtained was 15 (out of a possible 20). Finally, the

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study by Rabkin *et al.* [72] also used the SAHD, along with other instruments, to assess the presence of depressive symptoms and the WTHD in patients with amyotrophic lateral sclerosis (ALS), with high scores being obtained in 3.7% of patients.

One of the most widely cited prospective studies about the WTHD in non-cancer patients is that of Albert *et al.* [28]. These authors assessed 80 patients with end-stage ALS who had been given fewer than six months to live. Patients were followed up prospectively and 53 died during the follow-up period. Of these, all of whom were assessed using the SAHD of Rosenfeld *et al.* [37], 10 had expressed the wish to die. In these 10 patients, scores on the SAHD showed a strong wish to die, the mean number of items endorsed being 12.6, compared to 4.8 in the group of patients who did not express a wish to hasten their death [28].

At all events, the existing literature still falls short of enabling investigators to be clear about when the WTHD reflects an underlying psychological disorder as opposed to some other situation within the conceptual framework, including the acceptance of death. Expressions of the wish to die, suicidal ideation, and requests for euthanasia or PAS have been identified in between 8 and 22% of cancer patients in palliative care units [4,30,73]. In a sample of 378 HIV patients, Breitbart *et al.* [74] examined the relationship between an interest in PAS and variables such as pain and other physical or psychosocial symptomatology. They found that 55% of patients had considered PAS as a possible option at some point. Ganzini *et al.* [53] interviewed 100 patients with ALS in Oregon during the period 1995–1997, this being prior to the legalisation of PAS in this state. According to the authors, 56% of patients said they would consider PAS were it a legal option in the state [53]. Another study by Ganzini *et al.* [52] concluded that 20% of patients admitted to hospices in Oregon had requested prescriptions for lethal medication, although on many occasions they did not use it. Emanuel *et al.* [17] studied attitudes towards euthanasia or PAS among 988 terminally ill patients, of whom 10.2% had seriously considered it with regard to their personal circumstances. A survey of 256 relatives of these patients found that 14 of them (1.4%) had submitted a formal request for euthanasia to their physician and 6 (0.6%) had stored medication, although they did not use it. Finally, one patient died following euthanasia and another made a failed suicide attempt. It should be noted that the incidence of depression in this sample was significant. Specifically, depressive symptoms were reported in 159 of them (16%), and 19.5% of these expressed an interest in both euthanasia and PAS. A multivariate analysis revealed that the patients who had expressed an interest in euthanasia and PAS were more likely to have symptoms of depression (OR = 5.29). This study also confirmed the temporal instability of the WTHD.

One of the most detailed studies about the possible causes of the wish to die is that conducted by Seale and Addington-Hall [29]. These researchers analysed two surveys carried out in England, which focussed on the relative who cared for the patient during the last year of life. They found that 24% of those surveyed said that their deceased relative had, at some point, wished to die soon, while 3.6% said that the deceased relative had requested euthanasia [29].

The main limitation of the above-mentioned studies is that they fail to specify the type of wish expressed. In general, it is not known whether they refer to generic thoughts or desires or a genuine intention to hasten death. As such, determining the prevalence of the WTHD in chronically ill or end-stage patients continues to pose a serious challenge [75]. Although numerous studies carried out mainly in the United States [49,76–78], as well as in Holland [58,79], have sought to specify the prevalence of the WTHD, the above-mentioned limitations (especially the lack of conceptual clarity) make it difficult to obtain comparable results [10].

Other known prevalence rates regarding the wish to die are those derived from the number of people who choose to end their life under the PAS law in Oregon or the euthanasia and PAS law in Holland. Between 1998 and 2001, a total of 140 people, almost all of them with end-stage cancer, requested PAS under the law in Oregon [80]. Of these, 91 eventually died as a result of taking lethal medication prescribed under the law. Overall, the data show that 1% of patients at the end of their lives request PAS in Oregon, but only 0.1% of terminally ill patients actually die as a result of PAS [80,81]. In Holland, a study of patients with ALS found that 17% of a sample of 204 chose to die through euthanasia, while 3% opted for PAS [66].

This literature review shows that prevalence rates for the WTHD vary considerably from one study to another. These differences could be due both to conceptual aspects or sample characteristics as well as to the lack of a standardised measurement instrument. Taken together, the findings highlight the need not only for consensus and standardised criteria regarding the definition of the WTHD and related concepts but also for valid and reliable instruments to quantify it.

Final considerations

Although the WTHD is clearly of interest to clinicians and theorists, it poses considerable difficulties in terms of research. The WTHD is a complex phenomenon that raises questions about our current ability to care for and accompany patients through this most difficult of life stages. Moreover, in the context of serious or incurable illness, it affects a considerable number of patients,

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especially those facing the end of life. Medical advances, which have transformed diseases that once led to a quick death into chronic illnesses, coupled with increased life expectancy and other social phenomena linked to development, make it likely that far from being eradicated these situations will become more common.

Clinical studies show that the WTHD has a multi-factor aetiology. The growing body of literature over time suggests—perhaps in line with improvements in the treatment of physical pain—that overall suffering or the more general and spiritual aspects of the human being, including psychological and social aspects, are the most important factors underlying such a wish.

A better understanding of the WTHD, one which clarifies its conceptual limits and distinguishes between different stages or situations, is now necessary in order to further improve our knowledge and develop adequate interventions. Some strategies, such as the design of measurement instruments (for example, the SAHD of Rosenfeld *et al.* [38]), may help to quantify the phenomenon and enable comparisons to be made. However, given the nature of the WTHD, research would be incomplete without the contribution of qualitative methodology. In this regard, the conceptual framework developed by Schroepfer [43] may be a good foundation on which to develop our understanding and devise care plans for each of the stages or 'mind frames' through which people can pass.

In sum, a multidisciplinary initiative is now required to improve the emotional and physical care that is offered to terminally ill people. An adequate approach to the WTHD, one that integrates both anthropological and clinical viewpoints, and which works closely with palliative care units, should thus be regarded as a priority goal.

References

1. Back AL, Pearlman RA. Desire for physician-assisted suicide: requests for a better death? *Lancet* 2001;**358**: 344–345.
2. Battin MP, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen BD. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups. *J Med Ethics* 2007;**33**:591–597.
3. Wilson K, Scott JF, Graham ID *et al.* Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med* 2000;**160**:2454–2460.
4. Breitbart W, Rosenfeld B, Pessin H *et al.* Depresssion, hopelessness, and desire for hastened death in terminally ill patients with cancer. *J Am Med Assoc* 2000;**284**:2907–2911.
5. Hudson PL, Schofield P, Kelly B *et al.* Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliat Med* 2006;**20**:703–710.
6. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Terminally ill cancer patients' wish to hasten death. *Palliat Med* 2002;**16**:339–345.
7. Rodin G, Zimmermann C, Rydall A *et al.* The desire for hastened death in patients with metastatic cancer. *J Pain Symptom Manage* 2007;**33**:661–675.
8. Arnold EM, Artin KA, Person JL, Griffith DL. Consideration of hastening death among hospice patients and their families. *J Pain Symptom Manage* 2004;**27**:523–532.
9. van Bruchem-Van de Scheur GG, Van der Arend AJG, Spreeuwenberg C, Huijer Abu-Saad H, ter Meulen RHJ. Euthanasia and physician-assisted suicide in the Dutch homecare sector: the role of the district nurse. *J Adv Nurs* 2007;**58**:44–52.
10. Emanuel EJ. Euthanasia and physician-assisted suicide: a review of the empirical data from the United States. *Arch Intern Med* 2002;**162**:142–152.
11. Kinsella TD, Verhoef MJ. Assisted suicide: opinions of Alberta physicians. *Clin Invest Med* 1995;**18**:406–412.
12. Musgrave CF, Margalith I, Goldsmidt L. Israeli oncology and nononcology nurses' attitudes toward physician-assisted dying: a comparison study. *Oncol Nurs Forum* 2001;**28**:50–57.
13. Pessin H, Rosenfeld B, Burton L, Breitbart W. The role of cognitive impairment in desire for hastened death: a study of patients with advanced AIDS. *Gen Hosp Psychiatry* 2003;**25**:194–199.
14. Kelly B, Pelusi D, Burnett P, Varghese F. The prevalence of psychiatric disorder and the wish to hasten death among terminally ill cancer patients. *Palliat Support Care* 2004;**2**:163–169.
15. Kissane DW, Kelly B. Demoralization, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. *Aust NZ J Phychiatry* 2000;**34**:325–333.
16. Akechi T, Nakano T, Akizuki N *et al.* Clinical factors associated with suicidality in cancer patients. *Jpn J Clin Oncol* 2002;**32**:506–511.
17. Emanuel E, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *J Am Med Assoc* 2000;**284**:2460–2468.
18. Rabkin JG, Albert SM, Del Bene ML *et al.* Prevalence of depressive disorders and change over time in late-stage ALS. *Neurology* 2005;**65**:62–67.
19. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors. *Phychosomatics* 2004;**45**: 311–318.
20. Mak YY, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliat Med* 2005;**19**:343–350.
21. Lavery JV, Boyle J, Dickens BM, Maclean H, Singer PA. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. *Lancet* 2001;**358**:362–367.
22. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncol Nurs Forum* 2004;**31**:699–709.
23. Pearlman RA, Hsu C, Starks H *et al.* Motivations for physician-assisted suicide. *J Gen Intern Med* 2005;**20**: 234–239.
24. Kraus AS. Patients who want to die: a survey of 1000 adults. *Can Fam Physician* 1978;**24**:1282–1286.
25. Kraus AS. Patients who want to die: a survey. *Can Fam Physician* 1977;**23**:1353–1358.
26. Rosenfeld B. Methodological issues in assisted suicide and euthanasia research. *Psychol Public Policy Law* 2000;**6**:559–574.
27. Brown JH, Henteleff P, Barakat S, Rowe CJ. Is it normal for terminally ill patients to desire death? *Am J Psychiatry* 1986;**143**:208–211.

DOI: 10.1002/pon

28. Albert SM, Rabkin JG, Del Bene ML *et al*. Wish to die in end-stage ALS. *Neurology* 2005;**65**:68–74.
29. Seale C, Addington-Hall J. Euthanasia: why people want to die earlier. *Soc Sci Med* 1994;**39**:647–654.
30. Chochinov HM, Wilson KG, Enns M, Mowchun N. Desire for death in the terminally ill. *Am J Psychiatry* 1995;**152**:1185–1191.
31. Morita T, Sakaguchi Y, Hirai K, Tsuneto S, Shima Y. Desire for death and request to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care. *J Pain Symptom Manage* 2004;**27**:44–52.
32. Tiernan E, Casey P, O'Boyle C *et al*. Relations between desire for early death, depressive symptoms and antidepressant prescribing in terminally ill patients with cancer. *J R Soc Med* 2002;**95**:386–390.
33. Cohen LM, Steinberg MD, Hails KC, Dobscha SK, Fischel SV. Psychiatric evaluation of death-hastening requests. Lessons from dialysis discontinuation. *Psychosomatics* 2000;**41**:195–203.
34. Muskin PR. The request to die: role for a psychodynamic perspective on physician-assisted suicide. *J Am Med Assoc* 1998;**279**:323–328.
35. Block SD, Billings JA. Patient requests for euthanasia and assisted suicide in terminal illness. The role of the psychiatrist. *Psychosomatics* 1995;**36**:445–457.
36. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliat Med* 2006;**20**:685–692.
37. Rosenfeld B, Breitbart W, Galietta M *et al*. The Schedule of attitudes toward hastened death. Measuring desire for death in terminally ill cancer patients. *Cancer* 2000;**88**:2868–2875.
38. Rosenfeld B, Breitbart W, Stein K *et al*. Measuring desire for death among patients with HIV/AIDS: the schedule of attitudes toward hastened death. *Am J Psychiatry* 1999;**156**:94–100.
39. Rosenfeld B, American Psychological Association. *Assisted Suicide and the Right to Die*: *The Interface of Social Science*, *Public Policy*, *and Medical Ethics*. American Psychological Association: New York, 2004.
40. Mystakidou K, Rosenfeld B, Parpa E *et al*. The schedule of attitudes toward hastened death: validation analysis in terminally ill cancer patients. *Palliat Support Care* 2004;**2**:395–402.
41. Jones JM, Huggins MA, Rydall AC, Rodin GM. Symptomatic distress, hopelessness, and the desire for hastened death in hospitalized cancer patients. *J Psychosom Res* 2003;**55**:411–418.
42. Ransom S, Sacco WP, Weitzner MA, Azzarello LM, McMillan SC. Interpersonal factors predict increased desire for hastened death in late-stage cancer patients. *Ann Behav Med* 2006;**31**:63–69.
43. Schroepfer TA. Mind frames towards dying and factors motivating their adoption by terminally ill elders. *J Gerontol* 2006;**61**:S129–S139.
44. Georges JJ, Onwuteaka-Philipsen BD, van der Wal G, van der Heide A, van der Maas PJ. Differences between terminally ill cancer patients who died after euthanasia had been performed and terminally ill cancer patients who did not request euthanasia. *Palliat Med* 2005; **19**:578–586.
45. Hendin H. Suicide, assisted suicide, and medical illness. *Harv Ment Health Lett* 2000;**16**:4–7.
46. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;**338**:1193–1201.
47. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon—the first year's experience. *N Engl J Med* 1999;**340**:577–583.
48. Volker DL. Oncology nurses' experiences with requests for assisted dying from terminally ill patients with cancer. *Oncol Nurs Forum* 2001;**28**:39–49.
49. Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *J Am Med Assoc* 1996;**275**:919–925.
50. Akechi T, Okamura H, Yamawaki S, Uchitomi Y. Why do some cancer patients with depression desire an early death and others do not? *Psychosomatics* 2001;**42**: 141–145.
51. Beck AT, Trexler L, Lester D, Weissman L. The measurement of pessimism: the hopelessness scale. *J Consult Clin Psychol* 1974;**42**:861–865.
52. Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl J Med* 2002;**347**:582–588.
53. Ganzini L, Johnston W, McFarland B, Tolle S, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998;**339**:967–973.
54. Kinsella TD, Verhoef MJ. Alberta euthanasia survey: 1. Physicians' opinions about the morality and legalization of active euthanasia. *Can Med Assoc J* 1993;**148**: 1921–1926.
55. Hendin H, Klerman G. Physician-assisted suicide: the dangers of legalization. *Am J Psychiatry* 1993;**150**: 143–145.
56. Cherny NI, Coyle N, Foley KM. The treatment of suffering when patients request elective death. *J Palliat Care* 1994;**10**:71–79.
57. Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *J Pain Symptom Manage* 2002;**24**:312–317.
58. van der Maas PJ, van der Wal G, Haverkate I *et al*. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995. *N Engl J Med* 1996;**335**:1699–1705.
59. Alcázar-Olán R, Reyes-Chiquete D, Plancarte-Sánchez R. Valoración del paciente que solicita muerte asistida. *Rev Oncol* 2003;**5**:65–69.
60. Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med* 2002;**162**:1257–1265.
61. Leeman CP. Distinguishing among irrational suicide and other forms of hastened death: implications for clinical practice. *Psychosomatics* 2009;**50**:185–191.
62. Emanuel L. Facing requests for physician-assisted suicide: toward a practical and principled clinical skill set. *J Am Med Assoc* 1998;**280**:643–647.
63. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* 1999;**354**: 816–819.
64. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med* 2000; **342**:557–563.
65. Georges JJ, Onwuteaka-Philipsen B, Muller MT, Van Der Wal G, Van Der Heide A, Van Der Maas PJ. Relatives' perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: a retrospective cross-sectional interview study in the Netherlands. *Death Stud* 2007;**31**:1–15.
66. Veldink JH, Wokke JHJ, van der Wal G, Vianney de Jong JMB, van den Berg LH. Euthanasia and

DOI: 10.1002/pon

physician-assisted suicide among patients with amyotrophic lateral sclerosis in the Netherlands. *N Engl J Med* 2002;**346**:1638–1644.
67. Emanuel E, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996;**347**:1805–1810.
68. Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon—the second year. *N Engl J Med* 2000;**342**:598–604.
69. Mishara BL. Synthesis of research and evidence on factors affecting the desire of terminally ill or seriously chronically ill persons to hasten death. *Omega* (*Wesport*) 1999;**39**:1–70.
70. O'Mahony S, Goulet J, Kornblith A *et al*. Desire for hastened death, cancer pain and depression: report of a longitudinal observational study. *J Pain Symptom Manage* 2005;**29**:446–457.
71. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Factors associated with the wish to hasten death: a study of patients with terminal illness. *Psychol Med* 2003;**33**:75–81.
72. Rabkin JG, Wagner GJ, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosom Med* 2000;**62**:271–279.
73. Suárez-Almazor ME, Belzile M, Bruera E. Euthanasia and physician-assisted suicide: a comparative Survey of physicians, terminally ill cancer patients, and the general population. *J Clin Oncol* 1997;**15**:418–427.
74. Breitbart W, Rosenfeld BD, Passik SD. Interest in physician-assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996;**153**:238–242.
75. Bascom PB, Tolle SW. Responding to requests for physician-assisted suicide: 'These are uncharted waters for both of us…'. *J Am Med Assoc* 2002;**288**:91–98.
76. Lee MA, Nelson HD, Tilden VP, Ganzini L, Schmidt TA, Tolle SW. Legalizing assisted suicide—views of physicians in Oregon. *N Engl J Med* 1996;**334**:310–315.
77. Willems DL, Daniels ER, van der Wal G, van der Maas PJ, Emanuel EJ. Attitudes and practices concerning the end of life: a comparison between physicians from the United States and from the Netherlands. *Arch Intern Med* 2000;**160**:63–68.
78. Portenoy RK, Coyle N, Kash KM *et al*. Determinants of the willingness to endorse assisted suicide. A survey of physicians, nurses, and social workers. *Psychosomatics* 1997;**38**:277–287.
79. Onwuteaka-Philipsen BD, van der Heide A, Muller MT *et al*. Dutch experience of monitoring euthanasia. *Br Med J* 2008;**331**:691–693.
80. Steinbrook R. Physician-assisted suicide in Oregon—an uncertain future. *N Engl J Med* 2002;**346**:460–464.
81. Meier DE, Morrison RS. Autonomy reconsidered. *N Engl J Med* 2002;**346**:1087–1089.

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4.2 The wish to hasten death in patients with advanced diseases: a systematic review of qualitative research

The wish to hasten death in patients with advanced diseases: a systematic review of qualitative research

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ABSTRACT

Background It is not uncommon for patients who are faced with physical or psychological suffering, particularly those in the advanced stages of a disease, to have some kind of wish to hasten death (WTHD), although the true meaning of this wish and what motivates it remain unknown. The aim of this study was to explore the phenomenon of the WTHD in patients with advanced illness by synthesizing the available evidence from qualitative research on this topic.

Methods and Findings Published studies were systematically identified through six electronic databases, the findings being complemented by citation searches and consultation with experts. This led to the purposeful selection of seven qualitative studies that examined the WTHD from the patient's perspective. The quality of the studies included was assessed using a CASP tool. The seven-stage approach advocated by Noblit and Hare was then applied, using both reciprocal translation and line-of-argument synthesis. When synthesizing the translations six major themes emerged: WTHD in response to physical/psychological/spiritual suffering, loss of self, fear, WTHD as a desire to live but 'not in this way', WTHD as a way of ending suffering, and WTHD as a kind of control over life, 'to have an ace up one's sleeve'. The interpretation of themes produced an explanatory model describing the meaning of the WTHD in these patients. The results suggest that the WTHD is a multi-factor construct that is not necessarily pathological in the context of these patients, and that it has multiple meanings which do not imply that the individual will literally act on this wish. In this group of patients the WTHD emerges in response to extreme suffering that affects all aspects of their human existence. The study results are limited to the experience of the WTHD in terminally-ill cancer patients, elderly patients, and AIDS and palliative care inpatients from developed countries, who were receiving care in a large, urban cancer or AIDS centre.

Conclusions An explanatory model of the WTHD among patients in the advanced stages of disease has been derived. The synthesis has identified those elements which seem to be required in order to understand the needs of these patients and to enable the development of individualized care plans.

INTRODUCTION

For several decades now, clinicians and researchers have shown a growing interest in analysing the wish to hasten death (WTHD) in the context of serious or incurable illness. This phenomenon seems to affect a considerable number of patients, especially those facing the end of life or advanced stages of their illness [1-3]. Moreover, medical advances and increased life expectancy, as well as other social phenomena linked to development, make it likely that far from being eradicated these situations will in fact become more common [4-7].

One of the difficulties faced by any clinical study of the WTHD is how to define the concept. Indeed, studies have not distinguished clearly between a general wish to die, the wish to hasten death and requests for euthanasia or physician-assisted suicide [8]. Thus, one finds the indistinct use of terms such as 'wish to die' [9], 'want to die' [10] or 'desire to die' [11,12], as well as 'wish to hasten death' [13,14], 'desire for early death' [15] and other related expressions or synonyms for requests for euthanasia or assisted suicide, such as 'death-hastening request' [16], 'request to die' [17], 'request for euthanasia' [18] and 'request for physician-assisted suicide' [19].

In addition to this lack of consensus regarding the conceptual definition and terminology of the WTHD, another aspect to consider is that the phenomenon tends to vary over time, depending on the stage or circumstances in which patients find themselves [11,20-22], and this makes it enormously difficult to estimate its frequency. Nevertheless, some studies have sought to provide data regarding its epidemiology and prevalence in different settings [23-25]. Noteworthy in this regard has been the design of certain measurement instruments, such as the scale developed by Chochinov *et al.* [11], which was subsequently modified by Kelly *et al.*

[26], or the instrument created by Rosenfeld *et al.* [27]. These scales should, in theory, facilitate the quantification and comparison of the WTHD in different populations, although the construct they quantify is often too broad and imprecise [20].

Another fundamental aspect that has been studied in relation to the WTHD is its aetiology. Factors addressed by research include pain [28,29], depression [20,30,31], hopelessness [32-34], the feeling of being a burden [12,34,35] and loss of autonomy [28,36,37]. Although various socio-cultural aspects may also play an important role in relation to the origin of such a wish, empirical research has yet to be conducted in this regard [38]. In general, clinical studies highlight a multi-factor aetiology, and the evolving literature on the WTHD points — perhaps in line with improvements in the treatment of physical pain — toward the considerable influence of other factors related with the spiritual and psychological dimensions of the individual [13,14,39,40]. However, this appears to depend on the source of the data and the perspective taken by the authors of a given study. Furthermore, any research of this kind faces the inherent challenge of how to access data in these contexts. Thus, many of the data sources are indirect, for example, health professionals or the relatives and carers of the patient. Some studies do, however, report the attitudes or intentions of patients themselves in the early stages of their illness, presenting them with hypothetical scenarios of future suffering and asking them about their attitude towards such possibilities. In general, however, published quantitative studies select and evaluate different factors related to the WTHD, and in doing so limit and reduce the phenomenon to a small number of study variables [8].

Although quantitative research may provide highly valuable information about the WTHD it is difficult for such methods to fully penetrate the complex reality experienced by the patient who wishes to die [8]. Thus, there is a need for a more detailed approach to the meaning of the WTHD, one which helps to define its conceptual limits and to understand why such a wish may manifest. As regards health professionals, they need to have knowledge of and understand the meaning of a patient's wish to die in order to be able to respond adequately to that person's needs. Such an understanding is also required when it comes to drawing up appropriate health and social policies. Given that the patient's perspective is key to

providing this greater detail, qualitative research can make a significant contribution, as this method is specifically designed to understand subjective experience by focusing on the description and interpretation of the meaning of a given phenomenon, thereby enabling it to be explored in more depth [41,42]. A number of studies have already used such a qualitative approach to analyse the wish to die from the viewpoint of the patient who expresses it [14,43,44].

The aim of the present study was to analyse, through an interpretative systematic review of qualitative studies, the meaning and motivation of the WTHD in patients with chronic illness or advanced disease [45,46].

METHODS

Design

Systematic review and interpretative synthesis, following the meta-ethnography approach developed by Noblit and Hare [47] (see Figure 1).

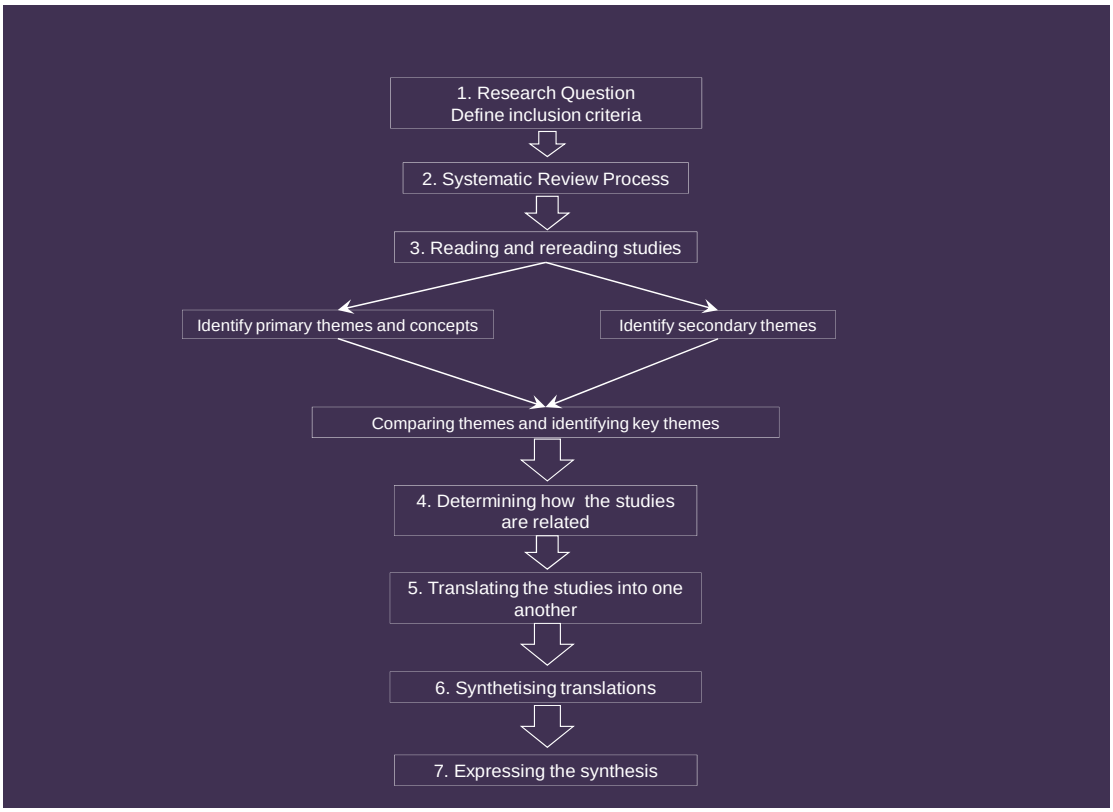

Figure 1| Meta-ethnography process by Noblit and Hare

Inclusion criteria

The criteria for sample selection required that the original studies described the 'wish to hasten death' in patients with a diagnosis of chronic or advanced disease, and that the data of these primary studies were gathered from the patient's own perspective. No language restrictions were placed on the search. The original reports also had to have been conducted using a qualitative approach. Despite the different methodological approaches or even philosophical underpinnings of studies in this field we followed other authors [48] in focusing on the substantive area addressed by the study rather than on the methodology used. Studies using mixed methods were eligible for inclusion provided it was possible to extract the findings derived from the qualitative research.

Search strategy and study selection

Studies were identified primarily through conventional systematic searches of relevant electronic databases using terms and text words from Medical Subject Headings (MeSH). The MeSH terms used were '*suicide, assisted*', '*euthanasia*' and '*qualitative research*'. The text words used were *advanced disease*, *advanced cancer*, *advanced illness*, *chronic illness*, *chronic disease*, *desire to hasten death*, *wish to hasten death* and *end of life decisions*. These terms and text words were combined with one another. In order to minimize the likelihood of excluding important studies a certain degree of experimentation was required to develop an appropriate search strategy. Indeed, in an attempt to focus more precisely on qualitative studies a search was also undertaken using the Rochester qualitative filter that was adapted by Nesbit [49] from MEDLINE hedges developed by McKibbon and Walker-Dilks [50], and which has been used by other researchers [51,52]. This filter was used in conjunction with terms relating to the topic of interest. Table 2 describes the final search strategy, which was adapted to each of the selected databases. Searches were conducted in MEDLINE (PubMed), PsycINFO, CINAHL, Web of Science and the Cochrane Register of Controlled Trials. The timeframe covered by the databases used in the search was from their inception to October 2009. The journals *Qualitative Health Research* and *Qualitative Research* were hand-searched for the period 1995 – October 2009. References of included studies were also reviewed. This process was complemented by search via expert referrals.

Tabla 2| Final Database search strategy

#	Bibliographic search strategy
1.	Desire to hasten death/
2.	Wish to hasten death/
3.	Euthanasia/
4.	Assisted Suicide/
5.	Decisions end of life/
6.	1 or 2 or 3 or 4 or 5
7.	Chronic disease/
8.	Chronic illness/
9.	Advanced disease/
10.	Advanced illness/
11.	Advanced cancer/
12.	7 or 8 or 9 or 10 or 11
13.	6 and 12
14.	Qualitative studies/ or qualitative
15.	Interviews/ or interview*
16.	Case stud*
17.	Case studies/ or case study
18.	14 or 15 or 16 or 17
19.	13 and 18
20.	Qualitative Studies/
21.	Phenomenological Research/
22.	Ethnographic Research/
23.	Ethnonursing Research/
24.	Grounded Theory/
25.	Exp qualitative validity/
26.	Purposive Sample/
27.	Exp observational method/
28.	Content analysis/ or thematic analysis/
29.	Constant comparative method/
30.	Field studies/
31.	Theoretical sample/
32.	Discourse analysis/
33.	Focus groups/
34.	Phenomenology/ or ethnography/ or ethnological research.mp. [mp= title, subject heading, abstract, instrumentation]
35.	(qualitative or phenomenol* or ethnon*).tw
36.	(grounded adj (theor* or study or studies or research)).tw.
37.	(constant adj (comparative or comparison)).tw.
38.	(purpos* adj sampl*).tw.
39.	(focus adj group*).tw.
40.	(emic or etic or hermeneutic* or heuristic or semiotics).tw.
41.	(data adj saturat*).tw.
42.	(participant adj observ*).tw.
43.	(Heidegger* or colaizzi* or spiegelberg*).tw.
44.	(van adj manen*).tw.
45.	(van adj kaam*).tw.
46.	(merleau adj ponty*).tw.
47.	(Husserl* or giorgi*).tw.
48.	(field adj (study or studies or research)).tw.
49.	(lived adj experience*).tw.
50.	Narrative analysis.tw.
51.	Discourse* analysis.tw.
52.	Human science.tw.
53.	Life experiences/
54.	Convenience sample/
55.	Exp cluster sample/
56.	Or/14-55
57.	6 and 56
58.	12 or 57

Key to abbreviations as used in Medline (PubMed):

*, truncation; tw, text word; adj, adjective

The lead researcher (CM) carried out the systematic literature search, which was then verified by another researcher (AB), who is an expert in systematic reviews. The retrieved citations were sifted in three stages, as in a systematic review of quantitative studies. CM was responsible for reviewing the 191 citations retrieved, first by title, second by abstract and finally by full text. Studies were excluded when they did not meet the inclusion criteria. The results of this search were then fed back to another researcher (AB). Disagreements were resolved by discussion between the two reviewers and through reference to the full article. Finally, the research team agreed on the studies (n=7) that should be included in the synthesis. Figure 2 illustrates the search process.

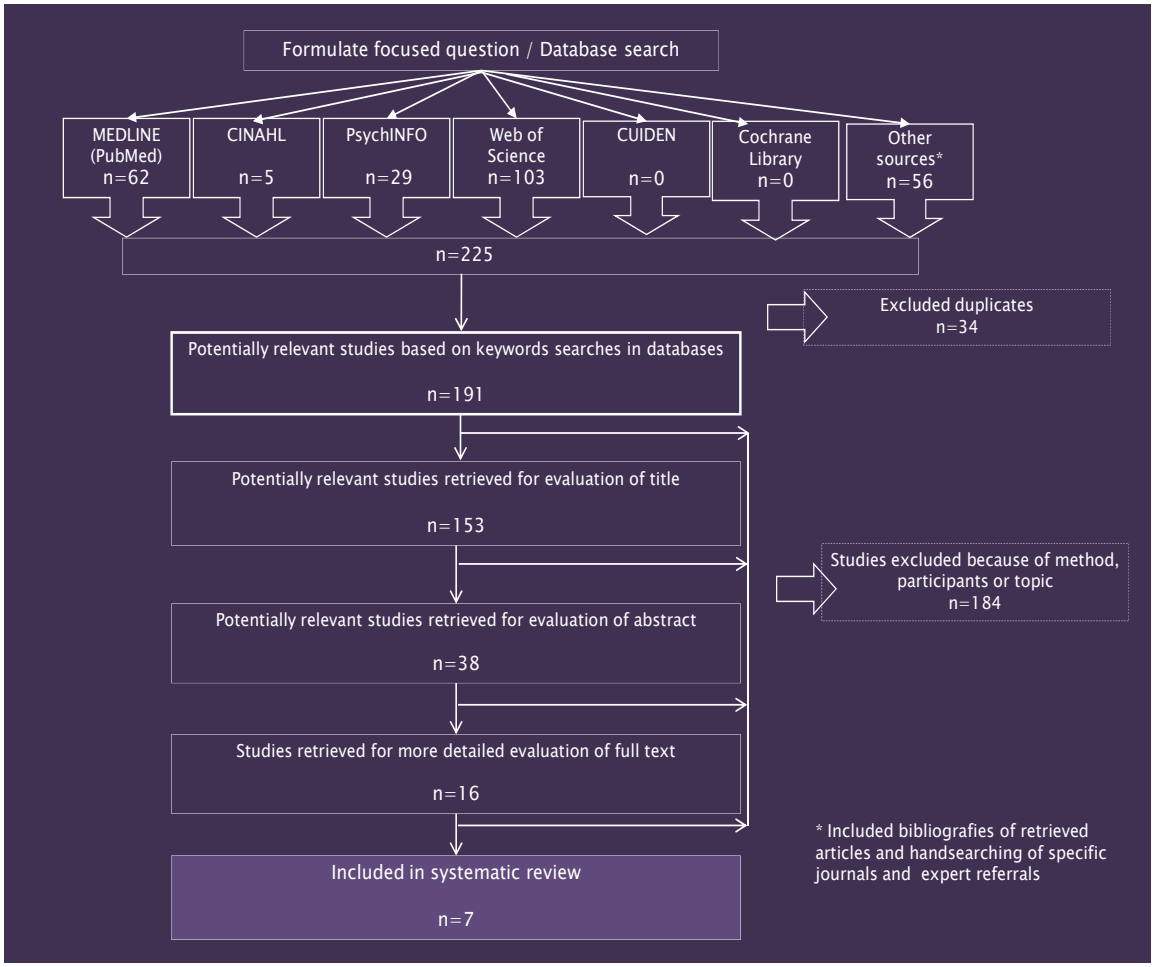

Figure 2| Flowchart of search results

Studies were excluded if they were insufficiently focused on the topic and if the data were not gathered from the patients' perspective, although studies were included if they gathered data from the perspective of both patients and their family (only one of the selected studies). Studies were also excluded if they used qualitative data collection methods but not a qualitative method of analysis.

Quality assessment

No uniform guidelines are available for reporting qualitative studies [53,54]. Indeed, although a wide range of quality assessment tools have been applied to qualitative studies [55-59], none of them has come to be regarded as a standard of reference. Here we decided to apply a Critical Appraisal Skills Programme (CASP) quality-assessment tool for qualitative studies [59], due to its extensive use among researchers [60,61]. Two researchers (CM and AB) independently assessed the reporting of selected studies (Table 3). The full proforma document is available from the corresponding author.

For a number of reasons no studies were excluded on the basis of quality. Edwards *et al.* [62] suggest including more than just those studies of a certain methodological quality, because reviews may underestimate the evidence. Other researchers have found that poorer-quality studies tend to contribute less to the synthesis, which therefore becomes weighted towards the findings of the better quality studies [63,64], raising the possibility that valuable and relevant data for the review might be eliminated [65]. Indeed, there is no consensus among researchers regarding the role of quality criteria and how they should be applied [66]. The appraisals are included here as we considered that this may indirectly lead to improvements in the quality of reporting of qualitative research and meta-ethnography results. However, we did not aim to assess the quality of each study, as our intention was to assess the explicitness and comprehensiveness of reporting.

This research did not require the approval of our local ethics committee, since all the studies included in the review were already approved by their respective ethics committee.

Table 3| Methodological Quality of included studies assessed with CASP (1999): qualitative research checklist

Reporting Criteria (CASP)	No (n=7)	References of studies reporting each criterion
1) Was there a clear statement of the aims of the research? ***Consider:*** (Yes // No // Comments) *- What the goal of the research was*	7	13, 14, 43, 44, 67, 68, 69
– Why it is important	7	13, 14, 43, 44, 67, 68, 69
– Its relevance	7	13, 14, 43, 44, 67, 68, 69
2) Is a qualitative methodology appropriate? ***Consider:*** *– If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*	7	13, 14, 43, 44, 67, 68, 69
3) Was the research design appropriate to address the aims of the research? ***Consider:*** *– If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)*	6	14, 43, 44, 67, 68, 69
4) Was the recruitment strategy appropriate to the aims of the research? ***Consider:*** *-If the researcher has explained how the participants were selected*	7	13, 14, 43, 44, 67, 68, 69
– If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study	7	13, 14, 43, 44, 67, 68, 69
– If there are any discussions around recruitment (e.g. why some people chose not to take part)	7	13, 14, 43, 44, 67, 68, 69
5) Were the data collected in a way that addressed the research issue? ***Consider:*** *- If the setting for data collection was justified*	7	13, 14, 43, 44, 67, 68, 69
– If it is clear how data were collected (e.g. focus group, semi-structured interview etc)	6	14, 43, 44, 67, 68, 69
– If the researcher has justified the methods chosen	3	44, 67, 69
– If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)	5	14, 43, 44, 67, 69
– If methods were modified during the study. If so, has the researcher explained how and why?	-	-
– If the form of data is clear (e.g. tape recordings, video material, notes etc)	7	13, 14, 43, 44, 67, 68, 69
– If the researcher has discussed saturation of data.	5	13, 43, 67, 68, 69
6) Has the relationship between researcher and participants been adequately considered? ***Consider whether it is clear:*** *-If the researcher critically examined their own role, potential bias and influence during:*	2	44, 67
formulation of research questions	3	14, 43, 67
data collection, including sample recruitment and choice of location	5	14, 43, 44, 67, 69
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	-	-
7) Have ethical issues been taken into consideration? ***Consider:*** *– If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*	6	13, 14, 43, 44, 67, 68
– If the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)	-	-
– If approval has been sought from the ethics committee	7	13, 14, 43, 44, 67, 68, 69

8) Was the data analysis sufficiently rigorous? ***Consider:***		
– If there is an in-depth description of the analysis process	5	14, 43, 44, 67, 69
– If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?	6	14, 43, 44, 67, 68, 69
– Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process	3	14, 43, 44
– If sufficient data are presented to support the findings	7	13, 14, 43, 44, 67, 68, 69
– To what extent contradictory data are taken into account	-	-
– Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation	-	-
9) Is there a clear statement of findings? ***Consider:***		
– If the findings are explicit	7	13, 14, 43, 44, 67, 68, 69
– If there is adequate discussion of the evidence both for and against the researcher's arguments	4	14, 43, 67, 69
– If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)	4	14, 43, 67, 69
– If the findings are discussed in relation to the original research questions	7	13, 14, 43, 44, 67, 68, 69
10 How valuable is the research? ***Consider:***		
– If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)	7	13, 14, 43, 44, 67, 68, 69
– If they identify new areas where research is necessary	7	13, 14, 43, 44, 67, 68, 69
– If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used	5	14, 44, 67, 68, 69

Synthesis

The seven qualitative studies were synthesized using Noblit and Hare's [47] seven-stage method, which makes systematic comparisons by translating studies into one another. In the first phase the researchers identified the topic of interest and research question that the qualitative studies might be addressing. The second phase involved selecting the studies for inclusion in the synthesis. Each paper was then read and re-read in order to draw up a list of key metaphors/themes in each study and to identify common and disparate concepts and themes both within and across the studies. The purpose of this reading was to obtain a more in-depth knowledge of the papers and to recognize the different metaphors, themes and concepts used in each. The findings sections of the research reports were divided into text units that were coded by words, sentences or paragraphs, according to content. These codes were then grouped into categories that defined characteristics or different dimensions of the phenomenon addressed by the study. Noblit and Hare's method [47] can be used to compare studies in a variety of ways, depending on the relationships between those studies. Here, and at the end of this phase, we decided that studies would be directly compared by means of *reciprocal translations*, that is, metaphors were written to express the similarities between study findings, with any exceptions being made clear. This method is appropriate when studies are essentially about similar issues [47]. The categories in each paper were initially identified by the main researcher (CM), and were later discussed and analysed by the whole research team. Disagreements were resolved by re-reading the full articles. Having identified the main concepts that emerged from each paper, a search was then undertaken for the presence or absence of these concepts in the seven papers. During this process the authors made sure that each key theme took on similar meanings in all the papers, although they also identified those which were unique or specific to one or more of the studies. The synthesis began with the earliest published paper, that of Lavery *et al.* [43], and then worked through the studies in chronological order of publication. The comparison process began with the categories identified in the first study, to which others were added as they emerged. At the same time, these categories were newly translated to the whole sample and to each individual study. The reciprocal translations enabled us to develop a table that shows each category with its subcategories, as well as quotations from participants to explain each category (see Table 4).

Table 4| Quotations from participants and authors of primary studies to illustrate each category

Categories 3rd order constructs	Quotations from participants in primary studies 1st order constructs	Interpretations of findings offered by authors 2nd order constructs
Loss of Self:		
Loss of function	'Um, the ability to perform simple things like you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can't no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn't. You get to the point where there's no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really' [43].	Loss of self
	'There were many times when I was in such pain and such misery. I said, let me go... finished...no more of this torture' [14].	The immediate situation was unendurable and required instant action.
	'You don't know how much I am suffering. Come and deal with me; I need your attention and help' [14].	
	'You turn them over, they're in pain. They're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just, they're going to suffer, the whole time, there's going to be no happiness, they're going to go down to 60-70 pounds, they're just going to, their whole last weeks of life is just going to be pain and agony and people coming in, people being upset, them being upset'" [43].	Disintegration
	'I'm inconveniencing, I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't enjoy it, I wouldn't, I wouldn't. No, I'd rather die' [43].	Disintegration. Symptoms and loss of function can give rise to dependency on others, a situation that was perceived as intolerable.
	'I can't move, just lie here... feeling like a vegetable...a useless person... needing people to feed me' [44].	Perception of suffering for self and significant to others
	'...the terrible weakness and the nausea and just not feeling like you can do anything. ...And it's kind of like goals that I actually have or things that I want to accomplish are slowly being taken away... it's kind of like the realm of the possible...is shrinking' [68].	Feeling weak, tired and uncomfortable. Illness-related experiences
	'There have been times I've felt so much a burden on my family that maybe it is best for me to die just to relieve them of going through the terminal phase of my disease' [14].	A gesture of altruism
Loss of control	'In the future when I can't manage, I would feel very bothersome and very suffering as if I'm really burdening them. I'm afraid of having others to serve me' [44].	Anticipation of a future worse than death itself
	'...if I'm going to be rolling around in my own faeces because I have no control, then forget it' [43].	Loss of self
	'Dignity is that I have control over my body, when, when, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do' [43].	
	'When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness' [67].	Desire to hasten death as an expression of despair
	'I will do things my way and the hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing...what will be, will be; but what will be, will be done my way. I will always be in control' [68].	Desire for control

Sense of 'loss of dignity'	'I think we should all be allowed to die with our dignity intact' [43].	Participants' experience of disintegration
	'No matter how much they love you, you are always a burden. You automatically become a burden to everyone. Even to your own missus' [13].	Being perceived as a burden to others.
	'...not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don't want that image of me for me, and I don't want that image to be kind of a last image that my daughters and loved ones have of me. And that's just a dignity issue' [67].	Loss of sense of self
	'I'm not comfortable, and I can't do anything, so as far as I'm concerned in quality of life I'm not living; I'm existing as a dependent non-person. I've lost, in effect, my essence' [68].	
	'Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that...' [43].	Loss of self
	'After a while, your family, who you love so dearly, will remember you as a washed-out role model… It will remind them of what they have to go through, the lack of strength, the weakness, and so forth' [14].	The dying process itself was so difficult that an early death was preferred
	'You've become a bag of potatoes to be moved from the spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live' [43].	Disintegration
Loss of meaning	'There's not any good reason for me to go on living. Nobody really needs me... I'm really not serving any purpose. If you don't, aren't needed by anybody, you kind of have a different feeling about life' [69].	Psychosocial factors (useless, boredom, burden, lack of enjoyment in life) motivating the serious consideration of a hastened death.
	'I'm just saying to myself when I go to sleep, 'Just let me die.' I don't want to have to wake up and face this... honestly I just pray that I would just die in my sleep. I have nothing to live for, absolutely nothing. There's nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn't happen' [67].	Desire to hasten death as an expression of despair.
	'One daughter explains about her mother: "The things that were meaningful to [my mother] in her life were her art, her ability to do her art and her friends, and spending time with her friends and cooking and eating. And she was...very convinced that when she couldn't do any of those things anymore, her life would be meaningless, and she wouldn't want to live anymore' [68].	Loss of function
Fear:		
Fear of dying process	'It'll be extremely terrible. It'll be coming up from there, just everywhere. I mean the complications and that would give me so much pain and suffering. I anticipate the future would be like this. Very severe, very scary when I think about it' [44].	Anticipation of a future worse than death itself
	'I, I fear some of the, uh, some of the physical stress that may come in the course of my dying. Nobody chooses to die little by little. At least, I can't visualize that' [69].	Factors motivating the serious consideration of a hastened death
	'I can't bear the dying process so I'll short circuit it by dying' [14].	The dying process itself was so difficult that an early death was preferred
	'I don't want to go through the dying process so I'll kill myself' [14].	
Fear of imminent death	'Not much hope, nor would there be any miracles...You doctors can't help when the patients deteriorate and then drop dead...' [44].	Reality of disease progression
	'This sort of disease ultimately leads to death. I have to walk that path' [44]	
	'I haven't been in hospital before. I wouldn't know the facts. I haven't been ill before' [44].	Anticipation of a future worse than death itself
	'...the end of many dreams for, plans, complete halt to things I was doing, want to do. The biggest thing is the weakness, which I absolutely hate, not being able to do things, to realize that this is virtually the end of it all. There's no future really.	Impact on the patient

	You can't plan anything' [13].	
WTHD as a desire to live but not in this way; WTHD as a sort of 'cry for help'		
	'The goal is now to die. ...I'm using my flexibility not to devote my time toward how I am going to die and praying, etc... I'm using my flexibility in time management to do things that the living do, not the dying' [14].	A manifestation of the will to live
	'Wish to live but can't live; wish to die but can't die' [44].	Perception of suffering for self
	'See, there's a problem while planning or pursuing your death... On the one hand, I am saying all these things, and, on the other hand, I am going down for radiation' [14].	A manifestation of the will to live
	'I've experienced such incredible pain over the last little while and more in the last week. Such incredible pain that it made me think that death is preferable to this...I'll sit there for 2 hours in terrible pain. Such pain where I can't yawn even, and I get only half a yawn and my whole insides turn and waiting for the medication to start to work... I'd love to have 48h let's say, I'd love to have this weekend where I could plan to have a nice weekend and have no pain. I'd love to do that and it doesn't happen, and the pain affects everything. It makes you tired. It affects how you can eat. It affects your mood. It affects other people, and the fact is that even if you try to hide it, you can't... So that's hard...and I know it's gonna get worse, so that's hard too. It's great to be alive, and pain takes that life out of you, and to sit there for 2 hours with a blanket around your just shivering, with no solution, is really hard' [67].	Desire to hasten death as an expression of despair.
WTHD as a way for ending suffering		
	'I can't bear the dying process so I'll short circuit it by dying' [14].	The dying process itself was so difficult that an early death was preferred
	'I feel, deep inside, I don't want to feel hurting... that I want to end this... I ask God why he don't take me, why I suffer so much' [14].	The immediate situation was unendurable and required instant action.
	'In a sense it's artificial that I'm still alive. Even a few years ago that would not have been the case for me to survive that long, but there are limits to what any organism will take or can do, and I have reached my limit' [67].	Desire to hasten death as a manifestation of letting go
	'Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die... The pain wants me to have vehicle to just, just stop my life' [14].	A hastened death was an option to extract oneself from an unendurable situation.
WTHD a kind of control, 'to have an ace up one's sleeve'		
	'If I had to go through [an episode of acute shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again' [14].	A manifestation of the last control the dying person can exert
	'If the pain gets worse, then I want to be dead' [14].	A hastened death was an option to extract oneself from an unendurable situation.
	'I just feel sometimes as though cancer is, uh, an opponent. And, it seems to me, it says to itself, 'I am in control of this body. This is mine, I will do whatever I want to with it' [69].	Sense of control; ultimate control through physician-assisted death

The reciprocal translations were then brought together by synthesizing them, starting from the identified categories and matching them with their respective quotations. This process involved further re-readings of the original studies, with the final categories obtained being once again compared at the end of the reciprocal translation process. This gave rise to what Noblit and Hare [47] refer to as the 'line of argument'. In this phase it was possible to re-conceptualize the findings, generating a new interpretation of the phenomenon explained by the data and leading to a synthesis that not only represents more than the sum of its parts but also preserves the integrity of each of the individual studies. This process was initially carried out by the first author, although conceptualizations of the emergent themes were newly discussed and considered in research team meetings, in which any disagreements were resolved by considering the background of the different research. Finally, an explanatory model of WTHD in patients with advanced disease was obtained.

RESULTS

Description of included studies

The main features of the seven studies included in this synthesis are summarized in Table 5. These studies were published between 2001 and 2009, and were conducted in Canada [43,67], the USA [14,68,69], Australia [13] and China [44]. They all explored the wish to hasten death from the patient's perspective and were conducted within a clinical or health service setting. Although all the studies justified their use of the qualitative approach, only four of them [14,43,44,67] specified the underlying theoretical framework; these four papers also specified the role of the researcher. The method of analysis was described in five papers [14,43,44,67,69]. Interview questions and prompts were not provided in all the articles. Studies generally provided insight into the experiences, perceptions and views of patients.

Table 5| Characteristics of included studies in the review

Source paper	Country setting	Participants	Research Design	Data collection	Setting	Sampling	Data collection
Lavery *et al.* 2001 [43]	Ontario, Canada	31 men and 1 woman with HIV or AIDS	Grounded Theory	In depth interviews	HIV Ontario Observational Database (HOOD), which is a provincial epidemiological database.	Purposive sampling.	October 1996 to september 1997
Kelly *et al.* 2002 [13]	Brisbane, Australia	30 terminally ill cancer patients, who endorsed some wish to hasten death	Mixed-Methods Study. Qualitative method: Descriptive qualitative study	Quantitative scale and Semi-structured interviews	Inpatient hospice unit and home palliative care service	Purposive sampling	Between 1998 and 2000
Coyle & Sculco 2004 [14]	New York, USA	7 terminally ill cancer patients that expressed to desire to hasten death	Phenomenology	In depth interviews	Pain and palliative care unit in an urban center cancer research	Purposive sampling	1-6 interviews to each patient in 6 months
Mak & Elwyn 2005 [44]	Hong Kong, China	6 patients that requested to hasten death	Hermeneutic Phenomenology	In depth interviews	Palliative care unit consisted of a 26-bedded hospice in China. This unit followed the UK model of palliative care with a multi-disciplinary team	Purposive sampling: theoretical	4 months period in 2000
Pearlman *et al.* 2005 [68]	Seattle, USA	35 patients who seriously pursued a hastened death	Descriptive qualitative study	Semi-structured interviews	Patient advocacy organizations that counsel persons interested in PAS, hospices and grief counselors	Purposive sampling	April 1997 to march 2001
Schroepfer 2006 [69]	Wisconsin, USA	18 terminally ill elders (50 or more years old) who desire to hasten death	Content analysis; inductive method in locating themes and patterns	Face-to-face interviews	2 palliative care programs, 2 hospital outpatient clinics and 6 hospices	Purposive sample	Not specify
Nissim *et al.* 2009 [67]	Toronto, Canada	27 ambulatory patients with advanced lung or gastrointestinal cancer	Grounded Theory	Semi-structured interviews and discovery-oriented	Outpatient clinics at a large cancer center in Toronto	Theoretical Sampling	March 2003 to November 2006

Description of themes

Six major themes emerged when synthesizing the translations: WTHD in response to physical/psychological/spiritual suffering, loss of self, fear, WTHD as a desire to live but 'not in this way', WTHD as a way of ending suffering, and WTHD as a kind of control over life, 'to have an ace up one's sleeve'. Overall, the WTHD emerges as a phenomenon that does not necessarily imply the wish to die, and it appears as a response to suffering among patients in the advanced stages of disease. Table 6 illustrates the categories identified in each study.

Table 6| Categories identified in each study

	Study Reference						
Categories/Subcategories	**13**	**14**	**43**	**44**	**67**	**68**	**69**
Wish to hasten death in response to physical-psychological-spiritual suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Loss of self:							
Loss of function	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Loss of control	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sense of 'loss of dignity'	--	Yes	Yes	Yes	Yes	Yes	--
Loss of meaning	Yes	Yes	--	--	Yes	Yes	Yes
Fear:							
Fear of dying process	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fear of imminent death	Yes	Yes	--	Yes	--	--	Yes
WTHD as a desire to live but not in this way; WTHD as a sort of "cry for help"	--	Yes	Yes	Yes	Yes	Yes	Yes
WTHD as a way of ending suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes
WTHD a kind of control, 'to have an ace up one's sleeve'	--	Yes	Yes	--	Yes	Yes	Yes

Desire to hasten death in response to physical, psychological and spiritual suffering

In all the selected studies the WTHD is explained as a complex phenomenon, of multi-factor aetiology, that is almost always triggered by the exacerbation of physical and/or psychological symptoms, leading to a situation of emotional distress and hopelessness. All the patients featured in the seven studies presented physical, psychological and spiritual suffering, and the WTHD emerged as a response to this.

Loss of self

The category *Loss of self* reflects a response to *loss of function*, *loss of control* and *loss of meaning*.

The loss of body function was a common denominator among all participants and contexts (HIV patients, cancer patients, palliative care in-patients and elderly patients). As the disease evolves it brings physical deterioration, weakness and various physical symptoms, and this is accompanied by a progressive loss of body function, whether in terms of an inability to go to the toilet, urinary or faecal incontinence, or difficulties eating or even breathing. The deterioration in body function was described by all the participants in the various studies as a negative experience, mainly in terms of the physical dependency that it implied. This dependency in relation to the simplest of tasks appears to be related to hopelessness and emotional distress. The perception of loss was intrinsically linked to the physical changes that were produced in all the participants of the seven studies. Incontinence and/or being dependent on others for help in using the toilet was described as an especially significant event that preceded or accompanied the WTHD.

The loss of body function leads, in turn, to a loss of the different roles that the person had acquired in life (professional, social, family, etc.), these being replaced by the new role of 'dependent individual'. Indeed, functional deterioration and dependency restrict not only the person's professional capacities but also the possibility of maintaining his/her social relationships or role within the family; for example, a person may cease to be the mother or father who looked after the family and become a patient who needs to be cared for.

Alongside the loss of body function that occurs as the disease progresses there is also a loss of control. In the studies reviewed this loss of control was interpreted in two ways. On the one hand there is loss of control over the body, which is linked to a decline in various physical functions (difficulty getting up unaided, with walking or eating, with sphincter control, etc.). However, this is accompanied by another, more internal loss of control, namely the control over one's own life and future. The loss of autonomy caused by dependency invariably leads the individual to feel that he/she is a burden to the family or caregivers, and prior to or alongside the emergence of this feeling the majority of patients say they feel useless. This sense of uselessness and of being a burden was occasionally expressed in terms of a 'sense of loss of dignity' [14,43,44,67-69], although the term 'dignity' was understood by the participants as *not being able to do anything unaided*, and is

therefore closer to a sense of dependency. Similarly, the patients sometimes alluded to the idea that life as they were living it was 'not dignified', and they went on to say that they *weren't like that before*, and that *they didn't want people to remember them in this way*, i.e. as fragile and dependent. This perception led some patients to feel a '*loss of meaning*' [14,44,67-69]. All these aspects lead to a progressive undermining of how patients see and regard themselves, and this would constitute a *Loss of Self*. [14,44,67-69].

The study by Lavery *et al.* [43], conducted with AIDS patients, is the only one to have described a meaning for the *Loss of Self* that is not covered by the above definitions. In addition to a loss of body function the participants in this study also expressed a loss of community, self-exclusion, a fear of social rejection and existential isolation. Lavery et al. [43] linked this loss of community to society's rejection of AIDS sufferers and suggested that its emergence has much to do with the lack of social support given to these patients.

Fear

The category *Fear* emerges in the interviews with the majority of participants in the studies reviewed, and it was identified with two related sub-categories: *Fear of the dying process* and *Fear of imminent death*.

Upon becoming aware of their prognosis the participants came to regard their own physical deterioration as being worse than death itself, this leading to a *Fear of the dying process*. The reasons for this fear fall into two groups: physical and psycho-social. Physical reasons include the fear of pain, the exacerbation of signs and symptoms, and a progressive deterioration in functional capacity, coupled with the fear that all this will become unbearable. Their previous experiences of pain and suffering led all the patients to fear that such experiences would be repeated. The suffering of relatives and/or ill acquaintances also led patients in three of the studies [44,68,69] to be fearful of the future. As for psycho-social reasons these took the form of foreseeing the loss of role, greater dependency and the fear of being a burden. These thoughts about a future with greater suffering were described by participants as being overwhelming and caused them enormous anguish.

The category *Fear of imminent death* emerges when patients become aware of the proximity of their own death. The acknowledgement of death's inevitability, coupled with the awareness that there was no way back from their situation [13,14,67], produced much anguish among participants and in many cases led to a feeling of hopelessness [14,44], of having no options left for the future [13], and to a sense of *being in a dark tunnel, without seeing any light* or a feeling of *paralysis* [67].

WTHD as a way of ending suffering

Among participants in the studies included, the WTHD also emerged as a way out, and in some cases [43,67] as the only way of ending their physical and psychological suffering. Death was not considered as an aim in itself, but rather as an escape. Indeed, the idea of putting an end to their life brought a sense of relief to some patients.

In the study by Schroepfer [69] the WTHD was regarded as a way out or as a means of relieving loneliness, fear, dependence, a lack of hope and the feeling that life was no longer enjoyable. The study by Nissim et al. [67] suggested that in the face of oppression and despair, death could be seen as the only alternative, with the WTHD being the essence of a plan to relieve suffering. Similarly, Lavery et al. [43] reported that the WTHD was seen by participants as a means of limiting disintegration and loss of self.

In five of the studies reviewed [14,44,67-69] the participants described the WTHD as a way of also reducing the suffering being caused to family and carers. Coyle and Sculco [14] interpret this as *a gesture of altruism*, since the WTHD is motivated by a desire to relieve the family of the burden of care and of witnessing the participant's progressive deterioration. However, although the WTHD was driven by such a motive in some patients [69], in others (or simultaneously in the former patients) the desire to cause no more pain to their relatives led them to precisely the opposite conclusion, i.e. they repressed the WTHD. As such, their wish to protect their family took precedence over their own wish to hasten death [69].

WTHD as a desire to live but not in this way; WTHD as a sort of 'cry for help'

Rather than manifesting as a genuine wish to die the WTHD appears more as a desire to live but not in this way. Almost all the participants in the studies included (163 of 165) showed through their behaviour a desire to live. For example, they agreed to continue with medical treatment until the end of their life, and many of them said they wanted to be treated as *a living person, not as someone on their deathbed* [14,44,69]. The only two behaviours which seemed to contradict this were those of participants 3 and 7 in the study by Coyle et al. [14] (participant 3 accepted transfer to a terminal care hospital, stating that this would hasten his death because he would no longer be in a kind of life-prolonging care, while participant 7 refused surgery that could have prolonged her life for several years without significant morbidity). The authors also interpreted these behaviours as contradicting the rest of their findings.

The apparent paradox between the desire to live and the WTHD is highlighted by Coyle and Sculco [14], whose findings clearly illustrate the will to live among their participants. Similarly, Mak and Elwyn [44] also note that despite expressing the WTHD, their participants hoped to receive holistic and good quality end-of-life care. An example is that of patient 4, who said: "*You want to be cured, that isn't possible, but at least give me back some of my energy"* [44]. It is also noteworthy that those patients in the study by Schroepfer [69] who expressed the WTHD also showed through their behaviour a desire to go on living; indeed, they themselves said that if they had not yet acted on the wish to hasten their death this was because, despite their deterioration, there was still something that gave meaning to their life.

The WTHD also emerges a cry for help in the face of suffering. The participants were aware of the precarious and extreme nature of their situation, which was experienced as unbearable and as something that required immediate action [14,43,44,67]. The patients' WTHD manifests in the different contexts as a way of letting others know what they are going through, and at the same time as a call for help in bearing the situation. Behind each WTHD one finds hidden desires for understanding and for someone to accompany them in their suffering and in the process of mourning for what has already been lost [14,44,67,69].

WTHD as a kind of control, 'to have an ace up one's sleeve'

Most participants considered the possibility of their own death as a kind of control over their life [14,43,67-69]. The wish to determine one's own death would be an extreme (or perhaps the sole) manifestation of the desire for control. When the participants perceived that they had very little left, and that they no longer had any control over many aspects of their life, the potential to decide how and when to die was seen by some of them as being all that remained of their autonomy, as if it were the last card left to play. In general, those patients who had decided to hasten their death, as a way of reaffirming their ability to make their own decisions, reported feeling more able to tolerate the pain of the present and the uncertainty of the future [14,43,67,69].

The desire for control was also expressed as a kind of safety net, or what Coyle and Sculco [14] called an *if-then* situation. Several of the participants turned to control strategies such as storing up barbiturates, fantasizing about planning their own death through a trip to the Netherlands (where it would be easier to achieve), or imagining that they would throw themselves into the sea despite not knowing how to swim. For them, the sense of control comes from having a hypothetical exit plan [14,67,69], akin to having an ace up their sleeve, because at the end of the day they did not act on it.

A slightly different aspect of this longing for control is when the WTHD appears as a way of manipulating the patient's surroundings. In this regard, Coyle and Sculco [14] interpret some patients' explicit declaration of the WTHD as being an attempt at manipulation of the family to avoid abandonment. In this case, the WTHD would follow from what is probably an unconscious desire to control the surroundings, with the patients finding no other way of doing so.

The findings of the whole synthesis are summarized in Figure 3.

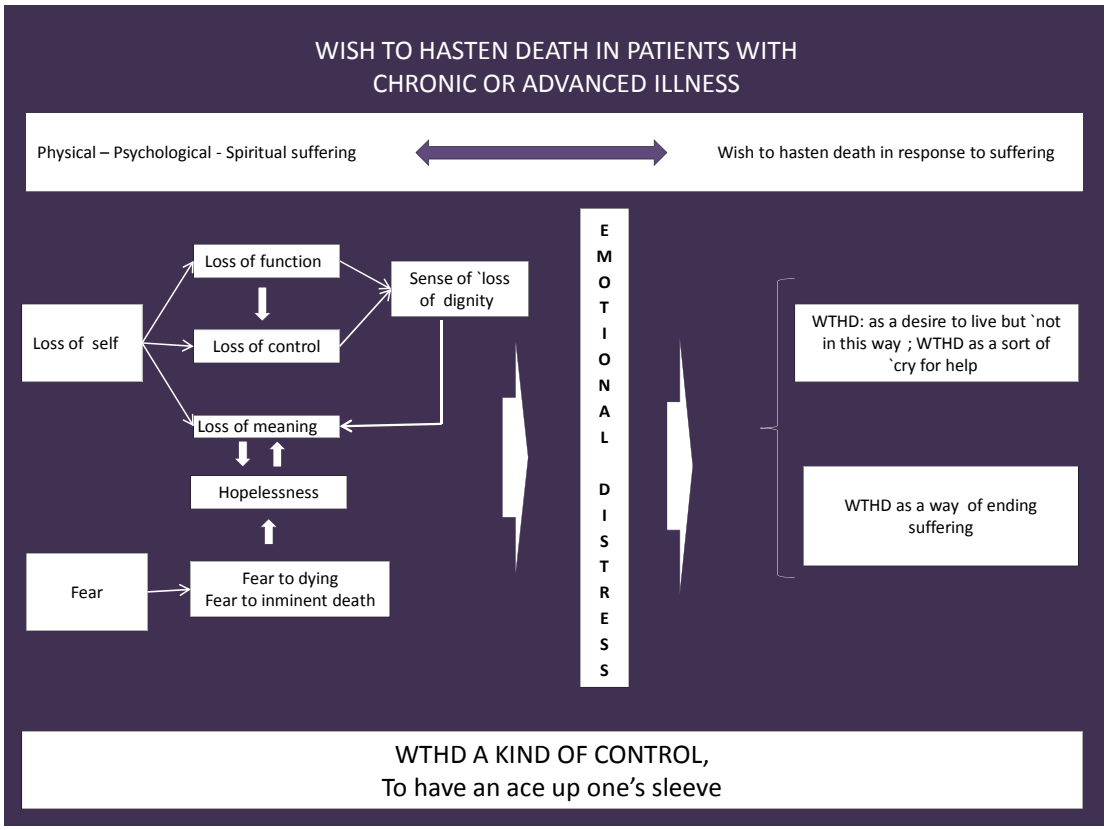

Figure 3| Line of argument: Explanatory model of WTHD

During the synthesis process, a new concept appeared in the study developed by Nissim et al. [67] which was clearly differed as unique and specific by Noblit and Hare's method [47]. This study provides another perspective for WTHD which does not imply a real desire to hasten one's death, but rather a manifestation of letting go. This situation arises only in some patients during their final dying phase, in which their deterioration and tiredness makes them surrender. It is rather "throwing the towel", which means, accepting and assuming a near death when they recognize that death is imminent and cannot be resisted to. In any case, these patients are too tired to keep fighting for their life. As mentioned by the authors [67], this could be compatible with the final phase of accepting the disease and, in this case, accepting death, as stated in Kübler-Ross's model [70].

DISCUSSION

Our synthesis suggests that the WTHD is a multi-factorial construct with multiple meanings that do not necessarily imply the literal action or wish of hastening death and it becomes apparent —in patients with an advanced illness situation—, as the response to an extreme suffering that concerns all human dimensions. The categories that explain the meaning of the WTHD in these patients were initially showed through a process of mutual translation. Subsequently, by employing a line of argument approach, it was revealed that the WTHD was a reactive consequence of extreme suffering. The current study has revealed that the WTHD is often a request for help and it also operates as a mechanism of control and self-management.

Regarding the six major categories that emerge in our synthesis, the first one, WTHD in response to physical-psychological and spiritual suffering, highlights the WTHD as a response, and not as the objective itself. We may state that in these cases and contexts that death is seen as the way to finish with the suffering.

The second category, loss of self, is the result of a gradual process of physical, psychological and spiritual losses to which the patient is subject of. The Loss of Self together with the third identified category, fear before the process of dying and the closeness of death, produces hopelessness and emotional distress in patients. Several studies have identified the syndrome of loss of hope and distress in patients at the end of their lives, although they may call it by different names and give slight connotations to it. As an example, Saunders [71], —modern hospice founder—, coined the idea of total pain in palliative care to designate the suffering not only physically, but also psychologically, socially and spiritually, as a consequence of the numerous losses experienced by their patients. Clarke and Kissane [72] have described *The Demoralization Syndrome* as a clearly defined syndrome of existential distress occurring in patients suffering from mental or physical illness, specifically ones that threaten life or integrity of being. The authors suggest that the situation is triggered by the feeling of inability to cope with a stressful situation and to generate hopelessness, helplessness, incompetence, isolation, sense of failure, disheartenment, low self-esteem, sense of meaninglessness and existential distress [72,73]. In this context the demoralized patients may want to die, but not as a

response to a life full of sense and fulfillment as an older person awaiting his death would wish, but the demoralized patient wishes to die impatiently and distressfully after having perceived a meaningless life. In this case the desire to die appears as another symptom of the *syndrome of demoralization*. A new instrument has been recently designed by these authors [72]: —*the Demoralization Scale* —, whose aim is to facilitate an early diagnosis, and its importance settles in the conceptual distinction with the diagnosis of depression.

Similar findings have been reported through another study carried out by Albert et al [9] who take a sample of patients with amyotrophic lateral sclerosis and analyze their desire to die people in their sample which expressed the wish to die were more likely to meet criteria for depressive disorders, less optimism, less comfort in religion, greater hopelessness, suffering, loss of interest in living, absence of pleasure and loss of interest in activity. The authors attribute this wide index of signs and symptoms to the named by Rosenfeld et al [21,74] *Syndrome of End-of-life despair*. The desire to die in this case would be again one more aspect of this *End-of-life despair*, in a similar way to what the *demoralization syndrome* is for Clarke and Kissane [72].

Somehow, the aforementioned syndromes: *total pain* [71], *demoralization* [72], *end-of-life despair* [74], refer to a similar reality and all of them would seem to have also a similar response in the patient: the emotional distress. Nevertheless, while the descriptions that the authors of the above commented syndromes (Demoralization Syndrome and end-of-life despair) include and explain the WTHD as an element, amongst others, of this syndrome, the model that emerges from our synthesis proposes the WTHD as a reactive phenomenon, a response to the multidimensional suffering, and not as an additional manifestation.

An additional feature that defines the category loss of self in this synthesis is, as understood by some patients, a perception of 'loss of dignity' associated with loss of autonomy and control. This term was also used by Chochinov et al [75], who developed *The Dignity Model* [76] and emphasized that the concept of dignity is not only used in literary terms; the notion of dignity is an internal moral quality strictly linked to human life itself [77]. However, when the value of autonomy is compared with the notion of dignity, dependant patients experience a loss of dignity, which

undermines the value of their lives [78]. In any case, the features that characterize Chochinov's Model (who found that patients with a compromised sense of dignity reported a higher desire for death [76]) would refer to the similar constituent characteristics of loss of self found in our study. Thus, the fact of reaching extreme levels of dependence would be interpreted by the patients and the society as something "unworthy" even though, actually, a certain degree of dependency is part of the human condition [79]. When patients themselves perceive a loss of dignity, it is attributed to a perception of threaten, vulnerability and feelings of inferiority [79].

Recently, the meaning of life (MiL), another constituent element loss of self in this synthesis, has also generated interest amongst clinicians and researchers in palliative care and has become a core element to psychotherapeutic interventions [33,80,81]. Patients who maintain the sense of life, despite having a poor prognosis, are able to assess the worthiness of their living [82]. By contrast, a lack of MiL is often associated with hopelessness and WTHD or a request for active euthanasia [20,73,74,83,84], as has been demonstrated by this synthesis.

The fourth category in this synthesis, WTHD as a mean for ending suffering, emerge when the patient perceives that he has nothing else but suffering. As a response, death seems to be the only alternative.

The fifth category, WTHD as a desire to live but 'not in this way'; WTHD as 'a sort of cry for help', appears as a paradox because these patients expose their desire to die but their actions are actually desire for help and support. This is similarly exposed in a Belgian study [85] which examines the experiences of nurses in their involvement with patients requesting euthanasia. The study concludes that many patients after feeling being listened to and followed behind in their despair and emotional distress, failed to express WTHD.

The last category in this synthesis, WTHD as a kind of control of my life, 'to have an ace up one's sleeve', emerge in all patients included in the study. The desire to control their life is manifested as a need for the person to continue maintaining its autonomy and decision-making about their lives and future. In this regard, while the control over their life seems proactive, it does really refer to control over life but over death. The sense of control seems an inherent element of every human being. There are several studies that expose the need for choice and control of patients in

various contexts: cancer patients, patients with neurodegenerative diseases [9], nursing home's inpatients [79], palliative care [40], etc. Considering the need to control patients at the end of their life, and including it as an element to consider in the comprehensive care plan for these patients, it seems essential to improve their perception of care.

Study Limitations:

Despite the already known correlation between depression and WTHD [20], the lack of exploration of this variable in the participants of the initial studies, is one of the limitations of the findings of this synthesis. From the 7 studies included in this review [13,14,43,44,67-69], three of them [43,44,69] do not refer to depression at any time of the study. Meanwhile, Coyle et al [14] approach the objective of his study justifying that depression is one of the factors that may cause WTHD. The study by Pearlman et al [68] state that experienced psychiatrists analyzed interviews made to participants in a search for signs and symptoms of depression. The authors [68] conclude that the participants showed no depression or despair, despite recognizing the limitations of the study regarding the selection of the sample as all participants were part of the Advocacy Organizations for Providing Support for Desire to Die. On the other hand the study carried out by Kelly et al [13] does not reject the presence of depression in patients included in their sample and interprets that patients may have a depressive mood state because they express low levels of satisfaction with their life. Additionally, the study made by Nissim et al [67] also describes the presence of hopelessness in all patients studied and, in the same way as Kelly et al [13], both studies include the possibility that signs and symptoms presented by patients from their studies could be compatible with the syndrome of demoralization defined by Kissane et al [73].

There is another limitation to the study which has a methodological origin; the included studies are approached from different qualitative designs. In this review, we prioritized the focus to which each of the studies was addressed. However, several authors [46,86] argue that this aspect is not necessarily a limitation but an asset when interpreting the synthesis. Moreover, different research methods can be included in a single synthesis of qualitative studies because the aims of synthesis are the findings, not the data used for it [87].

The study is limited to understanding the experience of the WTHD in terminal cancer patients, AIDS patients and elderly and palliative care inpatients receiving care in large urban cancer or AIDS centers. All the included studies were carried out in developed countries, mainly western countries, as the study of Mak and Elwyn [44] carried out in China where participants were patients treated at occidental-cultured hospices. We found no WTHD studies in Africa, neither in Central or South America, nor in the European context where family and other social factors play different roles [88]. On the other hand, the features of participants —age, sex, prognosis, socioeconomic aspects—, are not always formally described in each of the studies included, which difficult the transferability of the results.

Implications for policy and practice

These findings have significant implications for policies and clinical practices. They expose the wide range of factors that are emphasized in a patient at the end of its life and the need of psycho-spiritual-existential cares. The knowledge of the nature of the real meaning of the WTHD and the motivations that lead patients to it implies relevant challenges for health professionals, such as a deep understanding of the patients at the end of their life from a holistic perspective. These results stimulate the need to consider the personal circumstances of each patient, the individual suffering of each patient and the meaning that each one attributes to the WTHD.

Implications for Research

Future research may involve new patients groups that were not taken into account in current studies such as individuals with kidney failure, chronic respiratory disease, cardiac failure, and neurodegenerative disease, etc. even patients with domiciliary or ambulatory attention. Another possible population group to study would be residents in rural zones, where the available resources are different from those in urban zones, as well as the cultural and contextual factors.

The review's findings have significant implications for the assessment of WTHD. Each of the categories corresponds with different dimensions that should be analyzed in each patient who show WTHD. This would require the design of measuring instruments able to explore each of the dimensions in such patients.

Finally, although it was an inclusion search criteria of studies carried out from a perspective of a patient who shows WTHD, it would be interesting to know the meaning attributed to WTHD from a professional perspective and even from family members or caregivers' points of view, which could complement the knowledge of this desire and would help to design caring interventions.

Conclusions

Although the aim was not to develop a theoretical proposal, the results of the synthesis describe an explanatory model of WTHD that is common to people from different countries and health care systems. For people with WTHD there are commonalities in the ways in which people experience their illness and, moreover, this synthesis has identified the elements that seem to be required in order to understand the needs of these patients and to be able to develop individualized caring plans.

REFERENCES

1. Arnold EM. Factors that influence consideration of hastening death among people with life-threatening illnesses. Health Soc Work. 2004; 29:17-26.
2. Grzybowska P, Finlay I. The incidence of suicide in palliative care patients. Palliat Med. 2006; 11: 313-6.
3. Hudson PL, Kristjanson LJ, Ashby M, Kelly B, Schofield P, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. Palliat Med. 2006; 20: 693-701.
4. Lynn J. Learning to care for people with chronic illness facing the end of life. JAMA. 2000; 284: 2508-11.
5. Carmel S. The will to live: gender differences among elderly persons. Soc Sci Med. 2001; 52: 949-58.
6. Doyal L. Why active euthanasia and physician assisted suicide should be legalised. BMJ. 2001; 323: 1079-80.
7. Misono S, Weiss NS, Fann JR, Redman M, Yueh B. Incidence of suicide in persons with cancer. J Clin Oncol. 2008; 26: 4731-8.
8. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Balaguer A. The wish to hasten death: A review of clinical studies. Psychooncology. 2010; DOI DOI 10.1002/pon.1839.
9. Albert SM, Rabkin JG, Del Bene ML, Tider T, O'Sullivan I, et al. Wish to die in end-stage ALS. Neurology. 2005; 65: 68-74.
10. Seale C, Addington-Hall J. Euthanasia: Why people want to die earlier. Soc Sci Med. 1994; 39: 647-54.
11. Chochinov HM, Wilson KG, Enns M, Mowchun N. Desire for death in the terminally ill. Am J Psychiatry. 1995; 152: 1185.
12. Morita T, Sakaguchi Y, Hirai K, Tsuneto S, Shima Y. Desire for death and request to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care. J Pain Symptom Manage. 2004; 27: 44-52.
13. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, et al. Terminally ill cancer patients' wish to hasten death. Palliat Med. 2002; 16: 339-45.
14. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. Oncol Nurs Forum. 2004; 31: 699-709.
15. Tiernan E, Casey P, O'Boyle C, Birkbeck G, Mangan M, et al. Relations between desire for early death, depressive symptoms and antidepressant prescribing in terminally ill patients with cancer. J R Soc Med. 2002; 95: 386-90.
16. Cohen LM, Steinberg MD, Hails KC, Dobscha SK, Fischel SV. Psychiatric evaluation of death-hastening requests. Lessons from dialysis discontinuation. Psychosomatics. 2000; 41: 195-203.
17. Muskin PR. The request to die: role for a psychodynamic perspective on physician-assisted suicide. JAMA. 1998; 279: 323-8.
18. Block SD, Billings JA. Patient requests for euthanasia and assisted suicide in terminal illness. The role of the psychiatrist. Psychosomatics. 1995. 36: 445-57.
19. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat Med. 2006; 20: 685-92.

20. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funest-Esch J, et al. Depresssion, hopelessness, and desire for hastened death in terminally ill patients with cancer. JAMA. 2000; 284: 2907-11.
21. Rosenfeld B, Breitbart W, Gibson C, Kramer M, Tomarken A, et al. Desire for hastened death among patients with advanced AIDS. Psychosomatics. 2006; 47: 504-12.
22. Rosenfeld B. Methodological issues in assisted suicide and euthanasia research. Psychol Public Policy Law. 2000; 6: 559-74.
23. Brown JH, Henteleff P, Barakat S, Rowe CJ. Is it normal for terminally ill patients to desire death? Am J Psychiatry. 1986; 143: 208-11.
24. Onwuteaka-Philipsen BD, van der Heide A, Koper D, Keij-Deerenberg I, Rietjens JA, et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. Lancet. 2003; 362: 395-9.
25. Rodin G, Zimmermann C, Rydall A, Jones J, Shepherd FA, et al. The desire for hastened death in patients with metastatic cancer. J Pain Symptom Manage. 2007; 33: 661-75.
26. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, et al. Factors associated with the wish to hasten death: a study of patients with terminal illness. Psychol Med. 2003; 33: 75-81.
27. Rosenfeld B, Breitbart W, Galietta M, Kaim M, Funesti-Esch J, et al. The Schedule of attitudes toward hastened death. Measuring desire for death in terminally ill cancer patients. Cancer. 2000; 88: 2868-75.
28. Kelly B, Pelusi D, Burnett P, Varghese F. The prevalence of psychiatric disorder and the wish to hasten death among terminally ill cancer patients. Palliat Support Care. 2004; 2: 163-9.
29. Kinsella TD, Verhoef MJ. Assisted suicide: opinions of Alberta physicians. Clin Invest Med. 1995; 18: 406-12.
30. Chochinov HM, Wilson KG, Enns M, Lander S. Depression, Hopelessness, and suicidal ideation in the terminally ill. Psychosomatics. 1998; 39: 366-70.
31. Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet. 1998; 352: 1097-102.
32. Abbey JG, Rosenfeld B, Pessin H, Breitbart W. Hopelessness at the end of life: the utility of the hopelessness scale with terminally ill cancer patients. Br J Health Psychol. 2006; 11: 173-83.
33. Breitbart W. Reframing hope: meaning-centered care for patients near the end of life. Interview by Karen S. Heller. J Palliat Med. 2003; 6: 979-88.
34. Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. J Pain Symptom Manage. 2002; 24: 312-7.
35. Willems DL, Daniels ER, van der Wal G, van der Maas PJ, Emanuel EJ. Attitudes and practices concerning the end of life: a comparison between physicians from the United States and from The Netherlands. Arch Intern Med. 2000; 160: 63-8.
36. Pessin H, Rosenfeld B, Burton L, Breitbart W. The role of cognitive impairment in desire for hastened death: a study of patients with advanced AIDS. Gen Hosp Psychiatry. 2003; 25: 194-9.
37. Kissane DW, Kelly B. Demoralization, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. Aust N Z J Phychiatry. 2000; 34: 325-33.
38. Gourie-Devi M. Wish to die in end-stage ALS. Neurology. 2007; 68: 79.

39. Morita T, Tsunoda J, Inoue S, Chihara S. An exploratory factor analysis of existential suffering in Japanese terminally ill cancer patients. Phychooncology. 2000; 9: 164-8.
40. Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, et al. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. N Eng J Med. 2003; 349: 359-65.
41. Morse JM, Field PA. Qualitative research methods for health professionals. Thousand Oaks, CA: Sage. 1995; 272 p.
42. Editors TPM. Qualitative research: Understanding patients' needs and experiences. PLoS Med. 2007; 4: e258.
43. Lavery JV, Boyle J, Dickens BM, Maclean H, Singer PA. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. Lancet. 2001; 358: 362-7.
44. Mak YY, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. Palliat Med. 2005; 19: 343-50.
45. Mahtani Chugani V, Axpe Caballero M, Serrano Aguilar P, González Castro I, Fernández Vega E. Metodología para incorporar los estudios cualitativos en la evaluación de tecnologías sanitarias. Madrid: Plan Nacional para el SNS del MSC. Servicio de Evaluación del Servicio Canario de la Salud. 1996
46. Thorne S, Jensen L, Kearney MH, Noblit G, Sandelowski M. Qualitative metasynthesis: reflections on methodological orientation and ideological agenda. Qual Health Res. 2004; 14: 1342-65.
47. Noblit G, Hare R. Meta-ethnography: Synthesizing qualitative studies Newbury Park: Sage; 1988.
48. Schreiber R, Crooks D, Stern P. Qualitative meta-analysis. In: Morse J, editor. Completing a qualitative project. Thousand Oaks, CA: Sage. 1997; p. 311-26.
49. Nesbit K. Evidence-based Filters for Ovid Medline. University of Rochester. 2002.
50. McKibbon A, Walker-Dilks C. Evidence-based Filters for Ovid-CINAHL. 2002.
51. Lavin MA, Krieger MM, Meyer GA, Spasser MA, Cvitan T, et al. Development and evaluation of evidence-based nursing (EBN) filters and related databases. J Med Libr Assoc. 2005; 93: 104-15.
52. Jones ML. Application of systematic review methods to qualitative research: practical issues. J Adv Nurs. 2004; 48: 271-8.
53. Sale JE, Hawker GA. Critical appraisal of qualitative research in clinical journals challenged. Arthritis Rheum. 2005; 53: 314-6.
54. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesizing qualitative and quantitative evidence: a review of possible methods. J Health Serv Res Policy. 2005; 10: 45-53.
55. Dixon-Woods M, Shaw RL, Agarwal S, Smith JA. The problem of appraising qualitative research. Qual Saf Health Care. 2004; 13: 223-5.
56. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ. 2002; 320: 50-2.
57. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet 2001; 358: 483-8.
58. Rowan M, Huston P. Qualitative research articles: information for authors and peer reviewers. CMAJ. 1997; 157: 1442-6.
59. CASP P. Critical Appraisal Skills Programme. Ten questions to help you make sense of qualitative research. Oxford: CASP. 1999.
60. Campbell R, Pound P, Pope C, Britten N, Pill R, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. Soc Sci Med. 2003; 56: 671-84.

61. Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, et al. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. PLoS Med. 2007; 4: e238.
62. Edwards AG, Russell IT, Stott NC. Signal versus noise in the evidence base for medicine: an alternative to hierarchies of evidence? Fam Pract. 1998; 15: 319-22.
63. Smith LK, Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. Lancet. 2005; 366: 825-31.
64. Sandelowski M, Barroso J. Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. Res Nurs Health. 2003; 26: 153-70.
65. Jensen LA, Allen MN. Metasynthesis of qualitative findings. Qual Health Res. 1996; 6: 553-60.
66. Dixon-Woods M, Sutton A, Shaw R, Miller T, Smith J, et al. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. J Health Serv Res Policy. 2007; 12: 42-7.
67. Nissim R, Gagliese L, Rodin G. The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study. Soc Sci Med. 2009; 69: 165-71.
68. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, et al. Motivations for physician-assisted suicide. J Gen Intern Med. 2005; 20: 234-9.
69. Schroepfer TA. Mind frames towards dying and factors motivating their adoption by terminally ill elders. J Gerontol. 2006; 61: S129-139.
70. Kübler-Ross E. On death and dying. Touchstone. 1969.
71. Saunders C. The last stages of life. Am J Nurs. 1965; 65: 70-5.
72. Clarke DM, Kissane DW. Demoralization: its phenomenology and importance. Aust N Z J Psychiatry. 2002; 36: 733-42.
73. Kissane DW, Clarke DM, Street AF. Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. J Palliat Care. 2001; 17: 12-21.
74. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet. 2003; 361: 1603-7.
75. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. CA Cancer J Clin. 2006; 56: 84-103.
76. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med. 2002: 54: 433-43.
77. Pullman D. Human dignity and the ethics and aesthetics of pain and suffering. Theor Med Bioeth. 2002; 23: 75-94.
78. Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA. 2002; 287: 2253-60.
79. Strohbuecker B, Eisenmann Y, Galushko M, Montag T, Voltz R. Palliative care needs of chronically ill nursing home residents in Germany: focusing on living, not dying. Int J Palliat Nurs. 2011; 17: 27-34.
80. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, et al. Understanding the will to live in patients nearing death. Psychosomatics. 2005; 46: 7-10.
81. Monforte-Royo C, Tomás-Sábado J, Villavicencio-Chávez C, Balaguer A. Psychometric properties of the Spanish form of the Schedule for Meaning in Life Evaluation (SMiLE). Qual Life Res. 2010. DOI 10.1007/s11136-010-9796-0.
82. Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. Psychooncology. 1999; 8: 417-28.

83. Nelson CJ, Rosenfeld B, Breitbart W, Galietta M. Spirituality, religion, and depression in the terminally ill. Psychosomatics. 2002; 43: 213-20.
84. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, et al. A national survey of physician-assisted suicide and euthanasia in the United States. N Eng J Med. 1998; 338: 1193-201.
85. Dierckx de Casterlé B, Verpoort C, De Bal N, Gastmans C. Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics. 2006; 32: 187-92.
86. Sandelowski M, Docherty S, Emden C. Focus on qualitative methods. Qualitative metasynthesis: issues and techniques. Res Nurs Health. 1997; 20: 365-71.
87. Group CQM (2007) [http://www.joannabriggs.edu.au/cqrmg/index.html].
88. Giorgi Rossi P, Beccaro M, Miccinesi G, Borgia P, Costantini M, et al. Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer. J Epidemiol Community Health. 2007; 61: 547-54.

4.3 Psychometric properties of the Spanish form of the schedule for meaning in life evaluation (SMiLE)

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BRIEF COMMUNICATION

Psychometric properties of the Spanish form of the schedule for meaning in life evaluation (SMiLE)

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Abstract
Objective The objective of this study was to validate the Spanish version of the SMiLE (Schedule for Meaning in Life Evaluation). The SMiLE is a respondent-generated instrument: respondents are first asked to list three to seven areas, which provide meaning to their lives, and then to rate their current satisfaction with the listed areas, as well as the individual importance of each one. Indices of total weighting (IoW), total satisfaction (IoS), and total weighted satisfaction (IoWS) are calculated.
Methods Two hundred and fifty University students responded to the Spanish version of the SMiLE, as well as to instruments for measuring self-esteem, quality of life, depression, and anxiety.
Results The Cronbach alphas ($\alpha = 0.61$ for IoS and $\alpha = 0.41$ for IoW) and test–retest correlations were comparable to those found in the initial validation of the instrument (IoS: $r = 0.55$; IoW: $r = 0.61$). The SMiLE showed positive correlations with self-esteem ($r = 0.28$, $P < 0.05$ for IoS) and the mental dimension of the quality of life scale ($r = 0.31$, $P < 0.05$ for IoS), while negative correlations were observed with depression ($r = -0.23$, $P < 0.01$) and anxiety ($r = -0.17$, $P < 0.05$).
Conclusions The results support the validity of the Spanish version of the SMiLE as an instrument for assessing meaning in life.

Keywords Assessment scales · Instrumental study · Meaning in life · Personal satisfaction · Quality of life

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Abbreviations

DAI-R	Death anxiety inventory-revised
IoS	Index of satisfaction
IoW	Index of weighting
IoWS	Index of weighted satisfaction or total SMiLE index
KUAS	Kuwait University anxiety scale
MD	Mental dimension
MiL	Meaning in life
PD	Physical dimension
SD	Standard deviation
SDS	Self-rating depression scale
SEIQoL-DW	Schedule for the evaluation of individual quality of life-direct weighting
SF-12 health survey	Short form-12 health survey
SMiLE	Schedule for meaning in life evaluation
RSES	Rosenberg self-esteem scale

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Introduction

The concept of *meaning in life* (MiL) was introduced to the field of clinical psychology by Victor Frankl [1], who argued that the search for meaning provides the primary drive in the pursuit of answers to the questions raised by our existence.

Recently, Fegg et al. [2] designed and validated a schedule for evaluating MiL. They considered that the very nature of the concept to be measured (i.e. personal and individual) meant that an idiographic instrument (focusing on a single individual's experience) would be the most suitable. Drawing on the methodology used by O'Boyle et al. [3], they developed the *Schedule for Meaning in Life Evaluation* (SMiLE) [2], a self-administered instrument that enables MiL to be quantified at the same time as conducting a qualitative analysis of the concept on an individual level, since it is the respondent who defines the areas that give meaning to his/her life [2, 4].

MiL is relevant to healthy populations [2, 4, 5], but has also aroused interest among clinicians working in palliative care [2, 5, 6] and with neurodegenerative disorders [7]. As MiL is a central feature of certain psychotherapeutic interventions [8, 9], the SMiLE may be useful for evaluating them.

The present study aimed to develop a Spanish form of the SMiLE and to study its psychometric properties. In order to determine the instrument's convergent and discriminant validity, subjects completed the schedule alongside measures of depression, general anxiety, death anxiety, quality of life, and self-esteem. It was hypothesized that a lack of MiL would manifest in the form of tedium, despair and the absence of life goals, whereas a meaningful existence would be associated with a positive view of one's life and a satisfactory degree of self-realization [10].

Method

Sample

A sample of 250 undergraduates was recruited from the nursing and dentistry courses offered by two Spanish Universities. Of these, 213 students [59 men, mean age 24.7 ($SD = 7.0$) years; 154 women, mean age 24.0 ($SD = 6.2$)] returned properly completed questionnaires.

Instruments

The students responded to the following self-administered instruments during class time between March and April 2008.

Spanish form of the SMiLE [2]: This instrument comprises three steps. Respondents must first indicate three to seven areas that give meaning to their lives, thereby generating a list of areas. They are then asked to rate, on a numerical scale from −3 (very unsatisfied) to +3 (very satisfied), the degree of satisfaction or dissatisfaction felt at that time with each of these areas. Finally, respondents rate, on a scale from 0 (not important) to 7 (extremely important), the importance of each area with respect to the overall meaning of their lives. Once the three steps have been completed, a formula [2] can be applied to calculate the Index of Satisfaction (IoS), which indicates the mean satisfaction rating across the stated areas (range 0–100, with higher scores reflecting greater satisfaction), and the Index of Weighting (IoW), which expresses the mean importance ascribed by the respondent to each of the chosen areas. IoW scores range between 20 (not important) and 100 (extremely important). One can then calculate the Index of Weighted Satisfaction (IoWS, total SMiLE index), which combines the weighting and satisfaction scores into a single value, thereby providing an overall estimate of MiL (range 0–100, with higher scores reflecting greater MiL).

Spanish form of the Rosenberg Self-esteem Scale (RSES) [11]: This consists of ten items scored on a four-point Likert scale (from strongly disagree to strongly agree). Possible total scores range from 10 to 40, with 40 indicating the highest level of self-esteem.

Zung Self-Rating Depression Scale (SDS) [12] *Spanish form* [13]: The twenty items of this self-report instrument are scored on a four-point Likert scale, ranging from 1 (rarely/never) to 4 (almost all of the time or always). Possible total scores range from 20 to 80, with 80 indicating the highest level of depression.

Death Anxiety Inventory—Revised (DAI-R) [14, 15]: Originally validated in Spanish, the DAI-R comprises seventeen items scored on a five-point Likert scale. Possible total scores range between 17 and 85, with higher scores indicating greater death anxiety.

Kuwait University Anxiety Scale (KUAS) [16], *Spanish form* [17]: The KUAS comprises twenty items scored on a Likert scale from 1 to 4. Possible total scores range between 20 and 80, with higher scores reflecting greater anxiety.

Spanish form of the SF-12 Health Survey [18], as developed by Alonso et al. [19]: A brief version of the SF-36 Health Survey [20], the SF-12 comprises twelve items and provides scores regarding both mental and physical health. Possible total scores range between 0 and 100, with higher scores indicating better health.

Procedure

All subjects who responded to the questionnaires did so voluntarily and were informed by the researchers that all the data gathered would remain anonymous and

confidential. In order to match test and retest data, subjects assigned a code known only to them to their responses. The Spanish form of the SMiLE was obtained through a standard back-translation procedure involving bilingual subjects [21].

In order to assess the temporal stability of the SMiLE, it was re-administered to a random sub-sample of 58 students from both universities, with a test–retest interval of 1 month. The procedure was the same at each test administration, and 52 valid responses were obtained. A qualitative analysis was then performed of the areas defined in the first step of the SMiLE during the first administration of the questionnaire, comparing these with the responses given at retest. In addition, a statistical correlation analysis was performed regarding the number of areas chosen by respondents during the initial administration and at retest. The same procedure was applied to the indices of satisfaction, weighting, and weighted satisfaction.

Results

The first step involved calculating the index of satisfaction (IoS), the index of weighting (IoW), and the index of weighted satisfaction (IoWS) for the whole sample ($n = 213$). Table 1 shows the test–retest results for the sub-sample of 52 respondents.

The analysis of internal consistency yielded a Cronbach's alpha of 0.61 for the IoS and 0.41 for the IoW ($n = 213$). The mean number of areas defined in the first step of the SMiLE was 4.99 ($SD = 1.59$) at test and 4.92 ($SD = 1.5$) at retest. The test–retest correlation for the number of areas chosen was 0.81 ($P < 0.01$).

The convergent validity of the SMiLE was assessed using the RSES and the mental dimension of the SF-12 (MD/SF-12), it being hypothesized that a strong sense of MiL would be associated with a positive view of life and quality of life. With respect to both the RSES and the MD/SF-12, the coefficients were positive and significant for the indices of satisfaction and weighted satisfaction (see Table 2).

Discriminant validity was estimated by comparing scores on the SMiLE indices with those on the KUAS, the SDS, the DAI-R, and the physical dimension of the SF-12 (PD/SF-12). Table 2 shows a negative correlation between both IoS and IoWS and the above-mentioned scales.

The areas defined by subjects during the first step of the SMiLE were grouped into the same thirteen categories reported in the instrument's original validation [4]. Table 3 shows the frequency with which each of the areas was chosen at test and retest. It can be seen that the two percentages are markedly similar.

Table 1 Means and standard deviations for the index of satisfaction (IoS), the index of weighting (IoW), and the index of weighted satisfaction (IoWS) obtained at test and retest ($n = 52$), showing the Spearman's rho coefficients and significance level (P)

	Test	Retest	Rho	Sig.
IoS	82.72 ± 14.28	80.33 ± 15.40	0.55	$P < 0.01$
IoW	84.09 ± 9.5	83.49 ± 9.96	0.61	$P < 0.01$
IoWS	83.81 ± 13.62	81.43 ± 14.29	0.48	$P < 0.01$

Table 2 Spearman's rho coefficients between the SMiLE indices of satisfaction (IoS), weighting (IoW), and weighted satisfaction (IoWS) and the measures of self-esteem (RSES), quality of life (MD/SF-12), anxiety (KUAS), depression (SDS), death anxiety (DAI-R), and quality of life (PD/SF-12)

	RSES	MD/SF-12	KUAS	SDS	DAI-R	PD/SF-12
IoS	0.28*	0.31*	−0.23**	−0.17*	−0.19**	−0.14*
IoWS	0.30*	0.31*	−0.22**	−0.16*	−0.18**	−0.15*

* $P < 0.05$, ** $P < 0.01$

Table 3 Frequency (%) with which each area was chosen at test (T1) and retest (T2)

Areas	T1 (%)	T2 (%)
Family	99.5	100
Friends	80.75	73.07
Work/studying	76.05	88.46
Well-being	59.62	46.15
Partner	55.39	50
Health	30.04	38.46
Leisure time	28.16	21.15
Hedonism	14.55	5.76
Religiosity	14.08	21.15
Finances	10.32	17.3
Animals/nature	7.51	3.84
Altruism	6.57	5.76
Home/garden	2.34	0

Discussion

The analysis of internal consistency, estimated by means of Cronbach alpha, yielded values of 0.61 and 0.41 for the responses regarding satisfaction and importance, respectively. These coefficients, which would be considered as very low in the case of nomothetic scales, are perfectly acceptable in respondent-generated instruments such as the SMiLE [22–24], and they are also very similar to the values obtained in the reliability study of the original version (0.71 and 0.49, respectively) [2].

As hypothesized, the results confirm that the indices of satisfaction (IoS) and weighted satisfaction (IoWS) were

positively and significantly correlated with self-esteem (RSES) and the mental dimension of the quality of life measure (MD/SF-12), while showing a negative correlation with depression (SDS), anxiety (KUAS), and death anxiety (DAI-R). This provides evidence of the instrument's convergent and discriminant validity. Further research is required regarding the negative correlation found between both IoS and IoWS and the physical dimension of quality of life (PD/SF-12).

The Spanish form of the SMiLE maintained the length, format, and scoring system of the original instrument. Furthermore, the MiL areas chosen by respondents were classified into the same thirteen categories used in the German, English, and French versions. Although this categorization is purely conventional, it is regarded as useful for classifying those aspects that people consider give meaning to their lives. It should be noted that the Spanish form, like the German and English versions [2], was developed in a sample of health science undergraduates, whereas the French version was validated in a group of palliative care and cancer patients [5].

One limitation of the present study is that findings based on a sample formed exclusively by university students cannot be extrapolated to other populations. Further research is therefore required to study the instrument's properties in both the general population and clinical samples, either palliative care patients or those with chronic or degenerative disease.

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References

1. Frankl, V. (2004). *Man's search for meaning. An introduction to Logotherapy*. London: Random House.
2. Fegg, M. J., Kramer, M., L'Hoste, S., & Borasio, G. D. (2008). The schedule for meaning in life evaluation (SMiLE): Validation of a new instrument for meaning-in-life research. *Journal of Pain and Symptom Management, 35*, 356–364.
3. O'Boyle, C. A., McGee, H., Hickey, A., O'Malley, K., & Joyce, C. R. (1992). Individual quality of life in patients undergoing hip replacement. *Lancet, 339*, 1088–1091.
4. Fegg, M. J., Kramer, M., Bausewein, C., & Borasio, G. D. (2007). Meaning in life in the Federal republic of Germany: Results of a representative survey with the schedule for meaning in life evaluation (SMiLE). *Health and Quality of Life Outcomes, 5*, 59–66.
5. Stiefel, F., Krenz, S., Zdrojewski, C., Stagno, D., Fernandez, M., Bauer, J., et al. (2008). Meaning in life assessed with the "Schedule for meaning in life evaluation" (SMiLE): A comparison between a cancer patient and student sample. *Supportive Care in Cancer, 16*, 1151–1155.
6. Fegg, M. J., Brandstatter, M., Kramer, M., Kogler, M., Haarmann-Doetkotte, S., & Borasio, G. D. (2010). Meaning in life in palliative care patients. *Journal of Pain and Symptom Management, 40*(4), 502–509.
7. Fegg, M. J., Kogler, M., Brandstätter, M., Jox, R., Anneser, J., Haarmann-Doetkotte, S., et al. (2010). Meaning in life in patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis, 11*, 469–474.
8. Breitbart, W. (2003). Reframing hope: meaning-centered care for patients near the end of life. Interview by Karen S. Heller. *Journal of Palliative Medicine, 6*, 979–988.
9. Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology, 23*, 5520–5525.
10. García-Alandete, J., Gallego-Pérez, J., & Pérez-Delgado, E. (2008). Meaning in life and hopelessness: An empirical study. *Universitas Psychologica, 8*, 447–454.
11. Rosenberg, M. (1965). *Society and the adolescent self image*. Princeton, NJ: Princeton University Press.
12. Zung, W. (1965). A self-rating depression scale. *Archives of General Psychiatry, 12*, 63–70.
13. Conde, V.F., Franch, J.I. (1984). [Behavioral Assessment scales for quantifications of psychopathological symptoms in depression and anxiety disorders]. Valladolid: Department of medical psychology and psychiatry clinical hospital; Faculty of medicine.
14. Tomás-Sábado, J., & Gómez-Benito, J. (2005). Construction and validation of the death anxiety inventory. *European Journal of Psychological Assessment, 21*, 109–115.
15. Tomás-Sábado, J., Gómez-Benito, J., & Limonero, J. T. (2005). The death anxiety inventory: A revision. *Psychological Reports, 97*, 793–796.
16. Abdel-Khalek, A. M. (2000). The Kuwait University anxiety scale: Psychometric properties. *Psychological Reports, 87*, 478–492.
17. Abdel-Khalek, A. M., Tomás-Sábado, J., & Gómez-Benito, J. (2004). Psychometric parameters of the Spanish version of the Kuwait University anxiety scale (S-KUAS). *European Journal of Psychological Assessment, 20*, 349–357.
18. Ware, J., Jr., Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*, 220–233.
19. Alonso, J., Regidor, E., Barrio, G., Prieto, L., Rodriguez, C., & de la Fuente, L. (1998). Population reference values of the Spanish version of the health questionnaire SF-36. *Medicina Clinica, 111*, 410–416.
20. Vilagut, G., Ferrer, M., Rajmil, L., Rebollo, P., Permanyer-Miralda, G., & Quintana, J. M. (2005). The Spanish version of the short form 36 health survey: A decade of experience and new developments. *Gaceta Sanitaria, 19*, 135–150.
21. Scientific Advisory Committee of the Medical Outcomes T. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research, 11*, 193–205.
22. Joyce, C. R., Hickey, A., McGee, H. M., & O'Boyle, C. A. (2003). A theory-based method for the evaluation of individual quality of life: The SEIQoL. *Quality of Life Research, 12*, 275–280.
23. Rapkin, B. D., & Schwartz, C. E. (2004). Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. *Health and Quality of Life Outcomes, 2*, 14–25.
24. Schwartz, C. E., & Rapkin, B. D. (2004). Reconsidering the psychometrics of quality of life assessment in light of response shift and appraisal. *Health and Quality of Life Outcomes, 2*, 16–26.

5. DISCUSIÓN

DISCUSIÓN

OBJETIVO 1.-

Profundizar en el conocimiento del fenómeno del DAM en las personas con procesos crónicos o fases avanzadas de enfermedad, en su conceptualización y en su relación con otros fenómenos.

Aunque el estudio del deseo de adelantar la muerte resulta un campo de indudable interés para clínicos y teóricos, lo cierto es que en la práctica, su investigación presenta considerables dificultades. El DAM es una realidad compleja que pone en cuestión nuestra capacidad de cuidar y acompañar a los enfermos en sus momentos más difíciles.

Bajo la denominación de DAM se han englobado fenómenos heterogéneos y poco delimitados, dando lugar a estudios en los que las diferencias conceptuales y metodológicas limitan la comprensión y comparación de sus conclusiones. Asimismo, hay escasa literatura que explore el concepto del DAM desde la perspectiva del paciente.

Este fenómeno, relacionado con la enfermedad grave o incurable, afecta a un número considerable de pacientes, especialmente en las últimas fases de su vida. Los avances médicos, capaces de transformar enfermedades rápidamente mortales en patologías crónicas y el aumento de la esperanza de vida, así como otros fenómenos sociales ligados al desarrollo, hacen prever que esta realidad, lejos de disminuir, pueda incrementarse.

Tras la revisión de los diferentes estudios, puede observarse que las cifras de prevalencia del deseo de avanzar la muerte son muy dispares entre ellos. Estas diferencias tanto podrían deberse a aspectos conceptuales o de población, como a la falta de un instrumento que unifique los criterios de evaluación. Todo ello destaca la necesidad de consenso y unificación de criterios para la definición de DAM y conceptos relacionados y la adecuación de instrumentos válidos y fiables para su cuantificación.

Los estudios clínicos muestran que la etiología del DAM es multifactorial. La evolución de la bibliografía apunta a que —quizás a medida que ha ido mejorando el tratamiento del dolor físico— el sufrimiento global o las dimensiones más generales y espirituales

del ser humano, incluyendo aspectos psíquicos, y sociales, tengan el papel más importante entre sus causas.

Para avanzar en su conocimiento y en el diseño de estrategias para su abordaje es necesario profundizar en el entendimiento del DAM, precisando sus límites conceptuales y distinguiendo diferentes etapas o situaciones.

La evaluación del DAM se ha visto limitada por falta de instrumentos capaces de cuantificar esta vivencia. En respuesta a esta dificultad, Rosenfeld et al [99], desarrollaron la Escala sobre las actitudes hacia el deseo de adelantar la muerte (The Schedule of Attitudes toward Hastened Death = SAHD), que pretende evaluar el deseo de morir en pacientes con diagnóstico de enfermedad grave. La SAHD es una escala autoadministrada de 20 ítems con formato de respuesta dicotómico verdadero - falso. El instrumento fue validado inicialmente en una población de pacientes afectos de SIDA de Nueva York. La escala fue posteriormente utilizada por los propios autores en una muestra de pacientes oncológicos de cuidados paliativos [100]. Asimismo ha sido validada al griego en pacientes ingresados en cuidados paliativos [101]. Las propiedades métricas de la escala la hacen idónea en cuanto a validez y fiabilidad. Desde su publicación, la SAHD ha sido utilizada para evaluar el DAM en diversos contextos, oncología en diversos estadios de la enfermedad, cuidados paliativos y SIDA.

Hasta el momento no existen estudios en nuestro entorno sobre el deseo de adelantar la muerte, de manera que la validación de la escala SAHD de Rosenfeld et al [99], permitirá conocer datos pioneros sobre este fenómeno en la población española.

En el ámbito de los cuidados paliativos se ha observado que el concepto de SV está cobrando relevancia a partir de algunos estudios que han puesto de manifiesto que, en estos pacientes, la falta de percepción de 'sentido' se asocia a distrés psicológico [53] y podría relacionarse con el deseo de morir. Obtener la versión española de la escala SMiLE y analizar sus propiedades métricas fue uno de los objetivos de este estudio. A partir del análisis de sus propiedades métricas, podemos concluir que la escala SMiLE es un instrumento válido y fiable para analizar el SV en los sujetos evaluados [102]. Para la interpretación de sus propiedades deben considerarse algunas de sus características esenciales. Debe destacarse que la SMiLE es un instrumento de tipo ideográfico, cuyo objetivo es el análisis de respuestas individuales. Esto supone que cada medida obtenida con esta escala es personal y única. Al no

ofrecer una puntuación final interpretable de manera unívoca, la evaluación de las propiedades métricas de este tipo de escalas ha sido considerada por algunos autores [103], poco relevante, proponiendo análisis desde un prisma o paradigma más próximo al de las escalas de calidad de vida individualizadas [104], en cuya evaluación intervienen elementos eminentemente cualitativos. No obstante, y a pesar de estos condicionantes, se han estimado las propiedades métricas de la escala utilizando la misma metodología aplicada por los autores en la validación de la versión original [58], de manera que pudiera hacerse una comparación de las dos versiones del instrumento, además de aportar criterios consistentes respecto a su fiabilidad y validez, desde una perspectiva psicométrica.

Los resultados permiten concluir que la SMiLE es una escala útil para evaluar el sistema de valores de los sujetos evaluados. Aunque se trata de un instrumento aplicable y de utilidad para valorar el SV en todo tipo de personas [58,65], también podría incorporarse como herramienta de evaluación del bienestar de las personas enfermas, especialmente aquellas con patologías crónicas o que se encuentran en situaciones cercanas al final de la vida, en los que el SV puede cobrar una importancia especial en su devenir existencial [59,105,106]. De hecho, en el ámbito de los cuidados paliativos, el concepto de SV, está cobrando relevancia desde que algunos estudios han puesto de manifiesto que, en estos pacientes, la falta de percepción de *sentido* se asocia a distrés psicológico [62], y podría relacionarse con el deseo de morir.

Este estudio presenta la limitación de la naturaleza de la muestra utilizada, formada exclusivamente por estudiantes universitarios, lo que restringe la capacidad de extrapolación de los resultados obtenidos a otro tipo de poblaciones. Son necesarios trabajos posteriores dirigidos al estudio de las propiedades de la escala en población general y muestras clínicas.

La validación de la SMiLE en pacientes de cuidados paliativos o incluso en pacientes con enfermedades crónicas o degenerativas puede aportar una herramienta de evidente interés clínico. Asimismo, puede tener un interés considerable en el ámbito de la investigación de los aspectos psicológicos relacionados con aquellos aspectos que dan sentido en la vida de las personas. Disponer de la adaptación de este instrumento -del que contamos ya con versiones validadas en lengua alemana, inglesa y francesa- [58,59], hará posible el diseño de estudios multicéntricos y la comparación de resultados obtenidos en distintos países. En la actualidad estamos trabajando en este

ámbito con diseños muy similares a los ya efectuados en Alemania y en Francia por los autores originales de la escala. El tiempo dirá los beneficios que este instrumento puede aportar en la evaluación de los pacientes al final de la vida.

OBJETIVO 2.-

Explorar el significado del DAM desde la perspectiva de los mismos pacientes que lo manifiestan.

Los hallazgos de la síntesis cualitativa sugieren que el DAM es un constructo multifactorial con múltiples significados que no implican necesariamente la acción literal de querer adelantar la muerte. En primer lugar, a través del proceso de *traducción recíproca* se definieron las categorías o patrones de respuesta comunes en los pacientes que manifiestan DAM en el contexto de patología o proceso avanzado de enfermedad. Las categorías emergentes en este estudio, explicativas del significado del DAM, son las siguientes: el DAM en respuesta a un sufrimiento físico, psíquico y espiritual; la pérdida de uno mismo; miedo, tanto al proceso de morir como a la cercanía del final; DAM como medio para finalizar con un sufrimiento; DAM como un deseo de vivir, —pero no de esta manera—, como un grito de ayuda, y por último, el DAM como control, "tener un as en la manga". Posteriormente, aplicando una nueva comparación de las categorías emergentes a través de *línea de argumentación* de Noblit y Hare [68], emergió un modelo explicativo sobre el DAM, en el que pudimos comprender el fenómeno en su globalidad. El DAM es un fenómeno reactivo al sufrimiento extremo. Asimismo, el presente estudio ha revelado que el DAM no significa siempre un verdadero deseo de morir, sino una solicitud de ayuda, y a su vez actúa como mecanismo de control y autodeterminación, pues, una vez tomada la decisión de querer morir, puede inducir alivio ante la incertidumbre.

La primera categoría que emerge en la síntesis, *desear adelantar la muerte en respuesta a un sufrimiento físico-psicológico-espiritual* subraya el DAM como respuesta y no como objetivo en sí mismo. En estos casos y contextos, la muerte es el medio para acabar con el sufrimiento.

La segunda categoría, *la pérdida de uno mismo*, es el resultado, del proceso paulatino de pérdidas físicas, psicológicas y espirituales al que se ve sometido el paciente. La

pérdida de uno mismo, junto a la tercera categoría identificada, miedo tanto ante el proceso de la muerte como a la cercanía del final provoca en los en los pacientes desesperanza y distrés emocional.

Otros estudios han identificado este cuadro de signos y síntomas en el paciente al final de la vida, aunque lo denominan de diferentes formas y alguno distingue algún pequeño matiz. Por ejemplo, Saunders [107], —fundadora del movimiento hospice—, acuñó la idea de *dolor total o total pain* en cuidados paliativos, para designar el sufrimiento no sólo por el dolor físico, sino ampliado con dolor psicológico, social y espiritual, como consecuencia de las numerosas pérdidas que experimentaban sus pacientes. Clarke y Kissane [108], por su parte, han descrito el síndrome de desmoralización (SD), definido como el síndrome de distrés existencial que sucede en pacientes con sufrimiento físico o mental, especialmente en aquellos cuya vida o integridad se ven amenazadas. Los autores sugieren que el cuadro se desencadena por el sentimiento de incapacidad de afrontar una situación de estrés y engendra desesperanza, sentimiento de no ser útil, impotencia, aislamiento, sensación de fracaso, baja autoestima, percepción de falta de sentido de la vida y ditrés emocional [55,108]. En este contexto los pacientes desmoralizados pueden desear morir, pero no como una respuesta a una vida llena de sentido y plenitud como la de la persona mayor que aguarda su muerte, sino que el paciente desmoralizado desea morir con impaciencia y angustia al percibir una vida sin sentido. En este caso, el deseo de morir se presenta como una manifestación más del SD. Recientemente estos autores han diseñado un instrumento —The Demoralization Scale—, o escala de desmoralización [109], cuyo objetivo es facilitar su diagnóstico de forma precoz, y su importancia radica en la distinción conceptual con el diagnóstico de depresión. Resultados similares fueron hallados en el estudio de Albert et al [110], en el que analizan el deseo de morir en una muestra de pacientes con esclerosis lateral amiotrófica. Los pacientes que mostraron deseo de morir, presentaron depresión, menos optimismo, mayor desesperanza, sufrimiento, pérdida de las ganas por vivir y anhedonia. Los autores atribuyen este amplio elenco de signos y síntomas al denominado por Rosenfeld et al [111] *Syndrome of End-of-life despair*, síndrome de desesperanza al final de la vida (SDFV). El deseo de morir en este caso, volvería a ser una manifestación más de este SDFV, de manera similar a lo que el síndrome de desmoralización es para Clarke and Kissane [108].

De alguna manera, esos cuadros mencionados: *dolor total*, *síndrome de desmoralización*, *desesperanza al final de la vida*, harían referencia a una similar realidad y todos ellos parecerían tener también una respuesta similar en el paciente: el distrés emocional. Sin embargo, mientras que las descripciones que hacen los autores de los síndromes comentados (SDFV y síndrome de desmoralización) incluyen y explican el DAM como un elemento, entre otros, de ese síndrome, el modelo que emerge de nuestra síntesis propone el DAM como un fenómeno reactivo, una respuesta o huída del sufrimiento multidimensional, y no una manifestación más.

Otra de las características que define la categoría *pérdida de uno mismo* en esta síntesis es una, así entendida por los pacientes, percepción de "pérdida de dignidad", asociada a las pérdidas de autonomía y control. Este término también lo utilizaron Chochinov et al [112], quienes elaboraron el modelo de dignidad (The Dignity Model) y destacaron que el concepto de dignidad no siempre es utilizado de manera unívoca en la literatura; la noción de dignidad es una cualidad moral interna e inseparable de la misma vida humana, sin embargo, cuando el valor de la autonomía se equipara a la noción de dignidad, la dependencia del paciente al final de la vida, es experimentada como una pérdida de dignidad que socava el valor de la vida. En cualquier caso, los rasgos que caracterizan el modelo de Chochinov et al [113] (que encontró que los pacientes que manifestaron una percepción de pérdida de dignidad, obtuvieron puntuaciones mayores en deseo de morir) haría referencia a características constitutivas de la categoría *pérdida de uno mismo* similares a las halladas en nuestro estudio. De este modo, el hecho de llegar a grados extremos de dependencia, sería interpretado por los pacientes y la sociedad como algo "indigno", a pesar de que, en realidad, algún grado de dependencia forma parte de la condición humana [114].

Recientemente, el sentido de la vida (SV), otro de los elementos que constituye la categoría *pérdida de uno mismo* en esta síntesis, también ha suscitado interés entre clínicos e investigadores de cuidados paliativos [54,60,112], y ha pasado a ser un elemento central en intervenciones psicoterapéuticas [115]. Los pacientes que mantienen el sentido de la vida, a pesar de presentar un mal pronóstico, son capaces de valorar su vida como digna de ser vivida [116]. Por el contrario, una falta de SV también se ha asociado a menudo con desesperanza y DAM o peticiones de eutanasia [55,117-119], de igual modo que muestra esta síntesis.

La cuarta categoría que emerge en la síntesis, *deseo de adelantar la muerte como medio para acabar con el sufrimiento*, aparece cuando el paciente percibe que no le queda nada y lo único que tiene es sufrimiento. Ante esa situación, la muerte parece la única alternativa.

La quinta categoría, el *DAM como un deseo de vivir pero no de este modo; una especie de grito de ayuda*, se manifiesta como una paradoja ya que, al mismo tiempo, estos pacientes exponen el deseo de morir, pero, con sus actos en realidad están solicitando ayuda y deseo de acompañamiento. De igual modo se manifiesta este hecho en un estudio belga [12] en el que analizan las experiencias de las enfermeras en su implicación con pacientes que solicitan la eutanasia. El estudio concluye que muchos pacientes, tras sentirse escuchados y acompañados en su desesperanza y distrés emocional, dejaban de manifestar DAM.

La última categoría en esta síntesis, *DAM como una clase de control de mi vida; tener un "as en la manga"* emerge en todos los pacientes estudiados. El deseo de control se manifiesta como una necesidad de la persona de seguir manteniendo su autonomía y la capacidad de decisión sobre su vida y futuro. En este sentido, aunque el control se ha visto como algo propositivo, en este caso, realmente parecería no referirse a un control sobre la vida, sino sobre la muerte. La sensación de control parece un elemento inherente a todo ser humano. Son varios los estudios que exponen la necesidad de control de los pacientes en varios contextos, pacientes oncológicos, pacientes con enfermedades neurodegenerativas [110], pacientes atendidos en residencias o unidades socio-sanitarias [114], cuidados paliativos [9], etc. Contemplar la necesidad de control de los pacientes al final de la vida, e incluirlo como elemento a considerar en el plan de atención integral de estos pacientes, parece esencial para mejorar su percepción de cuidados.

Este estudio podría presentar una limitación que afectaría a su validez interna. A pesar de ser conocida la correlación existente entre depresión y DAM [28], encontramos una falta de exploración de la variable depresión en los pacientes de las muestras de los estudios primarios. De los 7 estudios incluidos en esta revisión, tres de ellos, no hacen referencia en ningún momento del estudio. Por su parte, Coyle et al [44] plantean el objetivo de su estudio justificando que la depresión es uno de los factores que pueden originar DAM. El estudio de Pearlman et al [67] expone que psiquiatras experimentados analizaron las entrevistas realizadas a los participantes en busca de

signos y síntomas de depresión. Los autores concluyen que los participantes no presentaban ni depresión ni desesperanza, aunque reconocen las limitaciones del estudio en relación a la selección de la muestra, al tratarse de participantes voluntarios de asociaciones de muerte digna y derecho a morir. Por otro lado el estudio de Kelly et al [29] no descarta la presencia de depresión en los pacientes de su muestra e interpreta que los pacientes podrían presentar un estado de ánimo depresivo, debido a que manifestaron niveles bajos de satisfacción con la vida. Asimismo, el estudio de Nissim et al [47] también expone la presencia de desesperanza en todos los pacientes estudiados y, al igual que Kelly et al [29], contemplan la posibilidad de que los signos y síntomas presentados por los pacientes de sus estudios podrían ser compatibles con el síndrome de desmoralización definido por Kissane et al [55].

Otra limitación clasificada como heterogeneidad sería la relacionada con los diferentes abordajes metodológicos de los estudios incluidos en la síntesis, que se realizan con diferentes diseños cualitativos. En esta revisión se priorizó el foco al cual estaba dirigido cada uno de los estudios. No obstante, diversos autores [120,121] argumentan que no necesariamente es una limitación, sino que, por el contrario, puede aportar mayores posibilidades a la síntesis interpretativa. Además, esta síntesis se ha realizado sobre hallazgos y no sobre los datos, por lo que se minimiza el riesgo de disminuir la validez del estudio.

Un último aspecto también relacionado con la heterogeneidad, sería el concerniente a las características de las muestras incluidas en los estudios primarios. En este caso, el entendimiento de la experiencia del DAM se limitaría a los pacientes con cáncer al final de la vida, en personas mayores, en pacientes con SIDA y pacientes que reciben cuidados paliativos, y a los contextos analizados, atención domiciliaria y unidades de hospitalización; sin embargo no hemos hallado estudios que analicen el DAM en pacientes con patología crónica como insuficiencia renal, cardíaca, respiratoria y enfermedades neurodegenerativas. Por otro lado, todos los estudios incluidos fueron llevados a cabo en países desarrollados y en su gran mayoría, occidentales, incluso en el estudio de Mak y Elwyn [45] realizado en China, los participantes eran pacientes atendidos en una unidad de cuidados paliativos con filosofía *hospice* occidental. No se han hallado estudios sobre el DAM en África, Centro o Sud América, ni tampoco en contextos europeos, donde la familia y otros factores sociales podrían jugar diferentes roles [122]. Por otro lado, las características de los participantes, edad, sexo, pronóstico, nivel socio-económico, etc., no siempre están formalmente descritas en

cada uno de los estudios incluidos, lo que podría dificultar la transferibilidad de los resultados.

Los hallazgos de este estudio exponen el amplio elenco de factores que se ponen de relieve en un paciente al final de la vida y la necesidad de cuidados psico-espirituales-existenciales, planteando importantes implicaciones, tanto para la práctica clínica como para las políticas sanitarias. El conocimiento de la naturaleza del verdadero significado del DAM y las motivaciones que llevan a los pacientes a ello, implica grandes retos para los profesionales de la salud, entre ellos, una profunda comprensión de los pacientes al final de la vida desde una perspectiva holística. Asimismo, estos resultados estimulan la necesidad de analizar las circunstancias personales de cada paciente, su sufrimiento individual de cada paciente y el significado que cada uno de ellos atribuye al DAM, para planificar los cuidados en función de sus necesidades.

Futuras investigaciones podrían implicar nuevos grupos de pacientes con fallo renal, enfermedad crónica respiratoria, fallo cardíaco, patologías neurodegenerativas, etc., e incluso pacientes en atención domiciliaria y/o ambulatoria. Otro posible grupo poblacional de interés serían los residentes en zonas rurales, donde los recursos disponibles, así como los factores culturales y contextuales son diferentes a los de las zonas urbanas.

Asimismo, los hallazgos de esta revisión tienen importantes implicaciones para la evaluación del DAM. Cada una de las categorías se corresponde con diferentes dimensiones que deberían analizarse en todos y cada uno de los pacientes que presenten DAM. Para ello sería necesario el diseño de instrumentos de medida capaces de explorar cada una de las dimensiones en pacientes de estas características.

Por último, aunque fue un criterio de inclusión la búsqueda de estudios realizados desde la perspectiva del propio paciente que manifiesta DAM, sería interesante conocer el significado atribuido al DAM desde los profesionales e incluso los familiares y/o cuidadores, ya que podría complementar el conocimiento de este deseo y ayudaría a diseñar intervenciones de cuidados.

A pesar de que el objetivo no fue desarrollar una propuesta teórica, los resultados de la síntesis describen un modelo explicativo del DAM que es común a personas de diferentes países así como sistemas sanitarios. En pacientes con DAM existen factores comunes en la vivencia de la enfermedad, además, esta síntesis ha identificado los

elementos que se requieren para entender las necesidades de estos pacientes y poder desarrollar planes de cuidados individualizados.

A modo de conclusión podemos decir que no existen estudios en nuestro entorno sobre el deseo de adelantar la muerte. La validación de la escala SAHD de Rosenfeld et al [100], permitirá conocer datos epidemiológicos sobre el DAM en nuestro contexto. El estudio del sentido de la vida en pacientes en cuidados paliativos tampoco ha sido abordado en el entorno español. La validación de la escala SMiLE de Fegg et al [58] en este grupo de pacientes, facilitaría la primera información sobre este constructo en nuestro medio. Este futuro estudio permitiría evaluar por primera vez la hipótesis planteada de una posible relación entre SV y DAM en pacientes con estas características. Demostrar una asociación entre SV y DAM permitiría abrir una puerta a posibles abordajes del DAM, de cara a optimizar la atención y bienestar de los pacientes al final de la vida. Este estudio está realizándose en la actualidad mediante una financiación del Col·legi Oficial d'Infermeria de Barcelona. (Anexo 7).

Estos constructos, a pesar de facilitar la cuantificación del DAM y del SV e incluso establecer interrelaciones y efectuar comparaciones, sin embargo y dadas las características de esta realidad, su estudio sería incompleto si no se tuviera en cuenta la contribución que la metodología cualitativa puede aportar. En este sentido el marco conceptual desarrollado por la síntesis interpretativa puede constituir un elemento esencial para progresar en la comprensión de esta realidad y en la adecuación de los planes de cuidados a cada una de las diferentes fases o etapas en las que se halle cada persona.

No obstante, a pesar de haber hallado un modelo explicativo del DAM —en pacientes con procesos avanzados de enfermedad—, transferible a otros contextos similares debido al grado de universalidad de las categorías halladas, parece ser necesaria la realización de un estudio cualitativo primario, de corte fenomenológico, con pacientes que presentan DAM en nuestro contexto. Algunas de las características de nuestro entorno como la cultura, el sistema sanitario catalán y la Ley de Dependencia podrían actuar como elementos diferenciadores, respecto a los pacientes analizados en los diversos estudios cualitativos primarios incluidos en la meta-etnografía. En este sentido, la combinación de metodologías podría complementar los conocimientos hallados sobre el DAM hasta el momento, profundizando todavía más en el fenómeno en toda su

globalidad. Este podría ser un estudio pionero en Europa en el análisis de estas características.

Asimismo, se ha analizado el DAM en pacientes oncológicos, en cuidados paliativos, pacientes con SIDA y en personas de edad avanzada. No obstante, no se ha estudiado en pacientes con patología neurodegenerativa y patologías médicas evolucionadas como insuficiencia respiratoria, cardíaca y renal, todas ellas lentamente progresivas, donde el DAM podría tener connotaciones diferentes en cada uno de los casos. Futuros estudios deberían contemplar muestras de pacientes de estas características.

En definitiva, el fenómeno del DAM es una realidad en nuestra sociedad. Conocerlo es requisito imprescindible para poder abordarlo. Esta tesis pretende aportar luces nuevas para el conocimiento del DAM y, en definitiva, para mejorar el acompañamiento y cuidados de nuestros enfermos que están cercanos al final de su vida. El correcto abordaje del DAM desde visiones antropológicas y clínicas integrales, de la mano de las unidades de cuidados paliativos, debería ser un objetivo prioritario en esta tarea.

6. CONCLUSIONES

CONCLUSIONES

- Las diferencias terminológicas y conceptuales existentes sobre el deseo de adelantar la muerte en la literatura, así como los diferentes instrumentos y metodologías utilizadas para analizarlo, limitan la comparación de los resultados sobre prevalencia del DAM.

- La manifestación de DAM en el contexto de pacientes con procesos avanzados de enfermedad, tiene múltiples significados que no implican la acción literal de querer morir.

- El DAM en pacientes con procesos avanzados de enfermedad es un fenómeno reactivo a la presencia de un sufrimiento físico, psíquico y espiritual, y no un objetivo en sí mismo.

- No existen instrumentos validados en lengua española que cuantifiquen el DAM en pacientes al final de la vida.

- Para avanzar en el conocimiento del DAM y en el diseño de estrategias para su abordaje es necesario disponer de instrumentos de medida pueden ser de ayuda para facilitar su cuantificación y efectuar comparaciones. Obtener la versión española de la escala SAHD de Rosenfeld et al [100], podría facilitarlo.

- Las propiedades métricas de la versión española de la escala SMiLE justifican su idoneidad para la evaluación del sentido de la vida.

- Los resultados obtenidos con la escala SMiLE en la evaluación del SV, podrían facilitar el diseño de planes de cuidados individualizados.

- Aunque la escala SMiLE es un instrumento aplicable y de utilidad para valorar el SV de todo tipo de sujetos, también podría incorporarse como herramienta para la evaluación del bienestar de las personas enfermas, especialmente en aquellas con patologías crónicas o que se encuentran en situaciones cercanas al final de la vida, en los que el SV puede cobrar una importancia especial en su devenir existencial.

- Disponer del modelo explicativo del DAM y analizarlo desde perspectivas hipotético-deductivas, puede constituir un elemento esencial para progresar en

el estudio del DAM y la adecuación de los planes de cuidados a cada una de las diferentes fases o etapas en las que se halle cada persona

- Es necesario un esfuerzo multidisciplinar para mejorar el acompañamiento y cuidados de nuestros enfermos cercanos al final de su vida. El correcto abordaje del DAM desde visiones antropológicas y clínicas integrales, de la mano de las unidades de CP, debería ser un objetivo prioritario en esta tarea.

REFERENCIAS

REFERENCIAS

1. De Bal N, Dierckx de Casterlé B, De Beer T, Gastmans C. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. Int J Nurs Stud. 2006; 43: 589-99.

2. Maté J, González-Barboteo J, Ibáñez-Solaz M, Martínez-Urionabarenetxea K, Limonero JT, et al. Ideación autolítica al final de la vida en pacientes oncológicos paliativos: a propósito de un caso. Psicooncologia. 2008; 5: 339-58.

3. Chochinov HM, Wilson KG, Enns M, Lander S (1998) Depression, Hopelessness, and suicidal ideation in the terminally ill. Psychosomatics. 39: 366-70.

4. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Balaguer A. The wish to hasten death: A review of clinical studies. Psychooncology. 2010; DOI 10.1002/pon.1839

5. Back AL, Pearlman RA. Desire for physician-assisted suicide: requests for a better death? Lancet. 2001; 358: 344-5.

6. Battin MP, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen BD. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. J Med Ethics. 2007; 33: 591-7.

7. Harris EC, Barraclough B. Suicide as an outcome for mental disorders. A meta-analysis. Br J Psychiatry. 1997; 170: 205-28.

8. Mortensen PB, Agerbo E, Erikson T, Qin P, Westergaard-Nielsen N. Psychiatric illness and risk factors for suicide in Denmark. Lancet. 2000; 355: 9-12.

9. Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, et al. (2003) Nurses' experiences with hospice patients who refuse food and fluids to hasten death. N Eng J Med. 2003; 349: 359-65.

10. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, et al. Physicians' experiences with the Oregon Death with Dignity Act. N Eng J Med. 2000; 342: 557-63.

11. Verpoort C, Gastmans C, Dierckx de Casterlé B. Palliative care nurses' views on euthanasia. J Adv Nurs. 2004; 47: 592-600.

12. Dierckx de Casterlé B, Verpoort C, De Bal N, Gastmans C. Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics. 2006; 32: 187-92.

13. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". JAMA. 2000; 284: 2502-7.

14. Jones JM, Huggins MA, Rydall AC, Rodin GM. Symptomatic distress, hopelessness, and the desire for hastened death in hospitalized cancer patients. J Psychosom Res. 2003; 55: 411-8.

15. The Hastings C. Guidelines on the termination of life-sustaining treatment and the care of the dying: a report. Bloomington: Indiana University Press. 1987.

16. Humphry D. Rational suicide among the elderly. Suicide Life Threat Behav. 1992; 22: 125-9.

17. Parker M. Medicalizing meaning: demoralization syndrome and the desire to die. Aust N Z J Psychiatry. 2004; 38: 765-73.

18. Grzybowska P, Finlay I. The incidence of suicide in palliative care patients. Palliat Med. 1997; 11: 313-6.

19. Arnold EM. Factors that influence consideration of hastening death among people with life-threatening illnesses. Health Soc Work. 2004; 29: 17-26.

20. Hudson PL, Kristjanson LJ, Ashby M, Kelly B, Schofield P, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. Palliat Med. 2006; 20: 693-701.

21. WHO. Indicadores para el desarrollo humano. Mundial EB. 2009.

22. Lynn J. Learning to care for people with chronic illness facing the end of life. JAMA. 2000; 284: 2508-11.

23. Carmel S. The will to live: gender differences among elderly persons. Soc Sci Med. 2001; 52: 949-58.

24. Doyal L. Why active euthanasia and physician assisted suicide should be legalised. BMJ. 2001; 323: 1079-80.

25. Misono S, Weiss NS, Fann JR, Redman M, Yueh B. Incidence of suicide in persons with cancer. J Clin Oncol. 2008; 26: 4731-8.

26. Callahan D. Can we return death to disease? Hastings Cent Rep. 1989; 19: S4-S6.

27. Wilson K, Scott JF, Graham ID, Kozak JF, Chater S, et al. Attitudes of Terminally ill patients toward euthanasia and physician-assisted suicide. Arch Intern Med. 2000; 160: 2454-60.

28. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funest-Esch J, et al. Depresssion, hopelessness, and desire for hastened death in terminally ill patients with cancer. JAMA. 2000; 284: 2907-11.

29. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, et al. Terminally ill cancer patients' wish to hasten death. Palliat Med. 2002; 16: 339-45.

30. Rodin G, Zimmermann C, Rydall A, Jones J, Shepherd FA, et al. The desire for hastened death in patients with metastatic cancer. J Pain Symptom Manage. 2007; 33: 661-75.

31. Arnold EM, Artin KA, Person JL, Griffith DL. Consideration of hastening death among hospice patients and their families. J Pain Symptom Manage. 2004; 27: 523-32.

32. van Bruchem-Van de Scheur GG, Van der Arend AJG, Spreeuwenberg C, Huijer Abu-Saad H, ter Meulen RHJ. Euthanasia and physician-assisted suicide in the Dutch homecare sector: the role of the district nurse. J Adv Nurs. 2007; 58: 44-52.

33. Kinsella TD, Verhoef MJ. Assisted suicide: opinions of Alberta physicians. Clin Invest Med. 1995; 18: 406-12.

34. Musgrave CF, Margalith I, Goldsmidt L. Israeli oncology and nononcology nurses' attitudes toward physician-assisted dying: a comparison study. Oncol Nurs Forum. 2001; 28: 50-7.

35. Emanuel EJ. Euthanasia and physician-assisted suicide: a review of the empirical data from the United States. Arch Intern Med. 2002; 162: 142-52.

36. Kissane DW, Kelly B. Demoralization, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. Aust N Z J Phychiatry. 2000; 34: 325-33.

37. Kelly B, Pelusi D, Burnett P, Varghese F. The prevalence of psychiatric disorder and the wish to hasten death among terminally ill cancer patients. Palliat Support Care. 2004; 2: 163-9.

38. Pessin H, Rosenfeld B, Burton L, Breitbart W. The role of cognitive impairment in desire for hastened death: a study of patients with advanced AIDS. Gen Hosp Psychiatry. 2003; 25: 194-9.

39. Rabkin JG, Albert SM, Del Bene ML, O'Sullivan I, Tider T, et al. Prevalence of depressive disorders and change over time in late-stage ALS. Neurology. 2005; 65: 62-7.

40. Emanuel E, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. JAMA. 2000; 284: 2460-8.

41. Akechi T, Nakano T, Akizuki N, Nakanishi T, Yoshikawa E, et al. Clinical factors associated with suicidality in cancer patients. Jpn J Clin Oncol. 2002; 32: 506-11.

42. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, et al. Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors. Phychosomatics. 2004; 45: 311-8.

43. Lavery JV, Boyle J, Dickens BM, Maclean H, Singer PA. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. Lancet. 2001; 358: 362-7.

44. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. Oncol Nurs Forum. 2004; 31: 699-709.

45. Mak YY, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. Palliat Med. 2005; 19: 343-50.

46. Schroepfer TA. Mind frames towards dying and factors motivating their adoption by terminally ill elders. J Gerontol B Psychol Sci Soc Sci. 2006; 61: S129-139.

47. Nissim R, Gagliese L, Rodin G. The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study. Soc Sci Med. 2009; 69: 165-71.

48. Bayés R. Psicología del sufrimiento y de la muerte. Barcelona: Ediciones Martínez Roca, SA; 2001.

49. Maté J, Bayés R, González-Barboteo J, Muñoz S, Moreno F, et al. ¿A qué se atribuye que los enfermos oncológicos de una unidad de cuidados paliativos mueran en paz? Psicooncologia. 2008; 5: 303-22.

50. Bayés R. La sociedad contemporánea ante el dolor y la muerte. Human Humanid med. 2003; 1: 67-74.

51. Tomás-Sábado J, Gómez-Benito J. Variables relacionadas con la ansiedad ante la muerte. Rev Psicol Gen Aplic. 2003; 56: 257-79.

52. Frankl VE. Hombre en busca de sentido. Barcelona: Herder & Herder SA; 1991.

53. Morita T, Sakaguchi Y, Hirai K, Tsuneto S, Shima Y. Desire for death and request to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care. J Pain Symptom Manage. 2004; 27: 44-52.

54. Breitbart W. Reframing hope: meaning-centered care for patients near the end of life. Interview by Karen S. Heller. J Palliat Med. 2003; 6: 979-88.

55. Kissane DW, Clarke DM, Street AF. Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. J Palliat Care. 2001; 17: 12-21.

56. Morita T, Kawa M, Honke Y, Kohara H, Maeyama E, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. Support Care Cancer. 2004; 12: 137-40.

57. Greenstein M, Breitbart W. Cancer and the experience of meaning: a group psychotherapy program for people with cancer. Am J Psychotherapy. 2000; 54: 486-500.

58. Fegg MJ, Kramer M, L'Hoste S, Borasio GD. The Schedule for Meaning in Life Evaluation (SMiLE): Validation of a New Instrument for Meaning-in-Life Research. J Pain Symptom Manage. 2008; 35: 356-64.

59. Stiefel F, Krenz S, Zdrojewski C, Stagno D, Fernandez M, et al. Meaning in life assessed with the "Schedule for Meaning in Life Evaluation" (SMiLE): a comparison between a cancer patient and student sample. Support Care Cancer. 2008; 16: 1151-5.

60. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, et al. Understanding the will to live in patients nearing death. Psychosomatics. 2005; 46: 7-10.

61. Krause N. Meaning in Life and Mortality. J Gerontol B Psychol Sci Soc Sci. 2009; 64: 517-27.

62. Morita T, Murata H, Hirai K, Tamura K, Kataoka J, et al. Meaninglessness in terminally ill cancer patients: a validation study and nurse education intervention trial. J Pain Symptom Manage. 2007; 34: 160-70.

63. Lee V, Cohen SR, Edgar L, Laizner AM, Gagnon AJ. Clarifying "meaning" in the context of cancer research: a systematic literature review. Palliat Support Care. 2004; 2: 291-303.

64. O'Boyle CA, McGee H, Hickey A, O'Malley K, Joyce CR. Individual quality of life in patients undergoing hip replacement. Lancet. 1992; 339: 1088-91.

65. Fegg MJ, Kramer M, Bausewein C, Borasio GD. Meaning in life in the Federal Republic of Germany: results of a representative survey with the Schedule for Meaning in life Evaluation (SMiLE). Health Qual Life Outcomes. 2007; 5: 59-66.

66. Morse JM. Asuntos críticos en los métodos de investigación cualitativa. Colombia: Universidad de Antioquia; Editoria SAGE; 2003.

67. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, et al. Motivations for physician-assisted suicide. J Gen Inter Med. 2005; 20: 234-9.

68. Noblit G, Hare R. Meta-ethnography: Sinthesizing qualitative studies Newbury Park: Sage; 1988.

69. Schreiber R, Crooks D, Stern P. Qualitative meta-analysis. In: Morse J, editor. Completing a qualitative project. Thousand Oaks, CA: Sage; 1997. p. 311-26.

70. Nesbit K. Evidence-based Filters for Ovid Medline. 2002.

71. McKibbon A, Walker-Dilks C. Evidence-based Filters for Ovid-CINAHL. 2002.

72. Lavin MA, Krieger MM, Meyer GA, Spasser MA, Cvitan T, et al. Development and evaluation of evidence-based nursing (EBN) filters and related databases. J Med Libr Assoc. 2005; 93: 104-15.

73. Jones ML. Application of systematic review methods to qualitative research: practical issues. J Adv Nurs. 2004; 48: 271-8.

74. Sale JE, Hawker GA. Critical appraisal of qualitative research in clinical journals challenged. Arthritis Rheum. 2005; 53: 314-6.

75. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. J Health Serv Res Policy. 2005; 10: 45-53.

76. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ. 2000; 320: 50-2.

77. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet. 2001; 358: 483-8.

78. Rowan M, Huston P. Qualitative research articles: information for authors and peer reviewers. CMAJ. 1997; 157: 1442-6.

79. CASP P. Critical Appraisal Skills Programme. Ten questions to help you make sense of qualitative research. Oxford: CASP; 1999.

80. Campbell R, Pound P, Pope C, Britten N, Pill R, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. Soc Sci Med. 2003; 56: 671-84.

81. Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, et al. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. PLoS Med. 2007; 4: e238.

82. Edwards AG, Russell IT, Stott NC. Signal versus noise in the evidence base for medicine: an alternative to hierarchies of evidence? Fam Pract. 1998; 15: 319-22.

83. Smith LK, Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. Lancet. 2005; 366: 825-31.

84. Sandelowski M, Barroso J. Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. Res Nurs Health. 2003; 26: 153-70.

85. Jensen L, Allen M. Metasynthesis of qualitative findings. Qual Health Res. 1996; 6: 553-60.

86. Dixon-Woods M, Sutton A, Shaw R, Miller T, Smith J, et al. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. J Health Serv Res Policy. 2007; 12: 42-7.

87. García-Alandete J, Gallego-Pérez J, Pérez-Delgado E. Sentido de la vida y desesperanza: un estudio empírico. Univers Psychol. 2008; 8: 447-54.

88. Rosenberg M. Society and the adolescent self image. Princeton, NJ: Princeton University Press; 1965.

89. Zung W. A self-rating depression scale. Arch Gen Psychiatry. 1965; 12: 63-70.

90. Conde VF, Franch JI. Escalas de Evaluación Comportamental para la Cuantificación de la Sintomatología Psicopatológica en los Trastornos Angustiosos y Depresivos. Valladolid: Departamento de psicología médica y de psiquiatría del Hospital Clínico de la Facultad de Medicina; 1984.

91. Tomás-Sábado J, Gómez-Benito J. Construction and validation of the death anxiety inventory. Eur J Psychol Assess. 2005; 21: 109-15.

92. Tomás-Sábado J, Gómez-Benito J, Limonero JT. The Death Anxiety Inventory: a revision. Psychol Reports. 2005; 97: 793-6.

93. Abdel-Khalek AM. The Kuwait University Anxiety Scale: psychometric properties. Psychol Reports. 2000; 87: 478-92.

94. Abdel-Khalek AM, Tomás-Sábado J, Gómez-Benito J. Psychometric parameters of the Spanish version of the Kuwait University Anxiety Scale (S-KUAS). Eur J Psychol Assess. 2004; 20: 349-57.

95. Alonso J, Regidor E, Barrio G, Prieto L, Rodriguez C, et al. [Population reference values of the Spanish version of the Health Questionnaire SF-36]. Med Clin (Barc). 1998; 111: 410-6.

96. Ware J, Jr., Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care. 1996; 34: 220-33.

97. Vilagut G, Ferrer M, Rajmil L, Rebollo P, Permanyer-Miralda G, et al. The Spanish version of the Short Form 36 Health Survey: a decade of experience and new developments. Gac Sanit. 2005; 19: 135-50.

98. Scientific Advisory Committee of the Medical Outcomes T. Assessing health status and quality-of-life instruments: attributes and review criteria. Qual Life Res. 2002; 11: 193-205.

99. Rosenfeld B, Breitbart W, Stein K, Funesti-Esch J, Kaim M, et al. Measuring desire for death among patients with HIV/AIDS: The schedule of attitudes toward hastened death. Am J Psychiatry. 1999; 156: 94-100.

100. Rosenfeld B, Breitbart W, Galietta M, Kaim M, Funesti-Esch J, et al. The Schedule of attitudes toward hastened death. Measuring desire for death in terminally ill cancer patients. Cancer. 2000; 88: 2868-75.

101. Mystakidou K, Rosenfeld B, Parpa E, Tsilika E, Katsouda E, et al. The schedule of attitudes toward hastened death: validation analysis in terminally ill cancer patients. Palliat Support Care. 2004; 2: 395-402.

102. Monforte-Royo C, Tomás-Sábado J, Villavicencio-Chávez C, Balaguer A (2010) Psychometric properties of the Spanish form of the Schedule for Meaning in Life Evaluation (SMiLE). Qual Life Res. 2010; DOI 10.1007/s11136-010-9796-0

103. Joyce CR, Hickey A, McGee HM, O'Boyle CA. A theory-based method for the evaluation of individual quality of life: the SEIQoL. Qual Life Res. 2003; 12: 275-80.

104. Rapkin BD, Schwartz CE. Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. Health Qual Life Outcomes. 2004; 2: 14-25.

105. Fegg MJ, Kogler M, Brandstatter M, Jox R, Anneser J, et al. Meaning in life in patients with amyotrophic lateral sclerosis. Amyotroph Lateral Scler. 2010; 11:469-74

106. Fegg MJ, Brandstatter M, Kramer M, Kogler M, Haarmann-Doetkotte S, et al. Meaning in Life in Palliative Care Patients. J Pain Symptom Manage. 2010; 40:502-9.

107. Saunders C. The last stages of life. Am J Nurs. 1965; 65: 70-5.

108. Clarke DM, Kissane DW. Demoralization: its phenomenology and importance. Aust N Z J Psychiatry. 2002; 36: 733-42.

109. Kissane DW, Wein S, Love A, Lee XQ, Kee PL, et al. The Demoralization Scale: a report of its development and preliminary validation. J Palliat Care. 2004; 20: 269-76.

110. Albert SM, Rabkin JG, Del Bene ML, Tider T, O'Sullivan I, et al. Wish to die in end-stage ALS. Neurology. 2005; 65: 68-74.

111. Rosenfeld B, Abbey JG, Pessin H. Depression and hopelessness near the end of life: Assessment and treatment. In: Werth JLJ, Blevins D, editors. Psychosocial Issues near the end of life: A resource for professional care providers. New York: Hardcover; 2005. p. 163-82.

112. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med. 2002; 54: 433-43.

113. Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA. 2002; 287: 2253-60.

114. Strohbuecker B, Eisenmann Y, Galushko M, Montag T, Voltz R. Palliative care needs of chronically ill nursing home residents in Germany: focusing on living, not dying. Int J Palliat Nurs. 2010; 17: 27-34.

115. Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. Can J Psychiatry. 2004; 49: 366-72.

116. Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. Psychooncology. 1999; 8: 417-28.

117. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet. 2003; 361: 1603-7.

118. Nelson CJ, Rosenfeld B, Breitbart W, Galietta M. Spirituality, religion, and depression in the terminally ill. Psychosomatics. 2002; 43: 213-20.

119. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, et al. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med. 1998; 338: 1193-201.

120. Thorne S, Jensen L, Kearney MH, Noblit G, Sandelowski M. Qualitative metasynthesis: reflections on methodological orientation and ideological agenda. Qual Health Res. 2004; 14: 1342-65.

121. Sandelowski M, Docherty S, Emden C. Focus on qualitative methods. Qualitative metasynthesis: issues and techniques. Res Nurs Health. 1997; 20: 365-71.

122. Giorgi Rossi P, Beccaro M, Miccinesi G, Borgia P, Costantini M, et al. Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer. J Epidemiol Community Health. 2007; 61: 547-54.

ANEXOS

ANEXO 1-. Documento aprobación proyecto de tesis doctoral

Universitat
Internacional
de Catalunya

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Tel. 93 254 18 00 Fax 93 254 18 50

Campus Sant Cugat
Josep Trueta s/n, 08195 Sant Cugat del Vallès
Tel. 93 504 20 00 Fax 93 504 20 01

Benvolguda Cristina Monforte,

Mitjançant la present, i com Directora del Doctorat en Ciències de la Salut que realitza la Facultat de Medicina i Ciències de la Salut de la Universitat Internacional de Catalunya, passo a comunicar-te que la Subcomissió de Doctorat reunida en sessió ordinària el passat dilluns, 10 de novembre de 2008, va decidir l'aprovació del teu Projecte de Tesi Doctoral que porta per títol;

"El deseo de adelantar la muerte en personas afectadas de procesos crónicos o avanzados"

i que serà tutelat pel Dr. Albert Balaguer.

Per qualsevol dubte o aclariment resto a la vostra disposició

Atentament,

Dra. Adela Zabalegui
Directora del Doctorat en Ciències de la Salut

Sant Cugat, 26 de novembre de 2008

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ANEXO 2-. Escala SMiLE versión inglesa original

1. Escala SMiLE versión inglesa original

SCHEDULE FOR MEANING IN LIFE EVALUATION

The search for **meaning in life** is important for most people. This question comes up in different phases of life, including both happy and unhappy situations.

In the following section we would ask you to nominate those areas of life which in your opinion **give meaning to your life**. These areas can be characterised as those which give you "grounding" in life, and give importance to your life. In short, things "worth living for".

These **areas** obviously differ from person to person. Therefore, there are no "correct" or "wrong" answers to this question. The best way is to answer is to be as truthful as possible and to think exactly about your individual areas. Refer to your present situation.

Please nominate 3 to 7 areas which give meaning to your life, regardless of how satisfied or unsatisfied you are with these areas at the moment. The order os your answer is not important.

Area 1: _____
Area 2: _____
Area 3: _____
Area 4: _____
Area 5: _____
Area 6: _____
Area 7: _____

Please make sure that the order of areas in the following is identical with the numbers on the previous page. Please rate every nominated area. Refer to your present situation.

Please rate how **satisfied or unsatisfied** you are with each nominated area. That is, how much – positively or negatively – the area affects your total meaning in life.

How satisfied are you with…	*Very unsatisfied*			*In between*			*Very satisfied*
Area 1	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 2	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 3	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 4	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 5	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 6	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Area 7	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**

Please rate how **important** each area is for your total meaning in life. Try to distinguish between the areas as best possible by considering all numbers.

How important is…	*Not important*			*Important*		*Very important*	*Extremely important*
Area 1	0	1	2	3	4	5	6	7
Area 2	0	1	2	3	4	5	6	7
Area 3	0	1	2	3	4	5	6	7
Area 4	0	1	2	3	4	5	6	7
Area 5	0	1	2	3	4	5	6	7
Area 6	0	1	2	3	4	5	6	7
Area 7	0	1	2	3	4	5	6	7

ANEXO 3-. Escala SMiLE versión española

2. Versión española de la escala SMiLE

ESCALA DE EVALUACIÓN DEL SENTIDO DE LA VIDA

La búsqueda del **sentido de la vida** es importante para la mayoría de las personas. Esta cuestión se plantea en los diferentes períodos de la vida, tanto en los momentos de felicidad como de tristeza.

A continuación le pedimos que escriba aquellas áreas o aspectos de la vida que en su opinión **dan sentido o significado a su vida**. Aquellos aspectos que dan soporte o importancia a su vida. En resumen, aquellas cosas por las que considera que merece la pena vivir.

Naturalmente estas áreas o aspectos son diferentes para cada persona. Por lo tanto no hay respuestas correctas o incorrectas. Procure contestar lo más sinceramente posible y pensar exactamente en estos aspectos concretos referidos a su actual situación en la vida.

Escriba entre 3 y 7 áreas o aspectos que dan sentido a su vida, independientemente del grado de satisfacción o insatisfacción que en ellos tenga en este momento. No importa el orden de sus respuestas.

Área 1: _____
Área 2: _____
Área 3: _____
Área 4: _____
Área 5: _____
Área 6: _____
Área 7: _____

Asegúrese de que el orden de las áreas en las respuestas siguientes coincida con el de la página anterior. Valore cada una de las áreas según su situación actual.

Indique su **grado de satisfacción o insatisfacción** en cada aspecto o área, es decir, la intensidad con la que el significado global de su vida se ve afectado –positiva o negativamente- por cada una de estas áreas.

Qué grado de satisfacción encuentra en…	*Muy insatisfecho*			*Regular*		*Muy satisfecho*	
Área 1	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 2	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 3	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 4	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 5	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 6	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**
Área 7	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**

Indique qué importancia tiene cada aspecto en el significado global de su vida. Intente **distinguir lo mejor posible** entre los diferentes aspectos, considerando todas las opciones posibles de 0 a 7.

Qué grado de importancia tiene para usted…	*Nada importante*		*Importante*		*Muy importante*	*Extremadamente importante*		
Área 1	0	1	2	3	4	5	6	7
Área 2	0	1	2	3	4	5	6	7
Área 3	0	1	2	3	4	5	6	7
Área 4	0	1	2	3	4	5	6	7
Área 5	0	1	2	3	4	5	6	7
Área 6	0	1	2	3	4	5	6	7
Área 7	0	1	2	3	4	5	6	7

ANEXO 4-. Consentimiento del Dr. Martin Fegg para validación de la escala SMiLE en lengua española

Asunto: AW: about SMILE
Fecha: Thu, 6 Mar 2008 08:31:19 +0100
De: Dr. Martin Fegg <fegg@psychologie-muenchen.de>
Para: 'Albert Balaguer' <abalaguer@csc.uic.es>
Referencias: <47CEA0B5.9010802@csc.uic.es>

Dear Dr. Balaguer,

thanks a lot for your email and the congratulations of your research group. Of course, you are very welcome to translate and validate the instrument in Spanish. Please find attached the (original) German and the validated English version.

If you need any further assistance you can contact me at any time. We can also arrange a telephone call for easier conversation if this will help you.

Yours sincerely,

Martin Fegg

Dr. Martin Fegg, Dipl.-Psych. Mag.
Psychologischer Psychotherapeut

INTERDISZIPLINÄRES ZENTRUM FÜR PALLIATIVMEDIZIN
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Von: Albert Balaguer [mailto:abalaguer@csc.uic.es]
Gesendet: Mittwoch, 5. März 2008 14:32
An: Martin J Fegg
Betreff: about SMILE

Dear Prof Fegg,

First of all we want to congratulate you for your development of the "Schedule for Meaning in Life Evaluation". We think this schedule could be a very interesting tool for the assessment of "meaning in life" in our society in general and in near death patients in particular.
We are a relatively new research group interested in the study of "wish to hasten death" and suicide through different approaches (medical, psychology, nursing). We would like to apply your schedule to our country (Spain) in future studies in that kind of situation. We are requesting permission to translate and to validate the spanish version of your schedule for this purpose. Our group includes experts in this type of task.
We look forward to hearing from you.
Kind regards,

Albert Balaguer, MD, PhD
Universitat Internacional de Catalunya, Barcelona. Universitat Rovira I Virgili, Reus-Tarragona .

Joaquin Tomas-Sábado, Psychologist, PhD
Escoles Universitaries d'Infermeria Ginbernat, Barcelona. Universitat Autónoma de Barcelona.

Cristina Monforte, CCRN, ND
Escoles Universitaries d'Infermeria Ginbernat, Barcelona. Universitat Autónoma de Barcelona.

Andres Aristayeta, RN, ND
Hospital General de Catalunya. Universitat Internacional de Catalunya, Barcelona.

--
::
Dr. J Albert Balaguer Santamaría
Universitat Internacional de Catalunya, Barcelona.
Campus Salut. Medicina
Josep Trueta, s/n
(Hospital General de Catalunya)
08195 Sant Cugat del Vallès. Barcelona
Tel. +34 935042000 (ext 5201)
Tel. +34 647 432 872

ANEXO 5-. Permiso de los autores para la utilización de la escala SF-12

Cristina Monforte

De: <BiblioPRO@imim.es>
Para: <cristina.monforte@cesc.es>
Enviado: lunes, 07 de julio de 2008 23:28
Adjuntar: Permiso_de_uso_de_cuestionario_SF-12v1.pdf
Asunto: Cuestionario Bibliopro

Estimado Investigador

En este email encontrará adjunto el documento de cesión de uso del cuestionario descargado desde BiblioPRO, la biblioteca virtual de cuestionarios de Calidad de Vida y otros resultados percibidos por los pacientes (Patient Reported Outcomes, PRO) para la población española.

Si desea utilizar el cuestionario descargado desde BiblioPRO, rogamos rellene el breve formulario de cesión que le adjuntamos. Una vez completado el documento, rogamos nos envíe el original firmado a la siguiente dirección:

BiblioPRO - Cesión de uso de cuestionarios
Unidad de Investigación en Servicios Sanitarios, Fundación IMIM,
c/ Dr. Aiguader 80, Barcelona 08003, España.

Se lo devolveremos con la firma del Propietario Intelectual.

Si no desea utilizar el cuestionario, no hace falta enviar el documento. Le rogamos que en caso de un uso futuro, vuelva a rellenar el formulario de descarga con los datos correspondientes y recibirá de nuevo el do cumento de cesión de uso del cuestionario.

A continuación le resumimos los datos que nos envió a través del formulario de descarga de cuestionarios. Le rogamos que, junto con la carta de cesión, nos envíe una copia de este mismo resumen confirmando o corrigiendo los datos.

Descarga: 2806
Fecha: '2008/07/07'
Nombre del Cuestionario: SF-12v1 estandar en castellano
Datos del Investigador:

Apellidos del investigador principal (*): Monforte Royo
Corrección:

Nombre del investigador principal (*): Cristina
Corrección:

e-mail (*): cristina.monforte@cesc.es
Corrección:

Teléfono (*): 652428214
Corrección:

Fax: (Fax)
Corrección:

Centro de trabajo(*): 1= privado 0= público **Usted seleccionó**: 0
Corrección:

Nombre del centro de trabajo: EUI Gimbernat Universitat Autònoma de Barcelona
Corrección:

Dirección:
Corrección:

Datos sobre el uso del cuestionario:

Uso del cue stionario (*): ProyectoInvestigacion
Corrección:

Otros usos:
Corrección:

Financiación mayoritaria por una entidad: 0.-Con ánimo de lucro 1.-Sin ánimo de lucro **Usted seleccionó**: 1
Corrección:

Objetivos:
Corrección:

Probable fecha de inicio:
Corrección:

Probable fecha final de:
Corrección:

Diseño del estudio(*): Otros
Corrección:

Especificar otros diseños: Validación de una escala
Corrección:

Descripción población (*): Alumnos de enfermería
Corrección:

Nº Sujetos:
Corrección:

Modo de administración del cuestionario: Autoadministrado
Corrección:

Comentarios:
Corrección:

Agradecemos su interés en BiblioPRO. Los objetivos de esta biblioteca son compilar cuestionarios, hacer difusión de los mismos, y evaluar la calidad de éstos, desarrollando y aplicando los criterios más avanzados. Esta biblioteca de acceso libre y gratuito pretende poner toda la in formación disponible al alcance de los profesionales interesados (investigadores, clínicos y gestores).

Esperamos que la información disponible en BiblioPRO le haya sido de utilidad y sin otro particular les enviamos un saludo cordial.

08/07/2008

Fundació IMIM

BiblioPRO
0040101 66 1 3

PERMISO DE USO DE CUESTIONARIO

SOLICITO EL PERMISO DE USO DEL CUESTIONARIO: SF-12 versión 2

PARA EL ESTUDIO TITULADO: Validación de la forma española de la escala SWLF, para la evaluación del significado de la vida. *(rellenar nombre del Estudio)*

NOMBRE DE LA ENTIDAD TITULAR DEL ESTUDIO: Universidad Internacional de Cataluña Campus Ciencias de la Salud EUI Gimbernat UAB

Rellenar la casilla que corresponda:

- **ENTIDADES SIN ÁNIMO DE LUCRO (CESIÓN GRATUITA)** ☒

*La cesión de la versión española del cuestionario es **gratuita** para todos aquellos investigadores pertenecientes a entidades sin ánimo de lucro que vayan a llevar a cabo un proyecto con financiación pública.*

- **ENTIDADES CON ÁNIMO DE LUCRO (CESIÓN SUJETA A TARIFAS)** ☐

*La cesión de la versión española del cuestionario **está sujeta a tarifas** para todos aquellos estudios promovidos o financiados mayoritariamente por entidades con ánimo de lucro.*

La versión española del cuestionario se cede exclusivamente para el uso declarado.

Las tarifas son:

- hasta 200 pacientes o administraciones 500€
- por cada 1-100 pacientes o administraciones adicionales 100€

(Nota: estas tarifas no incluyen IVA)

- Número de _____ Pacientes y _____ Administraciones = Total _____

Importe Total _____ €
(indicar el importe total)

Datos de Facturación:

NIF/ Datos fiscales: _____

Nombre de la entidad: _____

Razón social (dirección de la sede): _____

POR FAVOR enviar original completado a: **BiblioPRO** (Cesión de Cuestionarios),
Unidad de Investigación en Servicios Sanitarios, IMIM, c Dr. Aiguader 88, Barcelona 08003, España.
Se le devolverá la solicitud debidamente firmada, con la mayor brevedad.

CONDICIONES DE CESIÓN

1. El cuestionario sólo puede utilizarse para el uso declarado, y no para ninguna otra finalidad o investigación sin permiso específico.

2. Con el objetivo de evaluar las características métricas del cuestionario, los solicitantes se comprometen a ceder al autor de la versión para España los siguientes datos del estudio en el que utilicen dicho cuestionario: los ítems del cuestionario, datos sociodemográficos (el género, la edad y la clasificación socioeconómica si se ha recogido), la enfermedad principal y el nivel de gravedad de la misma y la existencia de otras enfermedades concomitantes o comorbilidad. Como queda expresado más arriba, esta información será utilizada *solamente* con la finalidad de evaluar las características psicométricas del cuestionario.

3. El (los) abajo firmante(s) se compromete(n) a respetar **TODAS Y CADA UNA** de las condiciones de cesión del permiso de la versión española del cuestionario SF-12 versión 2, mencionadas en el presente acuerdo.
   (*rellenar nombre del cuestionario*)

4. El (los) abajo firmante(s) declara(n) que este estudio:
   (marcar la casilla que aplica)

   ☒ **NO** forma parte de un estudio privado con ánimo de lucro.

   ☐ **SÍ** forma parte de un estudio privado con ánimo de lucro.

Por la Fundación IMIM, propietario intelectual:

Dr. Jordi Alonso Caballero
Coordinador
Unidad de Investigación en Servicios Sanitarios
Instituto Municipal de Investigación
Médica (IMIM).

Fecha hoy: 28-AGOSTO-2008

Firmado: _____

Solicitante: CRISTINA MONFORTE ROYO

Cargo: Profesora titular universidad Investigadora

Institución: EUI GUIMBERNAT UAB

Fecha hoy: 11/7/08

Firmado: _____

POR FAVOR enviar original completado a: **BiblioPRO** (Cesión de Cuestionarios),
Unidad de Investigación en Servicios Sanitarios, IMIM, c/ Dr. Aiguader 88, Barcelona 08003, España.
Se le devolverá la solicitud debidamente firmada, con la mayor brevedad.

ANEXO 6-. Documento aprobación del Comité de Ética de la Universitat Internacional de Catalunya

Universitat Internacional de Catalunya

Informe de Valoració
Comitè d'Ètica en la Investigació Humana

Sra. Isabel Elorduy Hernández-Vaquero, com secretària tècnica del Comitè d'Ètica en la Investigació Humana de la Universitat Internacional de Catalunya,

Fa constar que,

un cop revisat el projecte de títol "El deseo de adelantar la muerte en personas afectadas de procesos crónicos o avanzados" versió de protocol 1, investigador principal Cristina Monforte Royo rebut a la Facultat de Medicina i Ciències de la Salut el dia 26 de setembre de 2008

la seva valoració ha estat **ACCEPTAT** segons els criteris del Comitè d'Ètica en la Investigació Humana de la UIC, al no tractar-se d'un assaig clínic i complir amb els requisits ètics d'investigació adequats.

Universitat Internacional de Catalunya
Facultat de Medicina i Ciències de la Salut

Sra. Isabel Elorduy Hernández-Vaquero
Secretària Tècnica del CEI de la UIC

Sant Cugat del Vallès, 15 d'octubre de 2008

ANEXO 7-. Documento Financiación Proyecto de Investigación por el Col·legi Oficial d'Infermeria de Barcelona

COL·LEGI OFICIAL
INFERMERIA
DE BARCELONA

REGISTRE
COL·LEGI OFICIAL INFERMERIA DE BARCELONA
Entrada núm.:
Data:
Sortida núm.: 8001
Data: 03/12/2009

Benvolguda Sra. Monforte,

Finalitzat el procés d'avaluació dels projectes presentats a la Convocatòria d'Ajudes a la Recerca del COIB 2009, per part del Comitè Avaluador Extern Expert en Recerca, ens plau en primer lloc felicitar a tot l'equip investigador per la qualitat científica i metodològica del Projecte : 5177/09 sota el títol de : *Relació entre la percepció del sentit de la vida i el desig d'avançar la mort en pacients en tractament pal·liatiu.*

Així mateix volem comunicar-li que esmentat projecte ha estat seleccionat per a ser finançat amb un dotació econòmica de **5160€.**

En breu en posarem en contacte amb vostè per a decidir el dia més adient per a realitzar una reunió amb l'objectiu de informar del procediment a seguir i de la distribució de la dotació econòmica.

Una vegada més, felicitar-vos per l'esforç realitzat amb l'elaboració del vostre projecte i per l'aportació a la professió infermera.

Cordialment,

COL·LEGI OFICIAL INFERMERIA DE BARCELONA

Pilar Delgado i Llúcia Benito
Assessores de l'Àrea de Recerca

Barcelona, 3 de desembre de 2009

Alcoi 21, 08022 Barcelona
Tel. 93 212 81 08 • Fax 93 212 47 74 • info@coib.cat • www.coib.cat

ISO 9001 BUREAU VERITAS Certification